

To choose freely, we need information...

The impact of HIV mass media campaigns

This article seeks to explore some of the issues around access to information in the context of HIV and AIDS. It has been extensively argued (especially in this publication) that the core human rights enshrined in the Constitution¹, constantly undermined in the context of HIV and AIDS, are those of equality (Section 9), dignity (Section 10), and freedom of choice – especially choice around sexual and health related behaviour (Section 12).² It could further be argued that our key access to sustaining our ability to uphold and enact these rights is the right of access to information, or more specifically that:

Everyone has the right of access to any information held by the state; and any information that is held by another person and that is required for the exercise or protection of any rights. [Constitution, Section 32(1)]

In order to choose freely, we need information. Currently, there are large amounts of funding being poured into mass media communication as a form of disseminating information; yet, there is little examination being done around who the information is aimed at; what kind of information is being disseminated; whether or not

the information aligns with the constitutional guarantees; and whether or not the information has any impact at all on people's choices regarding health and sexual behaviour. For the scope of this article, the focus is on information around the impact of media and mass communication strategies, or 'marketing' HIV and AIDS awareness primarily in the area of HIV prevention, as there is little research that gives any indication of the impact of HIV treatment campaigns.³

Exposure to information

It must be acknowledged that there are multiple role players disseminating information on a number of levels and in a variety of mediums. Organisations, such as the Treatment Action Campaign (TAC), disseminate a large amount of information through their networks in the form of posters and brochures. There is also a vast archive of information available on the internet – but this form of communication is not a widely accessible one. Indeed, one survey noted that 80% of participants do not access the internet⁴. Thus, for the purpose of this article, the focus will be on examining the three 'major' South African

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Editorial...

...the right of access to information is often depicted as the 'oxygen of democracy' or the 'oxygen of knowledge' and underpins and supports other fundamental human rights and freedoms. [Richter, 2005]

It is within this context that this issue of the *ALQ* focuses on access to information and the extent to which the available information and messaging facilitates informed decision-making in the context of HIV and AIDS. The various articles in this edition examine a range of information sources, as they relate to HIV and AIDS realities and impact on people's choices. The impact of the information disseminated through HIV awareness and prevention mass media campaigns; the extent to which cultural information influences people's choices in the context of HIV and AIDS, religion impacts on HIV-related stigma, and sex and HIV information and education at schools facilitate informed decision-making; and language as an area informing sexual and reproductive choices; as well as legislative provisions promoting the right of access to information are some of the issues discussed in this edition. This issue continues with the integral features of the *ALQ*, introducing experiences and challenges from a project in Hillcrest, Kwa-Zulu Natal, aimed at behavioural change through providing access to sex and HIV information to learners, as well as from Yabonga, a project in the Western Cape, inspiring women living with HIV; 'making a point' about the need for public involvement in legislative processes; and 'commenting' on the dire need for community home-based care services to be recognised and protected.

In this edition, **Emma Harvey** explores the impact of HIV awareness and prevention mass media campaigns on people's sexual choices and behaviour. Examining three 'major' South African mass media campaigns as to their exposure, message content and impact, she argues that the impact of these campaigns is rather limited, since the information disseminated fails to provide facts required to make informed choices, and also fails to take into account the context in which messages are heard and decisions are made – thus, people are not in the position to make free and fully informed choices.

The extent to which culture, as one source of information, influences people's choices and, at times, defines people's risk of HIV infection, is explored by **Nonhlanha Mkhize**. Looking at the concept and meaning

of culture in people's lives, the ways in which cultural information is accessed, and the use of cultural information in decision-making within the context of HIV, she argues that there is a serious challenge in educating and engaging society in dialogues about HIV, since, cultural myths, misconceptions and stereotypes about HIV and HIV transmission, despite all the exposure to HIV information, remain largely unchanged and unchallenged.

Recognising the apparent gap between HIV prevention efforts focussing on the youth and the limited impact on HIV infection rates amongst the youth, **Johanna Arendse** and **Johanna Kehler** raise the question as to whether or not schools are adequately equipped to provide sufficient sex and HIV education that facilitates informed decision-making. Examining some of the realities of HIV education and management within the school environment, the article argues that as long as schools, and communities, are largely discriminatory and non-caring, and educators are 'inhibited' by their cultural and religious value, norm and belief systems, young people will remain at a disadvantage and at high risk of HIV infection.

The role of religion, and the extent to which religious messaging influence HIV-related stigma, are examined by **Adrian Blom**. Analysing the 'pillars' of HIV-related stigma within religion, and the paradoxical messages of religion as to their restrictive attitude to sex and sexuality, as well as their power to overcome stigma, he argues that while religion is the source and ultimate cause of stigma, it also holds the key to non-discrimination and holistic acceptance of people living with HIV and thus, the key to unleash its de-stigmatising energy, creating a freer and more supportive society for everyone.

Marion Stevens explores information and language used to describe women's rights as human rights in relation to sexuality and reproduction. Discussing international and national documents defining sexual and reproductive health and rights, she argues that the language of sexual and reproductive health and rights has become an area to inform decision-making and thus, the use of language, especially regarding the continuum of care in the context of HIV and AIDS, has to be monitored so as to ensure informed sexual and reproductive choices.

Challenges, successes and limitations of the behavioural change through access to information approach, utilised with learners in Hillcrest, are introduced by **Zandile Shange**. Discussing the experiences from a project providing sex and HIV and AIDS information and education to learners within the school environment, she argues that even though gender stereotypes and sexual relationships are understood and well-known, it is difficult,

mass media campaigns, namely Soul City, loveLife, and Khomanani. These campaigns all use mass media to convey part or all of their information or messaging; in what some consider to be a highly effective means. Collinge [2005:211] argues that

...the mass media are extremely effective in reaching the vast majority of South Africans.

Campaigns, as a method of information dissemination, are seen as a vital part of the 'fight against' HIV and AIDS. With infection rates as high as 18.8% in the adult population, and still increasing⁵, prevention of further HIV infection is a major priority. Despite this seemingly

unquestioned stance, questions remain about whether or not the information is indeed accessible; and if so, who is accessing the information, and what are the messages that are disseminated.

The three main projects currently operating in South Africa – namely Soul City, loveLife and Khomanani – all use radio, television and print media (ranging from supplements in newspapers to freely available leaflets and posters) to get their information across, though each has a unique methodology and slightly differing target audience. This basic information is summarised in the table below.

Summary of Media 'Reach' ⁶

Media type used	Soul City	Khomanani	loveLife
Television	Six different 'edutainment' drama series since 1994	Advertising for youth programme, circles of support, positive living, TB (though not the STI campaign)	Public Service Announcements (PSAs) and broadcasting of loveLife games
Radio	Radio drama series operating in conjunction with TV series and translated into multiple languages	Advertising as above	Weekly 30 minute programmes on 11 stations
Booklets	Three booklets tackling the 'issues', with print runs of one million or more	Massive free distribution of booklets and pamphlets set up	
Supplements in newspapers	Also distributed through NGOs, clinics		S'camto (10 million copies each year) and thethaNathi (over 16 million copies each year)
Outdoor media (billboards etc)			Billboards, water tanks and taxi's for the various campaigns
Other	Advocacy campaigns run in conjunction with programmes to facilitate a climate more supportive to individual change	Door to door community campaigns to collect donations; school roadshows; hotline support to children; STI week; soccer league related events; posters; health worker awards	loveLife's media and print is backed up by an extensive 'face-to-face' programme which includes call centre's, youth centre's, creating youth friendly clinics, training peer educators called 'groundbreakers' and 'mpintshis'; school programmes, sport programmes and a 'loveTrain' and 'loveTours'

especially for girls, to implement the acquired knowledge, since the understanding and knowledge is based within, and influenced by, their social and cultural contexts.

The constitutional and legislative framework, providing for the right of access to information, is introduced by **Urvashi Rajcoomar**. Looking at some of the sections within the Promotion of Access to Information Act (PAIA), as well as the judicial interpretation of the right of access to information, she argues that as long as the most vulnerable members of society, which are meant to benefit from the right of access to information are largely left out, due to a lack of information, the positive features of the legislation providing for access to information are overshadowed by its shortcomings.

The experiences and challenges of Yabonga, a Cape-based organisation focusing on education and training in the context of HIV and AIDS, are introduced by **Ulpha Robertson**. Discussing the development of the project, since its inception; the changing focus of activities and programmes as a response to the changing needs over time; and the interrelating factors that ensure its sustainability, she argues that women living with HIV are inspired through continued good practice of encouraging independence and individuality in both its peer educators and clients.

Michelle O'Sullivan is '*making a point*' about the need of public involvement in legislative processes. Examining the meaning and implications of the constitutional court challenges to the Choice on Termination of Pregnancy Amendment Act, brought forward by Doctors for Life, she argues that it is imperative to comply with the constitutional obligation to facilitate public involvement, so as to avoid significant disruptions and limited access to termination services, and to ensure that women's constitutionally guaranteed right of access to healthcare, including reproductive healthcare, is not limited and/or denied.

While the sources of the information examined in these articles may vary, the common argument seems to be that the available information does '*taint*' and/or limit people's choices, rather than facilitate a process of informed decision-making, since information tends to be normative, prescriptive and value-based; and fails to take into account the societal context in which the information is accessed and decisions are made. Thus, despite an enormous amount of HIV information available, there seems little measurable impact, in that HIV infection rates are not decreasing, women remain to be at greater risk of HIV infection, and large-scale behaviour change does not take place.

This seems to raise the question as to whether or not

access to information does indeed carry the potential of informed decision-making and/or behaviour change. Acknowledging the lack of factual information and the gendered, unequal and often discriminatory societal context in which the information is accessed and decisions are made, the answer seems to be '*no*'. Even if people would have access to factual information that could facilitate informed choices, and possible behaviour change, the gendered and unequal context of society would still '*disallow*' people to make informed choices. Thus, as long as the societal context, in which information is heard, accessed and '*implemented*', is gendered, unequal, moralised and judgemental, decision-making will be based as much on the information as on the fear of judgement and '*condemnation*' – and the right of access to information, as the '*oxygen of knowledge*' leading to behaviour change, will remain but an ideal.

If we are to agree that access to information is imperative to make informed choices, then we need to equally agree that the accessed information needs to be '*liberated*' from its gendered, prescriptive, normative and judgemental nature. Similarly, if we are to agree that the content of the information is as crucial as the societal context in which the information is accessed and '*translated*' into action, then we need to equally '*liberate*' society from its gendered, prescriptive, normative and judgemental nature, so as to create a '*safe*' environment for individuals to make informed choices. And finally, if we want to believe that access to information does carry the potential to behaviour change, then we need to ensure that the societal context is '*accommodating*' to the implementation of the acquired knowledge – thus, outside the paradigm of gendered expectations and the concept of '*good*' and '*bad*' choices.

Hence, only as and when the information itself, and the societal context in which information is heard, accessed and implemented, are '*liberated*' from their gendered, prescriptive, normative and judgemental nature, will individuals feel '*safe*' to make informed choices, and '*liberated*' to change behaviour. Until then, the limited access to information will manifest itself in limited access to, and realisation of, other fundamental human rights and freedoms; in the gendered nature of the HIV and AIDS pandemics; as well as in continuing HIV-related stigma, discrimination and violation of rights; whilst the '*liberated*' few, who have access to information and make informed choices, will continue to be judged and '*condemned*'...

Johanna Kehler

There are a couple of important points to keep in mind when looking at these campaigns. Firstly, Khomanani is a government sponsored campaign that aligns itself with the current ‘strategic plan’. Secondly, there are slightly different ‘target markets’ for these various campaigns. Soul City has a broad health mandate, and thus, does not only deal with issues of HIV and AIDS – in fact, its most notable successes have been around domestic violence and the Domestic Violence Act⁷. loveLife is specifically aimed at youth, defined as 15-24 years old⁸, and takes a slightly different approach, in that basic information is not part of their messaging. In fact, as Collinge [2005:206] commented,

...messaging in the mass media is non-didactic and sometimes extremely indirect...In loveLife’s main print materials, the major elements of HIV transmission and sexual practice are seldom systematically presented... The programme’s designers say the purpose of outdoor media is to spark a national conversation – which will not of itself produce behaviour change and must be backed by more content-heavy communication.

Messages

The messaging of the campaigns, whether directly in Soul City and Khomanani, or indirectly as with loveLife, still stress HIV prevention messages that revolve around the ‘ABC’ (Abstain, Be faithful, Condomise) or variants of that, preaching delayed sexual debut, reducing the number of partners, and then, if desperate, using a condom. The various shortcomings of this HIV prevention approach have been documented previously in this publication⁹ and will not be covered in this article. Suffice to say, few of the campaigns and little of the information (save for some of the Khomanani brochures) present basic HIV definition, transmission and prevention information in a way that is inclusive, easily understandable and non-discriminatory.

For example, both loveLife and Khomanani, aim their HIV prevention campaigns at ‘the youth’. There are a number of false perceptions that could, and sometimes do, occur as a result of this, such as a misconception that HIV is something that only infects ‘young’ people, when one of the highest climbing rates of HIV infection is with people over 50 years old¹⁰. Another misconception created is that if people ‘save’ themselves for marriage, and get through the risky teenage years, then sex will be safe. This notion is also highlighted in the number of people, who report using

condoms within a marriage (17%), as compared to outside marriage (51,9%)¹¹. Yet, recent research has shown that another climbing rate of HIV infection now exists amongst women who are married and are faithful to their partners¹². Thus, the information, which is accessible, seems to create false perceptions, rather than providing a person with the necessary information needed to make a free and informed choice. It could also be argued that information skewed towards ‘youth’ is discriminatory.

Another discriminatory notion is that the lack of information relevant to people, who chose not to engage in heterosexual sexual activity – campaigns generally focus on ‘taking your relationship to the next level’ and depict heterosexual couples. This bias towards heterosexuality impacts on the ‘ability’ of a person to access relevant information, and hence, the extent to which a person is in the position to make fully informed choices around sex and health issues.

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And even though stigma and discrimination are identified as major barriers in accessing HIV-related services, including information that could aid in HIV prevention choices, there is very little information pertaining to human rights, how they relate to the realities of HIV and AIDS, and how a person could seek recourse if their rights have been violated – something which may be of vital importance, considering the conditions of the societal context in which HIV and AIDS is such a pandemic.

The HIV and AIDS and STI National Strategic Plan for South Africa 2007-2011 identifies major contextual factors as poverty, gender and gender-based violence, cultural attitudes and practices, stigma, denial, exclusion and discrimination, mobility and labour migration and informal settlements.¹³ These contexts of the HIV and AIDS pandemics also describe the environments, in which the messages contained in these campaigns are heard. There is, arguably, a question as to whether or not any message, short enough to be on a billboard or in an advertisement,

can have an impact on people's choices around sex and health. As Kelly, Parker and Lewis [2001:6] point out:

The point is that behaviour is complexly determined and this makes a mockery of the expectation that appeals to change would have their intended outcomes.

Impact

Whether or not the messages actually make a difference in the choices people make is something that is almost impossible to measure. Kincaid (2004) notes that the people sampled, who access the information, are already biased towards making a change of behaviour in the first place, and that the only way to really measure impact is by conducting an experiment in a parallel universe.

Since no parallel universe exists (that we know of), we have to work with what we can measure, such as the exposure of people to the information that is conveyed by these three major campaigns. loveLife claims national coverage¹⁴ and that 85% of respondents know about it, though this is more urban (93%) than rural (75%). Khomanani puts its exposure rate at millions – 25 million, which is about half of the population of South Africa, but that is in relation to recognising the logo¹⁵. The literature reviewed did not indicate the scope of Soul City's exposure. Between the three programmes, it could be argued that there is significant exposure to information that is accessible across a variety of media forms, and supported, in most cases, by face-to-face and community-based interventions.

Does exposure cause a change in the choices people make though? There are many reports¹⁶ claiming that media 'marketing' of information has an impact on people's behaviour, but it is difficult to measure the actual impact on people's choices.

For example, 74% of people surveyed who know about going for an HIV test to 'take your relationship to the next level', only 7.3% say the message made a difference in talking about testing with their partner.¹⁷ The same research indicates in a response to a range of questions that awareness about an issue only translates into a change of behaviour/choices for between 3 and 16% of the people surveyed. While there seems to be some change in behaviour, it could also be argued that the impact is minimal for the amount of resources and effort that is expended.

loveLife's national survey¹⁸ indicates that 37% of youth

surveyed say they have not changed their behaviour; that 31% of youth still believe that using condoms is a sign of not trusting your partner; and that

...among sexually active young people 67% continue to think of themselves as being at low risk for HIV infection. 54% of young people who indicated never using a condom with their last sexual partner feel they are at low risk of infection. [Pettifor et al. 2004:56]

The same survey also highlights that 'just under two-thirds of youth reported knowing of any national HIV programmes/campaigns' [Pettifor et al. 2004:63]; and that 32% of the people surveyed say that the main source of information about HIV and AIDS was the school.¹⁹ All of these facts, as could be argued, are indicators that these campaigns have a minimal impact on the behaviour of the people that they are 'targeting'.

...Soul City, in over 10 years of programming, shows that the uptake of the messages of condom use ... only increased from 58 to 64%...

This is further evidenced in loveLife's 2004²⁰ report, which states that 67% of young people, aged 15-24 years, who are sexually active, say they haven't had sex in the last year, not out of choice for safety, but because there is no one available to have sex with. In addition, 63% of youth surveyed say that they have changed their behaviour to avoid HIV, without saying why. These responses, arguably, reveal that the 'desired' behaviour change is not actually taking place.

It is important to note that this impact on behaviour change is not confined to the loveLife campaign. Soul City, in over 10 years of programming, shows that the uptake of the messages of condom use and asking your partner to use a condom, only increased from 58 to 64% and from 59 to 69% respectively.²¹

And Khomanani claims that

...the campaign was effective in increasing HIV testing and dialogue about testing between sexual partners [but] Actual testing among couples is still uncommon. [Johnson et al. 2006]

The rate of uptake on specific messages, such as HIV

treatment literacy, is also unfavourable – of the 63% of people who said they heard the message; only 5% translated that into action.

These facts and figures prove that although there may be some impact on people's choices as a result of the information disseminated in these campaigns, the impact is not significant, complicated by the fact that direct impact of the campaigns is almost impossible to measure accurately.

A number of the studies point to multiple exposure, as in exposure to messages from a variety of sources, and combined with community-based or face to face interventions, as a key to increase the likelihood of behaviour change.

*Significantly, this strong association between loveLife services and lower rates of HIV could not be shown for young people who were only exposed to the television and radio components of loveLife – suggesting that face to face interaction is critical for large-scale behaviour change.*²²

Conclusion

Considering the scale of information dissemination and the minimal impact, what remains seem to be not so much a question as to whether or not the means of disseminating information is incorrect, but rather a question about the type of information disseminated. Do billboards showing messages, such as 'take your relationship to the next level', or 'I know my status, do you?', or '2010, love to be there' really provide access to the kind of information required to make an informed choice? It would seem as if they do not. These messages certainly fail to provide the facts required to make an informed choice. Moreover, there is little information in the messaging that addresses the context in which the decisions are made.

It could be argued that what is missing is creating a context in which the messages can be heard, and a context in which accessing information is just that; accessing factual information, rather than being subjected to messages pushing a specific agenda. It could also be argued that the context, in which this could happen, would be a context in which the fundamental human rights of equality, non-discrimination, dignity, and freedom of choice are respected and protected. And perhaps then there would be a space for all people to make free and fully informed choices.

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Nonhlanha Mkhize

Embracing and resisting change...

Culture as a source of information in the context of HIV and AIDS

Every year in KwaZulu and Swaziland, 'virgin' girls come out in numbers to attend the 'Umkhosi Womhlanga' (reed dance). In winter of every year, we read of many Xhosa boys, who are either almost dead or dead while gone 'ukuyakuluka ezintabeni' (for male circumcision in the mountains). Despite all criticism (positive and negative) about these; what they mean and what each possibly perpetuates; and the role each plays in the modern world – these cultural practices remain important to the relevant communities.

Aware and unaware, people are groomed to understand and believe that they subscribe to a particular culture – the significant aspects of it are known. People are aware of how they are expected to behave, dress and even speak in order to fit within the various 'cultures'. But has this socialisation around behaviour considered diseases like HIV, and how it can begin to curb – if possible – the rates of new and repeated HIV infections?

This article is aimed to share thoughts on the concept of 'culture'; its role as one 'source of information'; what cultural information is accessed and how, as well as how this cultural information influences people's informed choices or decision-making within the context of HIV and AIDS, and at times defines people's risk of HIV infection.

What is culture?

I took a moment and went through the couple of dictionaries at my disposal, questioned the youth at my organisation's common room, chatted to a few people on the bus and then looked at the online *Wikipedia's* (world encyclopedia), which explained that

...*culture is an adaptation of the Latin word cultura stemming from colere, meaning 'to cultivate'*¹.

I wondered if this could be understood to mean that through culture people are cultivated – assisted to grow in a certain way; make sense of things from a particular point of view; believe in and be guided by certain principles referred to as morals and values of their families, society and even by their particular grouping (affiliated into either by race, religion, class or by birth). I wondered what bearing this definition had within the context of HIV and AIDS; what it was and how people lived with it.

The *Wikipedia* also defined culture as generally referring to

...*patterns of human activity and the symbolic structures that give such activity significance. Different definitions of 'culture' reflect different theoretical bases for understanding, or criteria for evaluating, human activity. In general, the term culture denotes the whole product of an individual, group or society of intelligent beings. It includes technology, art, science, as well as moral systems and the characteristic behaviours and habits of the selected intelligent entities. In particular, it has specific more detailed meanings in different domains of human activities.*²

I have tended to think of culture with regards to who I am – a black, Zulu, woman who subscribes to 'Zulu Culture'. I also belong to and, thus, also subscribe to, the Mkhize and Ndlovu family traditions. Through my exposure to anthropology, I have learnt that culture goes way beyond this. It is about the 'way people live and engage with other living things based on what they understand and believe' (language, expression and experience – history, the way things are interrelated or interdependent; certain ways of doing things, the way we dress, etc.); lessons aimed at informing the basis of our understanding of human kind,

life, and making sense of why things are the way they are in the world.

For Goodall (1986), as quoted in *Wikipedia*, a ...common way of understanding culture is to see it as consisting of four elements that are 'passed on from generation to generation by learning alone': values; norms; institutions and artifacts.³

I would like to spend time on the analysis of these, as they bring us closer to understanding 'culture as a source of information', and how it is accessed and even implemented within the HIV and AIDS context.

...it is about the 'way people live and engage with other living things based on what they understand and believe'...

From listening to people talk, going through some organisational founding documents and reading from various authors, I have come to understand and share Goodall's (1986) definitions of values, norms, institutions and artifacts. In summary, **values** are **ideas** about what is important and **standards** by which a person's behaviour is judged. **Norms** on the other hand, seem to comprise **behavioural standards expected** from a person at various situations. At this point it will seem important to mention that with norms are also what Goodall (1986) calls 'sanctions' – the cultural methods of enforcing these norms. Goodall (1986) is also quoted in *Wikipedia* defining **institutions** as 'structures of a society within which values and norms are transmitted'. They are the vehicle of cultural civilisation. For me, these institutions are, at times, authority figures and even courses, expected to teach, guard, protect and promote culture. For example, the Zulu King is argued to be the custodian of Zulu Culture. Zulu lessons are not supposed to be about the language only, but also the transmission of culture. If we go abroad, the British and Swaziland monarchies are structures of society within which values and norms are transmitted. **Artifacts**, as defined by Goodall (1986), are

...things, or aspects of material culture – that are derived from a culture's values and norms.

How is culture accessed?

Culture is accessed through various ways; the simplest, more prevalent and commonly known format being socialisation. It is common knowledge by now that culture is 'passed on from generation to generation by learning'. People learn from what they are told (i.e. direct conversations, stories or folk-tales) and through what they see being done (and learn exactly how it is supposed to be done – the manner, the skill, the art and so on). People learn when they are reprimanded. People learn through experiences; if someone in the family is ill, people learn of the appropriate way to attend to, and deal with, illness and the person (and even death) through how those older than them respond to the situation – the expression of emotion, language use, tone, manners, attention to detail and so on.

Experimental learning of culture is also through association, who people are socialised to know as ideal or best company (be it according to age, class, gender, religion, education, personality and even interests), to associate with and how – the dress code, the manners through which to conduct the self, the language usage and even the format of the actual conversations. These, it seems, say a lot about who you are and if you are cultured.

Through working with different communities and groups, what seems to be cross-cutting in how each primarily accesses culture, the emphasis is more on the specific activities undertaken and if this were as per expected behaviour. These are the unwritten rules and regulations, rights and responsibilities and sanctions that are aimed at instilling certain **values** onto a person so they know, think, act, respond, believe and live as prescribed by their particular culture – they know who they are, where they belong, and how to exhibit that.

But culture is also becoming more and more accessible through written work, from lessons in learning institutions, history books and encyclopaedias. It is becoming more accessible through cultural exchange programmes (within schools, between schools and even countries e.g. 'Africa Day') and through media (e.g. articles, radio and TV programmes, like SABC Africa (SABC2), Curious Culture (SABC2), the Discovery Channel (DSTV), and even some series and soaps like Muvhango (SABC3), Isidingo

(SABC3) and *Roots* (SABC2). These expose people to various societies in the world, and inform who they are, how they live, what they do, what they eat, their kind of music, past-time activities, and what is not in their culture to do or be engaged in.

Knowledge about culture is also accessed through people's responses to what they read, hear or see. For example, SABC recently screened a four-part documentary on HIV and male circumcision in the Xhosa culture. There was uproar from Xhosa leaders about the misrepresentation of cultural facts about the male circumcision practice in the documentary, which was a learning curve. This cost the SABC a cow to apologise. The debate-orientated shows like *Asikhulumbe* (SABC1) and *Big Question* (SABC 2), which also allow the public to either be part of a studio audience or call/sms in, have previously debated topics like virginity testing, termination of pregnancy, same-sex marriages, commercial sex work and HIV – all based on cultural norms and values and the concept of 'Africanness'.

...I came across people who still held on to some of the myths, misconceptions and stereotypes held a long time ago about the relationships between parents and children; the role of women and men in society; but also the origins of HIV and how it is transmitted...

Questioning some youth and elderly about culture, how they have accessed it and how they have either used it or see it as a source of information within the context of HIV, I was shocked at some of the responses I received. The shock was not so much based on what I heard, but the fact that 13 years into a new era of democratic dispensation, I came across people who still held on to some of the myths, misconceptions and stereotypes held a long time ago about the relationships between parents and children; the role of women and men in society; but also the origins of HIV and how it is transmitted. Despite all the exposure and all the debate, there is a lot of information that has been accessed

through cultural socialisation that remains somewhat unchanged, unchallenged – worth a serious challenge in educating and engaging society in dialogues about HIV.

Culture as a source of information within the HIV and AIDS context



A 19th century engraving showing Australian 'natives' opposing the arrival of Captain James Cook' in 1770.⁴

In Anthropology, 'culture' is most commonly used to refer to the universal human capacity to classify, codify and communicate their experiences symbolically. On the basis of the Mexico Declaration of 1982, culture can also be broadly understood to include:

...ways of life, traditions and beliefs, representations of health and disease, perceptions of life and death, sexual norms and practices, power and gender relations, family structures, languages and means of communication; as well as arts and creativity.⁵

'Culture, by **predisposition**, embraces and resists change, depending on its traits'.⁶ Sex talks at home were taboo in the past, but in our time, as most people have agreed, there is a need for open, honest and informed talks between parents and children about sex, human sexuality, gender and disease. Where do babies come from? They are not delivered by storks or aeroplanes. They do not just pop-out of a woman's vagina either. We need to talk about our bodies and the meanings they embody; to understand and

even appreciate what is (and is not) true about our bodies. Why do girls menstruate? Why are women said to be physically more vulnerable to getting sexually transmitted infections than men? How to use condoms? Why talk about sex?

...many are quick to argue that if they teach their children, then what will the teachers do? Or, that they are paying for TV licences and expect TV programmes to provide the necessary education and information...

Not many people know the

...difference between human/individual character development information accessed through culture and career orientated information accessed through education in school⁷.

As a result, many people do not take the blame for the breakdown in the transfer of culture and very important cultural systems and meanings that are crucial for human and individual growth and development – all that is important for someone who is trying to make sense of life, relationships and disease. Many are quick to argue that if they teach their children, then what will the teachers do? Or, that they are paying for TV licences and expect TV programmes to provide the necessary education and information.

Information accessed through culture has a deeper meaning as it contributes to the ‘*who one is*’, as compared to the career-orientated information accessed through education, which is aimed at providing a person with the necessary tools required for the specific career of choice. One great thing about culture is its use of myths to educate. These narratives are constructed to provide meaning about various aspects of life (including disease) and guide behaviour. They are beliefs, adopted by a culture, in order to organise and make sense of things in an unpredictable world.

‘*Testing*’ (consulting a Sangoma or a Traditional Healer) is not taboo and has existed within society for generations.

In our context, testing for specific diseases is conducted in hospitals and clinics. The services of counsellors and psychologists are very similar in meaning to those of traditional peer leaders – save for the form in which the practice or activity is conducted. These are manifestations of cultural **diffusion**.

We see this within academic environments where authority figures are encouraging the fusion of education and testing for HIV and other disease as normal practice within the institution’s culture. In his address to mark the official opening of the academic year 2002, the Vice Chancellor of the University of South Africa, Barney Pityana, said:

I have suggested that the university should provide confidential testing and those moved to declare their HIV status should feel free to do so on the understanding that they can be guaranteed support and understanding. I understand that HIV/AIDS remains a deep secret within our institution. Hopefully we shall be able to break this taboo.

What does all this mean for cultural practices, like male circumcision and female virginity testing? Is there a need to re-narrate the myths, in that the meaning of the practices does not change, but the manner in which they are done? What does this mean for health organisations and their current HIV programmes? Is there a need to consult traditional leaders and communities in developing such programmes? When it comes to sex, can the moral of the story be normalising sex talks and even ‘*inspecting*’ your sexual partner’s private parts?

Yes, there are no simple answers and solutions to questions and problems that are rooted in culture. Thus, a **holistic** approach to the study and understanding of cultures and their environments (i.e. the context in which people live and how people live over time) is needed. This is important in understanding the epidemic. These are sentiments shared by Raphael Tuju, a Kenyan reporter, who in October 2006 delivered a talk to staff at AIDSCAP’s headquarters in Arlington, Virginia, about the need to understand the HIV and AIDS epidemics in its cultural context.

For Tuju, sensitivity to culture is inclusive of messaging about HIV and AIDS. He found himself unable to explain that

... 'AIDS is a problem caused by a virus called HIV, which goes into the bloodstream and affects your body's immune system' when you can not translate basic terminology – like 'germ' or 'virus' – into your mother tongue. ...solutions to cultural practices that put people at risk of HIV infection are even harder to come by. The cultural practice of having a wife being inherited by the brother of the late husband which is supposed to cleanse her of her dead husband's spirit is still very much alive. This ritual requires widows to have sex with a brother or other male relative of their husbands, and sometimes to marry them. This is difficult to disregard.⁸



What this article merely reiterates is the fact that culture is a pattern of human activity and the symbolic structures that give such activity significance to members of that group; that its beliefs, attitudes, values, norms and knowledge about the ways of life, traditions, representations, perceptions, practices, power relations, languages and arts that are an integral part of who a person is; that information accessed through cultural systems has a deeper meaning in a person's life, than that accessed through education at school; and also that myths continue to be a central component of the 'glue' that holds a culture together.

According to the UNESCO:

- There are many **different ways of contracting** HIV,
- There are just as many **different ways of preventing** HIV/AIDS,
- There are many **different groups of people** exposed

to HIV/AIDS,

- There are many **different ways of discriminating** against people living with HIV/AIDS,
- The **WHYs, HOWs** and **WHOs** change from **CULTURE** to **CULTURE**,
- We need **culturally-appropriate responses to HIV/AIDS prevention and care.**⁹

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FOOTNOTES:

1. [<http://en.wikipedia.org/wiki/Culture>]
2. Ibid.
3. Ibid. See also Goodall, 1986.
4. Ibid.
5. Culture and HIV. [<http://www.unesco.org/culture/aids>]
6. [<http://en.wikipedia.org/wiki/Culture>]
7. Ibid.
8. Family Health International.
9. Culture and HIV. [<http://www.unesco.org/culture/aids>]

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Johanna Arendse, Johanna Kehler

Are schools adequately equipped...?

Sex and HIV education at schools

HIV infection rates are seemingly ever increasing, especially in the age group 14 – 24 years, despite all the HIV awareness targeting the youth. HIV information is available and accessible to youth through various means, including radio, television, churches, print media, youth centres, clinics, schools and homes.

Recognising the apparent gap between HIV prevention efforts focusing on the youth and the limited impact on HIV infection rates amongst the youth, arguably, raises the question as to the adequacy of the information available, as well as its accessibility.

It could be argued that sex education should start at home. However, this belief is accompanied by a lot of challenges, since in most homes, sex is ‘*taboo*’ and, thus, not discussed or talked about. While the reasons may vary from home to home, there seems to be some common reasons for not talking about sex, including that parents and/or caregivers:

- feel uncomfortable talking about sex.
- have insufficient information
- tend to disseminate incorrect information, such as ‘*bought the baby at the hospital*’
- are not ‘*permitted*’ by their culture and religion to talk about sex.

Thus, a child already starts at a disadvantage, since the reluctance and ‘*inability*’ to talk about sex is often linked to the lack of adequate knowledge and information about HIV and AIDS. Therefore, the home is, arguably, not ‘*equipped*’ to provide adequate sex and HIV and AIDS education.

Similarly, the argument can be made that access to sex and HIV information is a responsibility of the school system – but are the schools adequately ‘*equipped*’ to provide this information? This article will look at some of the aspects of the education system and explore the adequacy and accessibility of sex and HIV and AIDS education at schools.

At school

While the Constitution¹ guarantees the rights to access

to information (Section 32), the National Education Policy provides specifically for HIV and AIDS information to be afforded at schools. The education system provides for HIV and AIDS information as part of the life skills programme at all schools, stating that HIV and AIDS information

*...should be integrated into Life-Skills programme and should be age appropriate and accurate... parents should be informed of this programme.*²

If the Life Skills programme is the means by which learners are to access information on HIV and AIDS, the question arises as to whether or not educators are ‘*equipped*’ to provide all the ‘*factual*’ information, as compared to ‘*moral*’ information, that learners need to know so as to ensure informed decision-making. In addition, it raises the question as to whether or not educators are in the position to facilitate adequate transfer of knowledge pertaining to the advantages and disadvantages of HIV prevention choices, HIV testing, and HIV disclosure. It also has to be noted that while life skills programmes are part of the learning areas, it is parents who make the decision as to whether or not their child participates in discussions about sex and sexuality.³

The reasons as to why sex is not discussed in the home are, arguably, the same reasons defining whether or not a learner will be part of the life skills programme at school. In other words, the cultural and religious value, norm, belief systems of the home impact, and at times, limit the extent to which a child has access to sex education and information on HIV prevention, testing and disclosure.

Similarly, the educators, which are meant to be a source of ‘*accurate*’ information, are also defined by their own cultural and religious value, belief and norm systems. This, arguably, impacts directly on the kind of information reaching the learner. Thus, the biggest challenge, seems to

be that the programme is taught by

...teachers uncomfortable and intimidated by the thought of standing in front of a class to talk about sex.⁴

If educators are ‘*uncomfortable and intimidated*’, then what impact can this programme have on informed decision-making of young people? Similarly, the question needs to be raised as to the value, ‘*correctness*’ and adequacy of the information shared.

...the question arises as to whether or not educators are ‘equipped’ to provide all the ‘factual’ information, as compared to ‘moral’ information...

Schools are a part of our communities. Schools not only operate within the community, but also often reflect the sentiment of the community, since what happens in the community often affects what happens at school. And these same links can be applied in the context of HIV and AIDS. Thus, the common perceptions of HIV and AIDS, as well as of people living with HIV, found in the community are also found within the school environment.

Policies responding to the challenges of HIV and AIDS in the school environment are aimed to ensure that:

- Right of learners and educators are respected
- Learners and educators living with HIV/AIDS are managed appropriately
- Further HIV infection is prevented
- Non-discriminatory and caring learning environment is created.⁵

It is the understanding that all education institutions should have a policy dealing with the management of HIV and AIDS. Moreover, it is the aim of such policy to protect people living with HIV. However, these policies do not address the HIV and AIDS realities and challenges in the community, nor the context in which the school is operating. Thus, the policy, even if implemented, has limited scope to protect learners and educators living with HIV, when they are abused and their rights are violated,

since the perceptions and views of the community seem to override legislative and policy provisions.

Policies are often based in a context of managing HIV and AIDS ‘*appropriately*’ and creating a ‘*non-discriminatory and caring learning environment*’. This seems to raise the question as to how HIV and AIDS can be managed in an environment in which learners and educators living with HIV are discriminated against. In many instances, the learner (or their parents/care givers) or the educator will have to first disclose her or his HIV status, in order for the school to be in the position to manage HIV and AIDS ‘*appropriately*’. In other words, it seems that only as and when the school is aware of the learner’s or educator’s HIV positive status, will the school be in the position to create a ‘*non-discriminatory and caring learning environment*’. Since people who disclose their positive HIV status receive, more often than not, a discriminatory and non-caring response, it could be argued that for schools to manage HIV and AIDS ‘*appropriately*’, the school environment needs to be ‘*non-discriminatory and caring*’ – not because, but irrespective of the HIV positive status of learners and educators.

Out of school

Acknowledging the challenges for youth to access correct information, within the education system, seems to also raise the question as to how and where youth is in fact accessing information. While some have access to the mass media, others access information through health services, since for many young people the ‘*first*’ exposure to information about sexual and reproductive health issues is linked to attending family planning and/or STI clinics. This will also be the first time that the person will be confronted by healthcare workers offering an HIV test. If the young person never had adequate access to factual information about HIV and AIDS and is confronted by a healthcare professional, who strongly believes that it is in the best interest of the patient to test for HIV, the ‘*uninformed*’ youth is likely to take an HIV test – at times, ‘*unprepared*’ and ‘*uninformed*’ about the implications of taking an HIV test.

In addition, it is important to bear in mind that healthcare centres are not frequently visited by the ‘*informed*’ youth

either, not only due to the lack of ‘youth-friendly’ clinics, but also due to the attitudes and judgmental behaviour of many healthcare workers. Indeed, young people’s rights are often violated in that healthcare workers share patients’ information, including an HIV test result with friends and colleagues. Subsequently, the ‘informed’ youth has limited access to services, including further information, due to fear of judgement and the lack of confidentiality.

Considering that there are so many challenges for young people to access correct information about sex, sexuality and HIV and AIDS, it seems obvious that young people opt to access information from their peers. Thus, ‘sex education’ often occurs amongst young people, perpetuating misconceptions about sex and risks of HIV transmission, rather than correcting the information.

Remaining challenges

One of the biggest challenges seems to be that while there is plenty of information available, young people seem to be at a disadvantage in accessing the available information, due to various reasons, including the school environment, which is often discriminatory and non-caring; educators, which are ‘inhibited’ by their cultural and religious value, norm and belief systems to facilitate access to information; as well as the community context, which is, at times, counter-productive to the information accessed at school.

Below are some thoughts of how to address these challenges:

- Raise awareness/educate parents and caregivers – since parents/caregivers are set in their beliefs, cultures and religions, schools, healthcare centres and community at large needs to take equal responsibility for facilitating this process.
- Start sex education as early as possible at school and at home
- Involve young people in the decision-making about what programmes are needed to address issues of sex, sexuality and HIV and AIDS – these programmes have to be developed and implemented at school and at the community level.
- Train and sensitise educators and healthcare

workers on ‘youth-friendly’ information dissemination and service provision.

- Raise awareness/educate communities on fundamental human rights and specifically the right of young people to make informed choices about sex, sexuality and HIV and AIDS
- Provide factual, inclusive and non-judgemental information and services

...only ... when the information provided is ‘correct’ and ‘free’ of cultural and religious values ... will young people be in the position to make informed choices about sex...

In summary it is argued that only as and when the information provided is ‘correct’ and ‘free’ of cultural and religious values, norms and beliefs, will young people be in the position to make informed choices about sex, sexuality and HIV. Similarly, only as and when schools and communities are ‘non-discriminatory and caring’, will there be a possibility to manage HIV and AIDS ‘appropriately’ – based on fundamental human rights principles of equality, non discrimination, dignity and equal enjoyment of all rights and freedoms.

FOOTNOTES:

1. Constitution of South Africa, Act 108 of 1996.
2. 2004 National Curriculum Statement on Life Orientation.
3. Ibid.
4. Personal conversations with Life Skills educators.
5. WCED HIV/AIDS: Know your rights and responsibilities. [http://wced.wcape.gov.za/planning&dev/support/special/ed/hiv_aids/info_2003.html]

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The intention is good, but...

Religion as a source of information in the context of HIV and AIDS

This article will address the role of religion and explore the extent to which the information of its messages influences the stigma around HIV and AIDS. As an ordained practising minister of religion I am more familiar with Christianity, than the other religions and more specifically with the reformed version of Christianity. However, despite my particular, rather than universal, knowledge of religion, I believe that people from other religions will be able to recognise in Reformed Christianity similar mechanisms functioning in their own religions.

The informative message of religion

In my experience, religion has a paradoxical influence on stigma. Religion is the source and ultimate cause of the stigma, while, at the same time, religion also holds the key to propel people to an authentic stance of non-discrimination and holistic acceptance of people living with HIV.

The paradoxical nature of the message communicated is expressed through several endeavours of the church regarding HIV. In general, church people are keen to do things about the problem. Mostly the two sides of the paradox locate themselves simultaneously in a single expression or action. The single expression usually gives contradictory messages. For example, *'our hearts are open for those poor AIDS-sufferers'*.

The feeling about the intention is good, but the language (*'those'* and *'sufferers'*) suggests distance and implies that those terrible things do not happen here with us. Church people are keen to deflect the investigative attention away from themselves and make others the object of their charity. Schmid [2002:125] calls this attitude *'othering'*. My experience of churches in the southern suburbs of Cape Town is that they would rather do something for people who live with HIV at a distance, than provide for their own members who live with the same virus.

Another example is: *'What can we do for the innocent AIDS-babies?'* The feeling is benevolent, but the choice of a word like *'innocent'* exposes an underlying belief

that somehow someone had been guilty and those guilty adult(s) should not expect a kind welcoming from the church community.

My way of making my point regarding the general paradoxical influence of religion will be to describe two separate contradicting instances, in which the church expresses a message and, in other words, communicates information regarding its attitude towards HIV.

To illustrate the negative side of the paradox, I will describe the practice of church discipline – a practice effectively fuelling stigma – in the congregation of Lavender Hill, which belongs to the Uniting Reformed Church in Southern Africa.

In order to illustrate the positive side of the paradox, I will briefly analyse the core message of salvation, which is preached by the reformed church. The church and I assume, religion in general, preaches the equal value of all people. Because all people are equal before God, religious people know the deepest reason why all people should accept each other, as they are, and therefore, refrain from stigmatising each other and subsequently discriminating against each other.

Stigma and the risk of HIV infection

On a superficial level, it might seem as if the stigma would prevent many people from getting infected with HIV. It might seem as if the danger of becoming stigmatised should serve as a deterrent to stay away from what could

be regarded as risky sexual behaviour. This false argument is based on an equally erroneous idea that fear of religious and other punishment would motivate people sufficiently to refrain constantly from sexual behaviour that carries the risk of HIV infection. Over the ages, people have become and been sexually active in spite of fears. Realistic fears of social sanctioning, pregnancy, contraction of sexually transmittable infections (STIs), etc, have not kept people from sexual activity. Neither have unrealistic fears, however honestly believed, like the threat of impotence, hair on the inside of one's hands as a result of masturbation, blindness and even death, prevented people from engaging in sex. In the Biblical book Song of Songs 8:6, it is realised that the power of sexual desire and erotic love is a divine force and as strong as death itself. *'For love is as strong as death, passion cruel as the grave; it blazes like a blazing fire, fiercer than any flame'*². People seem to be compelled to be sexual beings at a very deep level.

...religion is the source and ultimate cause of the stigma, while, at the same time, religion also holds the key to propel people to an ... holistic acceptance of people living with HIV...

It is closer to the truth that the stigma makes it more difficult for people to protect themselves when they do have sex, and in this way, the stigma increases the risk of infection and fuels the spreading of HIV. Stigma makes people do several things that prevent them from effectively protecting themselves, for instance:

- People are reluctant to carry condoms with themselves as a matter of routine, or deliberately take any other measures to protect themselves against HIV infection, for fear of being seen as sexually promiscuous. In church circles, I was

told the joke that in the past one could loudly ask for a packet of 20 cigarettes and softly mumble something about condoms. These days however, one should loudly ask for condoms and mumble about the cigarettes. I wish the joke had actually reflected reality.

...church people are keen to deflect the investigative attention away from themselves and make others the object of their charity...

- Without a good excuse, like often stipulated in an application for a home loan or medical insurance, people are reluctant to go for an HIV test, because they are concerned that others might think that either they themselves, or their partners, have been sexually promiscuous. And unaware of their own, or the HIV status of their partners, they continue to infect others and/or become re-infected. People are also reluctant to have themselves tested for HIV, because they would rather not be confronted with what could be regarded as a reminder of their imminent mortality. I know people who postpone tests for blood pressure and cholesterol for fear of the possible results. HIV is even scarier.
- Stigma makes people to speak in veiled terms about sexuality, sex, and the risks of getting infected with HIV. The veiled nature of our language, with regard to these matters, makes it difficult for poorly informed, often young people, to sufficiently understand the mechanics of HIV infection. Warped perceptions about the ways in which HIV could be transmitted make people more vulnerable to infection. It is not rare to hear from young girls of about ten years old that they would worry about pregnancy if they had only

slept with a boy in the same bed, while slightly older girls tell each other that you can not get pregnant or contract HIV on the first time you have sex.

*...without a good excuse, like ...
medical insurance, people are reluctant
to go for an HIV test, because they are
concerned that others might
think that ... they have been
sexually promiscuous...*

If the stigma could be removed or even only reduced, besides the reduced risk of HIV infection, other positive things could also happen:

- The first motivation for stigma reduction could find its way into a public healthcare textbook. People who do have HIV in their bodies already, would be more likely to get tested for HIV earlier in the process of the disease; have more time to prepare themselves adequately for living with HIV; seek medical and other help sooner; and live longer productively.
- Another good reason for stigma reduction is almost simply common sense: The general quality of life (call it '*happiness*' if you like) of people living with HIV, would be improved.

The pillars of HIV-related stigma

The stigma around HIV has three pillars, namely the

- Fear of contamination
- Taboo on death
- Taboo on sex and sexuality

Contamination: People tend to avoid others who have been unfortunate. The fear need not be rational, as might

be in the case of the contagious and common influenza virus. Disease is emotionally experienced as dirty. Even if factual information about HIV brings people to understand that only '*blood onto blood exposure*' and '*unprotected penetrative sexual contact*', are forms of engagement that can better be avoided with people who live with HIV, it does not always take all the fear and subsequent avoidance away.

Ubuntu Ministries³ organised meals in people's homes where community members who were unaware of their HIV status, invited others of whom it was known that they lived with HIV, and a couple of community members who were chosen at random. Hosts would often confide a few days after the meal that they had made the water extra hot and used a bit more soap to do the dishes '*just to make sure*' and perhaps also '*for the sake of their children*'.

Death: HIV has long been seen as a death sentence. This perception still carries a lot of truth in cases where people lack the resources to live healthily and cannot access medical treatment. Pharmacology's ability to postpone the onset of AIDS has done a lot to soften the death sentence. However, people still tend to avoid others who have been diagnosed with an ultimately incurable disease. Those who live, can never fathom death and never completely shake off the illusion that their lives will continue forever. Therefore, they are naturally filled with fear when confronted with the mortality of people with incurable disease. The fear of death is translated into avoiding those who have been diagnosed with HIV.

*...people still tend to avoid others who
have been diagnosed with an ultimately
incurable disease...*

Sex and sexuality: HIV is associated with sexual behaviour outside the confines of monogamy – of either the person in question or his or her sexual partner. For

many people this constitutes behaviour that is condemned from a religious perspective and a moral problem – and problems are mostly and preferably avoided. HIV can also remind people of their own ‘*transgressions*’ and/or the possibility of ‘*transgressions*’ by their partners. These unpleasant thoughts are mostly avoided, rather than faced. Besides the moral link that many people make, and the religious condemnation, which it evokes when they encounter someone diagnosed with HIV, the very existentially sensitive nature of sex and sexuality makes it into a complex issue for people to deal with. So again, the tendency of human nature to prefer the way of least resistance and difficulty, manifests itself.

...HIV counselling and testing take place behind closed doors in the township clinics, but if one has gone through ‘that door’, everybody ‘knows’ in any case, even before one gets home...

I know a parishioner personally who received the logical advice from her doctor to go for an HIV test, after she was diagnosed with Tuberculosis for the second time. She is unmarried, a bit shy, and said that she had never had a boyfriend. She was adamant about not getting the HIV test, because it would ruin her reputation in the community. HIV counselling and testing take place behind closed doors in the township clinics, but if one has gone through ‘*that door*’, everybody ‘*knows*’ in any case, even before one gets home. She fully understood that she was putting her health and life at risk, but chose social survival for a while, above a physically healthy life, without the approval of her community. I had to respect her choice.

What I want to say with the ‘*pillars of the stigma*’ is that the process of stigmatisation and subsequent discrimination is humanly understandable and, therefore, difficult to overcome. Removing the stigma requires special efforts.

The paradoxical messages of religion

Religion plays a largely negative role regarding the stigma through its restrictive attitude to sex and sexuality. The positive role of religion can be sought in its power to relativise death and the energy it provides to motivate people to overcome their naturally understandable tendencies to avoid what could superficially be regarded as ‘*difficult*’, ‘*dangerous*’ or ‘*unfortunate*’. In other words, besides its exacerbating effect on stigma, religion also has the power to overcome the discriminating effect of stigma.

The restrictive attitude of religion towards sex and sexuality

In the Christian tradition, the commandment ‘*You shall not commit adultery*’ is generally interpreted as meaning ‘*You may only have sex within marriage*’ or slightly stricter ‘*You may not have sex, except within marriage*’. Any form of sex outside the boundaries of marriage, is condemned – with a few exceptional churches, in which monogamous homosexual relationships are ‘*accepted*’ – or maybe the more accurate word would be ‘*tolerated*’.

Conservative churches would even condemn masturbation, while less conservative churches would remain silent on issues like masturbation.

The basic story behind the Biblical approach to sex and sexuality is the one about Adam and Eve eating from the tree of knowledge of good and evil (Genesis 3). The fruit is obviously the ‘*forbidden delicious fruit of sex*’. The Biblical Hebrew word for sexual intercourse in the sense of ‘*penetrative sex that can lead to pregnancy*’ can also be directly translated with ‘*know*’. (‘*Adam knew Eve, his wife, and she conceived and bore Cain*’. Genesis 4:1) The heading that most translations have added to this story of how the snake (another obvious sexual symbol) seduced Eve, and Eve on her turn, seduced Adam to eat of the forbidden fruit, is ‘*The Fall of Mankind*’.

The general message that is mostly deduced from this story is that, amongst all the different sins, sex is

primary and basic to all other sins. And women carry the primary responsibility for the entry of all evil into the world. Theologising has attempted to relativise the crude interpretation of the story with little effect on the collective consciousness.

...any form of sex outside the boundaries of marriage, is condemned..

There is variance amongst different churches regarding expressions of sexuality through clothing that is considered suitable for women, and activities, like dancing. My church, the Uniting Reformed Church in Southern Africa (URCSA) congregation of Lavender Hill is relatively lenient when it comes to everyday expressions of sexuality, like clothing and dancing. However, the norm regarding sex is simple and strict: Sex is for marriage only. Masturbation is not spoken of. There is no clarity as to how intimate kissing and mutual touching is allowed to be before marriage. In my church, marriage is not primarily understood as a state of being, which is constituted in a church ceremony. The general norm for marriage is the civil contractual institution, which is offered by a state to people in its area of jurisdiction, regardless of their citizenship. Even though the law book, the Church Order, officially allows customary marriages, in practice, only people who are legally married are considered to be married.

In my congregation of about 200 adults and 300 children, it happens on average about 4 times per year that an unmarried adolescent girl wants her baby to be baptised. A situation like this is a typical example of an instance, when church discipline would be applied. The church would only allow the baptism, after the mother has submitted herself with suitable remorse, to a disciplinary procedure, lasting for about three months. The mother's sin would be recorded as 'extra-marital intercourse'. For the duration of her period of discipline, she would be excluded

from the sacraments (baptism and holy communion); forfeit her voting powers as a member of the congregation; and be excluded from positions of leadership. She would be expected to regularly attend church services and pay her monthly contributions to the church. If her supervisory elder is satisfied with her cooperation, the church council would lift the discipline and she would be allowed to have her child baptised.

In the process of discipline, the mother would appear before the church council at the onset of the discipline, and at the end of the period. Council members would have the opportunity to pose questions to her, mostly about her intentions to marry the father of her child, and she could respond. A typical role of the minister of the church would be to stress the purpose of the discipline, namely to draw the mother closer to the influence of the church.

Many pious and caring words would be spoken when the mother appears in the council meeting. The intent to punish would even be denied. However, the netto experience of the disciplinary process would still be described by the recipient as punishment.

The first conclusion that can be drawn is that the information, or the message communicated by the church is not primarily contained in the words themselves, but mostly in the nature of the whole process. Statements like 'God hates sin but loves the sinner' may sound caring, while remaining true to doctrinal conviction, to the in-crowd of a church community. It smacks, however, of rejection by the one who is identified to have committed the sin. Even a murderer, who would condemn his or her own deed, would need at least understanding of the murder itself before he or she would feel accepted by the community.

...the general message that is mostly deduced from this story is that, amongst all the different sins, sex is primary and basic to all other sins...

Another important point about the nature of the information communicated by the church is the implications of its silence on other aspects of the same subject. Adolescent women who are known to be sexually active but are nonetheless lucky or wise enough not to fall pregnant, are generally not disciplined, because of the lack of concrete proof. The church elders are hardly witnesses to what happens in privacy, while a baby logically presupposes penetrative sex. Thus, the clever observer could only conclude, that the biggest problem is not the extra-marital intercourse itself, but the fact that one got into trouble or was caught out. The most important commandment is therefore the eleventh: *'You shall not be caught out.'* (No Biblical reference; it is meant in irony)

Furthermore, in general practice, church discipline is very rarely applied to other *'sins'*, like substance abuse, theft, or whatever other vice. Thus, one can conclude that the primary sin is sex practised outside marriage. This conclusion is corroborated by a gut level interpretation of Genesis 3 under the heading The Fall of Man.

The informative message of the most common practice of church discipline is that condemnation and punishment can be expected when a person reveals to the church community any condition that implies that sex almost surely must have taken place. Both a baby and a diagnosis of HIV beg the question under general circumstances: who is likely to have had unprotected penetrative sex with whom? (I think that it can be safely assumed that amongst adults HIV is spread in most cases by sexual contact and that the rare transmission by blood-onto-blood accidental contact is practically negligible.)

Thus, the likelihood that a person who lives with HIV, would be morally condemned as a *'sexually promiscuous transgressor'* or at least someone in defiling intimate union with such a person, and stigmatised as an *'unfortunate filthy sinner'*, in most church communities, is a real possibility. Given this underlying train of thought, it is unlikely that church communities would become safe and caring havens for people who live with HIV, even if they cover their

buildings with the popular banners that publicly declare many churches as *'AIDS friendly congregations'*. Church communities are more likely to encourage secrecy, lies and hypocrisy, and thus, form a formidable factor fuelling the underground spread of HIV, exacerbating everybody's risk of infection.

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The power of religion to overcome the discriminating effect of stigma

The essence of Christianity (and I suspect other religions also) is its paradoxical nature. While the moral condemnation in the religious sphere is fierce and pervasive, the hand of grace and acceptance is, in principle, in an equal state of readiness. After all, not only the bad ones, but all people are deemed to be sinners and worthy of nothing else but the wrath of God. In the eyes of God, the one sin is no better or worse than the other. Every, and any, sin is in principle unredeemable by human effort. Therefore, every human being needs the miracle of the grace of God in order to be saved from condemnation and rejection.

If the implications of this universal need of human beings to be saved through gracious forgiveness, is thought through, it would mean that no person would have the right to the moral high ground from which any other person could be condemned, or even worse, stigmatised, and subsequently be regarded as deserving of discriminatory treatment. The universal perdition of humanity is dialectically corroborated by the equal value of all people as being created in the image of God. So, the Biblical message is that God loves all people, regardless of what

they have done or left undone. People who see themselves as belonging to God would be motivated to take their cue for their attitude towards others, from their belief of what God's attitude is towards themselves. Hence, religious people are readily mobilised to invest time, money and energy for the welfare and well-being of others.

...religious people who consider themselves uninfected by the virus have to shake off their sense of superiority; and religious people who have been diagnosed HIV-positive could drop their sense of inferiority and challenge the 'superiority'...

Despite the common judgemental attitude of many religious people, it is often the very same religious people who populate organisations and projects responding to the challenge of HIV. Religious people are readily mobilised for action because at a very deep level, they do realise their equality with all other people. In addition to the basic equality, religious people sense the responsibility that all people have for each other.

Ubuntu Ministries harnessed this goodwill and energy by facilitating personal contact between church people and others (unfortunately, the word 'others' still reflects reality). Small groups of church people have moved from establishing personal relationships with people from distant areas living with HIV, to meeting with people living with HIV in their own neighbourhood. Ubuntu Ministries has 'outlawed' the rendering of help without personal contact with people living with HIV. I believe the time will come that these small groups will be able to recognise, accept and support people living with HIV within their own religious community.

A group of church women were supporting a

young attractive woman living with HIV. They were emotionally very supportive of the young woman's quest to find a suitable boyfriend. Then they learnt that the young woman was dating a young man living in their neighbourhood and belonging, nominally at least, to their religious community. Whereas their interest in the technicalities of safe sex used to be on the low side, the experience of closer involvement sparked their energy to investigate specific detail.

The energy to remove the stigma has to come from both sides. Religious people who consider themselves uninfected by the virus have to shake off their sense of superiority; and religious people who have been diagnosed HIV-positive could drop their sense of inferiority and challenge the 'superiority' of the others on theological grounds. In the same way as people living with HIV have been fighting for treatment and the right to treatment, they could identify the church and religion as a site of struggle for liberation.

Christianity has a specific facet, in that it is particularly motivating to adopt an attitude of a preferential option in favour of the stigmatised and the receivers of discrimination. The majority of the stories in the gospels about the life of Jesus tell about his involvement with people who were somehow marginalised, for example, lepers, prostitutes, poor people, etc. To put it in simple terms, it is obvious that if Jesus had lived these days, he would often have been found on the side of people living with HIV. Therefore, followers of Jesus Christ would also be found on the side of people living with HIV.

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There is another facet of Christianity which challenges its adherents to overcome their fear of people who are dying. The doctrine of the resurrection of the dead is not a belief in a supernatural magical possibility, but rather the paradoxical perspective which allows a person to discover life and opportunity, where reality only reflects death and loss. This paradoxical paradigm of interpretation equips Christians to experience HIV not as a scenario of ‘*doom and gloom*’, but rather a challenge to express something of the love of God in the world. Christians can experience life when a person is dying. Strengthened by this hopeful attitude, Christians are often well-equipped to engage appropriately with someone who has lost the illusion of physical immortality by having heard a diagnosis of incurable disease.

...christians can access the spiritual resources to reduce the stigma of death – removing at least one pillar of the stigma of HIV...

Death is not experienced as the epitome of hopelessness and the end of everything, but can be seen as a door to something else. Therefore, Christians need not take the utilitarian attitude that investing in dying people is a waste of resources, but can see opportunity even in imminent death. This kind of spiritual baggage has the power to relativise the fear that Christians have of death and the dying. Thus, Christians can access the spiritual resources to reduce the stigma of death – removing at least one pillar of the stigma of HIV.

Conclusion

If these basic interpretative keys could be applied to the context of HIV, Christianity’s tendency to be judgemental in the sphere of sex and sexuality would be neutralised

in favour of a netto attitude of de-stigmatisation, holistic acceptance and non-discrimination.

The larger tradition of Christianity does contain indications of a more positive attitude towards sexuality. One such instance is the description of sex as a gift from God. If theologians could work on this and similar possibilities, it is not unthinkable that a paradigm shift could happen. If the de-stigmatising energy of religion could be unleashed, we could look forward to a freer treatment programme, a freer and more supportive society and then, via a significant reduction of HIV transmission, to an eventual halt of the spreading of the HI virus.

FOOTNOTES:

1. Schmid, B. M. 2002. The churches’ response to the HIV/AIDS pandemic: A case study of Christian agencies in the Cape Town area. Dissertation submitted in partial fulfilment of the requirements for the degree of MSocSci in the Centre for the Study of Religion, University of Cape Town. February 2002.
2. New English Bible 1970, Oxford University Press.
3. Ubuntu Ministries, is a small NPO, which has been working to remove the stigma of HIV in the religious and community spheres and motivating church communities to take ownership of the challenge of HIV in their own midst.

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Language...an area to inform decision-making

There is a range of language and information used to describe women's rights as human rights in relation to sexuality and reproduction. Some of the information relates to health, others relate to rights in terms of choices. The language of sexual and reproductive health and rights has become an area to inform decision-making.

Some language is created by researchers, who want to understand more about people or women's sexuality – some, it seems, want to include a rights perspective, and other language choices appear bizarre and lacking in context. This is yet another area to monitor, especially in the era of HIV and AIDS, and to ensure that our voices, souls and beings are acknowledged.

Sexual and reproductive health and rights (SRHR) can be understood as the right for all, whether young or old, women, men or transgender, straight, gay, lesbian or bisexual, HIV positive or negative, to make choices regarding their own sexuality and reproduction – provided these choices respect the rights of others to bodily integrity. This definition also includes the right to access to information and services needed to support these choices and to optimise health or rights in women's and men's sexual and reproductive choices.

Definitions from international agreements

At the International Conference on Population and Development (ICPD) held in Cairo in 1994, the international community, for the first time, agreed on a broad definition of reproductive health and rights, recognising that

...reproductive health is a state of complete physical, mental and social well-being...in all matters relating to the reproductive system [ICPD Programme of Action]

In 1995, the Fourth World Conference on Women, held in Beijing, affirmed the definition of reproductive

health and rights agreed at the ICPD, and also called upon states to consider reviewing laws, which prosecute women for having illegal abortions (Beijing Declaration and Platform for Action).

Paragraph 96 of the Beijing Declaration extended the definition of reproductive rights to cover sexuality:

The human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.

Key aspects of sexual rights were included in the definition, although the term itself was rejected. South Africa was a key delegate in both the ICPD and Beijing processes advocating strongly for progressive language for these terms.

Working definitions from the World Health Organisation

The World Health Organisation (WHO) Department of Reproductive Health and Research provides working definitions of sexual health and rights. The WHO's working definition of sexual rights includes a right to achieve

...the highest attainable standard of sexual health, including access to sexual and reproductive health care services.

Other rights listed under sexual rights include the right to sexuality education and to bodily integrity, and the right to 'pursue a satisfying, safe and pleasurable

sexual life'. There is no universally recognised definition of SRHR amongst major international organisations.

IPPF Charter on Sexual and Reproductive Rights

In 1995, the International Planned Parenthood Federation (IPPF), and its 127 member associations, approved a Charter on Sexual and Reproductive Rights, based on international human rights instruments. South Africa is a member of IPPF. In summary, the Charter on Sexual and Reproductive Rights includes:

1. The right to life should be invoked to protect women whose lives are currently endangered by pregnancy.
2. The right to liberty and security of the person should be invoked to protect women currently at risk from genital mutilation, or subject to forced pregnancy, sterilisation or abortion.
3. The right to equality and to be free from all forms of discrimination should be invoked to protect the right of all people, regardless of race, colour, sex, sexual orientation, marital status, family position, age, language, religion, political or other opinion, national or social origin, property, birth or other status, to equal access to information, education and services related to development, and to sexual and reproductive health.
4. The right to privacy should be invoked to protect the right of all clients of sexual and reproductive healthcare information, education and services to a degree of privacy, and to confidentiality with regard to personal information given to service providers.
5. The right to freedom of thought should be invoked to protect the right of all persons to access to education and information related to their sexual and reproductive health free from restrictions on grounds of thought, conscience and religion.
6. The right to information and education should be invoked to protect the right of all persons to access to full information on the benefits, risks

and effectiveness of all methods of fertility regulation, in order that any decisions they take on such matters are made with full, free and informed consent.

7. The right to choose whether or not to marry and to found and plan a family should be invoked to protect all persons against any marriage entered into without the full, free and informed consent of both partners.
8. The right to decide whether, or when, to have children should be invoked to protect the right of all persons to reproductive healthcare services which offer the widest possible range of safe, effective and acceptable methods of fertility regulation, and are accessible, affordable, acceptable and convenient to all users.

...sexual and reproductive health and rights (SRHR) can be understood as the right for all ... to make choices regarding their own sexuality and reproduction – provided these choices respect the rights of others to bodily integrity...

9. The right to healthcare and health protection should be invoked to protect the right of all persons to the highest possible quality of health care, and the right to be free from traditional practices which are harmful to health.
10. The right to the benefits of scientific progress should be invoked to protect the right of all persons to access to available reproductive healthcare technology which independent studies have shown to have an acceptable risk/benefit profile, and where to withhold such technology would have harmful effects on health and well-being.
11. The right to freedom of assembly and political

South Africa's Sexual Rights Charter

South Africa's Constitution says that women and men must be treated equally and fairly. It also says that no one has the right to control or dominate another person. Both women and men are sexual beings with equal rights in their relationships. However, many people are not able to enjoy these rights. We know this, because South Africa has very high levels of:

- rape, including date rape, marital rape and incest
- domestic violence
- HIV and AIDS
- teenage pregnancy

If we follow the sexual rights and responsibilities in this Charter, our country will be less violent, safer and happier for all.

The right to enjoy sex

In sexual relationships, you have the right to:

- enjoy sex just for the pleasure of it
- enjoy sex right up into old age
- be treated as an equal sexual partner
- be treated with dignity and respect
- express your desires, needs and concerns - and be listened to
- be the one to initiate sex
- choose your sexual partner, whether they are the same or the opposite sex

You too have the responsibility to respect the rights of your sexual partner.

The right to safer sex

Safer sex is a way of having sex that protects you from sexually transmitted infections, including HIV/AIDS and from unwanted pregnancy. It is therefore your right to:

- have a clinic or healthcare centre nearby that can offer you safe and reliable ways to protect yourself from unwanted pregnancy
- be given the correct information about safer sex, so that you can choose how you want to have sex
- have access to affordable health care
- be treated by healthcare workers in a respectful, caring and sensitive way

- use male or female condoms to protect yourself from sexually transmitted infections, including HIV

You have the responsibility to protect yourself and your partner.

The right to say 'NO'

You have the right to:

- say 'no' and 'stop' if you do not want to go ahead with sex
- be listened to and respected

Other sexual rights

We also have the right to:

- laws, policies and practices that do not discriminate against anyone, especially not against women, gays, lesbians, young people, people with disabilities, and people living with HIV or AIDS
- more job opportunities so that people are not forced into commercial sex work
- specially trained, professional and caring services

How will the goals of this Charter be achieved?

To achieve this Charter's goals, you need to:

- understand and practise your sexual rights and responsibilities in your relationships
- acknowledge the rights of others, especially women
- see that government, business, civil society organisations, communities and households promote and uphold the rights in this Charter

The South African government signed an international agreement from the Fourth World Conference on Women held in Beijing in 1995. The agreement supports all the rights in this Charter. The government is therefore committed to promoting these rights.

How can you in your home, community and workplace make sure that everyone is able to enjoy the rights and accept the responsibilities in this Charter?

participation should be invoked to protect the right to form an association which aims to promote sexual and reproductive health and rights.

12. The right to be free from torture and ill treatment should be invoked to protect children, women and men from all forms of sexual violence, exploitation and abuse.

South Africa's Sexual Rights Charter

As from 2000, the Women's Health Project held a national consultative process to develop a South African Sexual Rights Charter. The Charter was developed over a period of years and launched in Parliament in 2003 – see facing page.

This Charter is a consensus document and has been the result of a process. There have been some concerns expressed by activists and sex workers who find the clause of *'being forced'* offensive.

This article has primarily introduced information about the language of sexual and reproductive health and rights as defined in various local and international documents. Within the continuum of care in relation to HIV and AIDS it would also be important to reflect and analyse what this would mean.

*...sexual rights include the right to
sexuality education and to bodily
integrity, and the right to
'pursue a satisfying, safe and
pleasurable sexual life!'*

Much of the focus in the recent past has been on treatment and specifically HAART, and the need to develop the health system with capacity to deliver services. Following the resolution of this contestation, with these issues being on the agenda and addressed, women's sexual and reproductive health and rights surface as being neglected. There is a need to monitor the provision of services and how research is defined within a sexual

and reproductive health and rights framework, as women's rights are often seriously eroded. There is a lot of analysis and work done to explore and define this area. Here are some examples of some areas pertaining to sexual and reproductive health and rights in relation to HIV and AIDS that would be important to understand.

Sexual and reproductive intentions

Following the taking of HAART, there are areas of research interested in people's sexual behaviour and what is termed *'sexual risk behaviour'*. Some of the language used is arguably disconcerting, as it implies judgemental attitudes or is devoid of any sense of a person. Some studies refer to *'sexual disinhibition'*. Disinhibition is a term used in a psychological diagnosis, which implies *'reckless and promiscuous'* type behaviour. While there will always be a small percentage of people who are promiscuous, the orientation of the study appears to judge the population as a whole. The possibility of women's experience of sexual violence, and lack of agency in negotiating safer sex, is not generally explored or correlated. Findings generally report on women, as most respondents recruited in clinics are women, and are surprised to note high levels of unsafe sexual expression. Other language that is used is rather odd. One study referred to a VEE – which was noted as a *'vaginal experience equivalent'*, while another study noted participants being *'oriface neutral'*. This language reduces sexual intentions to body parts. Sexual intentions are ordinary everyday lived experiences; women's sexual rights are not given. This kind of research, which does not acknowledge the contextual realities of people's sexual intentions, is of great concern.

Many women living with HIV, after dealing with the initial hurdle of diagnosis and treatment, express the desire to choose to have a child. Work has been done in this area by various researchers. There is a clear need to develop more work in this area. This is of particular importance as women infected with HIV begin to feel better on treatment and decide to choose to have a child. Contraception for women on HAART is not well understood. In some areas in South Africa, there are reports of women being forced to have

injectable contraceptives, as some HAART drugs are contra-indicated in pregnancy. It is also unclear, which contraceptives would be suitable to use as the emphasis has been on using condoms. There are clear interactions with particular hormonal contraceptives not being ideal in combination with certain HAART drugs and Intra Uterine Devices (IUDs) being viewed as possibly causing uterine infections.

Termination of Pregnancy

Pregnant women who are infected with HIV should be offered termination of pregnancy services as part of a continuum of care. Currently, only surgical abortions are available. However, medical abortion clinical guidelines are being finalised by the Department of Health.¹ If finalised, this should make early safe legal termination of pregnancy an option or choice for an HIV infected pregnant woman. Since medical abortion is generally performed in the first 56 days of pregnancy, it would assist greatly in reducing costs and the demands on a health facility. It may also be easier for health workers, who have moral concerns, to administer medical abortion, as the onus is on the client and not the health worker in commencing the termination of pregnancy.

PPTCT plus/PMTCT/perinatal transmission

It is important to note that there is a variation of ways to address programmes known initially as Prevention of Mother to Child Transmission (PMCT), Prevention of Parent to Child Transmission PPCT, and PPCT Plus – in which the plus indicates the need to treat the parent with HAART. Acknowledging the differences in emphasis, there is a need to advocate for responsibility and treatment to be borne by, and accessible to, all parties. It is within this context that it is imperative to increase the uptake in HIV testing services, so as to improve access to all treatment programmes.

Drugs for women

Particular drugs, including Evavirenz (Stockin) and Tenofovir, are contra-indicated for fertile, pregnant and

breastfeeding women. Women need to know this information and be given choices with regard to contraception and drug options. There also needs to be monitoring in this regard to learn more about the impact of these drugs.

Cervical Cancer

Cervical Cancer is an AIDS defining illness and HIV infected women do present with precancerous lesions more often. While the incidence of cervical cancer remains at 30:100 000 women, it is the cancer that affects most women in South Africa. There is a need to explore this area as it is unknown what the implications are for women on HAART. Previously, HIV infected women with cervical cancer died of another opportunistic disease.

Sexual violence

Sexual violence is devastating to women's sexual desire and pleasure; profoundly limits women's ability to negotiate safer sex; and being able to exercise their sexual and reproductive health and rights. This is an enormous challenge, as sexual violence is so prevalent.

Summary

In sketching the kinds of areas concerning sexual and reproductive health and rights in the continuum of care surrounding HIV and AIDS, a number of information, advocacy and research priorities have been unpacked. However, there is a great need to explore this more.²

FOOTNOTES:

1. A 'medical abortion' involves taking oral medication in the first 56 days of pregnancy and a 'surgical abortion' involves a surgical procedure.
2. The Treatment Monitor of the Health Systems Trust is hosting a dialogue on Sexual and Reproductive Health and Rights in relation to the continuum of care in HIV and AIDS. If you would like to participate, please contact Marion Stevens.

Marion Stevens is the Treatment Monitor at the Health Systems Trust. For more information and/or comments, please contact her on +27 21 448 3544 or at mstevens@hst.org.za.

It's not easy for girls to implement knowledge...

Behaviour change through access to information

Organisational Background

The Hillcrest AIDS Centre Trust (HACT) was established in 1991 by the Hillcrest Methodist Church. HACT is a registered non-profit organisation and, thus, relies on donations and donor funding to make its work possible. The project is situated in the centre of Hillcrest, and is accessible to people from the Outer and Inner West Metropolitan areas of Durban, Kwa-Zulu Natal.

The Hillcrest AIDS Centre Trust offers education, care and support. Our education activities include talks (in English and Zulu) offered in schools, churches and businesses; HIV and AIDS counselling courses offered in Zulu; as well as the distribution of pamphlets and posters. As part of our care and support activities, we provide Home-Based Care, counselling, voluntary counselling and testing for HIV, a feeding scheme, an income generation craft project, and a horticulture project, as well as a funeral fund and a school fee fund.

All our activities and projects are aimed to curb the spread of HIV, as well as the rising HIV infection rates, and to bring about behaviour change within the selected group of learners.

This article will introduce one of our projects aimed at behaviour change, through providing access to information, amongst learners, and explore some of the experienced challenges, successes and limitations.

Demographical background of the project beneficiaries

Our projects and activities are targeting two areas that are situated in the surroundings of Hillcrest. These areas are a combination of rural and newly developed urban areas, with both formal and informal settlements. The population is about 6600 in each area.

Both areas can be characterised as disadvantaged communities, and are 'headed' by the chiefs and

'izindunas', as well as by the municipal councillors. High rates of unemployment resulted in poverty. The working people are mostly not staying in their homes, but at their place of work, due to the distance – they then visit their families and children once a month. Therefore, the children are mostly on their own, either staying with their grannies or their extended families. Some of the children are looked after by elder brothers and sisters.

Most parents are either married or staying with their partners as married couples. Most of the unemployed women are dependent on men to feed their children and pay for school fees.

Children in these areas are exposed to poverty, domestic violence, as well as sexual, alcohol and drug abuse. Young girls are often subjected to abusive relationships that result in traumatic pregnancies. Most men still believe in multiple partner relationships. Some teenage mothers are still attending school, while staying with their boyfriends. There are also young girls, who are caring for their terminally ill family members.

In general, children in these areas are unaware of their rights, and are unable to negotiate safer sex in relationships. They are also unaware of HIV and its related infections, like STIs.

It is within this context that the primary beneficiaries of the project activities are a) primary school children in grades 5 and 6, from two primary schools located in two different areas (total number of children reached is about 487 between the ages of 9 and 16 years); and b) high school children in grades 10 and 11, also from two different areas (total number of high school children reached is about 436 between the ages of 13 and 19 years).

Strategy/Approach

The nature of our work, as an HIV and AIDS organisation, has always been a combination of approaches, as in education, facilitation, focusing on HIV prevention,

as well as support and pro-active measures, involving HIV counselling, testing and referrals for treatment where necessary.

As an organisation, we have always worked in schools in that we went to the school and educated learners. We used to work with larger numbers of school children. However, it was not effective. Children still got pregnant and sexually transmitted infections were still reported in their local clinics around the targeted schools. The life skills teachers also confirmed that young children are at risk, since teachers had many reports and suspicions of sexual abuse; and children did not say anything.

...girls know it is important to abstain from sex, or to delay sexual debut – stating that it would be easier if they could just avoid sexual relationships, because they often fail to say 'no', due to the competition they are faced with in their relationships...

We, therefore, thought of a new approach of how to respond to these challenges in a more effective way. Now, we work with four schools, two primary schools and two high schools, together with the life skills teachers of each school. The classes are now divided into manageable groups, working in hourly sessions once per fortnight.

It is the understanding that utilising this new approach, we would be able to observe the children, and the children would be able to express their feelings and experiences through art, role plays, debates and puppet shows. In addition, we would be able to follow-up whatever risks could be identified during these observations.

At times, we would separate the children (girls and boys in their own groups), since there are many issues that girls do not feel comfortable talking about, such as changes in their bodies, menstruation, as well as differentiating between caring and abusive relationships, sexual abuse and rape.

The children are supposed to work in small groups; to write their own short stories on the discussed issues around the programme; and then they will role-play the stories to express their feelings and understanding on the programme. The children have also learnt to make puppets to use as characters in their plays – this will be part of the evaluation, whereby the children will be expressing their feelings of the programme at the end. This will also give us a good understanding of the pupils' knowledge and personal experience of the epidemic.

Successes of the programme

In the high schools, children love to debate on gender and sexual issues, such as when to have sex, looking at the right time to have sex, and how do you know that you are ready for sex. The importance of delaying sex is more discussed by the girls in the smaller groups. The discussions indicate that girls know it is important to abstain from sex, or to delay sexual debut – stating that it would be easier if they could just avoid sexual relationships, because they often fail to say 'no', due to the competition they are faced with in their relationships. The girls explained that since boys have multiple partners, one might say 'no' to sex, while the other girlfriend says 'yes'; yet, at the end, the one who will be loved, will be the one who allows a partner to be intimate.

On the other side, boys stated that girls are vulnerable; and that most girls would do anything to show how much they love them, without thinking about what they actually want. It is even worse if girls are involved with someone who is older (and richer) than them; they really do not have any say and they keep on enjoying themselves with those guys. The boys went on saying that sometimes the boys try their level best to be good with their girlfriends, but it seems that if the boys delay sex; then the girls think that they are not romantic.

Abusive relationships were also discussed in these groups. The girls were not sure what kind of a relationship would be abusive, because they feel that whenever a man does anything good for a woman, it would be nice for a woman to respect whatever that man says or ordered a woman to do – otherwise a woman would lose everything.

This also involved the understanding of 'rape'; the younger girls do not perceive engaging in sex with someone, who is taking an advantage of you, as rape. But instead, they think that rape is when someone you do not know attacks you, hits you, and forces themselves on to you – not someone, who looks after you, buys wonderful things and feeds the family.

Through this process, we were able to identify girls who are being sexually abused, because of their home situations, and they have sessions with us. We have also managed to help, where we could, by providing food parcels, and paying for school fees, uniforms and books.

We also assessed how much the children knew about HIV and AIDS, by means of a questionnaire asking questions, such as the definition of HIV and AIDS, the differences between HIV and AIDS, where did HIV come from, and how you can tell if someone has HIV. Only few of the children answered the questions correctly. Many responded that to be HIV positive means that you are already dying of AIDS; that HIV is transmitted through mosquitoes and flies; and that anyone can get HIV through other contacts, which are not sexual or blood contacts. It was also mentioned that a person with the virus loses weight and hair.

For the children these debates helped them understand HIV and AIDS; although they have been taught at school, they seemingly had forgotten about it. The children said that the explanations were much clearer, especially when each letter of HIV and AIDS were defined. Many got scared, when they learned that one could live with the virus for a very long time, without any signs. When the common symptoms were mentioned, the children got worried and realised that they have family members, who had the mentioned symptoms, like persisting diarrhoea, persisting coughs, oral and anal thrush, sores all over the body, and peripheral neuropathy (which were mentioned as the common signs). It was then that children realised that they might have family members, who are living with the virus.

It was within this context that some of the girls shared with us how they take care of their mothers, aunties and sisters, while they were not sure what was wrong with them, and they got scared. We have also managed to bring

in people who live with the virus, who shared with the groups how they got infected with HIV and how they live positively with the virus. After these facilitated sessions, more high school learners came to our centre for HIV counselling and testing, and they are still coming. Some of the learners are HIV positive, while others already knew their HIV positive status; they are all monitored through our programmes. In addition, we encourage monitoring their CD4 cell counts and have already referred some clients to other healthcare facilities for further assistance.

...we are 'allowed' to come in after the break, but by then some children are unable to come back to their classes, because they would be drunk from alcohol and drugs...

In the primary schools, learners listened most times. They loved to talk about puberty, adolescence, gender stereotypes and 'abuse', which they understand very well in different forms, like to be shouted at by their parents, beaten up, and doing tougher chores within their households, while others just sit down and do nothing. The children liked the sexual relationship topics, and they also often knew who is being sexually abused in their communities. Some of the children, who are sexually abused, could be identified through the programme, by following-up these 'leads', going into the classes, and establishing whether or not teachers could confirm the suspicion of sexual abuse. About four cases have been reported to the police and social workers. The primary school children loved writing stories, making puppets, and role-playing with puppets.

Challenges

The times we had agreed upon with the school teachers were supposed to be an hour for each group. However, things changed dramatically, especially in the high schools, when the pass rate dropped and many of the targeted high school children failed. Responding to the pressure

by the Department of Education, teachers are *'fighting'* over the life skills period to use it as their extra period. Subsequently, our agreed times had to be decreased so as to upgrade teachers' commitments to teaching the children. This has largely destructed the programme, because we are now seeing again larger groups of children – and that is what we wanted to change.

The same situation impacted on the times that we were going to the schools. Now, instead of going to these schools for at least four days in a week, we are *'allowed'* two consecutive days. We are *'allowed'* to come in after the break, but by then some children are unable to come back to their classes, because they would be drunk from alcohol and drugs. Sometimes, the children would want to fight with us. The teachers are aware of this situation, but cannot do anything, because they are also scared. Subsequently, we are behind with our schedule; we are not meeting our objectives, and the impact of the project will remain limited.

...the boys... argued that all women in this situation are lazy; that they have to learn to do things for themselves, rather than depending on men...

While gender stereotypes and sexual relationships are understood and well known to the children, the understanding is largely based within their social and cultural context. Especially young girls are greatly impacted seeing their mothers and role models to be dependent on a man and waiting for the men to decide and initiate anything in their lives. Many of the children have seen their mothers tolerating whatever their husbands do to them, and they feel it is the right thing to do, and that *'perseverance is the mother of all successes'*. Thus, even though girls are aware of all these issues, it will not be easy for these girls to implement their knowledge, considering how their families and communities expect them to be, to behave, and to interact with men.

When these issues were debated in the groups, the girls made a few points. However, the girls were not very

assertive – when boys put pressure on them, they failed to defend themselves and their position, and ended up very quiet. Asking the boys to look at the behaviour of their fathers, what they can change and what they cannot change, they agreed that sometimes men are hard on women, and criticised their mothers for being so quiet for a very long time. The boys kept on asking *'how could anyone sit on a hot stove'*. They also argued that all women in this situation are lazy; that they have to learn to do things for themselves, rather than depending on men; that women play a part, when growing their children, since assigning of chores is mostly done by women as mothers; and that women created this problem from the beginning.

In relation to the sexually abused children, it seems like we have failed the children and their teachers. We have not received any correspondence from the police and/or social welfare yet. There are two cases we reported to the police, but the family of the children decided to move away from the area and from the school. In another case, we called the child welfare and they gave us the number of someone else who deals with children, but failed to provide the necessary assistance.

How did we respond to the challenges?

With the school programme itself, we have organised an evaluator to meet with us and to evaluate the programme. We might want to change the grades, target other communities, and visit each school for a shorter period, rather than a period of two years at the same schools. But the decision about possible changes will mostly rely on the outcome of the evaluation process.

We are still trying to locate local social workers that can work with us and offer assistance with the cases of sexual abuse and rape. We are also in the process of identifying other non-governmental and community structures, which could in future assist with these cases.

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Urvarshi Rajcoomar

Access to information – Your right to know

Freedom of information is important to Justice... In a world of secrecy and opaque government, serious wrongs can occur which may never come to light. Freedom of Information legislation is at once a means of casting light of scrutiny into dark corners of government and a contribution to a new culture of openness in public administration.¹

South Africa pioneered the enactment of the first freedom of information laws in Africa, and is one of 57 countries² in the world to have enshrined in law mechanisms to access information held by government and by private bodies. The nexus between freedom of information and the foundations of a democratic dispensation has been the subject of much discussion between legal academics. According to Richter [2005:219], the

...right of access to information is often depicted as the 'oxygen of democracy' or the 'oxygen of knowledge' and underpins and supports other fundamental human rights and freedoms.

The existence of access to information legislation makes it possible to have informed political debate; pierces the veil of secrecy of government departments and private bodies that undermine public debate; creates a culture of openness and transparency, which is a core element of good governance; and allows government departments to be accountable to the very people they serve.

South Africa's troubled past under the apartheid regime sanctioned and maintained clandestine and sinister activities through the denial of access to information to its citizens. However, with its new democratic dispensation, South Africa is moving away from a culture of opaqueness and secrecy to one of openness and transparency. Section 32 of the Constitution³ realises this transition and entrenched the broad framework to access to information legislation. In 2000, the Promotion of Access to Information Act (No 2 of 2000), or more commonly known as PAIA, has been enacted. PAIA is a lengthy and technical Act that is divided into seven parts and consists of 93 sections. This article will attempt to shed light on some important sections within PAIA and look at judicial interpretation of the right of access to information under PAIA.

The object and purpose of PAIA

An analysis of any legislation warrants the inquisition of its purpose and objective. PAIA's core purpose is to give effect to the fundamental human right of access to information, as enshrined in Section 32 of the Constitution⁴. The Act strives to achieve this constitutionally guaranteed right through, firstly, establishing mechanisms and procedures to give effect to this right in a manner which enables persons to obtain access to records of public and private bodies as swiftly, inexpensively and effortlessly as reasonably possible⁵; and secondly, to promote transparency, accountability and effective governance of all public and private bodies by, including, but not limited to, empowering and educating everyone.⁶ The crafters of the Act were mindful of the fact that in order to create an ethos of transparency and accountability, educating and empowering people about the Act, the functions and operations of public bodies, and the need for individuals to participate in the decision-making by public bodies⁷ that affects their rights, adds value to the Act and the foundational principles of democracy. The mandate to create awareness on the Act and the champion of PAIA was entasked to the South African Human Rights Commission. Section 10 of the Act specifically directs that the SAHRC must, within 18 months after the commencement of this Act, compile in each of the official languages a guide containing information, in an easily comprehensible form and manner as may reasonably be required by a person, who wishes to exercise a right in the Act. The guide is designed to be user-friendly and provide any user of the Act with information on the addresses and contact details of information officers of all public bodies⁸, the manner and form that a request for access to information in public

and private bodies should be compiled⁹, and the remedies available to a user who was unsuccessful in accessing information for various reasons.¹⁰

...the apartheid regime sanctioned and maintained clandestine and sinister activities through the denial of access to information to its citizens. However... South Africa is moving away from a culture of opaqueness and secrecy to one of openness and transparency.

The reality that the right to access to information is not absolute and is subject to the limitations clause is blatantly evident in Section 32(2)¹¹ of the Constitution and further reaffirmed in the Preamble and Section 9 of PAIA. The ‘internal qualification’ in Section 32(2) has been equated to the internal limitations contained in socio-economic rights, such as the right to access to health care, food, water and social security¹². These access rights are characterised by the positive duty on the state for their realisation.¹³ Simply put, these rights allow the state a margin of discretion in the realisation of the rights. So what does this mean for our right to access to information? One can argue that Section 32(2) of the Constitution affords the state a similar margin of discretion. On the other hand Section 9 of PAIA specifically tabulates the various instances, in which the limitation on the access to information would be justifiable. These include (a) the reasonable protection of privacy, commercial confidentiality and effective, efficient and good governance, and (b) in a manner, which balances this right with any other rights.

The distinction between public and private bodies

Section 1 of PAIA defines a ‘public body’ into three types, namely, any national and provincial state department or administration and any municipality in the local sphere of government, such as the Department of Health or the Department of Education (type (a) public bodies); any

functionary or institution exercising a power or performing a duty in terms of the Constitution, such as the Commission of Gender Equality, or a provincial institution (type b(i) public bodies); and; any functionary or institution exercising public power or performing a public function in terms of any legislation, such as Telkom and Eskom (type b(ii) public bodies). Part 2, Chapter 1 to 5 of PAIA deals exclusively with ‘public bodies’, whereas Part 3, Chapters 1 to 5 deals with ‘private bodies’.

‘Private bodies’ are defined as a natural person or partnership, which carries on any trade, business, or profession or any former or existing juristic person. One might ask why the drafters of the Act created the distinction between ‘private bodies’ and ‘public bodies’? This can be attributed to the original intention, which, according to Bosch [2006:615] is

...to impose more demanding standards of transparency and accountability on the public sector. The private sector, on the other hand, would only be obliged to grant access to information when such information had a ‘demonstrable and sufficient connection to the exercise or protection of any rights’.

PAIA recognises that hybrid bodies do exist, whereby a ‘private body’ would perform a public function, as well as a private function¹⁴. In this case, some of the records will be treated as those of a ‘public body’ and some of them will be treated as records of a ‘private body’. It is envisaged that the practicality of deciding what information falls within the ambit of a private function or a public function of a ‘private body’ will no doubt vest in the courts for interpretation. Many of the provisions in the Act relate to both ‘private’ and ‘public bodies’. There are, however, important differences which users of the Act need to be mindful of. One such difference is that only information that is required for the exercise and protection of rights may be requested from ‘private bodies’. ‘Public bodies’ need not concern themselves as to the reasons behind the request for access to information. Both ‘public’ and ‘private bodies’, in compliance with Section 14(1) and Section 51(1) must develop a manual that will provide the user of the Act with information as to who the information officer is, the contact details of the information officer, the manner and form in which information should be requested, and the types of records that are available in accordance with any legislation.

Who is a 'requester'?

According to Section 32 of the Constitution, *everyone* is entitled to access information. This implies that citizens, as well as non-citizens can access information under this section. However, PAIA makes a distinction between 'a requester' and a 'personal requester'. A 'requester' is any person (natural or juristic), or someone acting on their behalf (e.g., a parent acting on behalf of their child) other than a 'public body'. This means that government departments, as well as constitutionally mandated functionaries and institutions, such as the Commission on Gender Equality, are not recognised as 'requesters', and may not use PAIA to access information from 'public bodies'. A 'personal requester' is someone who is 'seeking access to a record containing personal information about the particular requester' [Beukes, 2003:29] In relation to a 'private body', any person, public body (including government departments and constitutionally mandated functionaries and institutions) or an official may make a request for access to information.

...it has to be noted that the Act, even though entitled access to information, does not apply to 'information', but to 'records'...

What constitutes 'information'?

It has to be noted that the Act, even though entitled access to information, does not apply to 'information', but to 'records'. A 'record' of, or in relation to, a public or private body, means any recorded information – (a) regardless of form or medium, (b) in possession, or under the control, of that public or private body, and (c) whether or not it was created by that public or private body respectively. 'Records' can be recorded in any way, including paper, in a computer, on film, and a person can still ask to have access to them. PAIA takes into consideration people with disabilities. If a requester is disabled and needs the record to be made available in a special form, then the information officer must take reasonable steps to ensure that this happens.

Who are 'information officers'?

Section 1 of the Act dictates who will be 'information officers' in public bodies. In respect of the national department, the director general will be the 'information officer'. The deputy director general will be the 'information officer' in the provincial sphere, and the municipal manager is the 'information officer' in respect of the local sphere. With regard to other public bodies, the chief executive officer or a person designated to act in this capacity, will be the 'information officer'. The task of making information available to a requester can be an onerous one; hence, the Act has made provision for the 'information officer' to designate deputy information officers¹⁵ -- such delegation must be in writing. The number of deputy information offices is solely at the discretion of the information officer.

What procedure needs to be followed to access information?

A requester requesting access to information from a 'public body' has to comply with procedural requirements, namely completing the prescribed forms.¹⁶ The request must contain information about the requester, such as name and contact details; the record requested; whether or not the record concerned is preferred in a particular language (e.g. IsiZulu); and in addition to a written reply, a requester could indicate alternative means of being informed of the information officer's decision (e.g. by telephone)¹⁷. In a bid to make the Act accessible to every person, oral requests to an information officer are deemed acceptable in instances where the requester is illiterate or has a disability.¹⁸ It is then the responsibility of the information officer to reduce the oral request to writing in the prescribed form and forward a copy to the requester.

Interestingly, the procedure to be followed in respect of a 'private body'¹⁹ is similar to that of a 'public body'. However, there is no obligation on a 'private body' to reduce oral requests to writing, especially if the requester is illiterate or disabled.

What are the cost implications for accessing information?

The distinction between 'requester' and 'personal requester' (discussed above) has cost implications.

According to PAIA, a ‘*personal requester*’ is exempted from paying any fees, irrespective if the information is requested from a ‘*private*’ or a ‘*public body*’.

...there are instances in which a request for a record ‘must’ be refused and instances where a record ‘may’ be refused...

The Act distinguishes between ‘*request fees*’ and ‘*access fees*’. The former is a fee that accompanies every request before further processing of the request is carried out²⁰, while the latter relates to how long it will take to find the records requested, the number of pages a requester is looking for, and the actual cost of reproducing the record.²¹ When a request has been granted, an ‘*information officer*’ can request that a deposit be paid (not more than one third) in respect of the access fee.²² If a request has been refused after a deposit has been paid, the deposit has to be repaid.²³

What grounds exist for the refusal of access to information?

Chapter 4 of PAIA eloquently lists the various grounds for refusal of access to information. Beukes [2003:31] argues that

...when considering that access to information is a constitutional right, the granting of access and not refusal of access should be the norm – as a matter of principle therefore, access should only be denied where clearly justified and doubts must be resolved in favour of disclosure.

There are instances in which a request for a record ‘*must*’ be refused and instances where a record ‘*may*’ be refused. Section 33 encapsulates the method of interpretation of the grounds of refusal of access to information. The ‘*information officer*’ of a ‘*public body*’ *must* refuse a request for access to a record, which contains information on the protection of the privacy of a third party, who is a natural person; commercial information of a third party; certain confidential information about the safety of individuals; information on the protection of property; protection of police dockets in bail hearings; protection of certain records of the South African Revenue services; and

protection of records privileged from production in legal proceedings.^{24, 25}

However, it is important to note, that the refusal of access to records in terms of Section 33 (1)(b) is solely at the discretion of the ‘*information officers*’. Therefore, it is imperative that ‘*information officers*’ have a thorough understanding of this Section in the Act.

Mandatory disclosure of information in the public interest, or more commonly known as the ‘*public interest override*’, applies to both private and public bodies.²⁶

Under this section a request of access to records must be granted even if there are grounds for refusal of the request, if the disclosure of the record would reveal evidence of (i) a substantial contravention of, or failure to comply with, the law; or (ii) an imminent and serious public safety or environmental risk. [Beukes, 2003:32]

Access to health and other records

If a ‘*requester*’ wants access to records that relate to her or his own health and the ‘*information officer*’ is of the opinion that the record might actually cause serious harm to the ‘*requester’s*’ physical or mental health, the ‘*information officer*’ must, before giving access to the record, speak to a doctor, who has been nominated by the ‘*requester*’. If the ‘*requester*’ is under 16 years old, then a parent must make such nomination. Where the ‘*requester*’ is not able to run her or his own affairs (e.g. mental illness), a curator bonis would choose which doctor gets consulted. If the doctor is of the opinion that the disclosure of the record would indeed cause serious harm to the ‘*requester’s*’ physical and mental health, then the ‘*information officer*’ may refuse access to that record, until the ‘*requester*’ has proven that she or he has made arrangements for counselling or other arrangements to avoid the harm. In such a situation, the person providing the counselling must be given access to the record, before the record is released to the ‘*requester*’.²⁷

What remedies are available to a requester, if access to a record has been refused?

Two avenues for relief are available to the ‘*requester*’, namely an internal appeal to a higher authority within certain public bodies and the courts. Section 74 of the Act entrenches the right of internal appeal to a relevant

authority. It is important to bear in mind that the option of internal appeals is only applicable to national departments, provincial departments and local authorities (type a public bodies). This implies that ‘private bodies’ that perform a public function (type b(ii) public bodies) are not mandated to hold internal appeals. The Act further stipulates that a ‘requester’ has to first seek relief from an internal appeal process before approaching the court.

In addition, internal appeals by a ‘requester’ are restricted to four categories of decisions, namely (a) refusal of requests for access, (b) refusal to provide access in the requested form, (c) decisions regarding the levying of fees (in terms of Section 22), and (d) decisions to extend the period within which a decision on access must be made (in terms of Section 26(1)). In other words, as stated by Beukes [2003:34], an application to court may be lodged when a ‘requester’ is unsuccessful in an internal appeal; when the ‘requester’ is aggrieved by a decision to disallow the late lodging of an internal appeal; and, as outlined in Section 75(2) of the Act,

...when the requester is aggrieved by the decision of the information officer of type (b) public bodies to refuse a request for access; to require payment of a fee (S22); to extend a period for dealing with a request (S26(1)) and to grant access in a form other than that required by the requester (S29(3)).

Judicial interpretation of the right to access to information under PAIA

Since its inception, the right of access to information under PAIA has been tested in our courts and the judicial interpretation has to a certain extent given effect to the very purpose for its enactment. However, there are those cases whereby the court’s decision has been disappointing, to say the least.

In *Earthlife Africa v Eskom Holdings Ltd*²⁸, the applicants, an NGO established by environmental and social activists in Cape Town, brought an application in the Witwatersrand High Court for the setting aside of the respondents decision for refusal of access to certain information. The applicant requested access to minutes from board meetings over a number of years. The applicant, in order to invoke the provisions of PAIA, had to show that the information sought is required for the exercise or

protection of any right. The applicants were particularly concerned about the safety and feasibility of the Pebble Bed Molecular Reactor Project and believed that the environmental assessment process was flawed. In this case, the applicants were relying on the constitutionally guaranteed right to a safe and healthy environment (Constitution, Section 24)²⁹. The applicants successfully satisfied the courts on the basis that they were accessing information for the exercise or protection of a right.

...the right to protect commercial information of a private body overrode the right to an environment that is not harmful to our well-being...

The court identified the respondents as a type b(ii) public body, in that Eskom serves a public function by generating 95% of the country’s power. However, Eskom was also very much a private body and traded as such. The respondents granted access to some of the records. However, they denied access to the rest on the basis that these records were relevant to Eskom as a private body and as such contained trade secrets and commercial information that would be compromised if disclosed. The court had to decide if the information sought was classified under one of the statutory exemptions provided for in terms of PAIA. In so doing, the court, due to the complexity and nature of the information, had to be guided by an expert witness. Unfortunately, the applicants were not able to produce an expert witness who would substantiate their argument. The respondents however, were able to furnish the court with an expert witness who enlightened the court on the fact that the information sought contained trade secrets that warranted the refusal of access to the records in terms of Section 68(1) of PAIA. The application was dismissed with costs, since Fevrier, AJ held that

*...the respondent has succeeded in demonstrating that the information and documentation sought by the applicant is protected from disclosure on the grounds set forth in this judgment.*³⁰

Sadly, the abovementioned case failed and the right to protect commercial information of a private body overrode the right to an environment that is not harmful to our well-being.

Another case which attracted interest was that of the *Institute for Democracy in South Africa & others (IDASA) v African National Congress & others*.³¹ According to Bosch [2006:617],

This case pitted civil society against political parties in testing the ambit of PAIA. The applicants approached the court to obtain access to records of private donations given to the respondent political party during the period of January 2003 to May 2004.

The sole aim of the applicant was to expose the identity of the donors, thereby limiting the potential for corrupt dealings between political parties and their donors. The issues that were in contention included the classification of the respondents as private or public bodies, and as a result of this classification, the applicants, under Section 50(1) of PAIA, had to show that the access to the donation record was required for the exercise or protection of a right.

The applicants argued that the respondents could be classified as type b(ii) public bodies, as they served an important public function. However, Griesel J, held that the records of donors requested by the applicants were that of their function as a private body. This implied that the applicants had to satisfy Section 50(2) of PAIA by showing that the access to these records was required to exercise or protect a right. The applicants substantiated their claim by relying on several rights, including the right to freedom of expression, to association, to make political choices, and to effective, transparent and accountable government. The applicants also argued that access to information was a necessary requirement to engage the public in political debates. In the judgement, Griesel J

*...concluded that the applicants had failed to show any justifiable right which required protection and would thereby permit access to the respondents' private records. The court concluded that the right of access to information must reasonably be found within the four corners of PAIA.*³²

Once again judicial interpretation in this case failed to promote access to information as contained in PAIA. It is clearly evident that this will be the first of many hybrid body cases (type b(ii)), which will seek judicial interpretation.

A case study, which is worth mentioning, even though the original action was withdrawn and the matter proceeded to court on the basis of a cost order, is that of the Treatment Action Campaign (TAC).³³ In 2004, the TAC

formally requested documents, which were construed to be annexure to the Operational Plan for the roll-out of ARVs, on 20 February 2004. TAC had received no response from the Department of Health as to whether or not their request was successful. Complying with the procedural requirements of PAIA, TAC instituted an internal appeal. Once again the Department of Health failed to respond to the internal appeal and this warranted the TAC to bring an application in court. The Department of Health, in its

*...answering affidavit by Dr Karmani Chetty, alleged that the deputy information officer did not reply to the request made by TAC due to work pressures and that the Department had no obligation to reply to the request as the obligation clearly lay on their deputy information officer.*³⁴

...the right of access to information is more meaningful to poor people, who have been left out of political and public debate, due to a lack of information...

Ironically, PAIA makes provision for the employment of several information officers in a public body so that requests for access to records are given due regard and are processed efficiently and speedily. A justification for non-responsiveness, due to work pressure, should not be tolerated at any level. The TAC was successful in obtaining a cost order against the Department of Health.

Conclusion

Clearly the TAC case study demonstrates that if individuals and departments do not acknowledge the importance of PAIA and give effect to its purpose and objective, then the fundamental human right of access to information as contained in the Constitution will remain an illusion. The right, as argued by Ntlama [2003:273], was framed with the intention of acting as a

...tool with which to monitor and claim more effective delivery of basic services as well as accountability to communities from government. It could also be used to lobby for higher budget allocations for disadvantaged communities and

fight corruption that takes scarce public resources away from poverty alleviation initiatives.

Therefore, the right of access to information is more meaningful to poor people, who have been left out of political and public debate, due to a lack of information. However, since poor people have little information about decisions taken by the government, and are least in the position to access information on important public policy and planning decisions, poor people also constitute the most vulnerable recipients of government inaction, and are less likely to litigate.³⁵

Thus, even though the Act has positive features, its shortcomings overshadow its glory.

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FOOTNOTES:

1. Kirby 'Freedom of Information: The seven deadly sins'. British Section of the International Commission of Jurists, 1-12 at 10. [http://www.hcourt.gov.au/speeches/kirbyj/kirbyj_justice.htm]
2. According to a survey conducted by the Open Society Justice Initiative (OSJI) in 2004.
3. Constitution of South Africa, Act 108 of 1996.
4. Section 32 of the Constitution states:
 - (1) Everyone has the right of access to-
 - (a) any information held by the state; and
 - (b) any information that is held by another person and that is required for the exercise or protection of any rights
 - (2) National legislation must be enacted to give effect to this right, and may provide for reasonable measures to alleviate the administrative and financial burden on the state.
5. PAIA, Section 9(d).
6. PAIA, Section 9(e).
7. PAIA, Section 9(e)(i), (ii) & (iii).
8. PAIA, Section 10(2)(b).
9. PAIA, Section 10(2)(d).
10. PAIA, Section 10(2)(g).
11. Section 32(2) of the Constitution states: 'may provide for reasonable measures to alleviate the administrative and financial burden on the state'.
12. Section 27 of the Constitution.
13. This refers to the 'progressive realisation of rights'.

14. Type (b)(ii) private bodies.
15. PAIA, Section 17.
16. Form A of the Regulations to the Act.
17. PAIA, Section 18(1), (2)(a) – (f).
18. PAIA, Section 18(3)(a).
19. PAIA, Section 53(1), (2)(a) – (f).
20. PAIA, Section 22(1).
21. PAIA, Section 22(2)(a-b) and Section 54(2)(a-b).
22. PAIA, Section 22(2)(b) and (3)(a-c), and Section 54(2)(b) and (3)(a-c).
23. In addition, the Act stipulates in Section 22(8) that the Minister may, in relation to accessing information from 'public bodies', exempt any person or category of persons from paying any fee. According to government notice from the Department of Justice and Constitutional Development, Bridgitte Mabandla, the Minister of Justice and Constitutional Development, exempted the following persons from paying access fees contemplated in Section 22(6) of the Act, namely (a) a single person whose annual income, after permissible deductions referred to in the Schedule to this notice are made, does not exceed R 14 712, 00 per annum; and (b) married persons or a person and his or her life partner whose annual income, after permissible deductions referred to in the Schedule to this notice are made, does not exceed R 27 192, 00 per annum. [www.sahrc.org.za]
24. PAIA, Section 34(1), Section 35(1), Section 36(1), Section 37(1)(a), Section 38(a), Section 39(1)(a), Section 40 or Section 43(1).
25. An information officer 'may' refuse access to a record contemplated in Section 37(1)(b), Section 38(b), Section 41(1)(a) or (b), Section 42(1) or (3), Section 43(2), Section 44(1) or (2) or Section 45, unless the provisions of Section 46 apply.
26. PAIA, Section 46 and Section 70.
27. PAIA, Section 30 and Section 61.
28. Unreported. The High Court of South Africa (Witwatersrand Local Division), Case No: 04/27514.
29. 'Everyone has a right to an environment that is not harmful to their well being and to have the environment protected.'
30. Para 80.
31. 2005(5) SA 39(C).
32. Bosch (2006:617).
33. As cited in Richter (2005:222).
34. As cited in Richter (2005:222).
35. Ntlama (2003:273).

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Yabonga inspires women living with HIV

Yabonga is a Cape Town-based NGO focusing on childrens' education and HIV and AIDS projects.

Yabonga was founded in 1998 by Ulpha Robertson and Ursel Barnes – both mothers with an interest in education, and concerned about the lack of quality school readiness programmes in impoverished communities. Yabonga's aim was to better prepare children for mainstream schooling. Within two years, and after establishing seven educare centres, Yabonga came across its first HIV positive child. The life of this child and his mother led Yabonga to a programme focussing on positive mothers.

In 2001, with no budget and the support of 20 volunteers, Yabonga piloted the training programme for mothers living with HIV. The objective was to empower women with education and skills to make positive lifestyle choices that would enable them to lead healthy lives and be effective parents. The success of the pilot caught the attention of the local clinics requesting that these women become educators and lay counsellors within the clinics.

The training programme – which runs over four months – covers HIV education, personal development and income generation skills. More specific training is offered to candidates, who show potential in various areas of service, such as home-based care, lay and youth counselling. The programme has recently expanded to include a *'men as partners'* module, in which partners of women infected with HIV, who are part of Yabonga's programme, are offered education and couple counselling.

To date, 170 women have completed the training programme, and 80 are employed as peer educators, lay counsellors, home-based carers and youth counsellors. 60% of the salary costs are covered by the Department of Health and the balance is raised

through local business and private funders. Yabonga-trained women have become sought after in the field and many are employed in similar positions by other organisations.

The demand of these services at the local clinics led to Yabonga setting up HIV support centres at various clinics in the communities where the women live. These centres are based in converted containers that are funded by local businesses.

There are currently ten centres in Khayelitsha, Crossroads, Phillipi, Kuils River, Eerste River and Gugulethu. Yabonga also serves a further five clinics and 55 schools. The teams at each centre include a team leader, peer educators, lay counsellors, home-based carers and youth counsellors. The services offered include HIV education in clinic waiting rooms and at schools, voluntary counselling and testing, individual and family counselling, nutritional support, support groups, and income generation programmes.

Current statistics show that Yabonga reaches over 12 000 clients per week through HIV education, with over 700 clients attending support groups, and 140 people who are reached through home-based care activities.

The Yabonga programme is monitored by fieldworkers, a social worker, and a project manager. Team leaders report weekly to discuss successes and challenges. Ongoing training for the full team takes place monthly, and guest speakers are regularly called upon to address the group on topical issues.

The fact that all the peer educators are themselves living with HIV is a key aspect to the success of the programme. Their HIV positive status generates a greater inclination on the part of the clients to want to

know their HIV status, as well as contributes greatly to the effectiveness of the peer educator's education and counselling.

As a crucial safe haven, the support centres offer community members the chance to share their HIV status, overcome denial, better deal with stress, as well as gain self-confidence. With a wide range of topics being discussed from how to live positively with HIV to coping with domestic abuse within the home, the psychosocial and emotional support from peer educators is invaluable.

Yabonga's peer education and support is having a positive and tangible impact on the lives of women and their partners infected and affected by HIV and AIDS. As a result, women infected with HIV have gained skills in HIV and AIDS education and awareness, acquired confidence, undergone self-growth and independence, and a commitment to positive living. These women are now active role models in their own communities and are proactively replicating learning to others.

Indicative of the increased community awareness and success of Yabonga's work is the steady rise in the number of schoolchildren and young people coming to the Yabonga containers for support. Yabonga peer educators also offer education at local schools, at the request from teachers.

In 2003, the educare programme initiated a 'Godparent' scheme, where members of the public could sponsor the schooling costs of a Grade 1 pupil for a year. The willingness of fellow South Africans to offer support also encouraged people to take cognisance of the increasing numbers of orphaned and vulnerable children presenting themselves at the centres.

At the beginning of 2006, Yabonga cautiously started a programme of support for 40 orphaned and vulnerable children, whose mothers were known to us through their attendance in the support groups. Initially, support was in the form of school uniforms, books and nutritional support. Within a year, the number had grown to 240 children, with a waiting list of more children requiring similar support. The services offered to the children have been expanded to include

specialised counselling, family interventions, life skills programmes, leadership workshops and further enrichment during school breaks. The overwhelming desire of these children (age 5 to 20 years) is to be given the opportunity to 'just be children', without having to face the trauma associated with HIV, poverty, abuse, and their parents' death.

This programme is run by youth counsellors, who are living with HIV, and are often struggling to deal effectively with the children's issues without unearthing their own. Yabonga ensures that all counsellors receive regular debriefing by psychologists, and, where possible, refers to organisations that are more equipped at dealing with such issues.

Whilst Yabonga projects have grown within Cape Town townships, special projects have been successfully completed outside Cape Town. By invitation of IDASA, Yabonga shared its mentorship programme with a number of NGO's working in ten rural areas within the Eastern Cape. In 2006, the Namaqualand educare project, offering fully-equipped outdoor play facilities to eight community crèches was completed. The teachers participated in an initial weekend workshop, in which the emphasis was on maximising the equipment to ensure optimal development in the children.

The strengths of Yabonga's HIV and AIDS programme are seen to rest on a number of interconnecting factors, including, the commitment and professionalism of the people co-ordinating the programme in the field; the improvement in communication between staff; as well as the consistent and effective monitoring and support element that Yabonga provides to the programme.

In essence, the ongoing sustainability of Yabonga's HIV and AIDS programme rests on a number of interrelated factors:

- **The linking of the Yabonga programme to existing health facilities within the communities**

By being attached to community-based clinics, Yabonga is able to complement the services offered by medical staff, and

also to offer relief at under-staffed clinics. The medical services receive a boost with Yabonga's holistic approach to dealing with HIV and poverty.

- **The genuine involvement of people living with HIV and AIDS**

Yabonga's real niche is that its programme is run and implemented by people living with HIV. This means, field workers, lay counsellors and peer educators truly understand, empathise with, and support clients.

- **Building Yabonga's organisational structure from within**

Yabonga is effectively contributing to the sustainability of its programme by building its organisation from within, using its current pool of staff, while new recruits to the programme are solicited from within the support groups.

- **Consistent programme monitoring and support**

Yabonga's regular and consistent monitoring of the programme is seen to be further contributing to its programme efficiency, as is the reliable support for its peer educators and clients. The fact that Yabonga's four-month peer educator training programme also focuses on the personal growth and development of women is of real value to the future and ongoing effectiveness of the programme. The supplementary ongoing training and support that Yabonga provides is seen to be most valuable. This includes extra training for peer educators who may be slightly weaker in their work, as well as once-off training addressing particular themes.

Yabonga's HIV and AIDS programme has demonstrated its appeal beyond the scope of the support centre containers. Demand can be seen for its services from schools, local military bases, and other

local organisations and businesses. Yabonga peer educators and field workers are asked, with increasing frequency, to represent Yabonga by giving talks, as well as providing HIV and AIDS education sessions.

In addition, Yabonga works closely with other NGOs in the same communities, particularly in joint efforts to respond to HIV and AIDS stigma and discrimination. The ultimate aim is that NGO networks develop across different target areas.

Through continued good practice, Yabonga is facilitating the progress on the ground by ongoing monitoring and support, encouraging capacity building of its staff, and ensuring greater participation of staff at different levels in the programme. To build on the independence and individuality that Yabonga is encouraging in its peer educators and clients, as well as to facilitate a move beyond a direct focus on HIV and AIDS, a greater focus on scaling-up its livelihood skills and income-generation component would be a valuable focus for the next stage of the programme.

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Public involvement in legislative processes

The implications for the Choice on Termination of Pregnancy Act

In *Doctors for Life International v the Speaker of the National Assembly*¹ ('DFL'), the applicant applied directly to the Constitutional Court for an order declaring that the National Council of Provinces (NCOP) and the nine provincial legislatures failed to comply with the obligations contained in Section 72(1)(a) and Section 118(1)(a) of the Constitution², namely 'to facilitate public involvement in their legislative processes', in enacting certain statutes, including the Choice on Termination of Pregnancy Amendment Act (No 38 of 2004). The majority judgment, written by Justice Ngcobo, in its order declared that Parliament had failed to comply with its constitutional obligation to facilitate public involvement before passing the Choice on Termination of Pregnancy (CTOP) Amendment Act, as required by Section 72(1)(a) of the Constitution. The majority held that the CTOP Amendment Act was as a consequence adopted in a manner that is inconsistent with the Constitution and was, therefore, declared invalid. However, the order declaring the CTOP Amendment Act invalid was suspended for a period of 18 months until 17 February 2008, so as to enable Parliament to re-enact the CTOP Amendment Act in a manner that is consistent with the Constitution.

This article will briefly set out the nature and purpose of the CTOP Amendment Act; some of the implications of *DFL* – both for public participation in legislative processes and for future potential constitutional challenges of this nature; and what is required after *DFL* to cure the constitutional invalidity. The article will also outline the consequences, if Parliament fails to re-enact the CTOP Amendment Act in a manner that is consistent with the Constitution.

The CTOP Amendment Act

The CTOP Amendment Act, which came into force on 11 February 2005, amends the Choice on Termination of Pregnancy Act (No 92 of 1996), to empower the provincial MECs to approve those health facilities where a termination of pregnancy may be performed. This function was previously exercised by the Minister of Health. It confers many of the powers previously exercised by the Minister to the Provincial MECs. It also provides that health facilities which provide a 24 hour maternity service, and comply with certain other requirements, may perform terminations of pregnancy up to 12 weeks without obtaining the approval of the MEC. Furthermore, the CTOP Amendment Act provides that in addition to registered midwives who have undergone the prescribed training in terms of the Act, registered nurses who have undergone such training may perform terminations of pregnancies of up to 12 weeks. The effect of the amendments is twofold – to make the regulation of terminations of pregnancy a provincial competency, and to increase access to termination services by increasing the pool of appropriately trained health workers who can provide termination services in the first trimester of pregnancy.

Challenges to the validity of parliamentary bills

DFL confirms that, with the exception of a constitutional challenge to the validity of legislation brought by the President in terms of Section 79 of the Constitution, any

challenges to the constitutional validity of a Bill passed by Parliament must await the completion of the legislative process, namely the President assenting to and signing the Bill. Once that process is complete, the public and interested groups may challenge the resulting statute.

Importantly, the fact that a statute has been assented to and signed by the President, but has not been brought into operation, does not deprive the Constitutional Court, or any other court of the jurisdiction, to consider its constitutional validity.

DFL also holds that in certain very limited circumstances, the Constitutional Court may issue declaratory relief to the effect that Parliament has failed to comply with its constitutional obligation to facilitate public involvement in the legislative process, before the parliamentary legislative process is completed:

The basic position appears to be that, as a general matter, where the flaw in the law-making process will result in the resulting law being invalid, Courts take the view that the appropriate time to intervene is after the completion of the legislative process. The appropriate remedy is to have the resulting law declared invalid. However, there are exceptions to this judicially developed rule or 'settled practice'. Where immediate intervention is called for in order to prevent the violation of the Constitution and the rule of law, courts will intervene and grant immediate relief. But intervention will occur in exceptional cases, such as where an aggrieved person cannot be afforded substantial relief once the process is completed because the underlying conduct would have achieved its object.³

Standing

Perhaps of greatest significance for any subsequent challenges to the constitutional validity of legislation based

on the lack of public participation in the parliamentary process is the standing requirement imposed by the majority judgment in cases of this nature. The applicant, Doctors for Life, had actively and repeatedly sought an opportunity to make submissions on the bills under challenge both at the National Council of Provinces (NCOP) and in the provincial legislatures, but their attempts were in vain. Doctors for Life applied to the Constitutional Court for relief as soon as possible after the Bill were promulgated.

The case of *DFL* limits when the Court will consider an application to declare legislation invalid on the grounds of lack of compliance with the constitutional obligation to facilitate public involvement to circumstances where (a) 'where the applicant has sought and been denied an opportunity to be heard on the Bills', and (b)

...where the applicant has launched his or her application for relief in this Court as soon as practicable after the Bills have been promulgated.⁴

The majority justified this requirement through the need for the Court

...to find a balance between, on the one hand, avoiding improper intrusions into the domain of Parliament, and, on the other, ensuring that a constitutional provision which requires Parliament to facilitate public involvement in the law-making process is sufficiently justiciable to ensure that the commitment to facilitating public involvement that it represents is not rendered nugatory.⁵

The majority also voiced its concern to

...prevent legislation being challenged on the ground of non-compliance with s 72 many years after the event by those who had no interest in making representations to Parliament at the time the legislation was enacted. It will thus discourage opportunist reliance by those who cannot show any interest in the duty to facilitate public involvement on that duty.⁶

This restricted form of standing further reflects the

concern to protect the institutional integrity of Parliament, while, at the same time, seeking to ensure that the duty to facilitate public involvement is given adequate protection.

The rider to this standing requirement is that if citizens do not have

...knowledge of the fact that there is a Bill under consideration, what its objective is and when submissions may be made, interested persons who wish to contribute to the law-making process may not be able to participate and make such contributions.⁷

This suggests that in appropriate circumstances, where reasonableness requires an opportunity for public participation, and no such opportunity occurs, because of lack of access to information, the standing requirements will obviously be relaxed.

The majority in *DFL* also cautioned future litigants that where

...Parliament has held public hearings but not admitted a person to make oral submissions on the ground that it does not consider it necessary to hear oral submissions from that person, this Court will be slow to interfere with Parliament's judgment as to whom it wishes to hear and whom not.⁸

It further states that

...where the public has been given the opportunity to lodge written submissions, Parliament will have acted reasonably in respect of its duty to facilitate public involvement, whatever may happen subsequently at public hearings.⁹

The constitutional duty to facilitate public involvement

Section 72 of the Constitution provides that:

(1) The National Council of Provinces must

(a) facilitate public involvement in the legislative and other processes of the Council and its committees; and

(b) conduct its business in an open manner, and hold its sittings, and those of its committees, in public, but reasonable measures may be taken -

(i) to regulate public access, including access of the media, to the Council and its committees; and
(ii) to provide for the searching of any person and, where appropriate, the refusal of entry to, or the removal of, any person.

(2) The National Council of Provinces may not exclude the public, including the media, from a sitting of a committee unless it is reasonable and justifiable to do so in an open and democratic society.

DFL concerns the nature and scope of the duty prescribed in Section 72 of the Constitution. Justice Ngcobo emphasises that the duty to facilitate public involvement in the legislative process is an aspect of the right to political participation, and that the South African constitutional framework requires a balance between the representative and participatory elements in our democracy.

Failure to comply with the constitutional duty to facilitate public involvement will render the legislation invalid. The test adopted by the majority in *DFL* is whether or not the procedure adopted by the legislature to facilitate public involvement is reasonable.

In such an enquiry, *'the nature and importance of the legislation and the intensity of its impact on the public'*¹⁰ are emphasised by the majority as especially relevant. Reasonableness also requires taking into account practicalities, such as time and expense, which relate to the efficiency of the law-making process:

...factors relevant to determining reasonableness would include rules, if any, adopted by Parliament to facilitate public participation, the nature of the legislation under consideration, and whether the legislation needed to be enacted urgently. Ultimately, what Parliament must determine in each case is what methods of facilitating public participation would be appropriate. In determining whether what

*Parliament has done is reasonable, this Court will pay respect to what Parliament has assessed as being the appropriate method. In determining the appropriate level of scrutiny of Parliament's duty to facilitate public involvement, the Court must balance, on the one hand, the need to respect parliamentary institutional autonomy, and on the other, the right of the public to participate in public affairs. In my view, this balance is best struck by this Court considering whether what Parliament does in each case is reasonable.*¹¹

In principle, the majority found it reasonable for the NCOP to facilitate public involvement in its legislative process through public hearings conducted by the provincial legislatures, provided that the provinces in fact held those hearings and that those proceedings were attended by members of the NCOP or, at the very least, that members of the NCOP had access to the reports of those proceedings.

However, the majority was of the view that once the NCOP has decided on the manner of public involvement and communicated this decision to interested parties, it must be held to its decision unless there is sufficient explanation for failure to give effect to that decision. They found that, viewed in their totality, the processes that were followed by the NCOP and the provincial legislatures in relation to the CTOP Amendment Act did not satisfy the NCOP's duty to facilitate public involvement in its legislative processes and those of its committees. Four provinces – Gauteng, KwaZulu-Natal, Limpopo and Northern Cape – wished to hold public hearings on the Bill, but only Limpopo conducted a hearing, while the Western Cape invited written submissions.¹²

Once it was conveyed to the NCOP that, contrary to its decision, a majority of the provinces did not hold public hearings, it had to hold such hearings. The court concluded that the NCOP and the provinces failed in their duty to facilitate public involvement in their legislative

and other processes in relation to the CTOP Amendment Bill; that the NCOP acted unreasonably in failing to hold public hearings on the CTOP Amendment Bill and did not, thereby, comply with its obligation to facilitate public involvement in relation to this Bill as required by Section 72(1)(a) of the Constitution.

Although the court recognised that there may be circumstances of emergency that require urgent legislative responses and short timetables, in this case, Parliament did not demonstrate that such circumstances existed.

Remedy

In terms of Section 172(1)(a) of the Constitution, the Constitutional Court was asked by the Applicant to declare that the conduct of the NCOP in this regard is inconsistent with the Constitution and is, therefore, invalid. Parliament's counsel argued that this would intrude into the domain of the legislative branch of government. The majority held that the obligation to facilitate public involvement is a requirement of the law-making process, that legislation must conform to the Constitution in terms of both its content and the manner in which it was adopted. Failure to comply with manner and form requirements in enacting legislation renders the legislation invalid:

*The obligation to facilitate public involvement is a material part of the law-making process. It is a requirement of manner and form. Failure to comply with this obligation renders the resulting legislation invalid.*¹³

Although the defect in the CTOP Amendment Act lay in the conduct of the NCOP, as the national legislative authority vested in Parliament, the majority held that Parliament has failed to fulfil its obligation in respect of the resulting statute. The consequence is that the matter must be remitted to Parliament for it to re-enact the law in a manner that is consistent with the majority judgment.

However, as the CTOP Amendment Act had come into

operation on 11 February 2005, and steps had been taken in terms of the amendment, the majority considered it just and equitable that the order of invalidity be suspended for 18 months, so as to enable Parliament to enact the CTOP Amendment Act afresh in accordance with the provisions of the Constitution. Parliament has until 17 February 2008 to do so.

In the unlikely event that Parliament does not meet this deadline, as it fails either to timeously reintroduce the Bill, hold hearings either in the NCOP or in the provinces, or to pass the bill thereafter, what are the consequences for access to termination services?

If the CTOP Amendment Act becomes invalid on 17 February 2008, all actions taken therein by provincial MECs to designate new health facilities between 11 February 2005 and 17 February 2008 will be invalid, and all those facilities would no longer be able to perform terminations. However, Section 8 of the CTOP Amendment Act stipulates that any facility designated in terms of Section 3(1) of the principal Act prior to the commencement of the Amendment Act must be regarded as having been approved by the MEC. In the event of invalidity, the effect of this transitional provision is likely to be that those facilities designated by the Minister prior to 11 February 2005 would continue to be able to provide termination services, as they would not have been subject to designation by an MEC.

All nurses who have completed the required training (as opposed to midwives) and perform first trimester terminations of pregnancy between 11 February 2005 and 17 February 2008 will no longer be able to do so.

Undoubtedly, if the CTOP Amendment Act is not passed in a constitutionally compliant manner before the February due date, the provision of termination services could be significantly disrupted and access to such services limited, thereby limiting women's constitutional right of access to healthcare, including reproductive healthcare services.

Let's hope that this does not come to pass.

FOOTNOTES:

1. 2006 (6) SA 416.
2. Constitution of South Africa, Act 108 of 1996.
3. At para 69.
4. At para 216.
5. At para 218.
6. At para 219.
7. At para 221.
8. At para 220.
9. At para 220.
10. At para 128.
11. At para 146.
12. At para 183 and 186.
13. At para 209.

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No recognition, no protection...

Community home-based care services in South Africa

South Africa, like most countries in Southern Africa, is greatly benefiting from community home-based care services. However, there are a number of gaps, which need to be addressed, looking at issues of policies guiding the implementation and safety of one of the biggest work force in South Africa – community home-based carers.

South Africa has developed and published a national guideline to develop and regulate community home-based care services. Like many policy documents, it never reached the people meant to benefit. These guidelines, if adequately implemented, would have assisted in reversing most of the challenges caused by current practices pertaining to community home-based care services, such as ‘*duplication of efforts*’ and ‘*mushrooming*’ of, many times, inadequate home-based care services.

Despite the contribution to HIV treatment, care and support efforts, community home-based carers remain to be a group of workers, who are not protected by any law, policy or guideline. Thus, there are no provisions to their work-related safety and security, and they are also ‘*undocumented*’ workers, in that there is no access for community home-based carers to unemployment benefits. The Department of Health and the Department of Social Development pay stipends every day to thousands of community home-based carers; yet, there seems to be no consideration for their health and emotional well-being, nor seems there to be any recognition of the services provided by community home-based carers.

Most of the community home-based carers are the ‘*bread winners*’ within their households. Community home-based carers are also the majority of people ‘*fostering*’ orphaned and vulnerable children within their

communities – without benefiting from social grants, such as the Foster Care Grant, afforded by government to people who ‘*foster*’ orphaned and vulnerable children. The same community carers are also the service providers offering the most accessible means of care in most rural communities, since care is available without the proof of identification, and reasons for accessing services.

It is also important to note that the community home-based carers are, in most cases, a highly vulnerable and exploitable group of workers. At times, community home-based carers are ‘*employed*’ as untrained healthcare professionals, performing odd jobs at different clinics, while ‘*trained*’ staff rests, drinks tea, and/or furthers their education.

This workforce, caring for thousands of people every day within different communities in South Africa, who without community home-based care interventions would have died, is not afforded any recognition and/or protection; despite the fact that government’s response to the HIV and AIDS pandemics largely relies on this workforce.

Acknowledging that a legislative and policy environment, which promotes, protects and respects the entitlements and rights of all people, promotes community-based and community-managed responses to the HIV and AIDS pandemics, also demands that community home-based carers are adequately recognised and protected.

South Africa lets do something about this...

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