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# **Executive Summary**

On September 13, 2003, over seventy people from legal, medical, academic, and civil-society backgrounds met at the Maharaja Conference Centre to discuss routine versus compulsory HIV testing in Botswana. Their discussion was to inform the extra-ordinary meeting of the National AIDS Council on Oct. 3<sup>rd</sup>, 2003, where a decision regarding routine testing in Botswana will be taken. The seminar was initiated by the Botswana Lawyers' Taskforce on HIV/AIDS and organized by the Botswana Network on Ethics, Law and HIV/AIDS (BONELA). Presentations were given by public medical practitioners, public and private attorneys, representatives of the private sector and the Ethics Institute of South Africa.

Recently, the Ministry of Health asked the National AIDS Council to consider making HIV testing routine in all health care settings. Through routine testing, the Ministry hopes to address several issues: reaching more people at an earlier stage of infection, availing necessary services as early as possible, and ultimately normalising the treatment of HIV infection, thereby removing stigma from the disease. In this fashion, it hopes to rein in the pandemic, and make the Vision 2016 goal of an AIDS-free generation realisable.

One important concern of seminar participants was the clarification of the terms of debate regarding routine testing, specifically the distinction of 'routine' from 'compulsory' testing. Routine testing, it was established, is testing that is commonly done by a medical practitioner on any individual he or she encounters in the consulting room, in the interests of that patient's continued health. The patient, however, can always decide to opt out of routine testing. Compulsory testing, on the other hand, would involve the testing of all patients whether or not they agree to be tested; the patient has no option but to test.

No participant advocated the use of compulsory testing in a public health care setting. It was widely argued, however, that for routine testing to be both effective and ethically defensible, it must adhere to basic human rights principles. The right to autonomy (control over one's own body), the right to privacy, and the right to health were specially noted, as they are enshrined in the constitution, are protected in international instruments to which Botswana is signatory, and inhere ultimately in the human person. To test someone without first receiving their consent would, it was argued, be an abrogation of that person's basic rights. In Botswana, it was noted further, an adult patient who is mentally and physically capable of exercising a choice *must* consent if medical treatment or testing of him or her is to be lawful. And yet, without wider HIV testing, the public's right to health is threatened. Discussants examined appropriate means of achieving balance between these rights, and between the rights of the individual and the public interest.

Ultimately, seminar participants agreed that routine testing carried out *after* obtaining the patient's informed consent would be consistent with a human rights approach, and should be made part of medical service provision in the public and private sectors of Botswana. They asserted, moreover, that compulsory testing in such settings should *not* be allowed. The degree of consent, the level of information a patient needs to receive, and the form in which a patient could give his or her consent is yet to be decided; however,

8:00-8:30

participants were adamant that basic human rights principles be adhered to in further defining 'informed consent' for the purposes of routine testing.

Finally, participants insisted that before any steps can be taken to introduce routine testing at medical facilities, adequate care and support structures must be provided in the form of social, medical and counseling interventions. The meeting also noted, with concern, that the concepts of compulsory, routine and mandatory testing have been used interchangeably in public discourse, leading to confusion among the general public. It was agreed that the public needs to receive thoroughgoing and correct information about routine testing, and that appropriate and precise language is of utmost importance. It is therefore crucial that the introduction of routine testing be preceded by an all-embracing Information, Education and Communication (IEC) strategy.

#### PROGRAMME of EVENTS

8:30-9:30	Breakfast
Master of Ceremonies:	Mr. O. Motumise - Chairperson Law Society of Botswana
9:30-9:40	Welcome Remarks Dr. Tiny Masupe – Board Member, BONELA
9:40-9:50	Opening Remarks Dr. Banu Khan - National Coordinator, NACA ***
Morning Session Chairperson	Dr. K. Ampomah - Representative to Botswana, UNAIDS
9:50-10:20	Presentation: HIV Testing from a Public Health Perspective Dr. P. Mazonde - Director of Medical Services, Ministry of Health
10:20-10:45	Question & Answer Period
10:45-11:15	Presentation Mr. D. Boko - Chairperson , Botswana Lawyers Taskforce
11:15-11:45	Presentation: Ethical Considerations in Routine Testing for HIV/AIDS  Prof. Willem Landman – Ethicist, Ethics Institute of South Africa
11:45-12:00	Question & Answer Period

Arrival of Guests & Registration

Seminar Report		
12:00-12:30	Presentation: HIV Testing from a Government Lawyer's Perspective Mrs. Beaulah Mguni – Principal State Counsel, Attorney General's Chambers	
12:30-13:10	Discussion ***	
13:10-14:10	Lunch ***	
Afternoon Session		
Chairperson	Mr. Dick Bayford - Botswana Lawyers Taskforce	
14:10-14:40 Mrs. No	Private Sector HIV Testing dwapi – Human Resource Manager, BDVC, Debswana	
14:4-15:10	Respondent – Mapping a Way Forward  Ms. C. Stegling - Director, BONELA	
15:10-15:40	Discussion	
15:40-15:50	Closing Remarks	

Mr. Forde - Resident Represtative, UNDP

Rapporteurs: Maame Awuah, Lindy Muzila

## **BACK**

## Welcome Remarks

Dr. Tiny Masupe - Board Member, BONELA

Ladies and gentlemen, it is my pleasure as a member of the BONELA board to welcome you all so early on a Saturday morning to the Botswana Lawyer's Taskforce Discussion Seminar on "*Routine or Compulsory Testing?*".

I would like to extend a special welcome to our presenters and speakers today:

Dr. Banu Khan, the Coordinator of the National AIDS Coordinating Agency;

Dr. Patson Mazonde, Director of Medical Services with the Ministry of Health;

Mrs. Beaulah Mguni, from the Attorney General's Chambers;

Mr. Forde, the Resident Representative of the UNDP;

Mrs. Ndwapi, from BDVC at Debswana;

Professor Willem Landman, who has flown up from the Ethics Institute of South Africa;

Mr. Duma Boko, the Chairperson of the Botswana Lawyers Taskforce;

and finally, Ms. Christine Stegling, the director of BONELA, who, together with the secretariat, have tirelessly overseen the organization of this event.

Also, thanks to those who have agreed to act as facilitators and chairpeople: to our Master of Ceremonies Mr. Motumise, the chairperson of the Law Society of Botswana; to Dr. Ampomah, the UNAIDS representative to Botswana;

to Mr. Dick Bayford, from the Botswana Lawyers Taskforce.

As well as Mr. Boko and Mr. Bayford, I'd like to introduce the other members of the Botswana Lawyers Taskforce with us today:

Herbert Sikhakhane of Sikhakhane & Company;

Maame Awuah of Awuah, Khan & Partners;

and Beaulah Mguni, Botsalano Motlhabane, and Lindy Muzila from the Attorney General's Chambers.

We would not be here without the generosity of our financial sponsors for this event, NACA and Debswana. Our thanks to them as well. We are particularly grateful to Dr. De Korte of ACHAP (African Comprehensive HIV/AIDS Partnership) for taking the initiative and flying in Prof. Landman from South Africa at such short notice.

For those of you who are unfamiliar with the Botswana Lawyers Taskforce and BONELA, the organizations responsible for today's seminar, I'd like to take a moment to introduce their work to you.

## The Botswana Network on Ethics, Law and HIV/AIDS

BONELA is a national network of NGOs, members of the legal profession, academicians and concerned individuals committed to protecting and promoting the rights of all persons affected by HIV/AIDS. Its goal is to ensure that human rights, legal and ethical considerations constitute the foundation of any response to the HIV epidemic in Botswana. BONELA's primary objectives include creating a network among local and regional stakeholders to establish and maintain a common response to ethical and legal challenges, much as we are doing here today.

Currently BONELA's work focuses on policy debate and development. The policy paper on Employment and HIV/AIDS is a major step we have taken towards developing appropriate legislation. The paper is a now a Bill that is in the final stages of revision. BONELA also provides the secretariat for the Ethics, Law and Human Rights Sector of the National AIDS Council, which is chaired by his Excellency the President.

The Botswana Lawyers Taskforce on HIV/AIDS is another of BONELA's initiatives that was established at a seminar on "Justice, Reason and Hope within the HIV Epidemic in Botswana" in October 2002, hosted by BONELA. I will leave it to their Chairperson, Mr. Boko, to elaborate on the Taskforce's activities in a little while.

Now, I would like to say a few words about the topic at hand. The issue of routine versus compulsory testing

is more relevant now than ever. Cast in the dual role of medical doctor and BONELA board member, the discussion today is of particular significance because I am at a vantage point of seeing both sides of the argument. That is, understanding the importance for testing to avail medical services and of patients' prior consent to testing as a human rights principle. It is my hope that you will take the opportunity provided to you today to consider the matter of HIV testing thoroughly, and to come to a conclusion amongst yourselves that will guide the way forward.

Lastly, I invite all present this morning to become members of the Botswana Network on Ethics, Law and HIV/AIDS. Apart from increasing the network's membership base and steering relevant debate as a unified collective, it would also give you as legal professionals, in your various capacities, an opportunity to actively contribute your skills and expertise in the fight against the pandemic. You will find a membership application form in your package. Please fill it in and hand it to one of the BONELA staff.

It is my sincere hope that you will enjoy our event today. I will now call upon our Master of Ceremonies, Mr. Motumise, to begin the proceedings.

**BACK** 

## **Opening Remarks**

Dr. Banu Khan - National Coordinator, NACA

Ladies and gentlemen,

(UNDP, UNAIDS, WHO, Judges of the High Court, Judges of the Industrial Court, Magistrates, Attorneys, representatives of the University of Botswana, members of the press, members of civil society organizations, representatives of the private sector)

I am delighted to open the second national meeting of legal practitioners in Botswana addressing HIV and AIDS. It is not so long ago, in late October 2002, that the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) got us here together to discuss how the legal profession could contribute to the national response to HIV. The meeting in October resulted in a very lively debate and in a joint commitment by all participants to make their time and expertise available to the national fight against the HIV epidemic.

The meeting in October 2002 selected a few private and public attorneys to take that commitment further and as we have witnessed in recent months this group has taken their task seriously. They recently published a communiqué, and have also identified the issue of routine or compulsory testing as a topic of national importance, which is why they have called us here today – to contribute to this national debate from a legal perspective.

The Botswana Lawyers' Taskforce on HIV/AIDS and BONELA form part of a wider initiative undertaken by the National AIDS Council to integrate a legal and ethical approach in the national response to HIV. To facilitate this integration, the National AIDS Council, chaired by HE the President, established a sector on Ethics, Law and Human Rights in June last year. The Law Society of Botswana chairs this sector, the Industrial Court provides the vice chairperson and BONELA houses the secretariat for the sector. You may have contributed to the work of the sector through your own institutions. I would like to point out that this sector is a good example for a partnership between the public sector and civil society. The sector has been active in drawing up a strategic plan which is in line with the National Strategic Framework (NSF). The NSF identifies one of the key areas of intervention as the need for the provision of a legal, ethical and human rights environment for all HIV/AIDS interventions and the mission of the sector therefore is to:

Facilitate the promotion and protection of human rights enshrined in the constitution of Botswana and international human rights instruments in the prevention, management and control of HIV/AIDS by all stakeholders. The sector seeks to ensure adherence to ethical standards and through the development of a culture of human rights through advice, education and advocacy for legislative and regulatory reforms.

You may be aware through the local press that the issue of testing has attracted a lot of attention recently, mainly through an initiative led by the Ministry of Health which was started with a small conference in June this year. The background to this discussion is an increased desperation by medical practitioners who feel that services offered in Botswana, including the ARV programme, are underutilized due to the reluctance of many Batswana to test for HIV. For any of us to offer any services to people infected and affected by HIV, be it social, legal or medical, the starting point needs to be that a person realizes his or her situation by knowing their HIV status.

Medical professionals also point out that the way that we handle HIV as a disease should change with the understanding that while HIV/AIDS is not curable, it can now be treated and we actually offer such treatment through the public health system free of charge for citizen patients. However, the majority of people still present themselves to health facilities at the very late stages of the infection, that is, when they are already ill with AIDS related diseases. This is a brief insight into the arguments brought forward by medical professionals who argue that they need to reach more people sooner.

I do not have to go into the details of what the national HIV/AIDS policy currently states on HIV testing. As legal professionals you will all be aware that in Botswana HIV testing is of a voluntary nature with the condition that people are adequately counseled before they decide to test and especially before they receive their test results. However blood is currently screened for HIV in blood donations, and for the sentinel surveillance which consist of anonymous and unlinked sero surveys. The policy currently states that routine testing is not required for pre-employment testing (except for expatriates), awarding of scholarships for further studies, periodic medical check-ups, routine health consultation and traveling into Botswana.

In my view, the meeting today will make a crucial contribution to understand the legal and rights context of this very complex matter. I would like to assure you that this is not an academic exercise but today's debate has very practical implications. In the last National AIDS Council meeting last week, members of the council had a lively and lengthy debate on the issue and it was decided that more arguments need to be made from all perspectives for the council to reach a conclusion on the matter. I would encourage you to come to some form of conclusion and make recommendations that the sector will present on your behalf at the next extraordinary meeting of the council when a policy decision will have to be made about whether and how to conduct routine testing in Botswana.

Once again, I am glad that the legal profession has joined the national response and that you feel this issue to be of such importance that you spend your time and energy contributing to the national debate.

Thank you.

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# **HIV Testing from a Public Health Perspective**

Dr. Patson Mazonde - Director of Medical Services, Ministry of Health

(no paper submitted – compiled from rapporteurs' notes)

After commending BONELA for organizing the seminar, Dr. Mazonde began with an explanation of why doctors use testing when it comes to health issues. A clinician, for example, may carry out diagnostic tests when he doesn't have adequate information from prior examinations. Diagnostic testing, he added, is usually individually-based. When a doctor wants to decide what treatment is most appropriate for an individual, he may perform further sensitivity tests. Testing is also an important way of determining whether what the doctor has been doing has achieved the desired results. And finally, he noted, the doctor may test patients anonymously to determine the health-related trends in a given community.

Within this context, Dr. Mazonde went on to define routine testing specifically. A routine test, he said, is "a test that you almost always commonly do whenever you come across an individual in your consulting room." As an example, he offered the case of pregnant women, all of whom must have their rhesus factor, blood grouping, hemoglobin, and urine tested, as well as undergoing tests for gonorrhea and syphilis. He was careful to note that he is *not* suggesting that compulsory testing be adopted in Botswana.

He then posed the question: Why a routine test for HIV? First, he suggested, "if you do not do that you are

going to have a health crisis". Pregnant women are tested, he reasoned, to help them have a healthy pregnancy, and to carry out any interventions that are necessary for their own or their baby's health. Secondly, he continued, there are some conditions that carry a stigma, like sexually-transmitted diseases. If you carry out routine tests on everyone, you are not isolating a particular individual or group of people, and you can therefore minimize the issue of stigma. Also, he added, you need routine testing if you want to arrest the spread of an infection. If you do not undertake routine testing, people won't know that they have a condition. Dr. Mazonde's fourth contention concerned public health specifically, when faced with a problem of a certain magnitude. In the face of an epidemic, he argued, the first thing is to decide who is positive – not in order to quarantine them, but in order to help them live a positive life; and also in order to know who is negative, so that we can ensure that they remain negative. He noted that the majority of Batswana are still negative, and insisted that it was crucial to keep them that way. Fifthly and finally, he expressed concern that many people who need assistance are coming in too late, and that we are therefore getting minimal returns on a huge expenditure of time, human and financial resources. Knowing people's status early, he suggested, allows us to budget for them; and ultimately, it will enable us to attain what we have been talking about in Vision 2016 – an AIDS-free generation.

Picking up on the goals of Vision 2016, Dr. Mazonde suggested further that it should be deemed professional negligence for any doctor not to test a pregnant woman for HIV/AIDS, in order to protect the baby. With routine testing, he added, you do not need to take someone into a separate room; you need not insist upon the rigamarole of pre-test counselling, where co-ordination is required among several groups, and the issue is removed from the patient-doctor relationship. This practice, he insisted, removes HIV/AIDS from the common arena of diseases – if you can routinely check someone for TB, he queried, why can you not do the same for HIV/AIDS? – and has the effect of scaring the patient.

In conclusion, Dr. Mazonde encouraged the participants to give the issue special thought, both because "we need to agree on what ought to be done", and because "we need to move quickly – if we don't we will have a situation that is totally unmanageable for future generations."

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## **Question and Answer Session**

Among several expressions of gratitude for his speech, seminar participants questioned Dr. Mazonde and expressed their own perspectives on the difference between routine and compulsory testing, and specifically the issue of consent. In response, Dr. Mazonde suggested that when a patient arrives at a health facility, they are consenting to be seen and checked by a practitioner, and that their consent to routine testing is assumed. In routine testing, he continued, the patient can still say, 'Doctor, don't do this'; in

other words, it is an opt-out system. If a patient refuses the test, the test will not be performed, and the patient will not be treated. Dr. Mazonde expressed some concern over this consequence, however; "...what we must decide as a community," he commented, "[is] what to do in those situations where it doesn't only affect the individual, but the community as a whole."

Further discussion sought definition for the kind of consent that would be required in routine testing; for the kind of counselling that would be involved; and for the issue of 'shared confidentiality', whereby the partners of patients (or fathers of unborn children) might be informed of the patient's HIV status once tested. Dr. Mazonde cited the Public Health Act in response, noting that if health officials believe that what someone is doing is a danger to the public, they can have that person arrested. He expressed skepticism about pre-test counseling, but insisted upon the necessity of post-test counseling – particularly in the case of a positive test, in order to help the patient learn to live positively with HIV. He was less specific on the issue of consent, noting that patients should know what their doctor is taking blood for, but simultaneously suggesting that a doctor who explains to a patient that she has the right to refuse a test inadvertently indicates his own fearfulness, and therefore makes the patient afraid.

Several participants pointed to a need to help people know their status, and help them alter their behaviour accordingly; several others noted a fearfulness of testing – and of HIV-related stigma – among Batswana as a significant barrier to their coming forward for testing. Still others called for an end to HIV exceptionalism, suggesting that with the advent of new care and treatment tactics, new policies needed to be developed and new possibilities explored. Dr. Mazonde adjoined, "It is true that those actually perpetuating the spread of HIV are the healthy ones. Therefore there must be more entry points as testing centres – we should not do this on a large scale if we don't have enough support structures in place."

# **HIV Testing from a Human Rights Perspective**

Mr. Duma Boko – Chairperson, Botswana Lawyers' Taskforce

(no paper submitted – compiled from rapporteur's notes)

Mr. Boko began by thanking the audience for consenting to listen to his arguments, and thereby re-focused participants' consideration of the issue on the subject of consent. In his opening, Mr. Boko drew a comparison between Dr. Mazonde's concept of consent in routine testing and the validation of marital rape. It has been argued, he explained, that by virtue of one's consent to a marital proposal, one has consented to everything that might happen within that marriage. He drew a further comparison between Dr. Mazonde's concerns about the allocation of resources in the fight against HIV/AIDS and a growing tendency for policemen to overlook the reading of rights to arrestees as a waste of time given the current high crime rate. With these contentious examples in hand, Mr. Boko insisted that today's discussion hits upon the very essence of our democracy, and of the democratic society Botswana dreams of becoming.

Why, he continued, must we seek consent? While acknowledging Dr. Mazonde's contention that seeking consent is time- and resource-consuming, Mr. Boko argued that there was a far more important concern at stake: that of maintaining human rights. Basic human rights, he specified – like the right to autonomy, or control over one's own body, and the right to privacy – are not negotiable; they are enshrined in the constitution, are protected in international instruments to which Botswana is signatory, and moreover they inhere in the human person. To test someone without first receiving their informed consent would, in this sense, be an abrogation of their basic rights.

Within this rights framework, Mr. Boko rephrased the issue of routine testing as a means-end calculation. What ends, he began, do we seek to achieve? If our goal is an AIDS-free generation, he persisted, then what are the means by which we can obtain this objective? His rhetorical inquiry continued: Are the means proper? What means can be adopted or adapted to achieve our goal within the broad framework of human rights?

The key to Mr. Boko's means-end calculation is informed consent. Is it so difficult, he challenged, to obtain informed consent that we can promote risky ways of obtaining information? And furthermore, what do we intend to do with the information we have received? There are many compelling arguments, he admitted, to restrict individual rights for the public good; his concern, however, was primarily for how far those arguments can be taken, and whether they might not represent a first step down a very slippery slope. He cited the criminalization of HIV transmission (wilfully or otherwise) and recent cases involving pre-employment and pre-scholarship testing as further indications of our slide down that slope. He also expressed concern over related issues of 'shared confidentiality', or the broadening of the doctor-patient confidentiality to include spouses, partners, children, or whomever else might be deemed 'affected'. One could argue, he hypothesized, that the pandemic is so severe that we should drag everyone out of their homes, round them up, test them, and tell everyone the results, all in the name of the public good. "The public good," he said, "must be examined less it become an excuse for tyranny."

According to Mr. Boko, informed consent involves "explaining to people what they are entering into". It involves more, he suggested, than telling patients they're being tested only if they want to know. He warned that universal precautions need to be taken; and that a thorough consideration of human rights needs to be at the very core of our response to the HIV/AIDS pandemic.

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## **BACK**

# Ethical Considerations in Routine Testing for HIV/AIDS

Prof. Willem Landman - Ethicist, The Ethics Institute of South Africa

Professor Landman began his presentation by establishing an 'ethics vocabulary' with which to discuss the ethical defensibility of routine testing for HIV/AIDS. The key terms of this vocabulary were: values, ethics, ethical dilemmas, ethical reasoning, ethics and the law, and ethics and religion. The following notes are taken directly from his Power Point presentation slides.

#### **Values**

- -Standards for measuring right, good and fair individual conduct, practices and institutions
- -Examples: respect; integrity; honesty; truthfulness; well-being (interests); fairness
- -Expressed as: Principles (guides for conduct)
  - Obligations (what I owe to others)
  - Rights (what I can claim from others)

#### **Ethics**

- -Reasoning about the core values driving the options we face
- -Choosing the option supported by the best values in the circumstance

#### Ethical Dilemmas

- -Clashes of agreed-upon values when choosing in a particular situation example: choosing between A's confidentiality and B's well-being
- -Disagreements about the application of values when choosing in a particular situation example: does my child's well-being demand support or punishment?

### Ethical Reasoning

- -Method
- Formulate problem
- Gather facts
- List choices
- Identify values
- Apply values to choices
- Act for the best ethical reasons (values, standards)

Considerations: Laws and regulations? Policies and procedures? Codes of Ethics – values and standards? How does it look in the sunlight (in front of family, media, society)? How does it fit with the Golden Rule (do unto others as you would have them do unto you)?

#### Ethics and the Law

- -Both guide conduct
- -Both deal with standards of right, good and fair conduct
- -But: \*What is legal may not be ethical ("unethical law")\*What is ethical may not be legal ("unlawful good deeds")

- \*"Law floats on a sea of ethics" former US Chief Justice Earl Warren
- -We need to decide the ethics of conduct and public policy independently of the law, but without disobeying the law.

## Ethics and Religion

- -Our ethical values and standards have many sources: tradition; authority; common morality, settled cases; the law; and religion
- -The ethics of public policy needs to be decided independently of particular religions, but core religious values are often identical with core ethical values, eg. respect for persons.

Within this context, Professor Landman went on to elucidate the ethical problem of routine testing for HIV/ AIDS, specifying the relevant facts, the ethical values at issue, and an ethical argument in support of routine testing (with provisions). To return to his Power Point presentation:

# Is it ethically justified for the state to require that citizens be routinely tested for HIV/AIDS when they present to clinics or hospitals for health care?

- -"Routine testing" means diagnostic testing is a part of medical and professional best practice, implying a default policy of testing unless one specifically elects not to have it
- -Not approached differently from other clinical investigations
- -Confidentiality but not anonymity
- -Should not require specific consent or pretest counselling provided clients/patients are informed that routine testing is part of the package of services for which they are voluntarily attending (*Lancet* 2002)

## Consider the ethics of the *reasons offered for routine testing*

- -Treatment but who will be treated if 50% of the population is tested in two years?
- -Gathering epidemiological data but how is the data to be used?
- -Accessing more treatment resources but how realistic is this expectation?

### Relevant Facts: HIV/AIDS in Botswana

- -HIV exceptionalism and voluntary testing
- -Prevalence 40%, but only 3-5% tested
- -Impact in terms of human suffering and economic consequences
- -ARV treatment for 10,000 (15,000 by 2005)
- -Need to narrow the gap between 40% and 5%
- -Public policy options: mandatory testing or routine testing

# Ethical values at issue: On the one side – Primacy of the values underpinning individual (human, moral) rights (civil liberties)

- -Subordinating the rights of all ("public rights") to the rights of the (HIV-positive) individual
- -Values: Well-being (interests)

## Autonomy (self-determination) - Privacy

- -Informed Consent
- -Confidentiality

## On the other side - Primacy of the values of the common good and public health

- -The good/interests ("public rights") of all (the community) is recognized as more than the sum of the goods (interests) of separate individuals ("individual rights")
- -Subordinating the rights of the individual to the rights of all (the community)
- -Is this not a communitarian notion valued in Africa in particular?

### An ethical argument:

## For individual rights ("don't test")

- -Individual rights should never be overridden, or only in extremis
- -Historical precedents for respecting individual rights even though the common good may be harmed:
  - Freedom to criticize government
  - Not torturing a suspected terrorist
  - Freedom of media

## For the <u>common good</u> and <u>public health</u> ("public rights") ("test")

- -Public healthcare emergency justifies overriding individual rights (analogy of loaded gun)
- \*When individual ill health presents on a wide scale and poses great dangers (of suffering) to (innocent) others and to society as a whole, then public policy that effectively overrides rights for the common good may be ethically justified.
- -Historical precedents for overriding individual rights for the common good:
  - \*Compulsory military service
  - \*Making other STDs or gunshot wounds reportable or notifiable

### The ethical challenge

-Balance/weigh rights against the common good and public health ("public rights") in the specific context of Botswana

If the state chooses routine testing, we need to consider and weigh whether such a changed public policy would:

\*Infringe individual *rights*?

\*Lead to bad *consequences* (harms) outweighing good ones (benefits)?

## Routine testing – <u>individual rights</u>

- -Individual rights (social justice) infringed by NOT testing and treating
- -Relevant individual rights:
  - \*Well-being (interests)
  - \*Respect

- \*Autonomy/self-determination (overriding a particular autonomous choice to promote an individual's overall autonomy)
- -The imperative to create societal structures and systems to protect individual rights prior to instituting routine testing
- -Having a clear endpoint for suspending individual rights or civil liberties beyond which public policy will not go

### Routine testing – weighing <u>consequences</u>

- -Good consequences (benefits)
- -IF routine testing leads to treatment and good behaviour modification (and thus prevention of transmission), *such testing promotes individual rights and, conversely, failure to test constitutes an infringement of individual rights*
- -Public health and resultant social and economic benefits the individual rights of potentially all members of society!
- -Good individual behaviour knowing one's status and taking precautions to protect the individual rights of identifiable others!
- -Knowing the scope of the disease, which encourages coordinated planning for preventive and other actions

Bad consequences (costs, harms)

- -If testing is not followed/matched by treatment (testing without treating):
  - \*Stigmatisation
  - \*Discrimination employment, insurance, etc.
- \*Bad individual behaviour knowing one's status and putting others deliberately at risk -If treatment is involuntary (forced treatment):
- \*Lack of compliance (low uptake) resulting in resistant strains but can it be controlled?

Routine testing for HIV/AIDS is an ethically defensible public-policy option, since it promotes the common good ("public rights") AND individual rights in the context of an overwhelming public health emergency, provided that:

\*The means used are maximally respectful of individual rights, given the goal of good health and scarce resources; and

\*Bad consequences are minimized by putting in place social and institutional conditions for the best protection of individual rights in the circumstances.

**BACK** 

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## **Question & Answer Session**

Participants responded to and discussed Mr. Boko's and Prof. Landman's presentations together, and explored several related points. A consensus began to emerge in support of routine testing, though the specifics of how to undertake such testing still proved contentious. Concerns remained around the nature of counselling and testing procedures, specifically with regards to the time it takes to counsel (pre-test) effectively and the amount of information a patient needs in order to give informed consent.

Concerns were also widely expressed about the limited involvement of the general public in the debate over HIV testing. One participant suggested a referendum; as an alternative, others suggested that interested parties could encourage critical debate or lobby for new policies. Among other groups specifically noted as pivotal to this debate were private, public and traditional medical practitioners, youth, and members of the judiciary. Discussants registered a strong desire to involve these sectors in order to ensure the successful implementation of any testing policy.

Additional concerns were voiced about the lack of confidence in the public health system with regard to testing. To increase the trust of citizens, it was proposed that the rights of those being tested be fully conveyed to the public. The public, it was stressed, must understand that opting out of testing is an option – particularly for those who cannot afford private healthcare. Discussants clarified the vocabulary surrounding the debate, noting that 'routine' and 'compulsory' testing were *not* synonymous, but there was a strongly stated need to ensure that a thorough communications strategy using the 'right language' was developed in communicating any decisions about HIV testing to the public.

# HIV Testing from a Government Lawyer's Perspective

Mrs. Beaulah Mguni – Principal State Counsel, Attorney General's Chambers

#### INTRODUCTION

The extent to which Botswana has been afflicted by HIV/AIDS is alarming considering that about 35.4% of the population is HIV positive.

In the words of Justice Amissah, in Makuto V. State 2000 B.L.R, 131 AT PAGE 139,

"By any measure, any Government, faced with such a sombre situation involving the survival of its people has an urgent duty to act to contain, or at least, to alleviate the suffering of its people."

The syndrome has been described as the modern scourge of the world. The suffering is not only physical. The trauma suffered by the people infected with HIV is increased by stigmatisation, discrimination as well as other violations of their fundamental human rights.

The stigmatisation and violation of human rights is often a result of the fear of those who wish to protect themselves from the disease. Much of this fear comes from the fact that the AIDS is a relatively new disease and has therefore evaded the understanding of many people.

Government is in the difficult position of having to contain, or at least alleviate, the suffering of the infected, on the one hand, while on the other hand it has to address the need to protect the uninfected. The duty of the Government is more complex than that. It has the duty of reconciling all the possible perspectives from which the issue of "Routine" or "Compulsory" HIV/AIDS testing can be addressed.

The unabating spread of the virus has caused the Government to review the national policy in order to adopt measures that are effective in stopping the spread of the disease, as well as alleviating its devastating consequences on those who are infected or affected by the disease, and on the national economy.

One of the measures that Government has been requested to consider is to make HIV testing routine in all health care settings, including ante-natal clinics and where there is a patient with clinical features of HIV/AIDS.

#### WHAT IS ROUTINE TESTING?

In medical practice, routine tests are those tests that are carried out on a patient on the understanding that by presenting himself at a medical facility, a patient has thereby consented to the carrying out of those tests. Making HIV testing routine means that patients would be tested for HIV on the strength of this implied consent. I would like to distinguish routine testing from compulsory testing. "Compulsory HIV testing" for purposes of this discussion is any HIV testing that is conducted in a situation where the person is being tested does not have the option of withholding his consent. An example of this situation is section 142(3) of the Penal Code that requires a person convicted of rape to undergo an HIV test. Compulsory HIV testing will be discussed later on.

## The rationale for routine HIV testing

The rationale for routine HIV testing is that it will allow the Government to reach infected people early enough to put them on antiretroviral drugs while the drugs can still be effective. The drugs improve the quality of life of a person infected with HIV provided he joins the antiretroviral programme before his immune system has deteriorated beyond some medically identified limits.

#### Standards that 'routine' has to meet.

Routine testing as a possible strategy has to be tested against the Constitution of Botswana and the existing international human rights standards. All HIV testing must be conducted with due regard to the human rights of the people to be tested.

#### THE BOTSWANA CONSTITUTION

The right to privacy, which is protected by section 3 of the Constitution, is fundamental to the issue of HIV testing. The right to privacy means that before a person to be tested for HIV such person has to first [2]

consent to the carrying out of the test.

Besides the Constitution, there is no legislation that specifically provides for the right to privacy in relation to HIV testing. There also being no Botswana cases on the matter, reliance therefore has to be placed on foreign case law which is of course of persuasive value.

The general rule is that no medical treatment or test can be administered on any person without his consent. An adult patient who is mentally and physically capable of exercising a choice must consent if medical treatment or testing of him is to be lawful, although the consent need not be in writing and may sometimes be inferred from the patien's conduct in the context of surrounding circumstances. <u>Joubert, the Law of South Africa, Vol 3.</u> at page 883.

The consent must be informed in order for it to be valid. The patient must understand what he is consenting to, i.e he must understand the nature of the test, and the meaning of HIV infection.

For consent to be valid, there must be confirmation that the matter has been properly explained to the patient by somebody in a position to explain to him and that having had the matter explained to the patient,

the patient fully understood the matter and consented thereto.

The right to privacy is not absolute. It is a right that is enjoyed subject to respect for the rights and

freedoms of others and for the public interest. Limiting the right to privacy in the context of routine

HIV testing must be done with great caution since some "Studies have demonstrated that HIV

prevention and care programmes with coercive or punitive features result in reduced participation

and increases alienation of those at risk of infection."

#### INTERNATIONAL STANDARDS

Botswana is a member of community of states that has undertaken to abide by certain standards of conduct. [6]

This community has taken a stand that

"Human rights promotion and protection is central to the response to HIV/AIDS."

It was therefore stated that an environment in which human rights are respected, vulnerability to HIV/AIDS is reduced, those infected with and affected by HIV/AIDS live a life of dignity without discrimination and the personal and societal impact of HIV infection is alleviated .

The Second International Consultation on HIV/AIDS and Human Rights, organised jointly by the United Nations Office of the High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS) held in GENEVA in September 1996 adopted guidelines that are intended to assist states in creating a positive, rights-based response to HIV/AIDS that is effective in reducing the

transmission and impact of HIV/AIDS and consistent with human rights and fundamental freedoms.

HIV/AIDS is acknowledged by these guidelines as a public health concern. States are therefore expected to ensure that their public health legislation adequately addresses the public health issues raised by HIV/AIDS and that the provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/

AIDS and that they are consistent with international human rights obligations."

The international standards that Botswana's policy and legislation would be measured against require that-

- apart from surveillance testing and other unlinked testing done for epidemiological purposes, public health legislation should ensure that HIV testing of individuals should only be performed with the specific informed consent of that individual. Exceptions to voluntary testing would need special judicial authorisation, granted only after due evaluation of the important considerations involved in terms of privacy and liberty.
- in view of the serious nature of HIV testing and in order to maximize prevention and care, public health legislation should ensure, wherever possible, that pre- and post-counselling be provided in all cases.

Botswana has already embraced the human rights approach to HIV/AIDS. Its commitment to this approach is reflected in the National HIV/AIDS Policy. The policy contains principles that meet these requirements. It states that HIV testing should not be conducted without the informed consent of the individual. It also states that pre- and post-test counselling and information should be offered, and also that confidentiality should be maintained.

#### COMPULSORY TESTING

Compulsory testing also has to be tested against the Botswana Constitution as well as the international

standards.

#### THE BOTSWANA CONSTITUTION

Section 142(3) the Penal Code provides that:

"(3) any person convicted of the offence of rape shall be required to undergo a Human Immunesystem Virus test before he or she is sentenced by the court."

This testing is conducted for the purpose of imposing an Enhanced penalty on HIV positive persons.

This subsection, together with the subsections that impose the heavier sentences have been challenged in Court as being unconstitutional. It was argued that the sections discriminate against HIV Positive persons who commit rape. It was further argued that the application of the provisions has the effect of punishing a person for the status of being HIV positive. The Court decided that compulsory testing for the purpose of discriminating against an HIV positive convicted rapist in order to impose a heavier sentence is not unconstitutional since it is reasonably justifiable in a democratic society. However the enhanced penalty was set aside because the test results did not state whether the appellant was HIV positive at the time of the offence. Before the enhanced punishment can be imposed it is necessary to establish that the convicted person was HIV Positive at the time of committing the offence. There is therefore a need to amend the law to ensure that HIV testing is conducted at a time when the results can reflect that the convicted person was HIV Positive at the time of committing the offence.

#### INTERNATIONAL STANDARDS

The international standards that Compulsory testing would be measured against require that-

criminal and correctional systems must be consistent with international human rights obligations, and should not be misused in the context of HIV AIDS or targeted against vulnerable groups. Makuto V. the State is an example where a convicted HIV positive person received protection of the law, by having his sentence reduced.

#### **CONCLUSION**

"...it is known the world over that Botswana is one of the few countries in Africa where liberal democracy has taken root. It seems clear... that all the three arms of the Government • the Legislative, the Executive and the Judiciary • must strive to make it remain so except to any extent as may be prohibited by the Constitution in clear terms... in so striving we cannot afford to be immuned from the progressive movements going on around ... in other liberal and not so liberal democracies, such movements manifesting themselves in international agreements, treaties,

[11]

resolutions, protocols and other similar understandings.

There is a need for the Government in addressing the issue of "Routine" or "Compulsory" HIV testing to critically assess the interdependence of human rights and public health.

**BACK** 

# **Private Sector HIV Testing**

Mrs. M. Ndwapi - Human Resources Manager, BDVC, Debswana

As a representative of one of the largest employers in Botswana, Mrs. Ndwapi provided an interesting counterpoint to the issue of routine versus compulsory testing. She re-defined the issue from a private-sector perspective and then explained Debswana's current testing policies and the reasoning behind them. The following notes are adapted from her Power Point presentation slides.

#### **DEFINITIONS**

- Routine testing: a situation where individuals who present themselves at medical facilities can have any test carried out that may help with the diagnosis of their illness
- Compulsory testing: a situation where unless a test is carried out on an individual, *x* may not be done for that individual

#### COMPULSORY HIV TESTING

Debswana currently undertakes compulsory HIV testing in the following situations:

- Preinvestment testing for scholarships and apprenticeships
  - \*Manpower planning
  - \*ROI (return on investment)
  - \*Opportunity for future business growth
- Non-employees
  - \*if positive, no sponsorship is given
- Employees
  - \*sponsorship given irrespective of HIV status (subject to prognosis and registration on DMP)

#### ROUTINE TESTING

Debswana currently undertakes routine testing (for non-HIV illnesses) in the following situations:

- Pre-employment tests
- Retests
  - \*annual for EXCO members

- \*half-yearly for food handlers
- \*biannually for rest of employees
- HBP, hearing, vision, lung functionality, stress, cholesterol

Ideally, Debswana would like to undertake routine testing in the following situations:

- Pre-employment tests
- Retests
  - \*annual for EXCO members
  - \*half-yearly for food handlers
  - \*biannually for rest of employees
- HBP, hearing, vision, lung functionality, stress, cholesterol etc. including HIV

#### RATIONALE FOR INCLUDING HIV TEST IN ROUTINE TESTS

- Normalise the disease as per Debswana's policies
- Early diagnosis and enrolment on the DMP
- Manpower planning

#### \*\*\*

# **Responding Session / Summary**

Ms. Christine Stegling - Director, BONELA

We started this seminar on the assumption that we were not going to have an academic debate on a topic of theoretical interest. Instead we knew at the start of our debate that today's deliberations will inform the discussions at the extra-ordinary National AIDS Council meeting on October 3<sup>rd</sup> 2003.

My intervention will attempt to do two things: summarise our proceedings today and point at the way forward. The summary, however, will concentrate on issues that we agreed upon and point out those areas that we still need to work on in order to fill gaps.

#### Summary:

- 1. It has been agreed that routine testing should be made part of medical service provision in the public and private sectors of Botswana.
- 2. Participants have also agreed that compulsory testing in such settings should not be allowed for.
- 3. Importantly it was agreed today that routine testing needs to be undertaken after a patient has consented to such a test. Everybody here today agreed that consent always needs to form part of the communication between the medical practitioner and the patient.
- 4. One area that this seminar has not managed to conclude on is the degree of consent and/or how detailed information a patient needs to receive and in what form the patient will be giving his or her consent. However, there was some form of agreement that consent does not necessarily need to be

in writing.

- 5. We have also agreed that Botswana as a country subscribes to certain human rights principles as stipulated in the constitution and in international human rights instruments that have been signed by our government. The same principles need to be valued and respected in any approach that we take to address the HIV epidemic in Botswana.
- 6. As Dr. Khan of the National AIDS Coordinating Agency so adequately pointed out, to agree on the principle of routine testing does not seem to be the problem. What we need to agree upon, however, is how to facilitate such testing.
- 7. The meeting has agreed that consent is not only important from a human rights point of view but also will enable a person to accept and live positively with the test result. We all agree that that acceptance is what will underline any responsible public health response.
- 8. We have also agreed that at the core of any intervention is its outcome. The meeting agreed that before any steps can be taken to introduce routine testing at our medical facilities, adequate support structures need to be put in place to provide care and support in the form of social, medical and counseling interventions.
- 9. This meeting notes with concern that the concepts of compulsory, routine and mandatory testing have been used interchangeably which has led to confusion in the general public. It was agreed that the use of correct and precise language is of utmost importance and that the public needs to receive adequate and correct information about routine testing. It is therefore important that the introduction of routine testing be proceeded by an all embracing Information, Education and Communication (IEC) strategy.
- 10. Our colleague from the Ethics Institute of South Africa reminded us about the ethical arguments for and against routine testing and asserted that any such intervention needs to be based on the very general principle 'do not do to others that you do not want to be done unto yourself'. It is my sincere hope that all of us who are discussing this possible intervention keep this moral principle in mind.

At this point I would also like to re-emphasise Mr. Boko's concerns with regard to making decisions about limiting individual rights as enshrined in our constitution in the interest of the public good. Such a decision may lead us, as he phrased it, onto a slippery slope which may pave the way for future human rights abuses not foreseen by us today. One needs to caution, therefore, against policy makers using 'short-cuts' out of desperation to solve a societal emergency. I would also like to remind you at this point in time that we always seem to start with draconic measures before we have even implemented and legislated the most basic interventions. A good point for that argument is the lack of legislation, policy and practice of ensuring that universal precautions are part of everyday life in Botswana.

A suggestion was made with regards to the existing compulsory testing in Botswana by private companies such as Debswana who test students for the ward of scholarships abroad. It seems that such compulsory testing is unnecessary since the provision of ARVs has become a reality in Botswana. Routine testing would probably be perceived and understood a lot better by the public if all forms of compulsory testing would be cancelled.

In closing my summary, I would like to remind people about the very real implications of stigma in this country. Real and perceived stigma is still a major hurdle to responding to HIV in Botswana. We are all aware that stigma leads to discrimination and discrimination prevents people from accessing the most basic of services. The crucial question of how and why stigma remains after so many years of education and service provision needs to be answered in order to make a real change to the epidemic.

## The way forward:

The Botswana Network on Ethics, Law and HIV/AIDS and the Botswana Lawyers' Taskforce on HIV/AIDS will do everything possible to draft a write-up of today's proceedings within the next week. An attempt will be made to distribute the draft to all of you electronically as soon as possible to allow you to make comments. Our intention is to have a document ready and circulated to all members of the National AIDS Council before the 3<sup>rd</sup> of October 2003.

We have discussed with Dr. Mazonde the possibility to join the Ministry of Health document with this document to allow us presenting a joint document to the council.

Finally, as the director of BONELA I would like to thank all of you present here today for your participation and active debate. In particular I would like to thank the Lawyers' Taskforce members that are here today and that have worked hard to make this meeting a reality: Duma Boko, Maame Awuah, Dick Bayford, Herbert Sikhakane, Beaulah Mguni and Lindiwe Muzila.

I hope that today's seminar has also proven that organizations like BONELA and initiatives like the Lawyers' Taskforce on HIV/AIDS can make a valuable contribution to policy debate. As an organization we are committed to pursue such critical policy debate and we hope that we will receive the necessary support to do so in future.

I would now like to invite Mr. Forde of the United Nations Development Programme in Botswana to close this meeting officially.



# Discussion of the Way Forward

With the seminar's conclusions – and shortfalls – established, several participants came forward with suggestions to guide further discussion around the implementation of routine testing.

Of particular concern was the practical application of the routine testing process, and making it as easy as possible for testing patients. Along these lines, several participants insisted upon a clear explanation to the public of what 'routine testing' means (and, conversely, what mandatory testing implies), so as to minimize confusion. A greater role for the public in the national debate around testing was also strongly advocated – making the subjects of this discussion an active part of it.

Many participants also insisted that every effort be made to ensure that appropriate and thorough counseling accompany routine tests. Others called for expanded government support and sponsorship for voluntary testing centres; still others suggested that the role of the spouse or partner be carefully considered in further debate of the issue. The vast majority of delegates, however, agreed that routine testing done properly would be a 'best practice' in the fight against the epidemic.

- Makuto v. State, 2000 B.L.R, 131 at 139
- Dingake, O (1999) HIV/AIDS and the Law, A guide to our Rights and Obligations, p11.
- C v. Minister of Correctional Services 1999(4) SA 292(T) at 292
- [4] Ex Parte Dixie, 1950 (4) SALR 748 AT 748.
- Dwyer, Legislating HIV/AIDS Away, p 63

- [6] Amissah J, Attorney General v Unity Dow, 1992 BLR 119, at 154
- Mary Robinson in the Foreword to the Guidelines adopted by the Second International Consultation on Hiv/AIDS and Human Rights, organised jointly by the United Nations Office of the High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS) p5. Held in Geneva from 23 -25 September 1996.
- [8] Ibid.
- Introduction to the Guidelines adopted by the Second International Consultation on HIV/AIDS and Human Rights, organised jointly by the United Nations Office of the High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS) p5. Held in Geneva from 23 -25 September 1996.
- [10] Ibid. Guideline No. 3.
- [11] Amissah J, Attorney General v. Unity Dow, 1992 BLR, 119 At 168 A-C.