

Human Rights Implications of the Compulsory HIV/AIDS Testing Policy: A critical  
appraisal of the law and practice in South Africa, Uganda and Canada

By

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## ABSTRACT

HIV/AIDS has been an obstacle to socio-economic development and a major cause of loss of human life. It has also caused vast inequities and frustration to the public health sector. One of the significant efforts made by the public health sector to combat the epidemic is the implementation of a mandatory HIV/AIDS testing policy to scale-up HIV treatment. This dissertation examines the impact of this policy on the human rights of people infected with and affected by HIV/AIDS. Coercive government policies aimed at controlling the AIDS pandemic often infringe on the rights of individuals known to be or suspected of living with HIV/AIDS and this decreases the effectiveness of public health measures.

The research methodology involved the study of written literature and a comparative literature study of the law and practice obtaining in South Africa, Uganda and Canada. It revealed that voluntary testing is effective and suitable in South Africa. This dissertation aimed to show that any public health approach that aims to achieve a comprehensive prevention strategy must be consistent with respect for human rights as enshrined in regional and international human rights law. Public health and human rights should, therefore, not be regarded as opposing forces; rather they should be seen as a unified system of protection of human welfare under the Bill of Rights and the Constitution.

The solution to the crisis lies not only in testing every single person but also requires a shift of focus to more pressing issues that include gender equality, stigma and discrimination; prioritizing human rights, institutional capacity and resources; and an end to extreme poverty. A human rights-based approach to HIV/AIDS testing, such as the Voluntary Counselling and Testing (VCT) is recommended. Therefore, failure to adhere to the core principles of testing - which are informed consent, counselling and confidentiality of the test result - will only hinder the global fight against HIV/AIDS. The rights of those affected by HIV/AIDS need to be protected in order to address public health imperatives. This can be done through the use of the law as an instrument of social change as well as education and awareness.

**Key words**, HIV/AIDS, mandatory testing, Voluntary Counselling and Testing, public health, human rights-based approach.

## **DECLARATION**

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## **DEDICATION**

I dedicate this thesis to my parents who have loved and supported me throughout my life and for their unconditional support with my studies. They have taught me that anything can be achieved through hard work and they have helped make me the person I am today.

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## LIST OF ACRONYMS AND ABBREVIATIONS

|        |   |
|--------|---|
| ABC    | Abstain, be Faithful, and Condomise   |
| ACHPR  | African Charter on Human and Peoples' Rights                                    |
| ACRWC  | African Charter on the Rights and Welfare of the Child                          |
| ACP    | AIDS Control Program  |
| AIC    | AIDS Information Centre of Uganda   |
| AIDS   | Acquired Immune Deficiency Syndrome   |
| ART    | Antiretroviral Treatment/Therapy  |
| BONELA | Botswana Network on Ethics, Law and HIV and AIDS                                |
| CDC    | Centre for Disease Control and Prevention                                       |
| CEDAW  | Convention on the Elimination of All Forms of Discrimination against Women      |
| CERD   | Convention on the Elimination of All Forms of Racial Discrimination             |
| CIC    | Citizenship and Immigration Canada  |
| CRC    | Convention on the Rights of the Child   |
| DMP    | Designated Medical Practitioner   |
| DRC    | Democratic Republic of the Congo  |
| ECHR   | European Convention for the Protection of Human Rights and Fundamental Freedoms |
| ESC    | European Social Charter   |
| GDP    | Gross Domestic Product  |
| GNP    | Gross National Product  |
| HCT    | HIV Counselling and Testing   |

|          |  |
|----------|--|
| HIV      | Human Immunodeficiency Virus   |
| HIV/AIDS | Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome |
| HRC      | Human Rights Council   |
| HPA      | Health Protection Authority  |
| HSLDA    | Home School Legal Defence Association                                |
| ICCPR    | International Covenant on Civil and Political Rights                 |
| ICESCR   | International Covenant on Economic Social and Cultural Rights        |
| ILO      | International Labour Organisation                                    |
| IME      | Immigration Medical Examination                                      |
| IOM      | Institute of Medicine  |
| KP       | Kyoto Protocol   |
| MDR-TB   | Multi-Drug-Resistant Tuberculosis                                    |
| NCPA     | National Committee for the Prevention of AIDS                        |
| NGO'S    | Non-Governmental Organisations                                       |
| NHA      | National Health Act of South Africa                                  |
| OHCHR    | Office of the United Nations High Commissioner for Human Rights      |
| PAHO     | Pan American Health Organisation                                     |
| PITC     | Provider-Initiated Counselling and Testing                           |
| PLWHA    | People Living with HIV/AIDS  |
| SAA      | South African Airways  |
| SADC     | Southern African Development Community                               |

|           |   |
|-----------|---|
| SADC PF   | Southern African Development Community Parliamentary Forums |
| SALRC     | South African Law Reform Commission                         |
| SAMA      | South African Medical Association                           |
| SDT       | Special and Differential Treatment                          |
| STD       | Sexually Transmitted Diseases                               |
| STI       | Sexually Transmitted Infections                             |
| TASO      | The AIDS Support Organization                               |
| TB        | Tuberculosis  |
| Three C's | Consent Counselling and Confidentiality                     |
| UAT       | Unlinked Anonymous Testing                                  |
| UDHR      | Universal Declaration of Human Rights                       |
| UN        | United Nations  |
| UNAIDS    | United Nations Joint Programme on HIV and AIDS              |
| UNCHR     | United Nations Commission on Human Rights                   |
| UNHCR     | United Nations High Commissioner for Human Rights           |
| UNDP      | United Nations Development Programme                        |
| UNECOSOC  | United Nations Economic and Social Council                  |
| UNHRC     | United Nations Human Rights Council                         |
| UNICEF    | United Nations Children's Fund                              |
| UNFCCC    | United Nations Framework Convention on Climate Change       |
| USAID     | United States Agency for International Development          |
| VAT       | Value Added Tax   |

|        |                                     |
|--------|-------------------------------------|
| VCT    | Voluntary Counselling and Testing   |
| WHO    | World Health Organisation           |
| WTO    | World Trade Organisation            |
| XDR-TB | Extreme Drug Resistant Tuberculosis |
| YMCA   | Young Men's Christian Association   |
| YWCA   | Young Women's Christian Association |

## **INTERNATIONAL INSTRUMENTS**

African Charter on the Rights and Welfare of the Child of 1990

African Charter on Human and Peoples' Rights of 1981

Atlantic Charter of 1941

Canadian Charter of Rights and Freedoms of 1982

Convention on the Prevention and Punishment of the Crime of Genocide of 1948

Doha Declaration on the TRIPS Agreement and Public Health 2001

European Convention for the Protection of Human Rights and Fundamental Freedoms of 1950

International Covenant on Civil and Political Rights of 1966

International Covenant on Economic, Social, and Cultural Rights of 1966

International Guidelines on HIV/AIDS and Human Rights 2006

The Kyoto Protocol of 1997

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa of 2003

The Universal Declaration of Human Rights of 1948

The Charter of the United Nations of 1945

The Conventions on the Rights of the Child of 1989

The Convention on the Elimination of All Forms of Discrimination against Women of 1979.

The General Act of the Berlin Conference on Central Africa of 1885

The Convention on the Elimination of All Forms of Racial Discrimination of 1965

Vienna Declaration and Programme of Action of 1993

Vienna Convention on the Law of Treaties of 1969



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National Health Act 61 of 2003 (South Africa)

The South African Constitution of 1996

Public Health Act of the United Kingdom of 1984

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- Jansen van Vuuren NNO v Kruger* 1993 4 SA 842 (A)
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- Minister of Home Affairs and Another v Fourie* 2006 (1) SA 524 (CC)
- Minister of Health and Others v Treatment Action Campaign and Others (TAC)* 2002 5 SA 721(CC)
- N v United Kingdom* (2008) 47 EHRR 885
- National Media Ltd and Another v Jooste* 1996 (3) SA 262 (SCA)
- National Coalition for Gay and Lesbians Equality v Minister of Justice* 1999 (1) SA 6 (CC)
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*Purohit and Moore v Gambia Communication* 241/200

*R v Morgentaler* (No2) [1988] 1 SCR 30

*S v Makwanyane*, 1995, (3) SA 391 (CC)

*S v Manamela* 2000 3 SA 1 (CC)

*S v Zuma* 1995 (2) SA 642 (CC)

*Soering v United Kingdom* (1989) (1) EHRR 439

*Steiner and Gross v The Polish State, Upper Silesian Arbitral Tribunal, Cases Nos.188 and 287*

*Stoffberg v Elliot* 1923 CPD 148 at 150

*The Government of the Republic of South Africa and Others v Grootboom and others* 2001(1) SA 46(CC)

## CHAPTER 1: INTRODUCTION TO THE STUDY

### 1.1 Background of the Study

HIV/AIDS has caused vast inequities and widespread stigmatisation in the public health sector. The rights of people affected by HIV/AIDS need to be protected in order to address public health concerns. This can be done through the use of law as an instrument of social change, thereby protecting the rights of those infected with and vulnerable to HIV/AIDS.<sup>1</sup> An environment can thus be created whereby stigma, violence and inequity can be reduced.<sup>2</sup> The Universal Declaration of Human Rights (UDHR)<sup>3</sup> begins with the recognition of the inherent dignity and the equal and inalienable rights of all people. This is where the fundamental relationship between human rights, health and non-discrimination is embedded. Tampering with this relationship may result in the violation of the human rights of people living with HIV/AIDS.<sup>4</sup>

The AIDS pandemic has revealed that a complex relationship exists between the fields of human rights and public health which historically have remained largely separate. It is evident that coercive government policies aimed at controlling the AIDS pandemic often infringe on the rights of people known to be or suspected of living with HIV/AIDS (PLWHA) and this decreases the effectiveness of public health measures.

The international system for the protection of human rights grew out of international revulsion at the atrocities committed during World War II.<sup>5</sup> The pre-war international system had focused solely on relations between states such that human rights violations that occurred within a country's borders were deemed to be an "internal affair".<sup>6</sup> The horrors of the war exposed the vulnerability of the individual in an international system that was based on the doctrine of state sovereignty and demonstrated the gross inadequacy of previous attempts to protect victims of war.

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<sup>1</sup> International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version available at <http://data.unaids.org/Publications/IRC-pub/07/jc1252-internationalguidelines-en.pdf>, (accessed 16 August 2011).

<sup>2</sup> *Ibid* at p.3.

<sup>3</sup> The Universal Declaration of Human Rights of 1948.

<sup>4</sup> Gostin and Lazzarini, *Human Rights and Public Health in the AIDS Pandemic* New York: Oxford Press 1997, p. 2.

<sup>5</sup> *Ibid*.

<sup>6</sup> *Ibid* at p. 2-3.

The post second world-war human rights movement altered the scope of international law.<sup>7</sup> It pierced the veil of national sovereignty and elevated human rights as a matter of international concern.

The preamble to the Charter of the United Nations<sup>8</sup> affirms the international community's determination "to reaffirm faith in fundamental human rights, in the dignity and worth of the human person...." One of the central objectives of the United Nations is to achieve international co-operation in "promoting and encouraging respect for human rights and for fundamental freedoms for all without distinction as to race, sex, language and religion".<sup>9</sup> The Charter was agreed upon by member states and later subscribed to by all new nations. It places an obligation on member states to promote solutions to international economic, social, health and related problems, among others.<sup>10</sup>

The UDHR, which was adopted in 1948, built upon the UN Charter's promise by identifying rights and freedoms that deserve promotion and protection.<sup>11</sup> The adoption of the UDHR gave birth to a treaty-based scheme of promoting and protecting human rights two decades later by the adoption of the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>12</sup> These two instruments, when read together with the UDHR, form the backbone of the international human rights system. The right to health is guaranteed in the UDHR which postulates that:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.<sup>13</sup>

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<sup>7</sup> Gostin and Lazzarini *Human Rights and Public Health in the AIDS Pandemic*, New York: Oxford Press, 1997, p. 3.

<sup>8</sup> The Charter of the United Nations was adopted in 1945.

<sup>9</sup> United Nations Charter, Article 1(3).

<sup>10</sup> United Nation Charter, Article 55 (b).

<sup>11</sup> The Universal Declaration of Human Rights was adopted after the end of World War II on 10 December 1948 by the United Nation (UN) General Assembly in Paris.

<sup>12</sup> These Covenants entered into force in 1976. The two Covenants share a common substantive protection, namely the right of self-determination (Art 1), and prohibition of discrimination (Art 2).

<sup>13</sup> Article 25 of the UDHR.

The UDHR has largely fulfilled the promise contained in its preamble, and it has provided a common standard for evaluating respect for human rights. Although it was not promulgated as legally binding on member states, its key provisions have found wide acceptance by member states and, therefore, the UDHR is considered to have attained the status of customary international law. Furthermore, the UDHR has been used by organs of the United Nations as a standard by which to measure the conduct of states.<sup>14</sup>

Health was also recognised as a human right by the World Health Organisation (WHO). In the preamble of its constitution, it is stated that the attainment of the highest standard of physical and mental health is a fundamental right of everyone.<sup>15</sup> The right to health cannot, however, be enjoyed in isolation from other rights: it is dependent on other rights such as the right to life, the right to dignity, freedom from inhuman and degrading treatment, liberty and non-discrimination. Conversely, a violation of the right to health may have an impact on other rights such as the right to life, human dignity, privacy, liberty and non-discrimination.<sup>16</sup>

The United Nations Centre for Human Rights (UNCHR), now referred to as the United Nations High Commissioner for Human Rights (UNHCR), and the Joint United Nations Program on HIV/AIDS, provided a key legislative tool for parliamentarians, namely, the International Guidelines on HIV/AIDS and Human Rights.<sup>17</sup> These Guidelines were developed in order to meet the needs of governments and to offer guidance on how best to promote, protect and fulfil human rights in the context of the HIV epidemic, both in terms of legislation and practice.<sup>18</sup> The International Guidelines consists of 12 principles along with related commentary and recommendations for implementation. Since the original publication and revision of the Guidelines, significant developments have taken place in the implementation of the right to health and access to HIV/AIDS with regard to prevention, treatment, care and support, including advances in accessing antiretroviral therapy.<sup>19</sup>

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<sup>14</sup> Dugard *International Law: A South African Perspective*, Juta and Company, 2005, p. 325-326.

<sup>15</sup> The preamble of the Constitution of the World Health Organisation (WHO), adopted in 1945.

<sup>16</sup> Durojaye, and Balogun, "Human Rights implications of Mandatory HIV testing in Nigeria", *International Journal of Law, Policy and Family* Vol 24:2, 2010 p. 245-265.

<sup>17</sup> The International Guidelines on HIV/AIDS and Human Rights were adopted in 1996 in Geneva following consultations with thirty-five experts in the field of HIV/AIDS and human rights.

<sup>18</sup> See Gostin and Lazzarini footnote 1 above, p. 4-6.

<sup>19</sup> *Ibid*, p. 6.

Regionally, the right to health is also guaranteed in the African Charter on Human and Peoples' Rights (ACHPR).<sup>20</sup> Article 16 of the African Charter provides that every individual has the right to enjoy the best attainable state of physical and mental health. A similar provision is also postulated in Article 14 of the Protocol to the African Charter on the Rights of Women in Africa (African Women's Protocol).<sup>21</sup> The Protocol further provides that states should respect and promote women's right to control their fertility, decide the number and spacing of their children, choose any method of contraception, self-protection from sexually transmitted infections including HIV/AIDS, and the right to have access to legal abortion in certain situations and family planning.<sup>22</sup> The African Women Protocol is thus the first international human rights instrument to explicitly recognise women's reproductive health as a human right and to provide specific provisions on women's protection in the context of HIV/AIDS. Article 14 (1) (d), which specifically guarantees health and reproductive rights, postulates that every woman has the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS.

The right to health is also expressed in article 14 of the African Charter on the Rights and Welfare of the Child. It guarantees that "Every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health."<sup>23</sup> In the case of *Purohit and Moore v The Gambia*, a communication brought before the African Commission on Human and Peoples' Rights, the Commission held that the enjoyment of the right to health, as it is widely known, is vital to all aspects of a person's life and well-being, and is crucial to the realization of all the other fundamental human rights and freedoms.<sup>24</sup>

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<sup>20</sup> African Charter on Human and Peoples' Rights was adopted by the Organisation of African Unity on 27 June 1981, and entered into force 21 October 1986.

<sup>21</sup> Protocol to the African Charter on the Rights of Women in Africa was adopted by the Assembly of Heads of State and Government in Maputo, it came into force on 25 November 2005.

<sup>22</sup> Article 14 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa.

<sup>23</sup> African Charter on the Rights and Welfare of the Child adopted in 1990 and entered into force, November 29, 1999.

<sup>24</sup> *Purohit and Moore V The Gambia* Communication 241/2001 decided at the 33<sup>rd</sup> Ordinary Session of the African Commission held from 15 to 29 in Niamey, Niger, May 2003 para 80 Mental patients' rights were said to be important and these are, the right to health, the nature of socio-economic rights obligations under the African Charter on Human and Peoples' Rights, respect for human dignity, right to liberty and security of the person, right to have one's cause heard, right to freely participate in one's own government.

Tension has always existed between public health policies and individual rights.<sup>25</sup> Durojaye points out that while the concern of public health has been the welfare of the community, little attention has been accorded to individual's rights. This tension necessitated judicial intervention in the often celebrated US case of *Jacobson v Massachusetts*.<sup>26</sup> This case concerned the issue of whether a state could forcibly vaccinate a citizen against his will in order to protect the public from small pox infection. The plaintiff in this case had refused to be vaccinated claiming that it was a violation of his right to liberty. In upholding the conviction of the plaintiff, the US Supreme Court of Appeal pointed out that, based on the principle of paramount necessity, a state community has the right to protect itself against an epidemic of a disease that threatens the safety of its members. The court in that case affirmed the need for the protection of the community which overrides individuals' rights; it also pointed out that public health laws or policies should not be applied arbitrarily or in an oppressive manner. However, in adopting a public policy, a state or community may need to balance the interests of the public against the infringement of an individual's rights.<sup>27</sup>

However, there is a widely held perception that in cases of public emergencies, human rights may become a secondary concern. The perception that human rights can be swept aside in cases of emergencies is not new. This was clearly seen in the US during the so called 'war on terror' where historically and constitutionally entrenched civil and political rights, such as the right to a fair trial, freedom of expression, the right to legal representation and to freedom from torture were suddenly suspended.<sup>28</sup> They were viewed as secondary or even as irrelevant in the face of a threat that was perceived to threaten the existence of the state. The same phenomenon was also evident with HIV/AIDS.<sup>29</sup> It should be recognised that HIV/AIDS is not just a medical problem in need of a medical solution: people that are most susceptible to infection are those that are most vulnerable to human rights violations.

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<sup>25</sup> See Durojaye footnote 16 above, p 249.

<sup>26</sup> *Jacobson v Massachusetts* 197 U.S, 11(1905).

<sup>27</sup> See Durojaye footnote 16 above, p. 249-250.

<sup>28</sup> Wilson (eds), *Human Rights in the war on terror*, Cambridge University press 2005, p. 347, available at [http://dissentmagazine.org/democratiya/article\\_pdfs/d6Montgomery.pdf](http://dissentmagazine.org/democratiya/article_pdfs/d6Montgomery.pdf), (accessed 12 February 2011).

<sup>29</sup> *Ibid.*



Wilson points out that the current debates about rights in a time of emergency go back to the origins of western democracy, starting with the tumultuous years of civil war, interregnum and restoration in Britain during the seventeenth century.<sup>30</sup> Wilson subsequently explains that, with restoration of the monarchy in 1660, the new government had to confront the problem of large numbers of republicans in prison who could not be put on trial because of public sympathy for the prisoners - nor could they be detained indefinitely because the prerogative order of *habeas corpus* could not be invoked.<sup>31</sup> Human rights are an indispensable constituent of democratic politics that require protection even in an emergency situation.<sup>32</sup> This is well attributed in s 37 of the Constitution of South Africa of 1996.

There is also an implicit assumption that neglecting the protection of human rights means being able to control and reverse the epidemic. However, the solution to the HIV/AIDS crisis is not as simple as testing every person or disclosing their status without effecting other concomitant changes such as gender equality and bringing an end to poverty. Ignoring these factors in the short term will only delay reversing the epidemic, cost more money and, most unfortunately, cost more lives<sup>33</sup>. HIV and AIDS should cease to be seen only as a medical problem but rather be viewed as one that cuts across gender, development and human rights issues.<sup>34</sup> Crewe further points out that HIV/AIDS has brutally exposed all the faults of our society, that is, poverty, gender, inequality and social services.<sup>35</sup> Similarly, Christine Chinkin aptly stated that the denial of human rights is both a cause and a consequence of being poor.<sup>36</sup>

The main aim of linking human rights and health is the advancement of human well-being. In expounding the linkages between human rights and health, it is important to approach them not as a theoretical puzzle that is worked through in a political

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<sup>30</sup> *Ibid.*

<sup>31</sup> *Ibid.*

<sup>32</sup> *Ibid.*

<sup>33</sup> Coercive measures such as mandatory testing which at first blush appear to be protecting the interests of the community may well jeopardize prevention opportunities and so produce the opposite of the desired effect.

<sup>34</sup> Statement by Crewe, Director of the Center for the study of AIDS at the University of Pretoria, during her presentation 'AIDS democracy development and human rights', given at stakeholder consultation on gender, human rights and HIV and AIDS: A UNDP-OHCHR joint initiative for Southern and Eastern Africa, Rosebank hotel, Johannesburg 27-29 June 2006.

<sup>35</sup> Crewe, Director of the Center for the study of AIDS at the University of Pretoria.

<sup>36</sup> Chinkin, "The United Nations Reader for the elimination of poverty: What role for International law? Current Legal Problems" *Journal of Political Science Vol 54:1* 2001, p. 54.

vacuum, but rather as a very concrete, contextualised inquiry that begins from the experience of those whose health and human rights are most at stake.<sup>37</sup> Public health policies, programmes or practices may adversely affect the enjoyment of human rights. For instance, while a public health policy to quarantine people infected with swine flu or Ebola fever may be justified, it may, in the case of HIV/AIDS, infringe their rights to liberty and dignity. This is because, unlike the former which poses great threats to lives, HIV/AIDS has now almost been reduced to a manageable chronic disease due to availability of antiretroviral therapy.

It must be noted that the ICESCR, which guarantees socio-economic rights, including the right to health, provides that state parties may subject such rights as determined by law and in so far as they are compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society.<sup>38</sup> The implication of this is that the right to health can be limited in certain circumstances provided such limitations are justifiable and are in the best interests of the community. The ICESCR, for instance, requires state parties to aim at the prevention, treatment and control of epidemic, occupational and other diseases.<sup>39</sup> This provision would seem to promote compulsory measures such as vaccination, treatment or isolation in order to protect public health in certain circumstances.<sup>40</sup> Mandatory testing may be permissible only if it is clearly necessary and effective in protecting public health, is performed by public health officials, and by using the least intrusive means.<sup>41</sup> However, compulsory testing should be restricted to individuals known to be infected, or at least suspected of having been infected, with HIV/AIDS and should be done in a fair and non-discriminatory manner.

Human rights have major relevance in shaping appropriate responses to the HIV epidemic and other global health challenges, and in identifying deficiencies in the public health research agendas.<sup>42</sup> It is important for policy makers when conceiving

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<sup>37</sup> Mann; Gostin; Gruskin; Grodin; Annas; (eds), *Health and Human Rights: A Reader* London: Routledge; 1999 p. 244.

<sup>38</sup> Article 4.

<sup>39</sup> Article 12(2) (c).

<sup>40</sup> See Mann *et al*/footnote 37 above, p. 7-20.

<sup>41</sup> Forum on Microbial Threats, "Ethical and Legal Considerations in Mitigating Pandemic Diseases" Workshop Summary, National Academies Press 2007, p. 82.

<sup>42</sup> Brundtland "Twenty Five questions and answers on Health and Human Rights" World Health Organisation: Geneva 2002, available at <http://who.int/hhr/NEW3787OMSOK.pdf> (accessed 24 August 2011).

public health policies to bear in mind the implications of such policies on human rights. Every public health policy<sup>43</sup> should be viewed as a potential threat to human rights, unless proved otherwise. In designing any public health policy, particularly in the context of HIV/AIDS, the duty to respect, protect and fulfil human rights should be the primary considerations of governments.<sup>44</sup>

## 1.2 Research Problem

Over the past decade, a growing number of governments, employment organisations, religious denominations and communities adopted mandatory HIV testing policies.<sup>45</sup> This trend has tended to infringe upon the human rights of people living with HIV/AIDS and threatened the three key principles of HIV testing, namely that the individual freely *consent* to testing; that *counselling* be provided before and after testing; and that the results be kept *confidential*.<sup>46</sup> Coercive government policies aimed at controlling the AIDS pandemic often infringe on these principles with respect of individuals known or suspected to be living with HIV/AIDS and this decreases the effectiveness of public health intervention measures.<sup>47</sup>

Sub-Saharan Africa is the epicentre of the HIV/AIDS epidemic. The statistics released by the Department of Health show that South Africa alone has an estimate of 5.41 million people living with the virus, slightly lower than the previous estimate of 5.54 million<sup>48</sup>. Other African countries such as Botswana, Uganda, Nigeria, Malawi and Zimbabwe have initiated different models and policies in an effort to reduce the hundreds of deaths occurring daily as a result of this deadly virus. It is thus clear that HIV/AIDS testing practices such as voluntary counselling and testing (VCT) have been effective in trying to reduce the transmission of this virus.

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<sup>43</sup> Mann, "Statement at an Informal Briefing on AIDS to the 42<sup>nd</sup> Session of the United Nations General Assembly", *Journal of the Royal Statistical Society. Series A (Statistics in Society)* Vol. 151, No. 1, 1988, p. 131-136.

<sup>44</sup> Gruskin and Tarantola *Health and Human Rights*, New York Routledge 2005, p. 3.

<sup>45</sup> Burns, "Mandatory Premarital HIV Testing: An Overview" available at <http://www.lawandhealth.org>, (accessed 09 March 2011).

<sup>46</sup> See Mann *et al*, footnote 37.

<sup>47</sup> See Gostin footnote 7, p, 16 -17.

<sup>48</sup> Government encouraged by latest HIV figures, available at <http://www.hst.org.za/news/government-encouraged-latest-hiv-figures>, (accessed 12 February 2012).

Mandatory HIV/AIDS testing as a policy to reduce HIV/AIDS transmission may do more harm than good as there are a lot of human rights principles at stake, for instance, inherently unethical testing, stigma and discrimination, two of the major challenges to HIV/AIDS prevention.<sup>49</sup> Compulsory HIV testing means that informed and free consent becomes meaningless, thus removing one of the most important ethical foundations of any clinical procedure.<sup>50</sup> It will be submitted that HIV/AIDS testing should be accompanied by counselling of the individual about the trauma and the accompanying consequences should the result of the test turn out to be positive. This is important because the result has a direct effect on an individual's sexual life style and having such awareness would prepare the individuals for the resultant stigma and discrimination. Should an individual test positive, antiretroviral drugs need to be available but this is not normally the case in poorer African countries.<sup>51</sup> A comprehensive long term solution best suited for the African region is needed to curb this virus and it cannot be done by compromising the respect for human rights.

The research problem to be addressed in this dissertation is that any compulsory HIV testing policy, if implemented, does infringe on the rights of individuals known to be or suspected of living with HIV/AIDS and thus decreases the effectiveness of such a public health measure. The introduction of compulsory HIV/AIDS testing, be it premarital, in educational institutions or as a form of routine check-up at clinics, may not reduce HIV/AIDS prevalence. Most research indicates that testing alone has little or no effect on changing behaviour.<sup>52</sup> Mandatory testing will increase stigmatisation and prove to be counter-productive. Research has shown that mandatory testing may 'discover' a minor proportion of the so called 'dangerous population' but it will scare off a large percentage of such people.<sup>53</sup> The crucial step is counselling and promotion of behavioural change for a better healthy living. A shift has to be made so that counselling is mandatory and testing voluntary.

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<sup>49</sup> Mekonnen, "Mandatory Premarital HIV testing as a challenge to Human Rights, A case study of Eritrea", *Interdisciplinary Journal of Human Rights Law* Vol. 5:1, 2010-2011 p. 3.

<sup>50</sup> Burns, "Mandatory Premarital HIV Testing: An Overview" available at. <http://www.lawandhealth.org>, (accessed 09 March 2011).

<sup>51</sup> See Mann *et al* footnote 37 above p. 4.

<sup>52</sup> See Durojaye *et al* footnote 16 above p. 250.

<sup>53</sup> Yadav, "Playing Politics with AIDS, Controversy over Mandatory Vs Voluntary Testing in Goa", 2006 p.24, available at, [http://www.manushiindia.org/pdfs\\_issues/PDF%20Files%20155/Neeja%20](http://www.manushiindia.org/pdfs_issues/PDF%20Files%20155/Neeja%20) (accessed 14 August 2011).

The study aims at establishing a close but conflicting relationship that exists between public health and human rights and resultant problems when policies, such as the Mandatory HIV Testing policy, are implemented. Ultimately, human health cannot be maintained without respect for the dignity and individual rights of persons; on the other hand, human rights cannot be deemed adequate and comprehensive without ensuring the health of individuals and populations. The two problems are in essence two faces of the same coin, and they have to be treated or confronted together as a single problem requiring a single solution.

### **1.3 Hypothesis**

The study is based on the assumption that mandatory HIV/AIDS testing as a public health policy has little or no effect on the behaviour of individuals. Mandatory HIV/AIDS testing infringes upon the rights of individuals, thus decreasing the effectiveness of public health measures. This means that promoting and protecting human rights must become one of the key means of preserving the health of individuals and populations. Forcing people to undergo HIV/AIDS testing without first dealing with stigma and discrimination will only fuel resentment against such testing and thus undermine the very objectives that health officials seek to achieve.

### **1.4 Significance of the Research**

The full realisation of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic. During the UN General Assembly Special Session on HIV/AIDS, the Heads of State and Representatives of Governments declared their commitment to:

enact, strengthen or enforce [by 2003] appropriate legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure full enjoyment of all human rights and fundamental freedoms of people living with HIV/AIDS and members of vulnerable groups; in particular to ensure their access to, *inter alia*, education, inheritance, employment, health care, social and health services, prevention, support, treatment, information and legal protection, while respecting their privacy and confidentiality; and develop

strategies to combat stigma and social exclusion connected with the epidemic.<sup>54</sup>

It is thus clear that any approach that aims to achieve a comprehensive prevention strategy must be consistent with respect for human rights norms and standards as enshrined in regional and international human rights instruments.<sup>55</sup>

Protecting and respecting the human rights of persons infected and affected by HIV/AIDS serve to promote rather than undermine public health goals. Where persons are at risk of HIV infection, they need to be able to access public health services. Where persons are coercively tested or may face stigma and discrimination following testing, they are unlikely to access such services and, most often, they will be driven underground.<sup>56</sup> Furthermore, infringing rights such as the right to privacy, dignity and bodily integrity is not justifiable<sup>57</sup> since compulsory HIV/AIDS testing frequently results in increased vulnerability of the affected groups.<sup>58</sup> HIV/AIDS and human rights activists have taken the position that infringing the right to privacy by, for example, making HIV/AIDS testing mandatory, effectively drives those affected underground, particularly where being infected is followed by persecution, ostracism, violence and destitution.<sup>59</sup>

The significance of this research is to show that, although there is no need to explore new approaches, there is a need to examine how existing interventions can be improved. The introduction of compulsory tests is most definitely a public health and a human rights violation.<sup>60</sup> The research also seeks to establish the benefits of compulsory HIV/AIDS tests which would contribute to arresting the spread of the HIV

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<sup>54</sup> UN Office of the High Commissioner for Human Rights, "A Human Rights-Based Approach to HIV/AIDS": UN General Assembly Special Session on HIV/AIDS 2001 para 54.

<sup>55</sup> See Mann *et al* footnote 37 above, p. 1.

<sup>56</sup> South African Law Reform Commission, Second Interim Report on Aspect of the Law Relating to Aids: Pre- Employment HIV testing, Pretoria: South African Law Reform Commission, 2001.

<sup>57</sup> Women's Legal Centre, Submission in Response to Draft Regulation No R 485 Relating to Aids Notification as Contained Within Government Gazette 23<sup>rd</sup> April 1999: Cape Town: Women's Legal Centre 1999.

<sup>58</sup> Heywood, "The Implication of AIDS Notification for Human Rights and HIV/AIDS Prevention in South Africa", Johannesburg: AIDS Law Project 1999.

<sup>59</sup> Canadian HIV/AIDS Legal Framework, "Outcomes of the symposium on HIV testing and human rights" 2005, available at, <http://www.genderhealth.org/pubs/testing.pdf> (accessed August 2011).

<sup>60</sup> Strode; Van Rooyen and Heywood "Scaling up HIV Testing in Resource Constrained Settings: Debates on Role of VCT and Routine 'opt-in opt-out' HIV testing", *The South African Journal of HIV Medicine*, Vol 2, 2005 p.45-48.

pandemic. This will be shown through a comparison of the law and practice in three countries which are South Africa, Uganda and Canada.

### **1.5 Aims and Objectives**

The study aims at establishing the effects of the Compulsory HIV/AIDS testing policy on the human rights of victims and the public at large. The objectives of this research are to:

- Examine the relationship that exists between human rights and public health policies generally and in three specific countries which are South Africa, Uganda and Canada.
- Establish the impact of compulsory HIV/AIDS testing on the human rights of individuals affected by HIV/AIDS.
- Compare the implementation of compulsory testing policy in the three countries and to assess their success.
- Establish whether other policies such as VCT have failed and hence the need to pursue other policy alternatives.
- Make recommendations for South Africa and other developing countries based on the experience of Canada and Uganda.

### **1.6 Research Questions**

The relationship between human rights and HIV/AIDS is complex. The protection of human rights is necessary to reduce vulnerability to HIV infection and to eliminate all forms of discriminatory practices against people living with HIV/AIDS, their families and friends. The research seeks to raise questions on the human rights implications that will arise if a mandatory HIV/AIDS testing policy is implemented, which include the following;

- To what extent does compulsory HIV/AIDS testing policy lead to a decrease in the spread of the HIV/AIDS pandemic?
- What is the effect of compulsory HIV tests on the moral behavioural change of individuals?
- Does compulsory HIV/AIDS testing make any positive changes in other developing countries that have implemented it?

- What can South Africa and other African countries learn from these results?

## 1.7 Literature Review

Extensive literature has been written about the relationship between public health policies and human rights and will be further elaborated in Chapter Two below. A considerable amount of literature has also been written about the negative and positive effects of compulsory HIV/AIDS testing in different countries. The literature that is going to be referred to in this dissertation aims at showing why human rights are a serious and integral part of the fight against the HIV/AIDS pandemic. The literature also comprises case studies from South Africa, Uganda and Canada since the research aims at investigating the success or failure of this policy in different countries and whether it would be wise to implement it in South Africa. Botswana and Nigeria will also be referred to because the two countries have implemented mandatory HIV testing in a bid to combat the spread of HIV.

In their work, Gostin and Lazzarini<sup>61</sup> emphasize the complex relationship that exists between public health and human rights and makes a compelling case for synergy between the two fields. Their book clearly exposes that human rights are critical as all people share an inherent worth and dignity which transcends even their own desire to be healthy.<sup>62</sup> The authors examine issues such as HIV testing, screening, partner notification, isolation, quarantine and criminalization of persons with HIV/AIDS.

Burns<sup>63</sup> highlights the importance of the three key principles of HIV testing which are consent, counselling and confidentiality. He further shows how Mandatory Pre-marital HIV testing might infringe these principles as well as other human rights. A critical analysis is also made of the arguments for and against premarital testing. However, the article recommends that governments, programme implementers and religious organisations should take immediate steps to identify and stop the practice and ensure that it is prohibited in law and policy as it seriously infringes on human rights.

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<sup>61</sup> See Gostin *et al* footnote 4 above.

<sup>62</sup> See Mann *et al* footnote 37 above.

<sup>63</sup> Burns, "Mandatory Premarital HIV Testing: An Overview", available at <http://www.lawandhealth.org>, (accessed 08 March 2011).



Durojaye and Balogun<sup>64</sup> also consider the implications of public health policy on the enjoyment of individual's fundamental human rights. The two authors specifically examine the appropriateness of mandatory pre-marital testing of HIV in Nigeria. They argue that this policy will do more harm than good in curbing the spread of the epidemic in Nigeria. They suggest that an alternative would be to encourage voluntary counselling and testing before marriage. This, they argue, would be more productive, less costly, and would avoid the human rights implications of mandatory testing. The two authors also point out that governments or political leaders would be able to focus on HIV/AIDS related stigma and discrimination.

Roehrs<sup>65</sup> expounds on the importance of protecting the privacy of HIV infected people. He points out that testing a person's blood for HIV and disclosing the test result without his/her consent constitutes an infringement of the common law and the constitutional right to privacy. He emphasises that with HIV/AIDS being the most stigmatised disease in modern history, the protection of privacy is crucial for the fulfilment of other human rights such as equality, dignity, bodily and psychological integrity. The article goes on to state that such rights can be justifiably limited, for instance, in the case of partner notification, that is, if the situation warrants that the other partner be notified of the other's status.<sup>66</sup>

Mindy<sup>67</sup> gives guidelines on what governments should do in order to respond to HIV/AIDS based on international human rights law. Like the other contributions mentioned above, this article also reiterates that human rights are fundamental to any response to HIV/AIDS. The article analysed different studies where human rights were used to fight stigma, discrimination and infringement of the rights of HIV/AIDS victims. The article does not, however, expose the impact of different government health policies on the human rights of HIV/AIDS victims.

Fee and Parry<sup>68</sup> depart from the views expressed by Mann and others<sup>69</sup> that AIDS is a social disease, flourishing in conditions of poverty, oppression, urban migration,

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<sup>64</sup> See Durojaye footnote 16 above, p. 245-265.

<sup>65</sup> Roehrs, "Privacy, HIV/AIDS and Public Health Interventions", Gender Health and Justice Research Unit, University of Cape Town, *South African Law Journal Vol 27:10* 2009.

<sup>66</sup> *Ibid*, p.376.

<sup>67</sup> Mindy, "HIV/AIDS and Human Rights in a nutshell" 2004, available at [http://hurilink.org/tools/HIV/AIDS\\_and\\_HRinNutshell\\_webversion/pdf](http://hurilink.org/tools/HIV/AIDS_and_HRinNutshell_webversion/pdf), (accessed 09 March 2011).

<sup>68</sup> Fee; Parry; Mann, "HIV/AIDS and Human Rights", *Journal of Public Health Policy Vol 29, 2008*, p. 54-71.

gender inequality and violence. The authors strongly argue against mandatory HIV testing and quarantine which are referred to as repressive policies.

The *Siracusa*<sup>70</sup> principles also explored how individual rights can be limited in favour of public health policies that intend to reduce the spread of a virus. These principles provide a basic framework for analysing the impact of health policies. In trying to achieve broader societal objectives, public health policies may impose significant conflicts on the realisation of human rights.<sup>71</sup> In this regard, the risk of HIV/AIDS transmission to HIV negative people may necessitate imposing restrictions on HIV positive people. According to the *Siracusa* principles, any such limitation of human rights is acceptable only when it serves a legitimate public interest and is essentially necessary in a democratic society.<sup>72</sup>

Mekonnen<sup>73</sup> writes about the failure of premarital HIV testing in Eritrea. He points out that such testing poses a great threat and challenge to human rights. Though the writer focuses on a case study of Eritrea, he exposes important effects of this testing policy which may have wider application to other African countries. The writer dismisses compulsory testing as a measure to combat the pandemic and points out that the respect for the rule of law, human rights, and democratic accountability are some of the fundamental elements of a successful HIV/AIDS strategy.

Bennet and Erin expose the ethical, legal and social issues that arise from testing and screening for HIV/AIDS.<sup>74</sup> The two authors also point out that there is a growing trend of opinion which sees testing and screening for HIV as a paradigm case of the tension between the rights of individual citizens and societies' interest in the protection and prevention of public health. This balance between the need to protect the public against infection and the need to protect HIV positive individuals against unethical treatment can be approached from a variety of viewpoints. There are those

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<sup>69</sup> Mann; Gostin; Gruskin; Grodin; Annas; (Eds), *Health and Human Rights: A Reader* New York: Routledge; 1999 p. 7-20.

<sup>70</sup> The Siracusa Principles are essential principles developed by a group of experts and endorsed by the UN. They are non-binding and are widely accepted by signatories of the ICCPR.

<sup>71</sup> Mekonnen, "Mandatory Premarital HIV testing as a challenge to Human Rights, A case study of Eritrea", *Interdisciplinary Journal of Human Rights Law* Vol. 5:1, 2010-2011 p.3.

<sup>72</sup> United Nations, Economic and Social Council, UN Sub-Commission on Prevention of Discrimination and Protection of Minorities, Siracusa Principles on the Limitation and Derogation of Provisions in the International Covenant on Civil and Political Rights, Annex, UN. Doc E/CN4/1984/4(1984).

<sup>73</sup> See Mekonnen, footnote 71 above.

<sup>74</sup> Bennet and Erin, *Issues in Biomedical Ethics, HIV/AIDS, Testing, Screening and Confidentiality*, Oxford Press 2003, p. 1-20.

who claim that coercive public health measures, such as routine or even mandatory screening and regular breaches of confidentiality in order to warn others, are necessary evils to prevent widespread harm.<sup>75</sup> However, others insist that both on the grounds of efficacy and ethics, HIV testing must be offered on a voluntary and strictly confidential basis.<sup>76</sup>

Mann and Gruskin base their work on the view that without human rights people and their communities cannot be fully healthy.<sup>77</sup> Their book mainly explores the responsibilities of health professionals for promoting and protecting human rights, thereby promoting and protecting the health of their patients and communities. Mann also acknowledges that human rights approaches seek to protect and promote the societal wellbeing in which each individual can achieve his or her full potential. Their work generally explores the connection between health and human rights.

## **1.8 Research Methodology**

The research methodology involves the study of written literature. A comparative literature study will be made on the law and practice in three main countries under study, which are South Africa, Uganda, and Canada. A study of the three countries stated above is important as the findings may assist South Africa as to whether or not to adopt Compulsory HIV/AIDS testing. This is paramount since South Africa has one of the largest populations living with HIV/AIDS<sup>78</sup> and this poses a serious threat to the country's effort to achieve its full potential in the social, economic and political spheres. Uganda has been chosen because of its success record in arresting the spread of the pandemic. Over the years, Uganda has achieved the greatest percentage reduction in the spread of HIV/AIDS and, further, a wealth of empirical research evidence shows that it has the most successful approach with combating HIV/AIDS.<sup>79</sup> Canada, on the other hand, has a very strict policy with regard to compulsory testing of immigrants before entering the country.

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<sup>75</sup> *Ibid.*

<sup>76</sup> *Ibid.*

<sup>77</sup> See Mann *et al* footnote 37 above.

<sup>78</sup> UNAIDS World AIDS Day Report 2012, p. 9, available at [http://www.unaids.org/en/.../unaids/.../JC2434\\_WorldAIDSday\\_results\\_en.pdf](http://www.unaids.org/en/.../unaids/.../JC2434_WorldAIDSday_results_en.pdf), (accessed 14 January 2013).

<sup>79</sup> Green; Halperin; Nantulya; Hogle, "Uganda's HIV Prevention Success: The Role of Sexual Behaviour Change and the National Response", *AIDS Behav Vol 10:4*, 2006, p. 335-346.

Academic writings will also be used to examine the relationship that exists between public health policies and human rights. An examination of various international and regional conventions and national legislation which relate to HIV/AIDS and human rights will be made. The research methodology is largely based on library research, internet sources and case studies.

### **1.9 Limitations of the Research**

The study largely focuses on the implications of compulsory HIV/AIDS testing of persons who visit hospitals for routine check-ups and immigrants as reflected in the case of Canada. This thus leads to vulnerability of victims of HIV/AIDS virus. The research is thus premised on human rights violations that may result from this policy and the impact that these violations may have on the pandemic. This research will, therefore, not focus on other HIV/AIDS testing policies such as prenatal compulsory HIV/AIDS and compulsory HIV/AIDS testing for sexual offenders.

The study will also focus on case studies of South Africa, Uganda and Canada. The case studies will expose the success and failure of these policies in the stated countries and the lessons that can be drawn from their experiences. Reference will also be made to Botswana and Nigeria summarily. Both countries adopted a compulsory HIV testing policy but later abandoned it. Their experiences in the implementation of the compulsory HIV testing policy and the reasons that led to the policy being abandoned and the lessons that can be drawn may be useful for South Africa.

### **1.10 Ethical Considerations**

The research will adhere to the University of Fort Hare policy and guidelines regarding the conduct of research. The research will not deal directly with those infected with or affected by HIV/AIDS and questionnaires or interviews will not form part of it. Issues of ethical consideration such as confidentiality will not arise.

### **1.11 Intellectual Property Implications of the Research**

All academic work, including internet sources used in this research, will be acknowledged using the *Speculum Juris* referencing style. The research will fully acknowledge sources used in this dissertation.

## 1.12 Outline of Chapters

The first chapter deals with the general outline of the research. It outlines the problem statement, underlying assumptions, the aims and objectives of the research, rationale, limitations and the methodology used.

Chapter Two provides a theoretical framework advanced by various scholars in favour of compulsory HIV/AIDS testing policy. This chapter, therefore, raises an important debate on the pros and cons of compulsory HIV testing policy. A balance between community rights and individual rights is also explored, highlighting where and when human rights can be curtailed. This chapter also considers when a government can override individual rights in the emergence of an epidemic.

Chapter Three discusses the various international conventions that have a bearing on human rights and, in particular, human rights related to health. Regional conventions as well as other regulations that have health related provisions are examined.

Chapter Four comprises case studies of the law and practice in South Africa, Uganda and Canada. Uganda has been chosen as it has, over the years, achieved the greatest reduction in the spread of HIV/AIDS. In addition, a wealth of empirical research shows that it has the most successful approach in combating HIV/AIDS.<sup>80</sup> Canada, on the other hand, has a very stringent policy with regards to compulsory testing of immigrants before entering the country. A study of the three countries stated above is important and recommendations drawn from the study will inform whether South Africa should adopt compulsory HIV/AIDS testing or not. This is important since South Africa has one the largest population of persons infected by this virus<sup>81</sup> and this poses a serious threat to the countries' effort to achieve its full potential in the social, economic and political spheres. In doing so, lessons will be drawn from Botswana and Nigeria, two countries that have adopted the compulsory HIV testing policy but later abandoned it. The impact of the compulsory testing in the advancement of human rights will be exposed.

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<sup>80</sup> Green; Halperin; Nantulya; Hogle, "Uganda's HIV Prevention Success: The Role of Sexual Behaviour Change and the Role of National Response", *AIDS Behaviour Vol 10:4*, 2006, p.335-346, available at, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1544373/>, (accessed 09 September 2011).

<sup>81</sup> World Health Organisation, "Sexually Transmitted Diseases: Initiative for Vaccine Research (IVR)" 2013, available at, [http://www.who.int/vaccine\\_research/diseases/soa\\_std/en/index4.html](http://www.who.int/vaccine_research/diseases/soa_std/en/index4.html), (accessed 18 January 2013).

Chapter Five discusses human rights that may be violated by a compulsory HIV/AIDS testing policy, in particular the right to dignity, privacy, freedom and security of the individual. This chapter also explores the extent to which these rights are affected if the compulsory HIV/AIDS testing policy is implemented.

Chapter Six provides the conclusion and findings of the research. The result of the comparative study will strengthen or weaken the hypothesis, whether mandatory testing is consistent with human rights and should be or not be adopted. The chapter also makes some future recommendations on a human rights-based approach to HIV/AIDS strategy and testing.

## CHAPTER 2: THE DEBATE ON COMPULSORY HIV/AIDS TESTING POLICY

### 2.1 Introduction

This chapter focuses on three related issues. Firstly, it provides a theoretical background of the debate between scholars and interest groups who argue in favour of or against compulsory HIV/AIDS testing policy. The chapter thus highlights the debate over compulsory HIV testing and the pros and cons of this policy. Secondly, it explores the extent to which rights can be limited, and the possibility of striking a balance between conflicting and competing claims advanced by the individual and those of the community or the public. Thirdly, it analyses when, and to what extent, a democratic government can override individual rights in the face of an emergency necessitated by an epidemic such as HIV/AIDS.

In the early years of the onset of the HIV/AIDS epidemic, most debates seemed to suggest that the choice was between VCT,<sup>1</sup> on the one hand, and some form of compulsory<sup>2</sup> or mandatory testing<sup>3</sup>, on the other. However, the bottom line is that the early detection of HIV infection, through testing and counselling, is seen as the most expedient way of providing individuals living with HIV with antiretroviral treatment (ART) and effective prevention and care. In the past few years, consensus has formed among public health experts that nearly all HIV-infected people and their families could benefit significantly from becoming aware of their HIV status.<sup>4</sup>

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<sup>1</sup> VCT, Voluntary Counselling and Testing, also known as the 3 C principles, involves the following elements: both pre and post *counselling*, *informed consent* and *confidentiality* of test results. VCT also meant that testing is done on an 'opt-in basis- ie, that is, the testing would take place following the person's deliberate decision to seek out HIV testing. UNAIDS /WHO Policy Statement on HIV Testing 2004, available at, <http://www.who.int/hiv/pub/vct/en/hivtestingpolicy04.pdf>, (accessed 3 March 2012).

<sup>2</sup> Compulsory testing' also known as involuntary testing' is defined as testing without a voluntary element – that is, without informed consent, at the behest of someone or some institution other than the person tested and, sometimes, with neither the fact of having been tested and nor the result communicated to the person tested. See Jurgens "HIV Testing and Confidentiality: Final Report" Canadian HIV/AIDS Legal Network and Canadian AIDS Society 1998 p. 11 and Mann AIDS and Human Rights: The future of the Pandemic' in Mann; Gruskin; Grodin; Annas (eds) *Health and human rights*, A Reader London Routledge 1999 p. 44.

<sup>3</sup> Mandatory testing is defined as testing that would occur as a condition for some other benefit, such as donating blood, immigration to certain countries, getting married, joining the military or as a precondition for other kinds of employment. See Jurgens footnote 2 above.

<sup>4</sup> Nieburg; Cannell; Morrison, "Expanded HIV Testing: Critical Gateway to HIV Treatment and Prevention Requires Major Resources, Effective Protections" Centre for Strategic and International Studies 2005, available at, [http://www.csis.org/files/media/csis/pubs/0501\\_expandedhivtesting.pdf](http://www.csis.org/files/media/csis/pubs/0501_expandedhivtesting.pdf) (accessed 24 February 2012).

HIV testing, available since 1985, has been restricted to medical as well as prevention purposes because of the strong emphasis on informed consent and counselling.<sup>5</sup> Unlike other infectious diseases such as syphilis and hepatitis B, for which consent for testing is implicitly assumed and encouraged by virtue of medical consultations and diagnosis, the diagnosis of HIV infection has been more similar to that of an incurable genetic disorder than that of an infectious disease. Although surveillance for AIDS has been widely supported, the switch from reporting cases of AIDS to HIV infections has been much debated.<sup>6</sup> Until recently, prevention efforts targeted specifically towards HIV infected people have been neglected<sup>7</sup> and the practice of contact investigation used in sexually transmitted diseases and tuberculosis has been fully used.

Policies towards HIV testing and counselling have been over simplified and viewed in a uniform manner, ignoring the diversity of goals and settings of testing.<sup>8</sup> Testing people who are well as a preventative intervention requires provision of different information and counselling compared with testing people who are ill, consulting for care or people attending health facilities for specific service delivery. Four contexts for HIV testing can be defined, namely: mandatory testing; voluntary counselling and testing for prevention; routine testing for delivery of specific preventive health care interventions; and diagnostic testing in the context of individual medical care.<sup>9</sup>

Before people can be treated they need to know they are infected. This requires not only HIV testing facilities but also wide-spread knowledge among ordinary people of the importance of testing and where it can be done.<sup>10</sup> It is not arguable that HIV

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<sup>5</sup> *Ibid.*

<sup>6</sup> Centre for Disease Control, "Guidelines for Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infections and Acquired Immunodeficiency Syndrome" *Morb Mortal Wkly Rep (MMWR)* 48, 1999 p.1-31, available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4813a1.htm>. (accessed on 24 February 2012).

<sup>7</sup> Janssen; Holtgrave; Valdisseri; Shepherd; Gayle; De Cock; "The Serostatus Approach to Fighting the HIV Epidemic: Prevention Strategies for HIV Infected Individuals" *Public Health journal Vol 91*, 2001, p. 1019-1025, available at <http://www.ncbi.nlm.nih.gov/pubmed/11441723>. (accessed on 14 January 2012).

<sup>8</sup> Nieburg; Cannell; and Morrison, "Expanded HIV Testing: Critical Gateway to HIV Treatment and Prevention Requires Major Resources, Effective Protections", Centre for Strategic and International Studies 2005, available at, [http://www.csis.org/files/media/csis/pubs/0501\\_expandedhivtesting.pdf](http://www.csis.org/files/media/csis/pubs/0501_expandedhivtesting.pdf) (accessed 24 February 2012).

<sup>9</sup> *Ibid.*

<sup>10</sup> Oloya and Salewi, "Human Rights Issues Pertinent to the HIV Epidemic in Africa", A Briefing Paper for Submission to: The Committee on the Protection of Rights of People Living with HIV and Those at Risk, Vulnerable to the Affected by HIV, Centre for Human Rights, University of Pretoria 2011.



testing raises concerns about stigma and infringement of the rights of HIV-infected people. The more central issues are autonomy and privacy, or, clinically, informed consent and confidentiality.<sup>11</sup> HIV testing is done for different purposes in different contexts, and, therefore, the application of one model, such as voluntary counselling and testing without reference to all other settings, is inappropriate.<sup>12</sup> According to De Cock self-initiated HIV testing and prevention counselling allow people to voluntarily learn their status and reduce the risk of acquisition or transmission of HIV infection. Ammann<sup>13</sup> recently advocated universal voluntary testing irrespective of the risk factors involved, and, as Friedman said: “Everyone who had ever had sex or used drugs should know their serostatus.”<sup>14</sup> Kevin further points out that one of the goals of a public health system should be for every African adolescent and adult to know his or her HIV status, and to be retested in case of potential exposure.<sup>15</sup>

Mandatory testing or the compulsory testing of specific individuals stirs much controversy, with the exception of testing of blood, semen and organ donors.<sup>16</sup> Examples of mandatory testing include pre-employment screening, testing people entering some religious orders and armed services, and screening for insurance purposes or for securing bank loans. Some countries require HIV testing for visa applicants, especially for prospective immigrants, and for scholarship and fellowship applicants.<sup>17</sup> Certain occupations require in service testing, such as sex workers who practise in regulated industries. Some countries require a negative HIV test result for military personnel deployed internationally for peace-keeping missions. Kevin,<sup>18</sup> points out that some of these examples of mandatory testing probably reduce HIV transmission while others yield little public health benefit and might further marginalise people infected with HIV. Further, if mandatory testing is practised, it should be based on scientifically supported rationales that apply to other infectious diseases, and should adhere to the same standards of provision of information,

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<sup>11</sup> De Cock; Mbori-Ngacha; Marum, “A Serostatus-Based Approach to HIV/AIDS Prevention and Care in Africa”, *The Lancet Vol 362*, 2003, available at <http://www.thelancet.com> (accessed 08 February 2012).

<sup>12</sup> *Ibid.*

<sup>13</sup> Ammann, “Preventing HIV”, *Bio Medical Journal Vol 326*, 2003, p. 1342-43, available at, <http://www.bmj.com/content/326/7403/1342?tab=responses>. (accessed on 21 November 2011).

<sup>14</sup> *Ibid.*

<sup>15</sup> See De Cock *et al* footnote 11 above.

<sup>16</sup> *Ibid.*

<sup>17</sup> Bennet; Erin, Issues in Biomedical Ethics, *HIV AND AIDS, Testing, Screening and Confidentiality*, Oxford University Press 2003, p. 1-19.

<sup>18</sup> *Ibid* p. 8-12.

assurance of confidentiality and referral for services and support as in voluntary testing. With a few exceptions, mandatory testing is likely to contribute little to HIV prevention.<sup>19</sup>

As opposed to mandatory testing, Kevin prefers voluntary testing, counselling and partner notification. He points out that in high prevalence settings, especially in Africa, a stated goal for prevention should be for every citizen, including sexually active adolescents, to know their HIV status, and for repeat testing to occur on regular intervals in the case of risky behaviour. He adds that this approach would demystify HIV/AIDS, place the responsibility for avoidance of acquiring or transmitting HIV on every individual, and empower the community to take charge of its own health.<sup>20</sup>

Routine HIV testing differs from mandatory testing in that it implies a default policy of testing unless an individual specifically elects not to have it.<sup>21</sup> Routine HIV testing is done as part of medical and prevention best practice analogous to blood pressure monitoring and syphilis screening, because specific actions are undertaken on the basis of a positive result.<sup>22</sup> Routine HIV testing should not require specific consent or pre-test counselling provided that all clients are informed that routine testing is part of the package of services for which they are voluntarily attending. Routine HIV testing should, however, be accompanied by structural changes such as legal and social interdictions against discrimination or abuse of infected people.<sup>23</sup>

The responsibility of HIV infected people to learn about their status and act accordingly has to be balanced by that of society in providing a supportive environment that provides strong protection against discrimination.<sup>24</sup> In 2003, because efforts to further reduce the overall HIV transmission in the United States had stalled, the US Centre for Disease Control and Prevention (CDC) began a new

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<sup>19</sup> See De Cock *et al* footnote 11 above, p. 7.

<sup>20</sup> *Ibid.*

<sup>21</sup> This is the approach that was used in Botswana. In December 2003, Botswana's President Festus Mogae published a new year's message to the nation, in which he stated that beginning in 2004, HIV testing in health care facilities would be routine but not compulsory and that health care workers would test for HIV unless they declined to be tested, Kenyon, "Routine HIV testing: A view from Botswana", 2005, p. 21, available at, <http://www.hhrjournal.org/archives-pdf/4065328.pdf>, (accessed on 13 March 2012).

<sup>22</sup> See De Cock *et al*, footnote 11 above.

<sup>23</sup> *Ibid.*

<sup>24</sup> *Ibid.*

programme of advancing HIV prevention which included encouraging routinely HIV testing in health care settings as part of medical care.<sup>25</sup> Routine testing has been very successful in developed countries as there is readily available antiretroviral treatment. It is clear that routine HIV testing on patients is meaningless if antiretroviral drugs are not given to patients. Before adopting routine HIV/AIDS testing in South Africa, factors such as the availability of antiretroviral therapy and support services of those who test negative should first be considered before it is implemented.

Proponents of mandatory HIV testing postulate that, “universal testing” for HIV should be implemented for all people who visit sexual health clinics, and in “areas” where the prevalence of HIV is high.<sup>26</sup> The United Kingdom’s Health Protection Authority (HPA) recommends that testing should be made compulsory for all new visitors to a general practitioner and all patients admitted to a hospital. Research by the HPA has shown that routine and universal testing are feasible to undertake and acceptable to patients. On the other hand, Delpech pointed out that increased testing and greater access will help reduce the number of people who are unaware of their HIV status and increase the chances of early diagnosis when treatment is more successful.<sup>27</sup>

Prevention and care in Africa need a serostatus based approach aimed at the universal voluntary knowledge of serostatus, a simplified clinical setting, and the prevention of discrimination.<sup>28</sup> Further, defining different categories of testing, consent and counselling is necessary. Kevin De Cock advises that international agencies should reassess their HIV testing policies on the basis of public health needs and targets, and the declared global emergency relating to treatment.<sup>29</sup> Paradoxically, for many Africans HIV/AIDS has become the main threat to the very notion that an approach based on individual rights is aimed to protect. The normalisation of HIV/AIDS in a philosophical context of public health, medical ethics

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<sup>25</sup> Janssen, “Advancing HIV Prevention: New Strategies for Changing Epidemic in the United States” *Morbidity and Mortality Weekly Report*, Vol. 52:15, 2003 p. 329-332, available at, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5215a1.htm> (accessed 13 March 2012).

<sup>26</sup> Herder, “Mandatory HIV Testing” *Canadian Medical Association Journal (CMAJ)* Vol 184:1 2012.

<sup>27</sup> Press release by Dr Delpech, available at <http://www.hpa.org.uk/NewsCentre/NationalPressRelease> (accessed 12 February 2012).

<sup>28</sup> See Bennet *et al* footnote 17 above, p.15-17.

<sup>29</sup> *Ibid.*

and social justice is not a threat to individual human rights; rather, failure to prevent HIV transmission constitutes an infringement of human rights that hampers Africa's human and social development.<sup>30</sup> Kevin and other authors further support the view that the concept of social justice is most relevant to the policy issue of how to increase access to effective HIV/AIDS treatment in Africa. In human rights discourse, emphasis is now placed on social and economic rights, such as the right to housing, employment and health, offering a bridge between social justice and human rights.<sup>31</sup>

The early identification of HIV through testing and counselling on a large scale is increasingly understood as the most critical gateway to providing individuals living with HIV with antiretroviral treatment (ART) and effective prevention care.<sup>32</sup> Nieburg *et al.* believe in what they refer to as expanded HIV testing, which offers a testing and counselling scheme. The latter includes traditional client-initiated counselling and testing at VCT centres or elsewhere. It has a component in which the initiative for HIV testing comes from health workers who actively and routinely offer HIV testing and counselling as an aspect of their contact with patients; and where those individuals offered HIV testing retain the ability to refuse the HIV testing policy.

Until now, the approach known as voluntary counselling and testing has been the dominant, recommended model for HIV counselling and testing among individuals without symptoms of AIDS. Further, VCT has generally been offered in free standing facilities that are limited in number; often they have few roles beyond VCT, and are typically only loosely linked to other components of local healthcare systems.<sup>33</sup> It is, however, pointed out that the traditional VCT approach remains the linchpin of HIV testing approaches, and this rests on:

- governments and other health care providers making HIV counselling and testing services available;
- public awareness of that availability;

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<sup>30</sup> The Economist, "The Politics of Human Rights. Righting wrong", *The Economist*, Vol 9, Aug 18 2001, p. 18-20, available at <https://www.economistsubscriptions.com/ecom325mea/global/index.php>, (accessed 08 February 2012).

<sup>31</sup> See Bennet *et al* footnote 17 above.

<sup>32</sup> Nieburg; Cannell; and Morrison, "Expanded HIV Testing: Critical Gateway to HIV Treatment and Prevention Requires Major Resources, Effective Protections", Centre for Strategic and International Studies 2005, available at, <http://www.csis.org/files/media/csis/pubs/050/expandedhivtesting.pdf> (accessed 27 February 2012).

<sup>33</sup> See Herder footnote 26 above.

- an individual's decision to seek out a facility providing VCT services; and
- the individual's subsequent conscious choice to return to receive test results along with the associated post-test counselling and referral.<sup>34</sup>

In accordance with the traditional VCT approach, it is the individual and not the health system that initiates action: she or he receives counselling and testing services only after having made an active decision to seek out a VCT centre and be tested. This approach evolved in the 1990s when access to ART was more limited and when stigma and discrimination were often virulent.<sup>35</sup> The other down side of VCT, as pointed out by Nieburg, is that, firstly, in many instances voluntary counselling and testing programmes fall short of attracting large numbers of individuals to come forward for HIV testing.<sup>36</sup> Secondly, the model for significantly expanding HIV testing that is now receiving increasing attention differs from the traditional VCT approach in that, while the decision to be tested remains voluntary, it is the health system itself and not the individual that initiates the action that results in the decision to be tested.<sup>37</sup> It is clear that this approach is not coercive; it is up to the individual to decide whether or not to be tested.

Bisaillon, a proponent for VCT testing, states that it is unclear whether VCT has failed as a policy approach or VCT has not been well supported.<sup>38</sup> He adds that during the early years of the epidemic, aggressive calls for punitive, forcible testing sparked widespread concern about the effects of such strategies on individual rights and the spread of the epidemic. Community advocates, human rights activists and public health professionals collectively forged a consensus that VCT was the most effective rights-based method of encouraging testing.<sup>39</sup> A major case against VCT is that it is resource and time intensive and thus impedes bringing testing up to scale. This, in turn, impedes efforts to scale up treatment even though it is not clear whether increased testing will be matched by increased access to treatment in many settings.<sup>40</sup>

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<sup>34</sup> See Nieburg *et al* footnote 32 above p. 12.

<sup>35</sup> *Ibid.*

<sup>36</sup> *Ibid.*

<sup>37</sup> See Herder footnote 26 above.

<sup>38</sup> Canadian HIV/AIDS Legal Framework, "Outcomes of the Symposium on HIV Testing and Human Rights 2005, available at, <http://www.genderhealth.org/pubs/testing.pdf> (accessed August 2011).

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid.*

An important drawback resulting from the expanded access to HIV testing and counselling is that it inevitably runs up against the gender dimension of the pandemic. This poses a serious disadvantage since in many heavily infected countries the subordinate status of girls and women fuels the spread of HIV /AIDS. Subsequently, girls and women are often blamed for bringing the virus into the household and may risk violence or discrimination of various kinds upon disclosing their HIV status.<sup>41</sup> A recent Horizons/Population Council study found that, “a serious barrier to disclosure for women is fear of a violent reaction by male partners and that HIV infected women and girls are at increased risk of partner violence.”<sup>42</sup> It is clear that, while expanded HIV testing benefits some women in terms of greater access to ART, it could put others at greater risk, leading some to avoid seeking health care until they are at an advanced stage of illness.

Rebecca Bennet and others do not support the view that the obligation is incumbent on the state to act in a manner which enables the HIV positive individual to fulfil his or her obligation to protect others.<sup>43</sup> Thus, in the context of HIV, it requires that the state create a social environment in which HIV positive persons can practically and psychologically exercise the responsibility for themselves and others. One of the lessons of the history of epidemics is that coercive measures rarely, if ever, work. However, some argue that HIV/AIDS should be viewed as just another epidemic, and demand similar draconian public health interventions as have been employed in the past for other epidemics.<sup>44</sup>

The above views on HIV/AIDS are different from others because:

- Often there is the intimate and private nature of the transmission routes, several of which lean crucially on what may broadly be termed an individual's life style.
- The second factor to take into account is the age in which we live and upon which AIDS has had an impact. We live in an age of human and civil rights

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<sup>41</sup> See Nieburg *et al*/footnote 32 above, p. 12.

<sup>42</sup> Maman; Mbwambo; Hogan; Kilinzo; Sweat; and Weiss, “HIV and Partner Violence: Implications for HIV Voluntary Counselling and Testing Programmes in Dar es Salaam, Tanzania” (New York: Population Council, 2001, p. 1, available at, <http://www.popcouncil.org/pdfs/horizons/vctviolence.pdf> (accessed 28 March 2012).

<sup>43</sup> See Bennet *et al*/footnote 17, p. 2.

<sup>44</sup> *Ibid* p. 3-15.

and thus we must be more cautious than ever before when implementing policies which infringe upon the liberties of others. It is against this background that the practical issues of testing and screening for HIV and questions of confidentiality of the results of such testing and screening must be examined and understood.<sup>45</sup>

The above cited authors reiterate that there is a growing trend of opinion which sees testing and screening for HIV as a paradigm shift of the tension between the rights of individual citizens and societies' interest in the protection and prevention of public health. This balance between the need to protect the public against infection and the need to protect HIV positive individuals against unethical treatment can be approached from a variety of viewpoints.<sup>46</sup> Bennet again suggests that there are those who claim that coercive public health measures, such as routine or even mandatory screening and regular breaches of confidentiality in order to warn others, are necessary evils to prevent widespread harm. On the grounds of efficacy and ethics, HIV testing must be offered on a voluntary and strictly on a confidential basis.

In making a cost benefit analysis<sup>47</sup>, Manuel argues that coercive measures such as mandatory testing, which at first blush might appear aimed at protecting the interests of the community, may well jeopardize prevention opportunities and so produce the opposite of the desired effect. In order to prevent this, Manuel suggests that voluntary testing, confidentiality and anti-discrimination must be favoured. Richards<sup>48</sup>, on the other hand, sets his argument against an historical account of the evolution of public health measures for the control of infectious diseases in America. While Manuel argues for an emphasis on individual rights and a greater reliance of public health efforts on the responsible behaviour of HIV positive individuals, Richard's avowed bias is towards disease control measures to protect the uninfected.

Authorities such as Sofia Gruskin<sup>49</sup> opines that rights-based approach to health have gained prominence not even imaginable when attention to non-discrimination against

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<sup>45</sup> *Ibid.*

<sup>46</sup> *Ibid.*

<sup>47</sup> *Ibid.*

<sup>48</sup> *Ibid.*

<sup>49</sup> Gruskin, "Rights-based approaches to health: Something for everyone", *Health and Human Rights Journal* Vol 9:2, 2006, p. 5-9.

People Living with HIV became entrenched in the first Global AIDS strategy over 20 years ago. She points out that it has been learnt that explicit attention to human rights shows not only who is disadvantaged and who is not, but also whether a given disparity is merely a difference or in fact constitutes an injustice. Instead, human rights are now understood to offer a framework for action and for programming, even as they provide a compelling argument for government responsibility both to provide health services and to alter the conditions that create, exacerbate, and perpetuate poverty, deprivation, marginalization, and discrimination.<sup>50</sup> However, a challenge has emerged regarding the term, “rights-based approaches to health”. This term is used to characterize a wide range of activities, and this has led to confusion both between those who consider being part of the health and human rights community and amongst those people whose work intersects with health and human rights activists.<sup>51</sup>

Approaches to the prevention and control of the HIV epidemic in Africa have been heavily based on early experiences and policies from the industrialised countries where the disease affected specific risk groups.<sup>52</sup> Kevin De Cock expounds that HIV/AIDS has been dealt with differently from other sexually transmitted diseases or lethal infectious diseases, despite being one of Africa’s leading causes of death. The argument brought by these writers is that some approaches to HIV/AIDS are poorly adapted to the crisis in Africa because the issue has not been defined and addressed as an infectious disease emergency.<sup>53</sup> Therefore, this requires a change in philosophy in order to produce a rapid and substantial effect on the African epidemic and to limit its devastation.

Kevin De Cock suggest that insistence on human rights in HIV/AIDS prevention has reduced the importance of public health and social justice, which offer a framework for prevention efforts in Africa that might be more relevant to people’s daily lives and more likely to be effective.<sup>54</sup> On the basis of epidemiological data, HIV/AIDS is the

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<sup>50</sup> Kass, “An Ethics Framework for Public Health” *Am J Public Health*, Vol 91, 2001, p. 1776-1782.

<sup>51</sup> UNAIDS Global Reference Group on HIV/AIDS and Human Rights: Issue Paper: “What Constitutes a Right Based Approach”, 4<sup>th</sup> Meeting 23-25 August 2004, available at, [http://www.data.unaids.org/Topic/Rights/hrissuepaper\\_rbadefinatio\\_en.pdf](http://www.data.unaids.org/Topic/Rights/hrissuepaper_rbadefinatio_en.pdf) (accessed 24 April 2012).

<sup>52</sup> De Cock; Mbori-Ngacha; Marum “Shadow in the Continent: Public Health and HIV/AIDS in Africa in the 21<sup>st</sup> Century”, *The Lancet*, Vol 360, 2002, p. 67-72.

<sup>53</sup> *Ibid.*

<sup>54</sup> *Ibid.*



greatest threat to life, liberty and the pursuit of happiness and prosperity in many African countries.<sup>55</sup> Interventions, therefore, must be quantitatively and qualitatively commensurate with the magnitude of the threat posed by the disease. Baggaley, in a paper presented at UNAIDS expert panel on HIV testing in the United Nations peacekeeping operations<sup>56</sup> on the other hand, confirms that the promotion of VCT as an essential element in the response to the HIV epidemic is a priority of UNAIDS. The paper reiterates that VCT is a key component of HIV programmes and, therefore, any approach that aims to achieve a comprehensive prevention strategy must be consistent with respect for human rights if it stands any chance to succeed and yield better results.<sup>57</sup>

Proposals for mandatory HIV testing of vulnerable populations have always met strong resistance from defenders of privacy. Testing patients against their will and then informing them of their HIV status is hardly the best way to offer effective treatment or persuade people to take steps to reduce the risks of transmission to others. If the state has the power to force a test, does it have the power as well to force unwanted treatment? What about taking away a parent's right to decide the treatment for her/his child? Mandatory testing also in the case of pregnant women can only make sense when the state is willing to do all three because, without the treatment, testing may be a hollow gesture.<sup>58</sup>

AIDS and human rights activists argue that VCT is the most effective and rights-based method of encouraging HIV testing.<sup>59</sup> Furthermore, they take the position that infringing on the right to privacy by, for example, making HIV testing mandatory, effectively drives the AIDS pandemic further underground. This is particularly so where being infected is followed by persecution, ostracism, violence and destitution. Endorsing this view, international organisations such as UNAIDS and WHO

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<sup>55</sup> *Ibid.*

<sup>56</sup> Dr Baggaley, "Voluntary Counselling and Testing (VCT)", Paper for UNAIDS Expert Panel on HIV Testing in United Nations Peacekeeping Operation, 17-18<sup>th</sup> September 2001, New York.

<sup>57</sup> *Ibid.*

<sup>58</sup> The American Civil Liberties Union (ACLU), "HIV Testing of pregnant women and new borns," 2001, available at, <http://www.aclu.org> (accessed 18 January 2012).

<sup>59</sup> Canadian HIV/AIDS Legal Framework, Outcomes of the symposium on HIV testing and human rights 2005, available at, [http://www.genderhealth.org/pubs/testing\\_symposium.pdf](http://www.genderhealth.org/pubs/testing_symposium.pdf) (accessed 06 March 2012) See also De Cock et al "A serostatus based approach to HIV/AIDS prevention and care in Africa" *The Lancet* Vol 362, 2003 p. 9398, available at, <http://www.thelancet.com/journals/lancet/articles/P11S0140673603149069/fulltext>( accessed 06 March 2012).

advanced the argument that VCT, in which the patient voluntarily elects to find out his or her status, was the only appropriate approach.<sup>60</sup> These two institutions argue that, save in cases of blood and body organ donation, compulsory or mandatory testing represents a violation of human rights and an ineffectual response in terms of public health.<sup>61</sup>

Despite these concerns, in some countries compulsory testing still occurs, and mandatory testing continues to be applied to certain groups of people such as immigrants, prisoners, sex workers and the military.<sup>62</sup> In as much as it seems justifiable to test these groups of people in a mandatory manner, it is doubtful whether, for instance, the restriction from entering a certain country or from working in the army is enough to stop the spread of the pandemic. If the answer is in the negative, what is important is to treat this infection as any other disease, to bring awareness to the individuals infected on how to live longer and, finally, to prevent transmission to other people.

UNAIDS/WHO support mandatory screening for HIV and other blood borne viruses of all blood that is destined for transfusion or for the manufacture of blood products. Mandatory screening of donors is required prior to all procedures involving transfer of bodily fluids or body parts such as artificial insemination, cornea grafts and organ transfers.<sup>63</sup> UNAIDS/WHO do not support mandatory testing of individuals on public health grounds.<sup>64</sup> They also support the view that voluntary testing is more likely to result in behaviour change in order to avoid transmitting HIV to other individuals. They recognized that many countries require mandatory HIV testing for immigration purposes and that some countries conduct mandatory testing for pre-recruitment and periodic medical assessment of military personnel for the purposes of establishing fitness.<sup>65</sup> UNAIDS recommended that such testing be conducted only when accompanied by counselling for both HIV positive and HIV negative individuals and

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<sup>60</sup> The South African Institute of International Affairs Special Feature: *States*, "AIDS experts tests boundaries of HIV testing" 1998 <http://www.saiia.org.za/modules.php?> (accessed 06 March 2012).

<sup>61</sup> See Canadian HIV/AIDS Legal Framework footnote 59 above.

<sup>62</sup> See Bennet and Erin footnote 17 above.

<sup>63</sup> UNAIDS/WHO, "Scaling up HIV testing and Counselling, A tool kit for programme managers", available at, <http://www.who.int/hiv/pub/vct/counsellingtestingtoolkit.pdf> (accessed 10 March 2012)

<sup>64</sup> See De Cock; Mbori-Ngacha; Marum, footnote 52 above.

<sup>65</sup> UNAIDS/WHO, "Scaling up HIV testing and Counselling, A tool kit for programme managers", available at, <http://www.who.int/hiv/pub/vct/counsellingtestingtoolkit.pdf>, (accessed 10 March 2011).

when referral to medical and psychosocial services is provided for those who receive a positive test result.<sup>66</sup> UNAIDS recommends that HIV testing must be voluntary, and this rights-based approach enhances service delivery in health facilities and communities. It is also critical for improving people's perceptions about the benefits of HIV testing and counselling and this also has a direct impact on the uptake of services. The UNAIDS states that a rights-based approach to HIV testing and counselling means that:<sup>67</sup>

- people have the right to know their status;
- HIV testing must be voluntary, the decision to test or not to test being based on an understanding of accurate, objective and relevant information;
- post-test counselling and services are crucial;
- confidentiality must be protected;
- non-discrimination in service delivery is critical; and
- testing and counselling must be scaled up, eventually leading to universal access.

States applying mandatory or compulsory HIV testing justify their actions with a public health rationale, which they claim is strong enough to restrict human rights in the context of HIV testing.<sup>68</sup> UNAIDS argues that considering its devastating effect, stemming the spread of HIV/AIDS is in the public interest.<sup>69</sup> Since there is neither a vaccine nor a cure for HIV/AIDS in sight, public interest is best served when people who are HIV positive abstain from engaging in those behaviours most likely to transmit the virus.<sup>70</sup> Learning about one's HIV status through HIV testing is a crucial step in modifying behaviour. Since VCT is slow or inefficient to help prevent the persistent spread of HIV, a call for more widespread and aggressive HIV testing is of paramount importance.

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<sup>66</sup> *Ibid.*

<sup>67</sup> *Ibid.*

<sup>68</sup> Report of the Secretary General, Second International Consultation on HIV/AIDS and Human Rights 1996, available at <http://www.unhchr.ch/Huridoca/Huridoca.nsf/E.CN.4.1997> (accessed 06 March 2012).

<sup>69</sup> UNAIDS Technical Update "Voluntary Counseling and Testing, UNAIDS" Best practice collection May 2000 p. 6. See also Stein *The Social Welfare of Women and Children with HIV/AIDS: Legal Protection Policy and Programmes*, New York Oxford Press 1998.

<sup>70</sup> *Ibid* p. 6.

In his case study of Eritrea, Neerja found that mandatory testing will increase stigmatisation and prove to be counterproductive, throwing all the hard work out of gear and driving people underground.<sup>71</sup> He argues that instead of mandatory HIV testing of couples before marriage which is rife in Goa, mandatory counselling and voluntary testing should be preferred.<sup>72</sup> How about mandatory counselling and voluntary testing. He suggests that along with a public awareness campaign, the government could include a pre-marriage counselling facility at the Registrar's office, where the couple wishing to marry could undergo pre-marital counselling. Again he suggests that outreach and education can significantly improve HIV testing acceptance and has the principle effect of reducing the number of HIV positive individuals and their offspring.<sup>73</sup>

The Council of Europe adopted a recommendation which states that:

In the absence of curative treatment, and in view of the impossibility of imposing behaviour modifications and the impracticability of restrictive measures, compulsory screening is unethical, ineffective, unnecessarily intrusive, discriminatory and counter-productive.<sup>74</sup>

According to WHO, mandatory testing and other testing without informed consent has no place in an AIDS prevention and control programme:

There are no benefits either to the individual or for public health arising from testing without informed consent that cannot be achieved by less intrusive means, such as voluntary testing and counselling.<sup>75</sup>

Coercive laws and practices such as mandatory testing which disregard human rights might backfire. An example is that of India's sterilization drive which led to

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<sup>71</sup> Yadav, "Playing politics with AIDS, controversy over Mandatory Vs Voluntary testing in Goa", available at, [http://www.manushi-india-org/pdfs\\_issues/pdf%20Files%20155/Neeja%Vaidya-Yadav](http://www.manushi-india-org/pdfs_issues/pdf%20Files%20155/Neeja%Vaidya-Yadav). (accessed 15 October 2011).

<sup>72</sup> *Ibid.*

<sup>73</sup> *Ibid.*

<sup>74</sup> Council of Europe Committee of Ministers, Recommendation No R (8) 14 on the Ethical Issues of HIV Infection in the Health Care and Social Settings, *International Digest of Health Legislation* 39, 1990, available at, <http://www1.umn.edu/humanrts/instree/coerecr89.html>, (accessed 23 October 2011).

<sup>75</sup> *Ibid.*

political as well as social backlash.<sup>76</sup> It caused upheaval in the government and set back India's family planning programme by at least two decades. Therefore, in trying to use law to contain the spread of HIV/AIDS, the government has to be careful not to send the wrong message to society or divide the community between those with HIV/AIDS and those without.<sup>77</sup> Public health experiences demonstrate that programmes that do not respect the right and dignity of individuals are not effective. It is essential, therefore, to promote the voluntary cooperation of individuals rather than impose coercive measures on them. In essence, mandatory testing will drive some people - who are already sceptical about the health care system - further away from it. It is unlikely to cause the expected changes in behaviour necessary to prevent the spread of HIV. On the contrary, although it might discover a minor proportion of the so-called dangerous population, it may scare off a large percentage of people, thereby proving to be counterproductive.<sup>78</sup>

UNAIDS and WHO, on the other hand, have also recommended the use of provider initiated routine HIV testing in three contexts, which are:<sup>79</sup>

- sexually transmitted infection clinics to permit counselling tailored to HIV status;
- the context of pregnancy to facilitate an offer of antiretroviral prevention of mother-to-child transmission; and
- clinical and community-based health services settings where HIV is prevalent and antiretroviral treatment is available.

It has been suggested that in the light of the above mentioned changes, VCT is too slow or inefficient to help prevent the relentless spread of HIV. It is also argued that the question of resources simply makes long drawn out counselling procedures unrealistic in resource constrained environments.<sup>80</sup> It is also suggested that the emphasis on the voluntariness of the HIV test as well as the requirements of informed consent and confidentiality are no longer necessary in the light of the

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<sup>76</sup> Compulsory, sterilization, also known as forced sterilization, programs are government policies which attempt to force people to undergo surgical sterilization, see, <http://www.dickshovel.com/IHSSterPol.html>. (accessed on May 23 2011).

<sup>77</sup> See Yadav footnote 71 above.

<sup>78</sup> See De Cock *et al* footnote 11 above.

<sup>79</sup> UNAIDS/WHO Policy Statement on HIV Testing 2004.

<sup>80</sup> *Ibid*, p. 70.

availability of treatment. They may slow down and jeopardise attempts to curb the spread of the disease, especially in Africa.<sup>81</sup>

Opponents of VCT have also pointed out that only a small number of people make use of VCT. Although treatment and care programmes have been expanded over the years, only few people benefit from these services due to scepticism about HIV testing. It is estimated that only about 10 per cent of the people in Africa have access to testing and counselling services.<sup>82</sup> Concern about this state of affairs has resulted in enormous changes in the perception of approaches and content of HIV testing on the part of public health practitioners and policy makers worldwide. There have been increasing calls to move away from the VCT model, more particularly in high prevalence areas where it has apparently not resulted in large numbers of people being tested.<sup>83</sup>

VCT is recognised as one of the most effective and important strategies for reducing the transmission of HIV in developing countries. According to WHO, VCT is said to have enormous advantages compared with compulsory HIV testing.<sup>84</sup> These advantages include early entry into treatment and care programmes, making antiretroviral therapy accessible before significant AIDS related morbidity, and ensuring fewer demands on clinical resources than late treatment presentation.<sup>85</sup> VCT can also stimulate discussion about HIV/AIDS and, in turn, this reduces stigma and discrimination.<sup>86</sup> Further counselling knowledge reduces stigma towards those living with HIV and AIDS and this decreases resistance in seeking VCT.<sup>87</sup> There is

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<sup>81</sup> *Ibid.*

<sup>82</sup> International Guidelines on HIV/AIDS and Human Rights, 2006 consolidated Version, available at, <http://data.unaids.org/Publications/IRC-pub/07/jc1252-internationalguidelines-en.pdf> (accessed 16 August 2011).

<sup>83</sup> The WHO pointed out that, the time has now come to implement HIV testing and counselling more widely using existing health settings, moving beyond the model of provision that relies entirely upon concerned individuals seeking out help for them to permit broader access for all. In this new approach, such services will become a routine part of health care, for example during attendance at antenatal clinics, or at diagnosis and treatment centres for tuberculosis and sexually transmitted infections. WHO report, "Increasing access to HIV Testing and Counselling", a report of a WHO Consultation, Geneva, Switzerland 19-20 November 2002.

<sup>84</sup> UNAIDS/WHO, "Policy Statement on HIV Testing", 2004, available at, [http://www.who.int/rpc/research\\_ethics/hivtestingpolicy\\_en.pdf](http://www.who.int/rpc/research_ethics/hivtestingpolicy_en.pdf), (accessed on 10 March 2012).

<sup>85</sup> Macphail; Coates; Pettifor; and Rees, "Attitude towards voluntary counselling among South African youths and parents", *Health and Educational Behaviour*, Vol 35:11, 2008 p. 87-104.

<sup>86</sup> Muwanguzi; Mbonye; and Maseruka "Prevalence and determinants of uptake of VCT services among University students", Mbarara University of Science and technology 2008.

<sup>87</sup> Kalichman and Simbayi, "Traditional beliefs about the causes of AIDS and AIDS related stigma in South Africa", *AIDS Care* Vol 16:5 2004 p. 572-580.

growing evidence that VCT is important for primary prevention, an important gateway for care and support of those affected.

Compulsory HIV testing which requires that the entire population, or at least certain high-risk groups, is tested for HIV has earned a bad reputation in recent years from human rights activists. The latter argue for a person's right to choose to know whether or not they have HIV. Katie Morris argues that studies have shown that usually once a person knows that he/she is HIV positive, he/she<sup>88</sup> will change his/her risky behaviour in order to avoid transmitting it to others. Katie fully supports the freedom of choice and the right to live and if compulsory testing can reduce the number of people dying from AIDS, it should at least be considered by policy makers around the globe.

In a statement made to Reuters,<sup>89</sup> Bill Clinton stated;

[W]e can save people's lives, and we can reduce the stigma. There is no way we are going to reduce the spread of this epidemic without more testing because 90% of the people who are HIV-positive don't know it.

He further stated that, "everyone who is sexually active, injecting drugs, receiving blood transfusions, or breastfeeding is at risk for contracting HIV, regardless of their age, skin colour, education, financial status, or sexuality."<sup>90</sup> Therefore, in order to increase more individuals' knowledge of their status so that they do not unknowingly spread HIV, testing needs to go beyond voluntary clinics. It is clear that most proponents of mandatory testing do not care about the means but the end.

What is important to proponents of mandatory testing is the number of people who are tested rather than whether their rights are violated, whether they really know the purpose of the test, or how the test results will impact on their subsequent lifestyle and behaviour. Proponents of public health utilitarianism argue that mandatory testing would help prevent infection among non-infected partners and new-borns,

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<sup>88</sup> Morris and Wessener, "Compulsory HIV testing: The AIDS pandemic", 2010, available at, <http://the-aids-pandemic.blogspot.com/2010/10/compulsory-hiv-testing.html> ( accessed 10 March 2012).

<sup>89</sup> *Ibid*.

<sup>90</sup> *Ibid*, Bill Clinton, the former President of the United States and founder of the Clinton foundation, which funds a great number of HIV/AIDS programs around the world, is an advocate for mandatory testing in developing countries with high HIV prevalence rates.

and that this outcome serves legitimate public interests.<sup>91</sup> The utilitarian argument emphasizes the ‘greatest amount of happiness for the greatest number’.<sup>92</sup> This view holds that as far as public health policy is concerned, communal good shall or should prevail over individual interest.<sup>93</sup> The utilitarian position on public health further contends that by emphasizing choice and free will, voluntary counselling and testing (VCT) simply allow people to delay the choice to test and discover their status, often until the choice is pre-empted by severe illness or pregnancy. This, it is argued, has fatal consequences to PLWHA and necessitates superfluous and massive consumption of resources.<sup>94</sup> The underlying assumption is that it is wrong for individual autonomy to triumph over public health with no regard for the negative consequences to the broader society.<sup>95</sup>

## **2. 2 Emergence of “public health powers” Philosophy in the Case of a State of Emergency**

### *2. 2 .1 A historical perspective on the treatment of infectious diseases*

Prior to the early 20<sup>th</sup> century, when the scientific basis of disease was poorly understood, public health and medicine worked together collaboratively. What were now known to be infectious diseases, such as tuberculosis, influenza, pneumonia, and streptococcal infections, were then the major causes of death and disability.<sup>96</sup> Prevailing medical treatments, such as purging and bleeding, were largely ineffective and public health measures, such as sanitation and quarantine, were relied on to control such diseases.<sup>97</sup> After the advent of bacteriology in the late 19<sup>th</sup> century,

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<sup>91</sup> HIV testing is compulsory for all who are preparing to get married in Eritrea. As a result, seropositive individuals are not allowed to have their marriages officially recognised by public or religious entities. The policy of the Eritrean government can be explained as a separate bid to halt the spread of the deadly virus. See Mekonnen: A case study of Eritrea: “Mandatory Premarital testing as a challenge to human rights”, *Interdisciplinary Journal of Human Rights law* VOL 5:1 2011, p. 13-17.

<sup>92</sup> Durojaye, “Addressing Human Rights concerns raised by mandatory HIV testing of pregnant women through the Protocol of the African Charter on the Rights of Women in Africa”, *Journal of African Law* Vol 52:1 2008, p. 46.

<sup>93</sup> *Ibid.*

<sup>94</sup> Mekonnen, “A case study of Eritrea: Mandatory Premarital testing as a challenge to human rights”, *Interdisciplinary Journal of Human Rights Law* VOL 5:1 2006, p. 13-17.

<sup>95</sup> Ministry of Health, UNGASS Progress report of Eritrea 2008, p.6, available at, [http://data.unaids.org/pub/Report/2008/eritrea2008countryprogressreport\\_en.pdf](http://data.unaids.org/pub/Report/2008/eritrea2008countryprogressreport_en.pdf), (accessed 15 October 2011).

<sup>96</sup> Lasker, “Medicine and Public Health: The power of collaboration” New York Academy of Medicine and Public Health 1997, available at, <http://www.acash.org/pdf/MPH.pdf> (accessed 10 March 2012).

<sup>97</sup> Salinsky, “Public Health Emergency Preparedness: Fundamentals of the System” National Health Policy Forum Background Paper 2002, p.21.



which established bacteria as the causative agent in many infectious diseases, the medical diagnosis and treatment of these diseases became dramatically more effective.<sup>98</sup>

As these medical practices became more advanced and sophisticated as scientific knowledge expanded dramatically after World War II, the biomedical paradigm for responding to infectious diseases began to eclipse the public health approach.<sup>99</sup> This evolution entailed an increasing emphasis on interventions targeted at individuals as a means of preventing the spread of disease through communities.<sup>100</sup> Public health became an important provider of health care services, for example, immunizations and treatment for tuberculosis (TB) and sexually transmitted diseases (STDs) particularly for low income persons or rural citizens who lacked access to private healthcare professionals.<sup>101</sup>

Presently, public health retains the responsibilities of preventing and controlling infectious diseases but also embraces a much wider set of obligations. Public health has a mandate to prevent epidemics and the spread of diseases; to offer protection against environmental hazards; prevent injury; promote and encourage healthy behaviours; respond to disasters; assist communities towards recovery and also assure the quality and accessibility of health care services.<sup>102</sup>

The term “public health” is exemplified by the eradication of small-pox, the “sanitary revolution” that established and applied the principles of modern hygiene, and dramatic progress made against historical scourges like tetanus, typhoid, poliomyelitis, diphtheria and tuberculosis.<sup>103</sup> Yet public health goes beyond the traditional infectious disease control.<sup>104</sup> Public health can be defined as “what we as

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<sup>98</sup> Institute of Medicine (IOM), “The future of Public Health” Washington D.C: National Academy Press 1988, available at, <http://www.nap.edu/catalogue/1091.html> (accessed 10 March 2012).

<sup>99</sup> Salinsky, National Health Policy Forum Background Paper, “Public Health Emergency Preparedness: Fundamentals of the “System”, 2002, p. 3.

<sup>100</sup> Macphail; Coates; Pettifor; and Rees, “Attitude towards voluntary counselling among South African youths and parents”, *Health and Educational Behaviour February; Vol 35:11, 2008, p. 87-104.*

<sup>101</sup> Steele; Melendez-Morales; Campoluci; Deluca; and Dean, “Health disparities in HIV/AIDS, viral hepatitis, Sexually Transmitted Diseases, and Tuberculosis in the United States: Issue, Burden and Response” *A Retrospective Review, 2000-2004*, available at, <http://www.cdc.gov/nchhstp/healthdisparities/pdf>, (accessed 14 March 2012).

<sup>102</sup> See Institute of Medicine (IOM) footnote 98 above, p. 63.

<sup>103</sup> Mann; Gruskin; Grodin; Annas, *Health and human rights*, Routledge New York and London 1999, p.29.

<sup>104</sup> *Ibid* p. 29-30.

a society do collectively to ensure the conditions in which people can be healthy”.<sup>105</sup> The mission of public health is to promote physical and mental health, prevent disease, injury and disability, and to protect the public from environmental hazards.<sup>106</sup>

It follows that public health actions seek to promote the health of the community. For instance, the addition of fluoride to water supplies in order to prevent childhood dental caries is a broad public health measure, affecting everyone who drinks the water. The procedure is designed to achieve a collective good, less tooth decay, and better dental health. This action will not guarantee every individual freedom from dental caries, but it will reduce the overall amount of caries occurring in the population.<sup>107</sup> The human rights question that will frequently arise in such situations is: whose rights are of greater value, those of the community or those of the individual?

From the above illustration it is clear that issues of safety and security arise when the public's health is threatened. Human rights law has recognised public health protection as a societal good that can, under certain limited circumstances, be invoked by governmental authorities to legitimately restrict the full exercise of certain human rights. In this respect, public health is representative of a category of issues, such as national security and public emergency, where restrictions on the rights of individuals and population groups are permissible. Thus, for example, the International Covenant on Civil and Political Rights specifically mentions public health as a valid justification for restricting rights such as freedom of movement and expression, and freedom of assembly and association.<sup>108</sup>

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<sup>105</sup> USA Institute of Medicine, “The future of the Public Health in the 21<sup>st</sup> Century”, 2002 p. 1- 8, available at, <http://www.iom.edu>, (accessed 17 March 2012).

<sup>106</sup> Public Health Functions Steering Committee, “Public Health in America,” U.S Department of Health and Human Services, June 1995, available at, <http://www.health.gov/phfunctions/public.htm> (accessed March 10 2012).

<sup>107</sup> See Macphail *et al*, footnote 100 above.

<sup>108</sup> See Mann *et al*. footnote 103 above, advocate in their book that there is need for genuine collaboration and open communication between public health community and human rights community. They point out that this is a substantial challenge, and one that requires careful attention to often unspoken assumptions and differences in attitude and language; it truly requires trans-disciplinary effort. Ultimately the common goal of human well-being through both public health and human rights strategies will lead us forward.

In the case of *Enhorn v. Sweden*,<sup>109</sup> the European Court of Human Rights (ECHR) recognized that ‘the Court has only to a very limited extent decided cases where a person has been detained for the prevention of spreading infectious diseases’. Most European states<sup>110</sup> have statutory powers<sup>111</sup> enabling a range of compulsory interventions, from compulsory vaccination to compulsory medical examination, compulsory quarantine and compulsory isolation or detention of infected persons.<sup>112</sup> The Court took the opportunity to determine in this case the criteria for determining whether public health powers in cases of infectious disease complied with conventional rights norms. Such criteria will be of importance to the interpretation of public health powers in the United Kingdom, given that the Public Health Act 1984 and its equivalents in Northern Ireland and Scotland contained detention powers similar to, but with fewer protections than, the Swedish laws under examination in this case.<sup>113</sup>

AIDS and TB have become the two primary examples that are used by critics of the public health vision to point out that prioritizing human rights has an effect of promoting contagion and death.<sup>114</sup> Human rights activists certainly will deflect on this view. Mann argues that this view finds little support in fact, and contemporary public health officials mostly have concluded that taking human rights seriously is a necessary component of an effective public health strategy.

In the case of *Enhorn v. Sweden*, the applicant was a homosexual man, aged 56, infected with the HIV virus. In 1990 he had transmitted the virus to a 19-year-old man. Subsequently, the county medical officer issued instructions to the applicant under the Infectious Diseases Act 1988 of Sweden, requiring the applicant to comply with a list of requirements, namely, that he should: inform sexual partners of his HIV

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<sup>109</sup> *Enhorn v. Sweden* [2005] E.C.H.R. 56529/00, para. 41.

<sup>110</sup> Some examples include United Kingdom, France and Scotland and Sweden.

<sup>111</sup> Coker and Martin “Public Health Powers and Infectious Disease”: A European Study, Paper given at the Hart Workshop, Institute of Advanced Legal Studies, June 2005.

<sup>112</sup> Quarantine involves the restriction of the activities of healthy persons who have been exposed to communicable disease, while isolation and detention involve the separation of an infected person to prevent spread of disease. See Gostin, “Public Power, Duty and Restraint” *Medical Law Review* Vol 14, Spring 2006, p. 132–143.

<sup>113</sup> Martin, “The exercise of public health powers in cases of infectious diseases: Human Rights implication’s”, 2006, available at, <http://www.medlaw/fwi038/Spring/mdoi:10.1093> (accessed 24 March 2012).

<sup>114</sup> Annas, “Control of Tuberculosis: The Law and the Public’s health”, *New England Journal of Medicine* Vol 328, 1998 p. 585-588 and Annas, “Detention of HIV positive- Haitians at Guantanamo: Human Rights and Medical Care”, *New England Journal of Medicine* Vol 329 1993 p. 589-592.

status; use a condom during intercourse; limit his alcohol intake; inform healthcare staff of his status when he sought medical treatment; and consult his physician on a regular basis.<sup>115</sup> The applicant failed to comply with these requirements. The county medical officer then successfully sought an order from the County Administrative Court that the applicant be compulsorily detained in isolation for up to three months. The applicant absconded, but was arrested and detained under the Order. He frequently absconded thereafter with the result that a series of court orders were made against him for further periods of detention over the following seven years. Medical evidence<sup>116</sup> suggested that because of a paranoid personality disorder, the applicant lacked some awareness of the risk of disease contagion resulting from his behavior.

The applicant complained to the ECHR that the compulsory isolation orders and his involuntary detention in a hospital had been in breach of Article 5 (1) of the European Convention for the Protection of Human Rights and Fundamental Freedoms of 1950, which states:

Everyone has the right to liberty and security of the person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.

The possible grounds for restrictions of liberty under the European Convention included, *inter alia*, 'the lawful detention of persons for the prevention of the spreading of infectious diseases'.<sup>117</sup> There were two strands to the applicant's argument. Firstly, he argued that the deprivation of liberty was not in accordance with the substantive and procedural requirements of domestic law. Secondly, he contended that the substantive provisions of Article 5 were not made out in his case, given that the detention did not constitute a proportionate response to the need to prevent the spread of infectious disease.

The Court held unanimously that there had been a violation of Article 5(1) of the European Convention on Human Rights. In its decision the Court noted that the Government had not provided any examples of less severe measures which might

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<sup>115</sup> *Enhorn v Sweden case*, para. 9.

<sup>116</sup> *Ibid* para. 19.

<sup>117</sup> European Convention for the Protection of Human Rights and Fundamental Freedoms of 1950, Article 5 (1) (e).

have been considered for the applicant in the period from 16 February 1995 until 12 December 2001, but had turned out to be insufficient to safeguard the public interest. There was no evidence or indication that during the period that the applicant transmitted the HIV virus to anybody, or that he did not use a condom, or that he had any sexual relationship at all for that matter.<sup>118</sup> The Court thus reached the conclusion that the compulsory isolation of the applicant was not a last resort in order to prevent him from spreading the HIV virus after less severe measures had been considered and been found to be insufficient or ineffective to safeguard the public interest. Other measures that could strike a balance between ensuring that the virus did not spread and the preservation of the applicant's right to liberty could have been explored. This is synonymous with the major theme reflected in this dissertation, namely, that compulsory measures put in place to protect public health safety have to be reasonable in that they should not have a negative impact on human rights. In essence, a balance should be struck between public health policies and human rights.

In *N v United Kingdom*<sup>119</sup> the applicant was seriously ill and, on her arrival in the United Kingdom on a false passport from Uganda, she was diagnosed as being HIV positive. She improved after prolonged medical treatment in the country. When steps were taken for her removal to Uganda, she claimed that this would violate her rights under Article 3<sup>120</sup> of the European Convention on the Prohibition of Inhuman or Degrading Treatment and Punishment,<sup>121</sup> as the medication that she needed would only be available at considerable expense and would not be easily accessible in Uganda. In para 44 of the judgement, the Court repeated the observation that it made in *Soering*<sup>122</sup> that inherent in the whole Convention is a search for a fair balance between the demands of the general interest of the community and the requirements for the protection of the individual's fundamental rights.

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<sup>118</sup> European Court of Human Rights, "Chamber Judgement *Enhorn v Sweden*", available at, <http://www.antidiscriminare.ro/pdf/ChamberJudgEnhvsSW.pdf> (accessed 04 April 2012).

<sup>119</sup> *N v United Kingdom* (2008) 47 EHRR 885.

<sup>120</sup> This provision usually applies, apart from torture, to cases of severe police violence and poor conditions in detention. The European Court of Human Rights has further held that this provision prohibits the extradition of a person to a foreign state if they are likely to be subjected there to torture. This article has been interpreted as prohibiting a state from extraditing an individual to another state if they are likely to suffer the death penalty. This article does not, however, on its own forbid a state from imposing the death penalty within its own territory.

<sup>121</sup> Article 3 of the European Convention on Human Rights and Fundamental Freedoms of 1950.

<sup>122</sup> *Soering v United Kingdom* (1989) (1) EHRR 439.

In the *Soering* case, the applicant complained that the decision to extradite him to the United States of America, if implemented, would give rise to a breach of Article 3 as, if he were to be sentenced to death; he would be exposed to inhuman and degrading treatment on death row. The Court stressed the need for a fair balance to be struck:

What amounts to 'inhuman or degrading treatment or punishment' depends on all the circumstances of the case. Furthermore, inherent in the whole of the Convention is a search for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individual's fundamental rights. As movement about the world becomes easier and crime takes on a larger international dimension, it is increasingly in the interest of all nations that suspected offenders who flee abroad should be brought to justice. Conversely, the establishment of safe havens for fugitives would not only result in danger for the State obliged to harbour the protected person but also tend to undermine the foundations of extradition.<sup>123</sup>

Advances in medical science, together with social and economic differences between countries, means that the levels of treatment available might vary considerably:

While it is necessary, given the fundamental importance of article 3 in the Convention system, for the court to retain a degree of flexibility to prevent expulsion in very exceptional cases, article 3 does not place an obligation on the contracting state to alleviate such disparities through the provision of free and unlimited health care to all aliens without a right to stay within its jurisdiction. A finding to the contrary would place too great a burden on the contracting states.<sup>124</sup>

The inherent governmental power to act to protect the public's health and safety is referred to as 'police power', which, in the United States, resides in the individual federal states, but in most states of the world this power resides at the national level.<sup>125</sup> When, for example, the state's power to permit local communities to require

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<sup>123</sup> *Ibid* para 89.

<sup>124</sup> *N v United Kingdom* para 44.

<sup>125</sup> See Mann *et al* footnote 103 above, p. 40.

vaccination against a smallpox outbreak was challenged at the beginning of the century, the U.S Supreme Court ruled in *Jacobson v Massachusetts* that:

The safety and the health of the people of Massachusetts are, in the first instance, for the Commonwealth to guard and protect. They are matters that do not ordinarily concern the national government. Using military metaphors the court ruled as a general matter that “upon the principle of self-defense, of paramount necessity, a community has the right to protect itself against an epidemic of disease which threatens the safety of its members.”<sup>126</sup>

In this case it was again pointed out that actions designed to contain an epidemic will be upheld as constitutional as long as they are not arbitrary or unreasonable and are rationally related to the goal of protecting the public’s health.<sup>127</sup>

The law has the potential to be a very useful tool for the attainment of public health. Bad law, however, can serve to create obstacles to public health.<sup>128</sup> Public health consultants in England and Wales have been cautious in using detention powers, even in cases of serious risk of spread of disease by a non-compliant patient, because of lack of clarity as to the status of these powers in relation to human rights.<sup>129</sup> The question of balancing the public and private interests in the context of infectious diseases needs to be addressed and consideration given to the incorporation of a precautionary approach to public health legislation. It is arguable, however, that such a debate should not take place in the wake of an oncoming threat, but rather the balance should be between public benefit and private rights. It can be deduced from the decision in the *Enhorn* case that priority was given to the private right to liberty over the public benefit of disease protection in a case of HIV/AIDS, despite the assessment of government public health officials that there was some risk to public health. The extent to which this decision can serve as a

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<sup>126</sup> *Jacobson v Massachusetts*, 197 U.S 11(1904).

<sup>127</sup> Mann *et al.* highlight that a responsible public health approach to infectious epidemics requires, surveillance, reporting, interventions and education of the health professionals. All four must be coordinated or their efficacy will drastically decrease. But an effective public health strategy does not require a military response or the trampling of basic human rights.

<sup>128</sup> Martin, “The Exercise of Public Health Powers in cases of Infectious disease: Human Rights implication, A commentary on the case of *Enhorn v Sweden*, *Medical Law Review*, 14, Spring 2006 p. 132-143.

<sup>129</sup> *Ibid.*

precedent where the risk is of large scale, fast spreading or of unknown epidemiology is questionable.<sup>130</sup>

### 2.3 Reconciling Individual Rights and Public Interest

Quoting some of the pioneering writers on the intersection between health and human rights, Durojaye argues that “every public health policy, no matter how good it may seem, is potentially a threat to the enjoyment of human rights.”<sup>131</sup> This position is further strengthened by London *et al.* who also argue that a public health policy that affects human rights has to be scrutinized meticulously according to a well-defined criteria developed by the United Nations. Broad societal objectives on public health policies may impose significant conflicts on the realization of human rights.<sup>132</sup> The most prominent of these are the *Siracusa* principles, which provide a basic framework for analyzing the human rights impact of health policies.<sup>133</sup> In this regard, the risk of HIV transmission to HIV negative people may necessitate restrictions to HIV positive people.<sup>134</sup> There is no doubt, for example, that mandatory testing currently carried out in Eritrea restricts the enjoyment of human rights by individuals.<sup>135</sup>

The *Siracusa* principles are essential principles developed by a group of experts endorsed by UN, and these principles are widely accepted by signatories of the ICCPR. In terms of their binding or non-binding nature, the *Siracusa* principles are not different from the General Comments of the Human Rights Committee or those of the Committee on ESCR, which means that they are guiding, interpretative principles meant to provide insight to the signatories of the ICCPR or the ESCR as the case may be. The principles are, however, highly regarded by signatories on the

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<sup>130</sup> *Ibid* p.143.

<sup>131</sup> Durojaye, “Addressing Human Rights concerns raised by mandatory HIV testing of pregnant women through the protocol of the African Charter on the Rights of women” *Journal of African Law* 52:1, 2008 p. 46.

<sup>132</sup> London, Orner and Myer “Even if you are positive, you still have rights because you are still a person”: Human Rights and the reproductive choice of HIV positive persons”, *DEV WLD Bioethics Vol* 8:5 2008, p.14-15.

<sup>133</sup> UN Human Rights Committee, General Comment 29.

<sup>133</sup> See Mekonnen footnote 94 above, p. 8.



implementation of the ICCPR with a solid democratic culture.<sup>136</sup> Based on the *Siracusa* principles, Durojaye and Balogun summarize the most important conditions in which the enjoyment of human rights can be limited as follows:<sup>137</sup>

- The restriction is provided for and carried out in accordance with law.
- The restriction is in the interests of the legitimate objective of public interest.
- The restrictions are strictly necessary in a democratic society to achieve the objectives.
- There are no less intrusive and restrictive means to reach the same goals.

With regard to limitation of human rights in the context of a democratic setting, further guidance is to be drawn from the ICCPR and the General Comments adopted by the UN Human Rights Council (UNHRC) in relation to the interpretation of the ICCPR, especially Article 4 which states:

In time of public emergency which threatens the life of the nation and the existence of which is officially proclaimed, the States Parties to the present Covenant may take measures derogating from their obligations under the present Covenant to the extent strictly required by the exigencies of the situation, provided that such measures are not inconsistent with their other obligations under international law and do not involve discrimination solely on the ground of race, colour, sex, language, religion or social origin.<sup>138</sup>

It is common practice in most democratic legal systems that limitation of human rights requires special procedures and mechanisms which are compliant with the requirements stipulated in the ICCPR. It should, however, be noted that even when there are democratic processes and institutions allowing for the adoption of effective HIV/AIDS policies and programmes, certain rights are always non-derogable under all circumstances. These include the right to life; the prohibition of torture or cruel, inhuman or degrading punishment; the prohibition of slavery, the slave trade and

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<sup>136</sup> See United Nations Economic and Social Council (UNECOSOC), "The Siracusa Principles on the Limitations and Derogations Provisions in the International Covenant on Civil and Political Rights", UN Document E/CN.4/1985/4, Annex Geneva: UNECOSOC.

<sup>137</sup> Durojaye and Balogun, "Human Rights Implications of Mandatory Premarital HIV Testing in Nigeria" *International Journal of Law Policy and the Family*, Vol 24:2 2010 p. 254-255.

<sup>138</sup> UN Human Rights Committee, General Comments 29, States of Emergency (article 4), UN Doc CCPR/C/21/Rev1/Add11, available at, <http://www.unm.edu/humanrts/gencomm/hrc29.htm> (accessed 12 March 2012).

servitude; and freedom of thought, conscience and religion.<sup>139</sup> These rights are absolute and international law does not allow their limitation under any circumstance. This is a pointer that there are certain categories of rights which should be more respected because of their importance to the protection of individuals as human beings.

In line with the general requirements of international human rights laws, Childress *et al.* define effectiveness, proportionality, necessity, least infringement, and public justification as the “justificatory conditions” for addressing the impacts of public health policies on human rights.<sup>140</sup> Working from the above theoretical formulation of Childress et al., Durojaye points out that under *effectiveness*, any public health policy which may impact on human rights must be ascertained to be truly protective of public health. As regards *proportionality*, this relates to the fact that the benefits to be derived from the proposed public health policy must outweigh its implications for the deprivation of rights. *Necessity* demands that a proposed public health policy, which may infringe a general moral consideration, could be a strong reason for seeking an alternative to such policy. Durojaye clearly states that even if a public health policy is effective, proportionate and necessary, it is the duty of the policy makers to seek to minimize infringement of human rights by reason of such policy. Where public health policies infringe multiple human rights, it becomes imperative that policy makers should justify to the public the reasons why such policies should still be pursued despite their negative consequences on human rights.<sup>141</sup>

It is inevitable that some tension will emerge between public health and human rights approaches to promoting human well-being. In spite of the importance attached to individual rights, situations arise in which it is considered legitimate to limit certain individual rights in order to achieve the broader public good.<sup>142</sup> This concept of public good is described in general terms in the International Covenant on Civil and Political Rights. The public good takes precedence over individual rights:<sup>143</sup>

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<sup>139</sup> See Lasker footnote 96 above.

<sup>140</sup> Childress, “Public Health Ethics: Mapping the Terrain”, *Journal of Law Med and Ethics* Vol 30:2, 2002 p.173.

<sup>141</sup> The Framework was developed by Gruskin and Tarantola for analyzing the impact of public health policies on human rights. Gruskin and Tarantola, “*Health and Human Rights*”, Oxford Text on Public Health 2001, p. 311-335.

<sup>142</sup> Durojaye and Balogun, footnote 137 above, p. 254-255.

<sup>143</sup> International Covenant on Civil and Political Rights (ICCPR) of 1966.

- to secure due recognition and respect for the rights and freedoms of others;
- to meet the just requirements of morality, public order, and the general welfare; and
- in times of emergency, where there are threats to the vital interests of the nation.

Jonathan Mann postulates that human rights are of paramount importance and should not be disregarded at all costs and that a balance should always be maintained between individual and community rights. The idea he exposes is that despite their different approaches, assumptions and language, public health and human rights goals and work can contribute positively to human rights objectives, and vice versa. It is interesting to note that these writers acknowledge the fact that, given the importance of health, it is not surprising that public health is considered a valid reason for limiting rights under some circumstances. However, any limitation of individual rights is a serious issue, regardless of the apparent importance of the public good involved. When a government limits the exercise or enjoyment of a right, this action must be a last resort, and should be permitted only when several specific and stringent conditions are met.<sup>144</sup> These stringent conditions as laid down by Jonathan Mann include:

- The goal of limiting rights may not be contrary to the purposes and principles of the United Nations Charter.
- The limitation must be justified by the protection of a legitimate goal such as national security, public safety and protection of public health or public order.
- Limitations can be allowed only in a democratic society which presumes a participatory decision-making process and a capacity for redress.
- A right may be restricted only if the limitation is provided for by the law.
- The limitation of rights must be strictly necessary in order to achieve the public good, which must be carefully assessed on a case by case basis.
- The limitation of individual rights must be proportional to the public interest and its objective (the so called proportionality test).
- The limitation must be the least intrusive and the least restrictive measure available which will accomplish the public health goal.

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<sup>144</sup> See Mann et al footnote 103, p. 47.

- The limitation of rights must not be applied in a discriminatory manner.

The points above emphasize a cardinal principle, namely, society will best be served by maximum realization of both human rights and public health goals. Nevertheless, a systematic approach is clearly needed to explore and negotiate the potential tensions between human rights and public health policies, programmes and practices.<sup>145</sup>

## **2.4 Conclusion**

In summation it is clear that society will best be served by maximum realization of both human rights and public health goals. Public health and human rights share a complex relationship which can only be simplified by treating these two components as complementary through respect of fundamental human rights and promotion of public health policies. In essence the two concepts are, as it were, two faces of the same coin; they have to be treated or confronted together as a single problem requiring a single solution.

Compulsory and VCT testing and counselling both have their advantages and disadvantages as highlighted above. It can, however, be concluded that VCT is more applicable in Africa, due to the shortage of anti-retroviral therapy. It is a futile exercise to increase the number of people who test positive for HIV/AIDS without, firstly, preparing them for the stigma and discrimination which might follow and, secondly, giving them the treatment that they need for the future, that is, a continuous supply of antiretroviral therapy. Mandatory testing which, at first blush, might appear necessary to protect the interests of the community, may well jeopardize prevention opportunities rather than produce the desired effect. Mandatory HIV testing inevitably runs up against the gender dimensions of the pandemic. The subordinate status of girls and women fuels the spread of HIV /AIDS. Girls and women are often blamed for bringing the virus into the house and, as such, they suffer from violence or discrimination of various kinds upon disclosing their HIV

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<sup>145</sup> *Ibid*, p. 48.

status.<sup>146</sup> To prevent this, voluntary testing, confidentiality and anti-discrimination measures must be preferred over compulsory testing.

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<sup>146</sup> Canadian HIV/AIDS Legal Framework, “Outcomes of the Symposium on HIV Testing and Human Rights” 2005, available at, <http://www.genderhealth.org/pubs/testing.pdf>, (accessed 18 August 2012).

## CHAPTER 3: INTERNATIONAL AND REGIONAL INSTRUMENTS THAT HAVE A BEARING ON HUMAN RIGHTS AND HIV/AIDS

### 3.1 Introduction

*“Human Rights and fundamental freedoms are the birth-right of all human beings.”<sup>1</sup>*

It is the paramount objective of human rights law, both national and international, to seek to protect individuals from the suffering inflicted on them through deprivation, exploitation, oppression, persecution, and other forms of maltreatment by organized and powerful groups of other human beings.<sup>2</sup> HIV continues to spread throughout the world, shadowed by increasing challenges to human rights, at both national and global levels. The virus continues to be marked by discrimination against population groups: those who live on the fringes of society or who are assumed to be at risk of infection because of risky behaviour, or race, ethnicity, sexual orientation, gender, or social characteristics that are stigmatised in a particular society.<sup>3</sup> It is, however, critical to analyse the impact of international law on HIV/AIDS. International, regional and SADC (Southern African Development Community) frameworks are important as they form the backdrop against which the national framework of South Africa should be considered.

Since 1948, human rights have been accepted and expressed in a plethora of international instruments and this has contributed to the development of substantive international human rights law, and, undoubtedly, raised public awareness and extended protection to individuals.<sup>4</sup> General human rights instruments apply to all individuals or certain groups of individuals because of their particular vulnerability and, therefore, they have been identified as needing additional protection. However lip service to human rights principles by governments is not sufficient and leads only to cynicism and derision of international human rights norms.<sup>5</sup> The greatest challenge that is prevalent in most African countries is the implementation of these principles.

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<sup>1</sup> Vienna Declaration and Programme of Action, 1993 para 1.

<sup>2</sup> Sieghart *The International Law of Human Rights*, Clarendon Press Oxford, 2003 p. 2.

<sup>3</sup> Gruskin, “Human Rights and HIV/AIDS”, Francois-Xavier Bagnoud Center for Health and Human Rights Harvard School of Public Health 2002, available at, <http://hivinsite.ucsf.edu/InSite?page=kb-08-01-07>, (accessed 15 March 2011).

<sup>4</sup> Wallace, Dale, *International Human Rights Text and Materials*, London Sweet and Maxwell, 2001.

<sup>5</sup> International Symposium on, the Ethics of State Involvement in Woman’s Health, University of California 2010 p. 2.

The other side of the coin which is discussed in this chapter is the importance of bringing HIV/AIDS policies and programmes in line with international human rights law. This is generally acknowledged but in reality rarely practised. It is also apparent that few international human rights instruments contain specific provisions relating to HIV/AIDS. What is intriguing is the fact that most of these instruments or treaties do not specifically mention HIV/AIDS or the rights of individuals affected by HIV/AIDS, yet all international human rights mechanisms responsible for monitoring government action have expressed their commitment to exploring the implications of HIV/AIDS for government.<sup>6</sup> It should be understood that the HIV pandemic should not only be seen as a medical problem, but also as a problem that cuts across gender, development and human rights. Therefore, HIV/AIDS should be clarified and addressed in plain language in international and regional human rights instruments.

In the 1980s, the relationship between HIV/AIDS and human rights was only understood as it involved people infected with HIV and with AIDS and the discrimination to which they were subjected. For HIV infected people and people with AIDS, the concerns included mandatory HIV testing; restrictions on international travel; barriers to employment and housing; and access to education, medical care, and health insurance. Other issues that rose related to names reporting, partner notification and confidentiality.<sup>7</sup> Sofia Gruskin states that almost 20 years into the epidemic, these issues have not washed away and, in some cases, they have become even more complicated. Old issues appear in new places or present themselves in different and new different ways. Mary Crew postulated that:<sup>8</sup>

HIV and AIDS has brutally exposed all the fault lines of our society, poverty gender inequality, violence, lack of access to education, healthcare, social service as well as the importance of employment and social security.

For example, in certain settings, access to employment has continued to be routinely denied to people infected with HIV. Even in places where this situation has improved, HIV infected individuals now run the risk of finding themselves excluded

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<sup>6</sup> *Ibid.*

<sup>7</sup> See Gruskin footnote 3 above.

<sup>8</sup> Statement by Mary Crew, Director of the Centre for the study of AIDS at the University of Pretoria during her presentation at the AIDS democracy development and Human Rights given at the stakeholder consultation on Gender, Human Rights and HIV/AIDS: A UNDP-OHCHR Joint Initiative for Southern and Eastern Africa, Rosebank Hotel, Johannesburg 27-29 June 2006.

from work place health insurance schemes, resulting in a considerable impact on their health and, therefore, on their capacity to work. The 1980s were extremely important in defining some of the connections between HIV/AIDS and human rights. A pertinent question that can be raised is whether presently these human rights are still protected under international law. Furthermore, is international law clear as to the extent of protection needed for advancing the rights of people living with HIV/AIDS? As a result of the lack of uniform and specific rules or norms relating to HIV/AIDS, it is clear that problems that have human rights implications keep spiralling and escalating. Presently, there are large and growing disparities and inequities regarding access to antiretroviral therapies and other forms of treatment and care.<sup>9</sup>

The legal status of the human rights instruments varies. Declarations, principles, guidelines, standard rules and recommendations have no binding legal effect, but such instruments have an undeniable moral force and provide practical guidance to the conduct of states. Statutes, protocols and conventions are legally binding for those states that ratify or accede to them. The international community is said to have failed unequivocally to recognise HIV as the human right that it is. International assistance is often short term and tied to conditions that run counter to responsible HIV management and intervention programmes.<sup>10</sup>

### **3.2 Historical Background of the Human Rights Law**

The international system for the protection of human rights grew out of international revulsion at the atrocities committed during World War II.<sup>11</sup> In the nineteenth century, international law developed a doctrine of the legitimacy of 'humanitarian intervention' in cases where a state committed atrocities against its own subjects which 'shocked the conscience of mankind' and this provided a limited exception to the doctrine of national sovereignty.<sup>12</sup> This principle was invoked largely against the Ottoman Empire in 1827 on behalf of the Greek people; by France in Syria in 1860-1; and again in 1876 when around 12000 Christians were massacred by irregular Ottoman

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<sup>9</sup> Tarantola, "Risk and Vulnerability reduction in the HIV/AIDS pandemic", *Current Issues in Public Health* 1995.

<sup>10</sup> Some countries have tied funding to the condition of non-discussion of condom usage, a concept nearly impossible to eliminate from any reasonable and responsible prevention strategy.

<sup>11</sup> See Sieghart footnote 2 above, p. 2.

<sup>12</sup> *Ibid.*



troops in what is today Bulgaria. By invoking the doctrine of humanitarian intervention in public and parliamentary speeches, the British Liberal politician, Gladstone, succeeded in promoting a foreign policy designed to support the freedom of the people of Bulgaria.<sup>13</sup> Following the First World War, Minority Treaties were concluded with the new League of Nations as a guarantor which sought to protect the rights of linguistic and ethnic minorities within the new state territories created by the Treaties of Versailles and St Germain, and these may be seen as the precursors of modern international human rights instruments.<sup>14</sup>

The same period saw the beginning of international collaborations in a number of specific 'humanitarian' fields. The abolition of national slavery and the international slave trade began to be pursued from the early part of the nineteenth century, and by 1885 the General Act of the Berlin Conference on Africa was able to affirm that trading in slaves is forbidden in conformity with the principles of international law.<sup>15</sup> Later through the influence of the Red Cross movement, international treaties ('The Hague Conventions', and ultimately the 'Geneva Conventions') were adopted in order to limit the suffering caused by wars, and to regulate the treatment of prisoners of wars.<sup>16</sup>

The International Labour Organisation (ILO) was established in 1919, and soon began to promote a succession of international conventions designed to protect industrial workers from gross exploitation, and to improve their working conditions.<sup>17</sup> The League of Nations took a continuing interest in humanitarian matters and certain

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<sup>13</sup> Scheffer, "Towards a Modern Doctrine of Humanitarian Intervention", 23 *Tol Law Review* 253, 1999, available at, [http://www.heionline/backup.com/hol-cgi/bin/get\\_pdf](http://www.heionline/backup.com/hol-cgi/bin/get_pdf), (accessed on 04 April 2012).

<sup>14</sup> Article 4 of the German–Polish Convention on upper Silesia of 1922 (this broke new ground in guaranteeing rights of individuals including, the rights to life, liberty, and the right to free exercise of religion, and equal treatment before the law even against states whose own nationals they were. Sieghart points out that A Pole and Czech were the first private individuals in the history of international law to establish personal rights against a state as a result of this treaty: *Steiner and Gross v The Polish State*, Upper Silesian Arbitral Tribunal, Cases Nos.188 and 287, Annual Digest 1927, p. 8.

<sup>15</sup> The General Act of the Berlin Conference on Central Africa of 1885.

<sup>16</sup> See Sieghart footnote 2 above, p. 13.

<sup>17</sup> Sieghart again postulates that even before the formal establishment of the ILO, two multilateral labour conventions were concluded in Berne and Switzerland in 1906, one against night work by women and the other against the use of white phosphorus in the manufacture of matches.

aspects of human rights. The first true international human rights treaty, the Slavery Convention, was adopted in 1926 and entered into force in the following year.<sup>18</sup>

When the Second World War ended, the victorious nations determined to introduce into international law new concepts designed to outlaw such events for the future, in order to make their recurrence at least less probable.<sup>19</sup> The means adopted were the establishment of new intergovernmental organizations such as the United Nations, the Council of Europe and the organisation of American States, and the development within those institutions of a new branch of international law, specifically concerned with the relations between governments and their subjects. The post second world-war human rights movement permanently altered the scope of international law.<sup>20</sup> It pierced the veil of national sovereignty and elevated human rights as a matter of international concern.

### **3.3 An Overview of the Applicable International and Regional Norms**

HIV is truly a global issue. As of the end of 2011, approximately 34.0 million people were living with HIV and each year 2.5 million more people become infected with it.<sup>21</sup> In every corner of the world, people living with HIV face the obstacles of obtaining health care, overcoming stigma, ensuring confidentiality, and enjoying equal rights. Because HIV knows no borders, the response to these obstacles must also be global in its scope, entailing international institutions, national governments, regional bodies, and networks of community advocates to participate in the fight to combat this pandemic.

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<sup>18</sup> Office of the United Nations High Commissioner for Human Rights, "Slavery Convention", available at, [http:// www2.ohchr.org/english/law/slavery.htm](http://www2.ohchr.org/english/law/slavery.htm), (accessed on 22 May 2012).

<sup>19</sup> The landmarks in the movement were, the Atlantic Charter of 14 August 1941, with its call for freedom from fear and want; The Declaration of 1 January 1942 by the 26 'United Nations' then fighting the Axis powers, to the effect ' that complete victory over their enemies is essential to defend life, liberty, independence and religious freedom , and to preserve human rights and justice upon their lands as well as in other lands; and the Dumbarton Oaks Proposals in 1944 for the establishment of the UN which would, among other things, 'promote respect for human rights and fundamental freedoms', the phrase to which the San Francisco conference of the following year added the words,...for, all, without distinction as to race, sex, language or religion.'

<sup>20</sup> Gostin and Lazzarini " *Human Rights and Public Health in the AIDS Pandemic* Oxford 1997.

<sup>21</sup> UNAIDS Report on the Global Epidemic 2012, available at, [http://www.unaids.org/documents/20101123\\_globalreport\\_em.pdf](http://www.unaids.org/documents/20101123_globalreport_em.pdf), (accessed 22 May 2012).

### 3.3.1 Universal Declaration of Human Rights

The Universal Declaration of Human Rights which was adopted in 1948<sup>22</sup> was built upon the UN Charter's promise by identifying rights and freedoms that deserve promotion and protection. The Universal Declaration of Human Rights (hereinafter referred to as the UDHR) is the cornerstone of the modern human rights movement. The preamble to the UDHR states: "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." The UDHR considered the attainment of "social progress and better standards of life," including the prevention of "barbarous acts which have outraged the conscience of mankind," and, broadly speaking, individual and collective well-being, as dependent upon the "promotion of universal respect and observance of human rights. Although the UDHR is not a legally binding document, states have endowed it with great legitimacy through their actions, including its legal and political invocation at the national and international levels.<sup>23</sup> Health and human rights stakeholders, together with state governments, have a responsibility to ensure that HIV/AIDS issues are codified in these documents.

The adoption of the UDHR gave birth to a treaty-based system of promoting human rights and was followed two decades later by the adoption of the International Bill of Rights (The International Covenant on Civil and Political Rights and the International Covenant on Economic, Social, and Cultural Rights)<sup>24</sup> which forms the backbone of the international human rights law. The right to health is guaranteed in the UDHR. Art 25 states that:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack

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<sup>22</sup> The Universal Declaration of Human Rights was adopted by the U.N. General Assembly on December 10, 1948.

<sup>23</sup> Mann; Gruskin; Grodin; Annas; *Health and human rights*, Routledge New York and London 1999 p. 9.

<sup>24</sup> The two Covenants entered into force in 1976. These Covenants share certain substantive common protection namely the right of self-determination (Art 1) and prohibition of discrimination (Art 2).

of livelihood in circumstances beyond his control also protected in this international instrument.<sup>25</sup>

The UDHR has largely fulfilled the promise of its preamble in that it has become the common standard for evaluating respect for human rights. Although it was not promulgated to be legally binding on member states, its key provisions have often been accepted and applied by member states and they are widely considered to have attained the status of customary international law and also further incorporated in subsequent international instruments, thereby providing a standard by which to measure the conduct of states.<sup>26</sup>

### 3.3.2 *International Covenant on Economic, Social and Cultural Rights*

The International Covenant on Economic, Social and Cultural Rights (the “ICESCR”) together with<sup>27</sup> the International Covenant on Civil and Political Rights (ICCPR), and the Universal Declaration of Human Rights constitute what is collectively referred to as the International Bill of Rights.<sup>28</sup> The ICESCR outlines universal economic, social and cultural rights; particularly relevant among them to HIV/AIDS is the right to the highest attainable standard of health.<sup>29</sup> This ICESCR further requires states to take the necessary steps to achieve the realisation of this right, which simply means that states have the obligation to incorporate health issues in their national legislations.<sup>30</sup>

The wording of the above provision clearly states that everyone has a right to the *highest attainable standard of health*, which means that health is of paramount importance and it should be respected. General Comment No14<sup>31</sup> further elaborates on the content of the right to health by explaining that it includes,

the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health and a

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<sup>25</sup> Article 25 of the UDHR.

<sup>26</sup> Dugard *International Law: A South African Perspective* Juta and Company 2005 p. 314-315.

<sup>27</sup> International Covenant on Economic, Social and Cultural Rights (ICESCR) which was adopted in 1966 and entered into force in 1976.

<sup>28</sup> International Covenant on Civil and Political Rights (ICCPR) of 1966.

<sup>29</sup> ICESCR Article 12.

<sup>30</sup> ICESCR Article 12(2).

<sup>31</sup> Committee on Economic, Social, and Cultural Rights General Comment 14 para 8 and 9, Twenty-Second Session, Geneva, 25 April to 12 May 2000, 11/08/2000 E.C. 12/2000/4.

right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable level of health.

General Comment No 14 further underlines that the right to health includes access to health related education and information, including education and information on sexual reproductive health.<sup>32</sup>The International Guidelines on HIV/AIDS and Human Rights specify that state obligations under the right to health include “ensuring access ... to voluntary and confidential testing with pre-test and post-test counselling”.<sup>33</sup> Clearly these guidelines advocate for more awareness and education about HIV/AIDS, including testing, treatment and prevention. Public health issues are sometimes advanced as justifications to limit the right to health, but the Covenant’s limitation clause is intended for the opposite purpose, that is, to protect the rights of individuals.<sup>34</sup>

As a convention, the ICESCR is binding on all parties that ratify it; those who sign but do not ratify are obligated not to act contrary to the object and purpose of the convention as stipulated under Article 18 of the Vienna Convention on the Law of Treaties of 1969. Like the ICCPR, parties to the ICESCR are obligated to make periodic reports on their compliance with the convention to the Committee on the Implementation of Economic, Social and Cultural Rights. The Committee also prepares “General Comments” interpreting the ICESCR and exchanging general views on the implementation of the rights under the ICESCR.

The ICESCR also has a support organ which is the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights which is an international treaty establishing a complaint and inquiry mechanism for violation of the rights under the Covenant.<sup>35</sup> The Protocol also includes an inquiry mechanism and parties may permit the Committee to investigate, report on, and make recommendations on "grave or systematic violations" of the Convention. Parties may opt out of this obligation upon signature or ratification.<sup>36</sup> The Optional Protocol to ICESCR allows victims of violations of ESCR to present complaints before a United

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<sup>32</sup> The right to the highest attainable standard of health 11/08/2000 E.C.12/2004 General Comments para 11.

<sup>33</sup> General Comment 14 para.144.

<sup>34</sup> The right to the highest attainable standard of health 11/08/2000 E.C.12/2004 General Comment 14 para 28.

<sup>35</sup> It was adopted by the UN General Assembly on 10 December 2008.

<sup>36</sup> ICESCR Article 11.

Nations body against a state that violates the obligations established in the Covenant if the state has ratified this protocol.<sup>37</sup>

It has, however, been observed that there are serious obstacles in the implementation of economic, social and cultural rights.<sup>38</sup> It is contended that there is lack of conceptual clarity and vagueness in most of its provisions, particularly those relating to the international human right to health.<sup>39</sup> To start with, this provision has definitional problems as well as problems of implementation. It has been contended that there is confusion and disagreement over what is the most appropriate term to address health as a human right. Various terms have been used which include: “the right to health;” the “right to healthcare” or to “medical care;” and, to a lesser extent, the “right to health protection.”<sup>40</sup> However, at the international level, the term “right to health” is commonly used as it best matches the international human rights treaty provisions that formulated health as a human right.<sup>41</sup> John Hopkins provides that the term “healthcare” would accordingly not cover this broader understanding of health as a human right. In practice, the term “right to health” is generally used as a shorthand expression for the more elaborate treaty texts.<sup>42</sup> It can be further noted that the use of such shorthand expressions is rather common in human rights discourse; terms such as the right to life, privacy, a fair trial and housing have observed a very specific practical connotation, as has the right to health.<sup>43</sup>

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<sup>37</sup> International Network for Economic, Social and Cultural rights, “Resource page on the Optional Protocol to ICESR”, available at, <http://www.escr-net.org/docs/i/431553>, (accessed on 06 January 2013).

<sup>38</sup> Jackson, “The Liemburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights”, *Human Rights Quarterly*, Vol 9:2, 1987 p. 122-135.

<sup>39</sup> Miller; Mindy; and Friedmen, “Sexual Health and Human Rights, United States and Canada”, 2010, available at, [http://www.ichrp.org/140\\_Miller\\_Rosemary\\_Friedman\\_uscan\\_2012/pdf](http://www.ichrp.org/140_Miller_Rosemary_Friedman_uscan_2012/pdf) (accessed on 18 April 2012).

<sup>40</sup> The right to healthcare is often used in discussions on access to healthcare services at the national level, Article 11 of the European Social Charter (ESC) stipulates the “right to protection of health.” The term “right to health security” has recently been applied by WHO. See World Health Organisation, “The right to Health Security as a basic Human Right: A Preliminary Analysis (draft)” 1996. The term also “health rights” is occasionally used. See, e.g., Tomasveski, *Health Rights in Economic, Social and Cultural Rights*, Oxford 1995 p. 125-43.

<sup>41</sup> John Hopkins in his article comments that the Provisions in International Conventions do not only proclaim a right to healthcare but also a right to other services such as environmental health protection and occupational health services.

<sup>42</sup> Leary, ‘Implications of the Right to Health’ in Mahoney and Mahoney(eds) *Human Rights in the Twenty-First Century: A Global Challenge*, Martinus Nijhoff Publishers, Dordrecht/Boston/London 1993, p. 481-485.

<sup>43</sup> *Ibid.*

There is also no doubt that the right to health (care) has been codified in most international provisions as presented in this chapter. Similarly, most constitutions, including the South African Constitution of 1996, have also made provisions for the right to health.<sup>44</sup> Constitutions of most African countries further stipulate or impose on states duties with regard to the health of their people. After a close analysis, it is apparent that the problem is clearly not arising from lack of codification of the right to health but,

rather an absence of a consistent implementation practice through reporting procedures as well as before judicial and quasi-judicial bodies, as well as lack of conceptual clarity. These problems are interrelated: a lack of understanding of the meaning and scope of a right makes it difficult to implement it, and the absence of a frequent practice of implementation in turn hampers the possibility of obtaining a greater understanding of its meaning and scope.<sup>45</sup>

The use of rights language in connection with health has led to controversy in the United States, despite its acceptance internationally. Furthermore, whereas the concept of a right to health care is more specific and more readily understood than the right to health, the use of this more specific phrase has also been criticized.<sup>46</sup> For example, a recent publication entitled *The Right to Health Care* contains a number of chapters by philosophers and economists, some favouring the concept of the right to health care and some opposing it as rhetorical, lacking in specificity and diversionary from real problems of medical care.<sup>47</sup> There is thus a variation in the manner in which the right to health is interpreted and applied due to considerations such as how health is defined, what minimum entitlements are encompassed in a right to health, and which institutions are responsible for ensuring a right to health.

### 3.3.3 *International Covenant on Civil and Political Rights (ICCPR)*

The ICCPR has indirect linkages to health.<sup>48</sup> The ICCPR enshrines rights which are indirectly linked to the enjoyment of the right to health and includes the right to non-discrimination in Articles 2 and 3. Article 2 however specifically provides for non-

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<sup>44</sup> Section 27, The South African Constitution of 1996.

<sup>45</sup> See John Hopkins in Leary, footnote 42 above.

<sup>46</sup> Leary, "The right to Health in International Law", *Health and Human Rights Journal*, Vol1:1, 1994.

<sup>47</sup> Thomas; Bole; William; Bondeson, *Rights to Health Care*, Dordrecht: Kluwer Publishers 1991.

<sup>48</sup> The International Covenant on Civil and Political Rights (ICCPR) of 1966.

discrimination in respect of race, color, sex, language, religion, political opinion, national or social origin, property, birth or other status. Article 3 gives state parties the duty to ensure equal enjoyment of civil and political rights by men and women. The right to life is also postulated in Article 6(1) which states, “Everyone human being has the inherent right to life and this right shall be protected by law and no one shall be arbitrarily deprived of his life”. The Human Rights Committee states that Article 6 of the ICCPR creates positive obligations on states to protect life. Further, “the Committee considers that it would be desirable for State parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially by adopting measures to eliminate malnutrition and epidemics.”<sup>49</sup>

The right to health is also laid out in the Special Rapporteur of the Commission on Human Rights (now the Human Rights Council)<sup>50</sup> on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. It deals exclusively with the right to health for everyone, independent of whether a state is a party to a human rights treaty that incorporates the right to health or not. This clearly points to the fact that the right to health is a norm that has to be respected world-wide as it is an important component of the entire human race.

State parties to the ICCPR are obliged to guarantee that any person whose rights under the convention are violated shall have an effective remedy determined by a competent authority provided by the legal system of the state, and that the state will develop the possibilities of a judicial remedy. State parties also undertake to ensure that the competent authorities shall enforce such remedies when granted.<sup>51</sup> As a convention, the ICCPR is binding on all parties that ratify it; those who sign but have not ratified it are obliged not to act contrary to the purpose and objective of the convention as stipulate under Article 18 of the Vienna Convention in the Law of Treaties, 1969. Article 40 of the ICCPR requires state parties to submit reports on the national human rights situation every five years which are studied and commented on by the Human Rights Committee. Article 41 establishes an optional procedure by which states grant other states the right to bring a complaint against

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<sup>49</sup> General Comment No 6 on the Right to Life, para 5 and 6.

<sup>50</sup> The United Nations Commission on Human Rights has been replaced by the United Nations Human Rights Council as per United Nations General Assembly resolution A/RES/60/251 adopted on 15 March 2006. The Commission on Human Rights ceased to exist on 16 June 2006, see Press Release at <http://www.un.org/News/Press/docs/2006/ecosoc6192.doc.htm>.

<sup>51</sup> ICCPR Article 2 (3) (a) - (c).



them before the Committee alleging that a violation of the convention has been committed.

There is also an Optional Protocol which allows individuals who are victims of violations of ICCPR to present complaints before the Committee alleging that a state party has violated their rights. The United States is a party to the ICCPR, but not to the Optional Protocol, and has made several “reservations” that purport to exclude or modify the legal effect of certain provisions of the treaty as they apply to the USA. However, the validity of some of these reservations is subject to debate; many states objected to the reservations as contrary to the ‘object and purpose’ of the ICCPR. A dispute arose regarding the legal effect of reservations made by several states to the United Nations Convention on the Prevention and Punishment of the Crime of Genocide of 1948.<sup>52</sup> The General Assembly requested the International Court of Justice to rule on whether a reservation made either on ratification or on accession, or on signature followed by ratification, the reserving State may be regarded as being a party to the Convention while still maintaining its reservation, if the reservation is objected to by one or more of the parties to the Convention but not by others.<sup>53</sup> The court submitted that in its treaty relations a State cannot be bound without its consent, and that consequently no reservation can be effective against any state without its agreement thereto.

Further the court highlighted that it is a generally recognized principle that a multilateral convention is the result of an agreement freely concluded between parties. Consequently none of the contracting parties is entitled to frustrate or impair, by means of unilateral decisions or particular agreements, the purpose and *raison d’être* of the convention. To this principle was linked the notion which, in its traditional concept, involved the proposition that no reservation was valid unless it was accepted by all contracting parties without exception, as would have been the case if it had been stated during negotiations.<sup>54</sup> The Court observed that this question refers not to the possibility of making reservations to the Genocide Convention, but solely to the question whether a contracting state which has made a reservation can,

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<sup>52</sup> United Nations Convention on the Prevention and Punishment of the Crime of Genocide of 1948.

<sup>53</sup> Reservations to the Convention on Genocide, International Court of Justice, Advisory Opinion 1951 I.C.J. 15.

<sup>54</sup> Reservations to the Convention on the Prevention and Punishment of the Crime of Genocide, International Court of Justice May 28 1951, General List No. 12.

while still maintaining it, be regarded as being a party to the Convention, when there is a divergence of views between the contracting parties concerning this reservation, others refusing to accept it.

The international and regional human rights treaties examined do not include any HIV/AIDS specific provisions. Nevertheless, a number of articles can be highlighted in the various treaties as they indirectly impact on people living with HIV/AIDS or their families. For instance, the *International Covenant on Economic, Social and Cultural Rights (ICESCR)* affirms that state parties to the Covenant should recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.<sup>55</sup> The Covenant further obliges state parties, in order to achieve this right, to take measures to prevent, treat and control epidemic, endemic, occupational and other diseases.<sup>56</sup> These provisions clearly apply to those infected with and affected by HIV/AIDS.

Nevertheless, specific provisions of these treaties may be applied to various legal situations affecting people living with or affected by HIV/AIDS. The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) is similar, having been adopted in the early days of the epidemic.<sup>57</sup> The Convention on the Rights of the Child (CRC), however, was adopted in 1989, nearly ten years after the first reported case of HIV/AIDS.<sup>58</sup> The fact that in the CRC no mention is made of HIV/AIDS with respect to children can be viewed as a missed opportunity to develop policy specific to this vulnerable group.

### 3.3.4 The World Health Organisation

A number of human rights treaties recognize the right to the “highest attainable standard” of health.<sup>59</sup> Health is recognised as a human right by the WHO in the preamble of its constitution where it is stated that the attainment of the highest standard of physical and mental health is a fundamental right of everyone.<sup>60</sup> The right to health cannot, however, be enjoyed in isolation from other rights; it is dependent on rights such as the right to life, dignity of a person, freedom from

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<sup>55</sup> Article 12(1) of the ICESCR.

<sup>56</sup> Article 12(2)(c).

<sup>57</sup> The Convention on the Elimination of All Forms of Discrimination against Women of 1979.

<sup>58</sup> The Conventions on the Rights of the Child of 1989.

<sup>59</sup> World Health Organisation of 1945.

<sup>60</sup> The Constitution of the World Health Organisation (WHO) adopted in 1945.

inhuman and degrading treatment, liberty and non-discrimination. Conversely, a violation of the right to health may have an impact on other rights such as life, human dignity, privacy, liberty and non-discrimination.<sup>61</sup>

The “enjoyment of the highest attainable standard of health” has been recognised as a “fundamental right” by the international community since the adoption of the constitution of WHO in 1946.<sup>62</sup> The right to health is apparent in most human rights instruments as well as in state legislations. However,<sup>63</sup> there is no clarity in terms of the meaning and scope of the right to health, though presently the right to health as a human right is only gradually being clarified.<sup>64</sup> With the notable exceptions of an excellent study by the Pan American Health Organisation (PAHO)<sup>65</sup> and the conclusions of a workshop held at The Hague Academy of International Law,<sup>66</sup> there have been few serious efforts by international organisations or scholars to consider the scope of the right to health.<sup>67</sup>

The shorthand, “right to health”, emphasizes the link between health status with dignity, non-discrimination, justice and participation.<sup>68</sup> However, according to WHO, “the enjoyment of the highest standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”<sup>69</sup> It is, however, clear that women’s health affects everything. Discrimination against women in healthcare is characterized by a mortality rate for female infants which is generally higher than that for males, lower female life expectancy, a death rate which is higher partly due to very high maternal and mortality rates, and lower access to health care services. A violation of a woman’s right to health, including reproductive care, affects the ability of that woman to enjoy the highest standard of health care.

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<sup>61</sup> Durojaye; Balogun “Human Rights implications of Mandatory HIV testing in Nigeria”, *International Journal of Law, Policy and Family* Vol 24:2, 2010 p. 245-265.

<sup>62</sup> The Constitution of the World Health Organisation, in Basic Documents, Thirty-ninth Edition, 1992

<sup>63</sup> See Leary footnote 42 above, p. 25.

<sup>64</sup> *Ibid.*

<sup>65</sup> Hernan; Puelma; Connor, “The Right to Health in the Americas (Pan-American Health Organisation”, (eds) *A Comparative Constitutional Study*, Scientific Publication No. 509, Washington D.C. 1989.

<sup>66</sup> Dupay, “The Right to health as a Human Right to Health”, Workshop, the Hague Academy of International Law and the United Nations University 2008, p.73.

<sup>67</sup> See Leary footnote 42 above p. 26.

<sup>68</sup> *Ibid.*

<sup>69</sup> Preamble of the Constitution of the World Health Organisation.

In its Global Strategy for Health for All by the Year 2000, WHO provided guiding principles that a state should follow to achieve its most cost effective means of improving health status. Some cost-effective means for promoting health enumerated by WHO and public health experts include emphasis on preventive rather than curative and the adoption of primary health care as the basic orientation of health policy. All these general statements, however, must be converted into practical measures. A pertinent question that constantly surfaces is whether these provisions are effected in real life situations. Taking the HIV and AIDS situation as an example, it is without doubt that the focus is not on prevention but on cure. Mandatory HIV/AIDS testing is certainly not a preventative measure but rather a campaign to lure the general public to get treatment. It is thus clear that provisions adopted by international conventions as well as guidelines are not really put into practice.

Van Boven, on the other hand, noted that “Three aspects of the right to health have been enshrined in the international instruments on human rights: that is the declaration of the right to health as a basic human right; the prescription of standards aimed at meeting the health needs of specific groups of persons; and the prescription of ways and means for implementing the right to health.”<sup>70</sup> The author further contends that approaching health issues with a human rights perspective adds an important dimension to consideration of health status, especially in rural areas where there is inadequate access to health care services.<sup>71</sup>

### *3.3.5 The Convention on the Elimination of all Forms of Discrimination against Women*

The Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) addresses women’s rights within political, social, economic, cultural, and family life.<sup>72</sup> This was an attempt to rectify the effects of centuries of untold discrimination and inequality against women. In 1979 the General Assembly adopted CEDAW, entering into it forcefully in 1981. CEDAW prohibits private and public

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<sup>70</sup> *Ibid*, p.54 -55.

<sup>71</sup> Raissiguier ‘ Women from the Maghreb and Sub-Saharan Africa in France: Fighting for Health and Basic Human Rights’ in Nnaemeka and Ezeilo (eds) *Engendering Human Rights: Cultural and Socio-Economic Realities in Africa*, St Martin Press 2005, p. 147.

discrimination against women, and it outlaws discrimination against women in all spheres of society.<sup>73</sup>

Discrimination against women is a major problem in Africa. Women lack amenities such as access to adequate health care services, access to employment opportunities, land and educational opportunities. On the other hand, women face domestic violence when they wish to use condoms or notify their husbands that they are HIV positive. In studies conducted in sub-Saharan Africa and Southeast Asia, between 3.5 to 14.6 percent of women reported a violent reaction from their partner following disclosure of their HIV status and these reactions include blame, stigmatization, violence, abandonment and loss of support.<sup>74</sup> The International Guidelines on HIV/AIDS and Human Rights further recognize the need for:

a supportive and enabling environment for women...and other vulnerable groups by addressing underlying prejudices and inequalities through ... specially designed social and health services and support to community groups.<sup>75</sup>

They specifically recommended that, “legal and support services should be established to protect individuals from any abuses arising from HIV testing”.<sup>76</sup>

In its preamble CEDAW calls for state parties to overcome barriers of discrimination against women in areas of legal rights, education, employment, health care, politics, and finance, and sets benchmarks for accomplishing these goals. Particularly relevant to HIV/AIDS issues are: the definition of discrimination against women (Article 1); a mandate that states condemn discrimination in all its forms and ensure a legal framework that provides protection and embodies the principle of equality (Article 2); a mandate for the end of discrimination in employment, including the right to work, employment opportunities, equal remuneration, free choice of profession and employment, social security, and protection of health, including maternal health (Article 11); a requirement of steps to eliminate discrimination in health care, including access to family planning (Article 12); a focus on the unique problems that

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<sup>73</sup> CEDAW Article 12.

<sup>74</sup> Public Health Fact Sheet, “Women and HIV Testing policies, practices, and the impact on health and Human Rights”, 2008, available at, <http://www.soros.org/health>, (accessed 03 November 2012).

<sup>75</sup> The International Guidelines on HIV/AIDS and Human Rights, Guideline 8, para.60.

<sup>76</sup> *Ibid* para 38.

rural woman face in accessing health care and adequate living conditions (Article 14); and a requirement of steps to ensure equality in marriage and family relations, including the right to freely determine the number and spacing of children (Article 16).

On the other hand, WHO has provided an invaluable guide to women's right to health in its publication, *Human Rights in Relation to Women's Health: The promotion and Protection of Women's Health through International Human Rights Law*.<sup>77</sup> Cook also points out that a state's obligation to respect health may require both negative and positive action on its part. For instance, a state *should not* obstruct access to information regarding sources of HIV infection, but *should* undertake a public education programme to provide that information. Women's rights to freedom from discrimination, to survival, to liberty and security of the person, to family life and private life, and to education are all closely related to the realisation of the right to health and health care. The obligation to respect women's health is discussed in relation to the right to life. Cook points out that;

This right has traditionally been discussed only in the context of the obligation of states parties to ensure that courts observe due process of law before capital punishment is imposed. This understanding of the right to life is essentially male-oriented, since men assimilate the imagery of capital punishment as more immediate to them than death from pregnancy or labour. Feminist legal approaches suggest that this interpretation of the right ignores the historical reality of women, which persists in regions of the world from which almost all of the 500,000 women estimated to die each year from pregnancy-related causes.<sup>78</sup>

### 3.3.6 *The Convention on the Rights of the Child (CRC)*

The Convention on the Rights of the Child is an international treaty that discusses many of the rights of children, some of which are also enjoyed by adults. Provisions particularly relevant to HIV/AIDS issues are: the right to life and corresponding obligation of the state to ensure to the maximum extent possible the survival and

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<sup>77</sup> The World Health Organisation/DGH/93.1, Geneva, 1993.

<sup>78</sup> *Ibid.*

development of the child.;<sup>79</sup> the right to the highest attainable standard of health, including preventative health care; guidance for parents, and family planning education and services is also provided for in Article 24. The latter provision is also supported by Article 14 of the African Charter on the Rights and Welfare of the Child which guarantees that “*Every Child shall have the right to enjoy the best attainable state of physical, mental and spiritual health.*”<sup>80</sup>

States are also obliged to respect and ensure the rights in the CRC without discrimination of any kind, irrespective of the child’s or his or her parent’s disability.<sup>81</sup> The ‘best interests of the child’ must be a primary consideration in all actions concerning children. The principle of ‘the best interests of the child’ is set out in the United Nations Convention on the Rights of the Child. The Convention explains that in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, ‘the best interests of the child shall’ be a primary consideration.<sup>82</sup>

Moreover, Article 3 obliges states to ensure that the child has such protection and care as is necessary for his or her well-being, and to ensure that institutions, services, and facilities responsible for the care or protection of the child conform to the standards established by competent authorities, particularly in the area of safety and health. As a treaty, the CRC is binding on all parties that ratify it. Under the CRC, state parties must submit periodic reports to the Committee on the Rights of the Child detailing their progress in upholding the treaty’s provisions. CRC is the most ratified of all the United Nations Human Rights treaties Canada signed the Convention on May 28th, 1990 and ratified the Convention on December 13th, 1991.

Uganda ratified this convention in 1990 but went a step ahead in 1996 and domesticated the CRC by enacting a law for children, the Children Statute, now the Children Act (Cap 59) of the Laws of Uganda. To further strengthen the protection of children, Uganda also ratified the Optional Protocol to the CRC on the Sale of

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<sup>79</sup> Article 6 of the Convention on the Rights of a Child of 1989.

<sup>80</sup> The African Charter on the Rights and Welfare of the Child, adopted and opened for signature, ratification and accession on 20 November 1989 and entered into force, *November 29 1999*.

<sup>81</sup> Article 2 of the African Charter on the Rights and Welfare of the Child.

<sup>82</sup> Article 3.

Children, Child Prostitution and Child Pornography on 19<sup>th</sup> August 2002.<sup>83</sup> The CRC was the first international convention to be ratified by South Africa and its provisions have been incorporated in the Children's Act No 38 of 2005.

The United States has signed but not ratified the CRC, although the United States, alongside Somalia which has also not ratified it, played an active role in the drafting of the Convention. It has been claimed that opposition to the Convention stems primarily from political and religious conservatives such as that of the Heritage Foundation which sees it as threatening national control over domestic policy.<sup>84</sup> The Home School Legal Defence Association (HSLDA) argues that the CRC threatens home schooling.<sup>85</sup> David Smolin argues that Article 29 limits the fundamental right of parents and other stakeholders to educate children in private schools by requiring that all such schools support the principles contained in the United Nations Charter and a list of specific values and ideals. He argues that the Supreme Court case law has provided that a combination of parental rights and religious liberties provide a broader right of parents and private schools to control the values and curriculum of private education free from state interference.<sup>86</sup>

The Committee drew state parties' attention to the particular challenges of early childhood HIV/AIDS infections. All necessary steps should be taken to: (i) prevent infection of parents and young children, especially by intervening in chains of transmission between father and mother and from mother to baby; (ii) provide accurate diagnosis, effective treatment and other forms of support for both parents and young children who are infected by the HIV virus (including antiretroviral therapies); and (iii) ensure adequate alternative care for children who have lost parents or their primary caregivers due to HIV/AIDS, including healthy and infected orphans.<sup>87</sup>

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<sup>83</sup> Implementation of the Optional Protocol to the Convention of the Rights of the Child, On Sale of Children, Child Prostitution and Child Pornography, Report of the Government of Uganda to the UN Committee of the Rights of the Child, 2008, available at, <http://www.ohchr.org/english/bodies/crc/docs/.../CRC.C.OPSC.UGA.1.doc>, (accessed 21 May 2013).

<sup>84</sup> Smolin, "Overcoming Religious Objections to the Convention on the Rights of the Child", *Emory International Law Review*, Vol.20, 2006, p. 83.

<sup>85</sup> Farris, "Home Schooling and Parental Rights: Don't let America be Brazil", 2011, available at, <http://educate-yourself.org/ite/homeschoolingbrazil08nov11.shtml>, (accessed 18 December 2012).

<sup>86</sup> See Smolin, footnote 84 above.

<sup>87</sup> General Comment No 3 of 2003 on HIV/AIDS and the Rights of the Child.



### 3.3.7 *International Convention on the Elimination of All Forms of Racial Discrimination (CERD)*

The Convention on the Elimination of All Forms of Racial Discrimination ("CERD") is an international treaty designed to protect individuals from discrimination based on race and the promotion of understanding among all races.<sup>88</sup> Particularly relevant to HIV/AIDS issues are: the requirement that state parties take concrete measures in social, economic, cultural, and other fields to ensure the adequate development and protection of certain racial groups or individuals belonging to such groups for the purpose of guaranteeing their full and equal enjoyment of human rights and fundamental freedoms (Article 2). Also relating to HIV/AIDS is the requirement that state parties undertake to prohibit and eliminate racial discrimination in all its forms and to guarantee the right of everyone to equality before the law in the enjoyment of rights, including the right to work and the free choice of employment, the right to housing, the right to public health, medical care, social security, and social services, and the right to education and training (Article 5).

State parties are obliged to submit periodic reports to the Committee on the Elimination of Racial Discrimination detailing how they have given effect to CERD. Moreover, under Articles 11-13, if a state party is not giving effect to the provisions of CERD, another state party may bring this matter to the attention of the Committee, which will collect information from the relevant state parties and, if the dispute cannot be reconciled, will form an *ad hoc* commission to investigate and issue recommendations. Under Article 14, a state party has the option of allowing the Committee to receive and consider complaints from individuals claiming that the state party has violated their rights under CERD, and the Committee will issue recommendations to the state party accordingly. Uganda ratified this Convention in 1980. The Ugandan Constitution of 1995 incorporated the basic principles of the Convention in Article 21 of the Constitution, which showed the Government's

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<sup>88</sup> The Convention on the Elimination of All Forms of Racial Discrimination ("CERD") of 1965.

determination to fight racial discrimination.<sup>89</sup> South Africa and Canada have also ratified this Convention in 1970 and in 1998 respectively.<sup>90</sup>

### 3.3.8 *The African Charter on Human and Peoples' Rights (ACHPR)*

The (ACHPR) was adopted in 1981 but also makes no specific reference to HIV/AIDS. The African Charter on the Rights and Welfare of the Child (ACRWC) was adopted nearly ten years later, in 1990, but still does not include any reference to HIV/AIDS. It is only within the guidelines on state reporting to the African Committee on the Rights and Welfare of the Child that mention is made of HIV/AIDS.<sup>91</sup>

Article 16 of the ACHPR is less explicit than Article 12 of the ICESCR in terms of acknowledging the right to the best attainable state of health. Although the ICESCR instructs state parties to take necessary measures to protect the health of the people, it does not spell out the specific measures that states are obliged to take. In comparison to the ACHPR, the ACRWC has expressed the right to health with more clarity as it imposes specific obligations on state parties.<sup>92</sup> ACRW, *inter alia*, expressly requires state parties to protect and promote the right of a woman to self-protection and to be protected against sexually transmitted infections including HIV/AIDS.<sup>93</sup> In the case of *Purohit and Moore v The Gambia Communication*, the ACHPR postulated that the enjoyment of the right to health, as it is widely known, is vital to all aspects of a person's life and well-being, and is crucial to the realization of all the other fundamental human rights and freedoms. The court recognised that the right to health under the African Charter includes the right to health facilities and access to goods and services and these should be guaranteed to all without discrimination of any kind. Also of significance to this case is principle of state responsibility which presupposes that a state will take all necessary steps towards

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<sup>89</sup> United Nation, International Convention on the Elimination of all Forms of Racial Discrimination, Summary Record of the 1562<sup>nd</sup> meeting held at the Palais des Nations, Geneva on 7 March 2003.

<sup>90</sup> United Nations Treaty Collection: The International Convention on all forms of Racial Discrimination, of 1966.

<sup>91</sup> The African Committee of Experts on the Rights and Welfare of the Child, "Guidelines for Initial Reports of States Parties", p. 7, available at, <http://www.africaunion.org/child/Guidelines%20for%20Initial%20reports>, (accessed 19 November 2012).

<sup>92</sup> *Ibid.*

<sup>93</sup> Article 14 of The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa of 2003.

the achievement of not only the guaranteed rights but also all such rights as are ancillary to the guaranteed rights.<sup>94</sup>

### *3.3.9 The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa*

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (hereinafter referred to as 'The African Women's Protocol')<sup>95</sup> was adopted by the African Summit of Heads of State and Government in Maputo. The Protocol to the ACHPR and the African Women's Protocol which were adopted on 11 July 2003 and came into force on 25 November 2005, mention HIV/AIDS in a cursory manner. The African Women's Protocol is a very instructive instrument that has a mandate to protect women's rights. It guarantees a women's right to protection from sexually transmissible infections, including HIV/AIDS, and the right to adequate, affordable and accessible health services.<sup>96</sup> The Woman's Protocol is, however, the best regional instrument thus far that addresses the right to health in the context of HIV/AIDS.<sup>97</sup> Health is the foundation upon which all that we ever will be is built and goes beyond the physical, mental and social well-being of an individual.<sup>98</sup> It is the first treaty to specifically address women's rights in relation to HIV/AIDS as a key component of women's sexual and reproductive rights.

The Protocol, however, is significant in three ways. It is the first instrument in international law explicitly to enshrine women's sexual and reproductive rights, including medical abortion when pregnancy results from rape or incest, or when the continuation of pregnancy endangers the health of the mother. It reinforces the status of women's rights that have been established and elaborated in other

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<sup>94</sup> *Purohit and Moore V The Gambia*, Communication 241/2001 decided at the 33<sup>rd</sup> Ordinary Session of the African Commission on Human and Peoples' Rights held from 15 to 29 in Niamey, Niger, May 2003 para 80 Mental patients' rights were said to be important and these are: the right to health, the nature of socio-economic rights obligations under the African Charter on Human and Peoples' Rights, respect for human dignity, right to liberty and security of the person, right to have one's cause heard, right to freely participate in one's own government.

<sup>95</sup> 38 out of 53 member states have signed the protocol as of July 2010. Of these, eleven countries had ratified the Protocol at the time of writing.

<sup>96</sup> Aniekwu, "The additional protocol to the African Charter on Human and Peoples' Rights: indication of capacity for African municipal systems" 2009, p. 30, available at, <http://www.saflii.org/za/journals/LDD/2009/12.pdf>, (accessed 19 November 2012).

<sup>97</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, adopted in July 2003 and entered into force in November 2005.

<sup>98</sup> Wakhweya "Women's health and human rights in Uganda: to be or not to be, that is the question" in Fox and Hasci (eds) *The challenges of women's activism and human rights in Africa* New York, Edwin Mellen Press 1999 p. 274.

international and regional instruments. It is also the first instrument in international law that calls for the legal prohibition of female genital mutilation. Finally, it is the first instrument of its kind developed by Africans for Africa that specifically addresses women's rights in relation to HIV/ AIDS.<sup>99</sup>

### *3.3.9.1 Reproductive choice*

The Protocol is the first legally binding human rights instrument to expressly articulate women's reproductive rights as human rights and guarantees a woman's right to reproductive health and family planning services.<sup>100</sup> Article 14 of the African Women's Protocol further calls on state parties to ensure that women's right to health, including sexual and reproductive health, is respected and promoted. It further provides that women have the right to protection against sexually transmitted infections, including HIV/AIDS.

### *3.3.9.2 HIV/AIDS*

What is also striking about this instrument is that it is one of the few instruments which specifically address the HIV/AIDS issue. It does not only address this issue generally, but it also makes special reference to women as being one of the most vulnerable groups affected by this pandemic. Given the high prevalence of HIV/AIDS in the Southern African region, the provisions of the Protocol for the protection of women against HIV infection could help to address the challenges of HIV positive women in Africa. The Protocol also guarantees a woman's right to protection from sexually transmissible infections including HIV/AIDS and her right to adequate, affordable and accessible health services.<sup>101</sup> It again articulates the state's duty to protect girls and women from practices and situations that increase their risks of infection, such as child marriage, wartime sexual violence, and female genital mutilation.<sup>102</sup>

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<sup>99</sup> Gawaya and Mukasa, "The African Women's Protocol: a new dimension for women's rights in Africa", *Gender and Development Journal*, Vol 13:3, 2005, p. 42-50.

<sup>100</sup> Article 14.

<sup>101</sup> Article 14(1)(d) and (2)(a) of the Protocol.

<sup>102</sup> Article 5, 6 and 11 of the Protocol.

### 3.3.9.3 Abortion

In 2004, a declaration adopted by the Summit on Gender Equality noted with concern that many obstacles faced by African women preventing them from exercising and enjoying their full human rights.<sup>103</sup> The obstacles include conflict, poverty, and the impact of the HIV/AIDS pandemic. It noted further that women are subjected to gender-based violence, including harmful traditional practices. Women are also subjected to different forms of exclusion, for instance, at work, in decision making, even about their health. Women are exposed to violence after disclosing their HIV status or sexually transmitted diseases. The African Women's Protocol, however, has a mandate to curb all these forms of violence and discrimination. The Protocol is the first treaty that specifically authorises medical abortion in cases of sexual assault, rape and incest, or where the continued pregnancy endangers the mental and physical health or life of the mother or foetus.<sup>104</sup> The African Women's Protocol covers 32 social, cultural, economic, legal and political concerns.<sup>105</sup> It thus commits signatory states to sign and ratify it and to adopt measures necessary in order for women to be able to enjoy their human rights, including the provision of resources to make this possible.

The major impact of this Protocol is that it supports women by confronting problems that were not addressed in either the Convention on all Forms of Discrimination against Women or the African Charter on Human or Peoples' Rights. These problems include violence against women, HIV/AIDS, and the denial of women's health and reproductive health. The overall importance of this protocol is that it is a home grown instrument that specifically addresses the concerns of African women, such as HIV/AIDS, as well as customary law, among other things. It further can strengthen the legal and policy framework of countries, and assist to promote action to protect the rights of women. It can also help to bridge the gap between law and policy on the one hand, and practice and reality on the other. HIV/AIDS has produced devastating results for the African continent. Therefore, it is imperative that both international and Regional instruments should be implemented in order to combat this pandemic.

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<sup>103</sup> See Gawayia footnote 99 above, p. 43.

<sup>104</sup> Article 14 of the Women's Protocol.

<sup>105</sup> *Ibid.*

### 3.3.10 SADC Framework on HIV/AIDS

Of all the regional economic institutions, SADC has been the most active in responding to the HIV/AIDS pandemic as it is the region that has been hit hardest by it. In the SADC, member states commit themselves to uphold human rights, democracy and the rule of law.<sup>106</sup> Although SADC was initially silent on HIV and AIDS, after the 2001 amendment, the SADC treaty now includes a commitment to 'combat HIV/AIDS and other deadly communicable diseases' as one of the objectives of the organisation.<sup>107</sup> The SADC Protocol on Health was adopted by 14 member states in 1999 and came into force in August 2004.<sup>108</sup> According to this Protocol,<sup>109</sup> state parties shall harmonise HIV/AIDS policies, standardize surveillance systems and exchange information. State parties shall endeavour to provide high risk and trans-border populations with basic, curative services for HIV and AIDS and Sexually Transmitted Infections (STI's).

Article 10 of the SADC Health Protocol specifically deals with HIV/AIDS and sexually transmitted diseases (STDs). The latter urges state parties to harmonise policies and approaches for the prevention and management of HIV/AIDS and STDs, and to develop regional policies and plans that work towards an inter-sectoral approach to the epidemic. Africa is also faced with a great challenge of researching more about this pandemic in order come up with solutions that are tailor made to suit African challenges and problems.

In September 1997, the SADC Council of Ministers adopted the first relevant document addressing HIV/AIDS related issues, the *Code of HIV/AIDS and Employment in SADC*, developed by the Employment and Labour Sector. Its main objective is to sensitise employers on issues of employee rights and HIV/AIDS, and it provides a framework for states to consolidate national employment codes on

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<sup>106</sup> Article 4(c), Treaty of the Southern African Development Community of 17 August 1993.

<sup>107</sup> SADC Treaty, Article 5(1) (i).

<sup>108</sup> SADC Health Protocol, 1999, available at, <http://www.healthprotocol/196.36.153/doh/departmentsadc/docs/protocol199.html>, (accessed 14 November 2012).

<sup>109</sup> Article 10 of the SADC Protocol on Health of 1999.

HIV/AIDS related issues.<sup>110</sup> It addresses public sector employers, legislators, employees and trade unions.

In July 2003, the SADC Heads of State and Government meeting in Maseru adopted a declaration on HIV/AIDS, the Strategic Framework (2003-2007) which replaced the 2000-2004 frameworks. The strategic framework aims to “decrease the number of individuals living with HIV/AIDS and families affected by the epidemic in the SADC region, so that HIV and AIDS is no longer a threat to public health and the socio-economic development of member states.”<sup>111</sup> The SADC Secretariat, on the other hand, has also established an HIV and AIDS Unit within its Department of Strategic Planning, Gender and Policy Harmonisation. The mandate of the framework is to lead, coordinate and manage SADC’s response to the epidemic through the operationalisation of the HIV and AIDS Strategic Framework of Maseru.<sup>112</sup>

The SADC Parliamentary Forum (SADC PF) has also contributed significantly to policies that can help curb the spread of the pandemic. In 2004, the SADC PF published a survey of legislative efforts to combat HIV and AIDS in the SADC region.<sup>113</sup> It is thus important for SADC members and other non-members to adhere to the provisions of these frameworks as this will not only reduce the spread of the HIV and AIDS pandemic but it will also make Africa more prepared for other pandemics that are slowly becoming prevalent in Africa. The founding provisions of SADC clearly state, as one of its objectives, that it endeavours to “harmonise socio-economic policies” of member states. This objective should serve as a basis to harmonise their legal response to the epidemic, for instance, by developing model legislation that could serve as a SADC bill of rights. By pooling together the resources, knowledge and capabilities of SADC members, the development of one comprehensive HIV and AIDS model legislation would be both possible and beneficial.<sup>114</sup>

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<sup>110</sup> Code on HIV and Employment in Southern African Development Community SADC, available at, <http://www.chr.up.ac.za/undp/subregional/docs/sadc5.pdf>. (accessed on 17 May 2012).

<sup>111</sup> The SADC HIV and AIDS Strategic Framework and Programme of Action 2003-2007 p. 17.

<sup>112</sup> SADC HIV and AIDS Business Plan 2004 p. 12.

<sup>113</sup> Survey of legislative efforts to combat HIV and AIDS the SADC region, Report on a survey conducted by the National Democratic Institute for International Affairs (NDI) and the Southern African Development Community Parliamentary Forum (SADC PF) in 2004. See also Centre for the Study of AIDS and Centre for Human Rights, University of Pretoria, HIV and Aids and human rights in SADC 2004, available at, <http://www.asc.za.org/filemanager/list/10/>, (accessed 18 March 2012).

### 3.3.11 *The International Guidelines on HIV/AIDS and Human Rights*

The International Guidelines on HIV/AIDS and Human Rights is an exceptionally critical instrument that plays the role of closing the dramatic gap between professed policies declared in international instruments and practices in their international implementation.<sup>115</sup> These guidelines were generally adopted in 1996 and were sponsored by the Joint United Nations Program on HIV/AIDS (UNAIDS) and the Office of the United Nations High Commissioner for Human Rights (OHCHR). They represent best practice drawn from various national or regional charters and declarations on the application of international human rights on the HIV/AIDS epidemic.<sup>116</sup> This policy brief further points out that,

in fact the guidelines extend far beyond internationally recognized human rights and seek to impose controversial policies that would weaken the institution of the family.<sup>117</sup>

Ironically, the guidelines recommend protecting behaviours that actually fuel the AIDS pandemic.<sup>118</sup> The International Guidelines on HIV/AIDS and Human Rights reinforce the obligations already contained in existing human rights declarations and conventions.

The purpose of the Guidelines is “to assist States in creating a positive, rights-based response to HIV that is effective in reducing the transmission and impact of HIV and AIDS and is consistent with human rights and fundamental freedoms.”<sup>119</sup> The Guidelines are a joint project of the OHCHR and UNAIDS. The consolidated guidelines include the revised Guideline 6, which reflects the human rights dimensions of access to HIV prevention, treatment, care and support.<sup>120</sup>

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<sup>115</sup> Heywood, Altman, “Confronting AIDS: Human Rights, Law, and Social Transformation”, *Human Rights and Health Vol 5:1*, 2000, p. 149-179.

<sup>116</sup> See International Guidelines on HIV/AIDS and Human Rights 2006 Consolidated Version (UNAIDS/OHCHR).

<sup>117</sup> Family Watch International, “The International Guidelines on HIV/AIDS and Human Rights: A Troublesome Paradox for Containing HIV/AIDS Epidemic 2009, p. 1, available at <http://www.familywatchinternational.org/.../fwiPolicyBriefonInternationalGuidelines>, (accessed 18 March 2012).

<sup>118</sup> *Ibid.*

<sup>119</sup> See International Guidelines footnote 116 above.

<sup>120</sup> See Aniekwu footnote 96 above.



The International Guidelines on HIV and AIDS and Human Rights were endorsed by most African countries. They postulate that;<sup>121</sup>

People will not seek HIV related counselling, testing, treatment and support if this could mean facing discrimination, lack of confidentiality and other negative consequences. [C]oercive public health measures drive away the people most needed of such services and fail to achieve their public health goals of prevention through behavioural care and health support.<sup>122</sup>

The Guidelines present a real paradox in the name of public health. They over reach in terms of protecting the infected at the risk of infecting more of the public at large. These Guidelines clearly take a human rights stand, that is, they are human rights based. Ironically, UNAIDS has recognized that there have been examples where alleged violations or derogations from human rights may well be associated with effective HIV prevention and one of the examples cited refers to mandatory testing of identified rapists to enable victims to choose whether or not to utilize post exposure prevention methods.<sup>123</sup>

UNAIDS, however, acknowledged that there is no consensus on what constitutes a human rights-based approach. It is thus important to first establish what a human rights-based is in order to implement viable policies. It further again acknowledged that there is need for better evidence that can show that promoting and protecting human rights can make a difference in combating HIV/AIDS.<sup>124</sup> An expert advisory body to UNAIDS reported that “lack of general understanding of human rights (what they include and what they do not, how they operate, etc.) is an impediment in

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<sup>121</sup> The Centre for the Study of AIDS and Centre for Human Rights, survey found that all Southern African Countries surveyed were aware or have endorsed the International Guidelines on HIV and AIDS and Human Rights.

<sup>122</sup> Office of the UN Commissioner for Human Rights and the Joint United Nations Programme on HIV and AIDS “HIV and Human Rights International Guidelines”, Guideline 4 para 74 1998.

<sup>123</sup> UNAIDS Global Reference Group on HIV/AIDS and Human Rights: Issue Paper “Review and Assessment of HIV/AIDS Strategies that Explicitly Include Attention to Rights – Prevention”, 4<sup>th</sup> meeting, 23-25 August 2004, available at, <http://www.data.unaids.org/topics/human-rights/hrissuepaper-prevention-en.pdf>, (accessed 03 May 2012)

<sup>124</sup> UNAIDS Global Reference Group on HIV/AIDS and Human Rights: Issue paper on What Constitutes a Rights-based Approach? Determining Rationale, Objectives and Areas of Focus for Our Work, 4<sup>th</sup> Meeting, 23-25 August 2004, available at, <http://www.data.unaids.org>, (accessed 24 April 2012).

bringing human rights into the HIV/AIDS framework”.<sup>125</sup> The same expert body also remarked that “lack of evidence and documentation (whether epidemiological, social or legal) of the value of integrating human rights in the response to HIV/AIDS is increasingly proving to be an obstacle in ensuring the integration of human rights in governmental and UN HIV/AIDS efforts”.<sup>126</sup>

The Guidelines stress that a multitude of general rights found in various UN treaties are relevant to the HIV/AIDS epidemic, for example, the right to life, privacy, equality, health, freedom of association and expression. However, rather than showing how specific treaty language supports their recommendations, UNAIDS and OHCHR rely on treaty monitoring bodies for their expansive readings of the relevant treaties. A clear example is that the Guidelines cite the statement by the Human Rights Commission (HCR) that “other status” in non-discrimination provisions of certain treaties is to be interpreted to include health status and HIV/AIDS, even though that interpretation was never discussed by the signatories<sup>127</sup>

The Guidelines also note that the member states often cite public health as a basis for restricting human rights in the context of HIV, and recognize that states may impose restrictions on some narrowly defined circumstances, “if such restrictions are necessary to achieve overriding goals, such as public health, the rights of others, morality, public order, the general welfare in a democratic society and national security”.<sup>128</sup> But after citing problematic examples of mandatory testing and differential treatment with regard to access to education, employment, health care, travel, housing, etc, the Guidelines assert that a, “public health exception is seldom a legitimate basis for restrictions on human rights in the context of HIV”.<sup>129</sup>

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<sup>125</sup> The International Guidelines on HIV/AIDS and Human Rights 2006, available at, <http://www.familywatchinternational.org> Accessed 28 May 2012.

<sup>126</sup> Public Report –First Meeting of the UNAIDS Global Reference Group on HIV/AIDS and Human Rights, January 23-25 August Geneva Switzerland, 2003 p. 6-7.

<sup>127</sup> International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version.

<sup>128</sup> *Ibid* p. 81-83 para 104-105.

<sup>129</sup> *Ibid*.

### 3.3.12 Declaration of Commitment on HIV/AIDS: Midway to the Millennium Development Goals

This Declaration analyzes the global progress made towards achieving the goals stated in the Declaration of Commitment and the Millennium Goals.<sup>130</sup> It specifically looks at progress and the remaining challenges in the areas of: the status of the epidemic; young people's knowledge about HIV; prevention of mother-to-child transmission; HIV prevention for populations most at risk; women and HIV; HIV treatment; children orphaned or made vulnerable by HIV; discrimination and HIV; and financing for HIV-related activities.<sup>131</sup> The report also makes key recommendations in the areas of: national leadership; sustainability of the response to HIV; scaling up prevention in severely-affected countries; mounting an effective response in concentrated epidemics; sustaining treatment scale-up while strengthening measures to address HIV/tuberculosis co-infection; and addressing the role of gender inequities.<sup>132</sup>

### 3.3.13 Political Declaration on HIV/AIDS

The Political Declaration, adopted by the United Nations General Assembly in June 2006, renews the General Assembly's commitment to the Declaration of Commitment on HIV/AIDS issued in 2001.<sup>133</sup> It commits to several actions as part of a human rights-based approach to HIV/AIDS, including: promoting prevention, treatment, care, and support; overcoming legal or other barriers to block access to effective HIV prevention, treatment, care, and support; ensuring pregnant women have access to antenatal care, including voluntary and confidential counselling and testing with informed consent; intensifying efforts to enact, strengthen, or enforce legislation and other measures to ensure those with HIV have full enjoyment of all human rights; eliminating gender inequalities and protecting women's rights; and addressing the vulnerabilities of children affected by and living with HIV/AIDS.<sup>134</sup> The Declaration undertook to provide comprehensive reviews of its progress in these

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<sup>130</sup> Declaration of Commitment on HIV/AIDS and Political Declaration on HIV/AIDS: Midway to the Millennium Development Goals, The Secretary General, U.N. Doc. A/62/780. Suffice to say that in international law declarations are generally not binding, but offer guidelines.

<sup>131</sup> *Ibid.*

<sup>132</sup> *Ibid.*

<sup>133</sup> Political Declaration on HIV/AIDS, G.A. Res. 60/262, U.N. Doc. A/RES/60/262.

<sup>134</sup> *Ibid.*

areas in 2008 and 2011 within the annual reviews of the General Assembly. It requested that the Secretary General of the United Nations include in his annual report the status of the implementation of the 2001 Declaration of Commitment.

### **3.4 The Universal Application of Human Rights**

The growing consensus in the West that human rights are universal has been contested by critics in other parts of the world.<sup>135</sup> Tharoor expounds that the concept of human rights is an essentially Western concept that ignores the very different cultural, economic and political realities of the other parts of the world. Pertinent questions posed by Tharoor are that, firstly, can the values of the consumer society be applied to societies that have nothing to consume? Secondly, is talking about universal rights not the same as saying that the rich and the poor both have the same right to fly first class and to sleep under bridges? Thirdly, are human rights as laid out in the international covenants not ignoring the traditions, the religions, and the socio-cultural patterns of what used to be called the Third World?<sup>136</sup> It is a well-known fact that human rights are endorsed and applied worldwide. The essential purpose of human rights is relevant everywhere as it protects vulnerable individuals and groups against outrages and distress. However, what is locally perceived and experienced as human rights violations differs from society to society, though some basic conditions are universally human. They relate to the protection of dignity and integrity: food, water, housing and protection against state violence.<sup>137</sup>

Another pertinent question is, how can universal human rights exist in a culturally diverse world?<sup>138</sup> The philosophical objection asserts essentially that nothing can be universal; that all rights and values are defined and limited by cultural perceptions. If there is no universal culture, there can be no universal human rights.<sup>139</sup> Cultural relativism is the assertion that human values, far from being universal, vary a great deal according to different cultural perspectives.<sup>140</sup> Some would apply this relativism

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<sup>135</sup> Tharoor, "Are Human Rights Universal? ", *World policy Journal-World Policy Institute Volume XVI, No4, Winter 1999/2000*, available at <http://www.worldpolicy.org/tharoor.html>, (accessed 08 August 2013).

<sup>136</sup> *Ibid.*

<sup>137</sup> Shenker, "Are Human Rights Universal?" Challenge of Human Rights and Cultural Diversity United Nations background Note 1995, available at <http://www.un.org/rights/dpi1627e.html>, (accessed 08 August 2013).

<sup>138</sup> *Ibid.*

<sup>139</sup> See Tharoor footnote 135.

<sup>140</sup> See Shenker footnote 137.

to the promotion, protection, interpretation and application of human rights which could be interpreted differently within different cultural, ethnic and religious traditions. In other words, according to this view, human rights are culturally relative rather than universal.<sup>141</sup>

According to Tharoor's perspective human rights cannot be universal and values are defined and limited by cultural perceptions. Perhaps it is important to craft policies and human rights-based approaches best suited for the African context. This dissertation clearly acknowledges the importance and the value in following a human rights-based approach to HIV/AIDS testing. It is important to establish whether mandatory HIV/AIDS testing is rights-based and whether it is a concept best suited for developed or developing countries.

A clear example of solutions that best suit South Africa, the African continent and other developing countries is that found in International Trade Law. World Trade Organisations (WTO) agreements contain special provisions which give developing countries special rights and allow developed countries to treat developing countries more favourably than other WTO members.<sup>142</sup> These special provisions include, for example, longer time periods for implementing agreements and commitments, or measures to increase developing countries' trading opportunities.<sup>143</sup> Special and Differential Treatment (SDT) is the term used for the way in which developing countries are treated differently to developed countries within the WTO system.

The principle of SDT is that international trade rules should be adapted to the particular economic situation of developing countries.<sup>144</sup> It is important to recognise that developing countries are not a homogenous group and will be affected differently by agricultural trade liberalisation, depending on their net trade status, the commodity composition of their trade, etc. This same principle should be applied in human rights and public health circumstances. Practices and policies implemented should complement the African region's culture, history and economy.

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<sup>141</sup> *Ibid.*

<sup>142</sup> Doha Declaration 2001.

<sup>143</sup> *Ibid.*

<sup>144</sup> EU Agricultural Policy and World Poverty "Special and Differential Treatment (SDT) for Developing Countries" 2010 available at <http://www.tcd.ie/iis/policycoherence/wto-agricultural-trade-rules/special-differential-treatment-developing-countries.php>, (accessed 08 August 2013).

Another example is that of the Kyoto Protocol (KP), an international agreement linked to the United Nations Framework Convention on Climate Change (UNFCCC). It set binding targets for 37 industrialized countries and the European Community for reducing greenhouse gas emissions.<sup>145</sup> The UNFCCC and the KP have also exempted developing countries from greenhouse gas emissions targets, based on the Rio principle of common but differentiated responsibilities of states according to their respective capabilities and their need for social and economic development.<sup>146</sup> By the same token, it is important to implement human rights and public health policies best suited for South African as well as for African society.

### **3.5 Concluding Remarks**

Human rights law is an evolving field and human rights violations are comprehensively addressed by existing legal standards and precedents. Through on-going documentation and advocacy, public health and human rights advocates can rebuild a stronger body of jurisprudence on HIV/AIDS and human rights. It is clearly the duty of African states to extend the work started by the different conventions discussed above and develop a strong base of legislation on HIV/AIDS which is tailor-made for Africa, since the continent, especially sub-Saharan Africa, has the highest number of people affected by the virus. All declarations and general statements or commitments should be put into practice so as to achieve an HIV free generation. Lip service to human rights principles by governments is dangerous and leads only to cynicism and derision of international human rights.<sup>147</sup> Implementation is the greatest challenge faced by Africa.

From the analysis of above, it is high time that the focus is shifted from the debates of whether public health or human rights is more paramount. It is without doubt that human rights have major relevance in shaping appropriate responses to the HIV epidemic and other global health challenges and in identifying deficiencies in the

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<sup>145</sup> The Kyoto Protocol of 1997.

<sup>146</sup> Sankar, "trade measures in climate change policies: compatibility with WTO and UNFCCC, 2009, available at, <http://www.mse.ac.in/trade/tm%20cc%20mse%20te%20.pdf>, (accessed 08 August 2013).

<sup>147</sup> International Symposium on, "The ethics of State Involvement in Woman's Health" ,University of Carlifonia 2010.

public health research agendas<sup>148</sup> Policy makers should know that when conceiving public health policies they should have in mind implications of such policies on human rights. Every public health policy<sup>149</sup> should be viewed as a potential threat to human rights, unless proved otherwise. In designing any public health policy, particularly in the context of HIV/AIDS, the respect, protection and fulfilment of human rights should be the primary consideration of governments'.<sup>150</sup> This public health pandemic should be faced head on and this can be done by also protecting human rights in order to achieve the desired results of a stigma-free society.

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<sup>148</sup> Brundtland "Twenty Five questions and answers on Health and Human Rights", World Health Organisation, Geneva 2002, available at, <http://who.int.hhr/NEW3787OMSOK.pdf> (accessed 24 August 2011).

<sup>149</sup> Mann, "Statement at an Informal Briefing on AIDS to the 42<sup>nd</sup> Session of the United Nations General Assembly", *Journal of the Royal Statistical Society, Series A (Statistics in Society) Vol. 151:1* 1998.

<sup>150</sup> Gruskin, Tarantola, *Health and Human Rights*, New York Routledge 2005, p. 3.

## **CHAPTER 4: A COMPARATIVE SURVEY OF HIV/AIDS LAW AND PRACTICE IN UGANDA, SOUTH AFRICA AND CANADA**

### **4.1 Introduction**

Chapter four presents the case studies of the law and practice in South Africa, Uganda and Canada. South Africa is automatically included in the comparison because the main focus of the study and the comparisons preferred are based on its law and practice. Lessons will be drawn from the experiences of Uganda and Canada. HIV/AIDS testing policies and practices implemented in these countries will be explored paying particular attention to what has worked or what has not worked.

### **4.2 Background to the Inception of HIV/AIDS in Uganda**

It is without doubt that Southern Africa is the epicentre of the global HIV/AIDS epidemic and prevalence rates vary from 15% to 28% of the population.<sup>1</sup> As the President of the World Bank noted, “Nothing we have seen is a greater challenge to the peace and stability of African societies than the AIDS epidemic. Africa faces a major development crisis, and more than that a security crisis”.<sup>2</sup> Though Southern African has suffered the most from this pandemic, Senegal in West Africa and Uganda in East Africa are often referred to as two sub-Saharan African success stories since 1997 in the fight against HIV. Senegal has kept its rate of infection below one per cent, while Uganda has done a tremendous job of lowering its infection rate from approximately 15 per cent in 1991 to 5.4 per cent in 2007.<sup>3</sup> At the end of 2007, South Africa had 5.7 million HIV-positive citizens and had an adult HIV prevalence rate of 18.1 per cent.<sup>4</sup> Although HIV has devastated Africa far more than any other continent, it has also ravaged developed countries such as the United States of America. In 2007, the Centre for Disease Control and Prevention estimated

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<sup>1</sup> Human Rights Future, “HIV/AIDS and SADC”, 2012, available at, <http://www.hrfuture.net/wellness/hiv-aids-and-sadc.php?Itemid=183> (accessed 14 January 2013).

<sup>2</sup> Speech delivered by the President of the World Bank at the UN Security Council Session on “The impact of AIDS on Peace and Security in Africa”, The 4087<sup>th</sup> Security Council Meeting, 10 January 2000 New York: UN.

<sup>3</sup> Global Report: UNAIDS Report on the Global AIDS epidemic 2010.

<sup>4</sup> Central Intelligence Agency (CIA) Fact book, “HIV/AIDS, people living with HIV/AIDS 2009”, available at, [http://www.photius.com/.../hiv\\_aids\\_people\\_living\\_with\\_hiv\\_aids\\_2009](http://www.photius.com/.../hiv_aids_people_living_with_hiv_aids_2009), (accessed 28 September 2012).



that approximately 1.1 million Americans were living with HIV/AIDS and one in every five HIV-positive Americans was unaware of his or her diagnosis.<sup>5</sup>

In Uganda, AIDS was first identified in 1982 in a fishing village in the Rakai District, 180km outside the capital city of Kampala on the western shores of Lake Victoria.<sup>6</sup> Superstition and witchcraft characterized the initial response from communities amidst the lack of a clear government response to HIV/AIDS.<sup>7</sup> Consequently, the epidemic spread very fast to all parts of the country, initially afflicting urban and semi-urban centres.<sup>8</sup> The first stage saw the rapid spread of HIV through urban sexual networks and along major highways. Doctors in this area had become aware of a surge in cases of severe wasting, locally known as the 'slim disease', as well as a large number of fatal opportunistic infections.<sup>9</sup> By the late 1980s, the country was experiencing a full blown epidemic, the virulence of which was exacerbated by social dislocation and insecurity related to the country's economic crisis and war.<sup>10</sup>

In 1982, the first AIDS case in Uganda was diagnosed, and the link between 'slim disease' and AIDS was clinically recognised. In this year seventeen traders in the southern district of Rakai died of symptoms that came to be associated with the disease.<sup>11</sup> Epstein points out that initially the virus was detected in the districts of Masaka, Rakai and Kampala but by 1989 it was detected in all eighty of Uganda's districts, spreading primarily along main transportation routes. Men and women were equally infected, although mostly men's deaths were reported to the local officials. The majority of AIDS cases occurred among people aged between 16-40 years, but by the late 1980s, the increasing number of babies born HIV-positive resulted in a

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<sup>5</sup> Centre for Disease Control, "HIV/AIDS Surveillance Report: Cases of HIV infection and AIDS in the United States and dependent areas, 2007, available at, <http://www.cdc.gov/hiv/topics/2007report/pdf> (accessed 11 September 2012).

<sup>6</sup> Thornton, "Native Category": AIDS as local knowledge in Uganda: The Beginning of debate and knowledge" 2007, p. 88, available at, <http://www.wiredspace.wits.ac.za/.../06.LockKnowlUg> (accessed 11 September 2012)

<sup>7</sup> Tumushabe, "The Politics of HIV/AIDS in Uganda" United Nations Research Institute for Social Development, Social Policy and Development Programme Paper No 2, 2006.

<sup>8</sup> Uganda AIDS Commission, "Sharing the challenges" 2011, available at, [http://www.aidsuganda.org/hiv\\_aids.html](http://www.aidsuganda.org/hiv_aids.html) (accessed 11 September 2012).

<sup>9</sup> Serwadda; Sewankomba; Carswell; Bayley; Tedder; Weiss; "Slim disease: A new disease in Uganda and its association with HTLV-III Infection" *The Lancet* Vol. 2(8460), 1985, p. 849-852, available at, <http://www.thelancet.com>, (accessed 03 September 2012).

<sup>10</sup> Putzel "The Politics of action on AIDS: a case study of Uganda", *Public administration and development Journal*. Vol. 21:1, 2004 p. 19-30.

<sup>11</sup> Epstein, "The Lessons of Uganda", *The New York Review of Books* 2001, available at, <http://www.nybooks.com/articles/14309>, (accessed 18 August 2012).

high rise in the infant mortality rate which shocked many Ugandans into changing their risky behaviour.<sup>12</sup>

By 1997, the health system was strained to breaking point in a country where the health care expenditure per capita at its best was \$31.<sup>13</sup> Patients with HIV/AIDS related illness occupied more than 55 per cent of the hospital beds<sup>14</sup> and by 2000 the occupancy rate had increased to 70 per cent.<sup>15</sup> In 1998, an estimated 1.9 million people were living with HIV/AIDS.<sup>16</sup> AIDS had overtaken malaria as the leading cause of death among people aged 12-49 years and was responsible for 12 percent of all deaths. Mac Adam reported that more than 800,000 people in Uganda had lost their lives to the HIV/AIDS epidemic, leaving behind an estimated two million orphans who had lost one or both parents<sup>17</sup>. Extended family systems were hard pressed to care for this vast and sudden number of uprooted children.

As the epidemic continued to spread and intensify in Africa and other areas of the world in the early and mid-1990s, the prevalence rates in Uganda were reported to be declining, especially starting from 1993. Strong government leadership, broad-based partnerships and effective public education campaigns all contributed to the decline in the number of people living with HIV and AIDS in the 1990s. It was not until 1986 when the Ugandan civil war ended and President Museveni was firmly in power that the country had a major HIV prevention programme. By this time, the country was in the midst of a major epidemic, with a prevalence of up to 29 per cent in urban areas.<sup>18</sup>

It is clear that the political environment had a huge influence on the ups and downs of the pandemic. Most Ugandans were initially sceptical of Yoweri Museveni as the President but they were quickly reassured by his commitment to ushering Uganda

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<sup>12</sup> *Ibid.*

<sup>13</sup> McFarland, "HIV/AIDS statistics and epidemiology" 1997, available at, <https://cdc.confex.com/cdc/std2012/webprogram/Person25013.html>, (accessed 24 September 2012).

<sup>14</sup> Kayita and Kyakulaga, "HIV/AIDS Status Report" Uganda AIDS Commission Kampala 1997.

<sup>15</sup> Ministry of Health of Uganda 2001, available at, <http://www.docs.mak.ac.ug/sites/default/files/Health%20Systems.pdf>, (accessed 15 October 2012)

<sup>16</sup> United Nations Programme on HIV/AIDS, "Key issues and ideas for action" (UNAIDS), 1999, available at [http://www.data.unaids.org/pub/Report/1999/19990201\\_key\\_issues\\_en.pdf](http://www.data.unaids.org/pub/Report/1999/19990201_key_issues_en.pdf), (accessed 24 September 2012).

<sup>17</sup> MacAdam, "Uganda offers hope: Beating AIDS in Africa" 2003, available at, <http://www.sustainabletimes.ca/articles/aidsinfrica.htm>, (accessed 14 October 2012).

<sup>18</sup> Hooper, "AIDS epidemic moves south through Africa", *New Scientist, Magazine issue 1724*, 1990, available at, <http://www.newscientist.com/article/mg>, (accessed 14 October 2012).

into a peaceful and secure era.<sup>19</sup> There was a massive government involvement, open communication about HIV/AIDS, and extensive campaigns during this period. The above factors are commonly cited as the reasons for Uganda's relative success in combating AIDS as well as welcoming foreign aid to fight the disease.<sup>20</sup> Epstein points out that as South Africa, Zimbabwe and other sub-Saharan African countries continued to ignore the growing epidemics in their respective countries, Uganda faced HIV/AIDS head on and drastically decreased its spread through support groups, education programmes and treatment campaigns.

In September 1986, Museveni first truly learned of the destructive impact of AIDS at a Non-Aligned Heads of State meeting in Harare, Zimbabwe, where Fidel Castro informed the former that 18 of 60 Ugandan soldiers who had been sent to Cuba for high-level military training were HIV-positive.<sup>21</sup> Museveni immediately created the National Committee for the Prevention of AIDS (NCPA) in October 1986. The NCPA, which included physicians, academics, educators, administrators, security forces, politicians, church leaders and non-governmental agencies, was designed to coordinate technical and operational activities and institute an AIDS Control Programme (ACP) to devise HIV/AIDS policy guidelines for Uganda's fight against HIV/AIDS. The NCPA proposed a five-year plan to focus on health education, blood screening, improved sterilization practices and terminal patient care.<sup>22</sup>

In 1986, the Government of Uganda responded to the AIDS epidemic by becoming one of the first countries in Africa to collaborate with the WHO to create a national AIDS control programme. The programme includes 13 AIDS Control Programmes operating from 12 Government Ministries. The Uganda AIDS Commission was charged with coordinating the overall programme and it carried out extensive education campaigns aimed at preventing further spread of HIV. Strategies for HIV prevention in Uganda include promotion of safer sexual behaviour, prevention and treatment of sexually transmitted diseases (STDs), condom education and distribution, HIV counselling and testing, and community mobilization in support of

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<sup>19</sup> Kasfir, "Addressing HIV/AIDS in South Africa and Uganda", 1990, available at, <http://wescholar.wesleyan.edu/cgi/viewcontent.cgi>, (accessed 14 October 2012).

<sup>20</sup> See Epstein footnote 11 above.

<sup>21</sup> Tumushabe, "The Politics of HIV/AIDS in Uganda" United Nations Research Institute for Social Development, Social Policy and Development Programme Paper No 2, 2006.

<sup>22</sup> Putzel, "The Politics of action on AIDS: A case study of Uganda", *Public Administration and Development Vol. 24:1*, 2004, p. 19-30.

behavioural change.<sup>23</sup> Uganda's first AIDS control programme was set up in 1987 to educate the public about how to avoid becoming infected with HIV.

The programme promoted the ABC approach (abstain, be faithful, condomise), ensured a safe blood supply and started HIV surveillance. The International community focused on two elements of Uganda's strategy: (i) the important role played by political leadership in speaking publicly about the epidemic at an early stage; and (ii) the government's assumed use of the approach of abstinence, being faithful and condom use (ABC) as a factor that reduced HIV prevalence.

In the 1990s, the ABC campaign was augmented by "Zero Grazing" (monogamy) and "Love Carefully" partner fidelity messages targeting the widespread cultural practice of having two or more sexual partners at a time.<sup>24</sup> The term 'Zero Grazing' comes from the agricultural practice of tying livestock to a post, and restricting them to a zero-shaped section of grass. These slogans mainly promoted partner fidelity, being careful in the relationship, and having one sexual partner and condom use.<sup>25</sup> It is clear that these national efforts helped modify behavioural patterns which, in turn, resulted in an increasing number of individuals reporting greater use of contraceptives and a two year delay in first sexual activity. Only a few people engaged in casual encounters or chose multiple partners.<sup>26</sup>

Prevention work at grass-roots level also began in this era, with a multitude of small organisations educating their peers about HIV. One of the first community-based organisations formed was The AIDS Support Organization (TASO), which was run by sixteen volunteers personally affected by HIV/AIDS. TASO later became the largest indigenous AIDS service organisation providing HIV/AIDS services in Uganda and Africa, and, in addition, it also provided emotional and medical support to many thousands of people who are HIV positive.<sup>27</sup>

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<sup>23</sup> Alwano-Edyegu, Marum, "Knowledge is power: Voluntary HIV counselling and testing in Uganda", UNAIDS Case Study June 1999, available at, <http://www.unaids.org/en/media/unaids/.../jc680-knowledgepower-en.pdf>, (accessed 24 September 2012).

<sup>24</sup> Kelly, "HIV/AIDS in Uganda", *Guardian*, December 1 2008, available at, <http://www.csub.edu/kej/documents/economic-research-rsch/2012pdf>, (accessed 18 May 2012).

<sup>25</sup> AVERT, International HIV/AIDS Charity, "The ABC of HIV/AIDS Prevention", available at, <http://www.avert.org/abc-hiv.htm>, (accessed 24 September 2012).

<sup>26</sup> See Kelly footnote 24 above.

<sup>27</sup> Eckholm, 'Confronting the cruel reality Of Africa's AIDS epidemic' and TASO", *New York Times*, 19 September 1990, available at, <http://www.nytimes.com/1990/.../confronting-the-cruel-reality-of-africa-s-aids>, (accessed 18 May 2012).

The second phase of the Ugandan HIV epidemic ran from 1992 to 2000. The year 1992 was a turning point in Uganda's war against HIV/AIDS when the AIDS Commission adopted the "Multi-Sectoral AIDS Control Approach" and formulated a national HIV/AIDS policy.<sup>28</sup> The Commission implemented a variety of approaches to HIV/AIDS education, ranging from promotion of condom use to abstinence programmes; proper birth practices; and safe infant feeding counselling.<sup>29</sup> During this period, the HIV prevalence fell dramatically from a peak in 1991 of around 15 per cent among all adults and over 30 percent among pregnant women in the cities<sup>30</sup> to around 5 per cent in 2001.<sup>31</sup> As of 1998, UNAIDS estimated that 930 000 Ugandans were living with HIV infection or AIDS.<sup>32</sup> It was estimated that 1.8 million Ugandans had already died of AIDS and that there were as many as 1.7 million children who had lost their mothers or both parents to AIDS. In 1997, it was estimated that 160 000 Ugandans had died of AIDS.

The third phase of HIV/AIDS in Uganda saw the stabilisation of the prevalence between 2000 and 2005, with a slight increase in prevalence since 2006.<sup>33</sup> Free antiretroviral drugs have been available in Uganda since 2004. It is thought that the introduction of HIV drugs may have led to complacency about HIV as people no longer saw HIV as an immediate death sentence.<sup>34</sup> Many experts have also speculated that Uganda's shift in prevention policy away from ABC towards US-backed abstinence-only programmes may also have been responsible for an

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<sup>28</sup> Abbas, "HIV/AIDS in Uganda: An unfinished success story", Economic Research Centre 2012, available at, [http://www.csub.edu/kej/documents/economic\\_rschr/2012-06-05.p,df](http://www.csub.edu/kej/documents/economic_rschr/2012-06-05.p,df) (accessed 04 September 2012).

<sup>29</sup> Uganda AIDS Commission, Uganda UNGASS Progress Report 2008-2009, available at, [http://www.data.unaids.org/.../Report/2010/uganda\\_2010\\_country\\_progress\\_rep](http://www.data.unaids.org/.../Report/2010/uganda_2010_country_progress_rep), (accessed 15 October 2012).

<sup>30</sup> Stoneburner; Low-Beer, "Population-level HIV declines and behavioural risk avoidance in Uganda" *Science, Journal 304 (5671)* 2004, p. 714-8.

<sup>31</sup> STD/AIDS Control Programme "Trends in HIV prevalence and sexual behaviour 1990-2000 in Uganda", 2002.

<sup>32</sup> Joint United Nations Programme on HIV/AIDS, UNAIDS World Day AIDS Report 2011, p. 7, available at, <http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/.pdf>, (accessed 14 November 2012).

<sup>33</sup> AIDS Map, "Routine or opt-out counselling and testing findings from the 2006 PEPFAR meeting", available at, <http://www.aidsmap.com/HATIP-71-27th-July-2006/page/1174742/>, (accessed 04 September 2012).

<sup>34</sup> AVERT, "HIV/AIDS in Uganda", available at, <http://www.avert.org/aids-uganda.htm>, (accessed 04 September 2012).

increase in risky behaviour, as comprehensive sex education and condom promotion is no longer mainstream.<sup>35</sup>

However, the drop in HIV prevalence in Uganda in the 1990s cannot be attributed to a single factor. It is likely to have been a result of both a fall in the number of new infections (incidence) and a rise in the number of AIDS-related deaths that changed the behaviours and attitude of the Ugandan population. It has been suggested that the high number of AIDS-related deaths in the 1990s may have been largely responsible for the decline in the number of people living with AIDS in Uganda during this period.<sup>36</sup> The reason so many people died in this decade is that there was no available treatment to delay the onset of AIDS, and high numbers of people infected with HIV in the 1980s were reaching the end of their survival period. In 2000 the Ugandan health ministry estimated that 800 000 people had died of an AIDS-related illness since the beginning of the epidemic.<sup>37</sup>

The frank and honest discussion of the causes of HIV infection seems to have been a very important factor behind the changes in people's behaviour. Music and educational tours by a popular musician, Philly Lutaaya (who was the first prominent Ugandan to openly declare he was HIV positive), also spread understanding, compassion and respect for people living with HIV.<sup>38</sup> Another component of Uganda's AIDS control programme was a comprehensive nationwide school education programme initiated by government health officials in 1987 to prevent the spread of HIV among the youth. The campaign implemented nationwide blood screening and public education programmes, including television, radio and local press warnings in English and local languages.<sup>39</sup>

Uganda is noted for the numerous agencies and institutions that have been active and effective in educating the population about AIDS and how to avoid infection. These groups have also mobilized communities to support changes in social norms

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<sup>35</sup> *Ibid.*

<sup>36</sup> Kaiser "Uganda's decline in HIV/AIDS prevalence attributed to increased condom use, early death from AIDS, study says", *The body*, the complete HIV/AIDS Resource 2005, available at, <http://www.thebody.com/content/art9249.html>, (accessed 07 October 2012).

<sup>37</sup> Government of Uganda, "UNGASS country progress report", March 2012, available at, <http://www.unaids.org/en/Regionscountries/Countries/Uganda/>, (accessed 07 October 2012).

<sup>38</sup> See AVERT, footnote 34 above.

<sup>39</sup> Human Rights Watch, "The less they know the better: Abstinence only HIV/AIDS programs in Uganda", *Human Rights Watch Vol.17:4 (A)*, 2000 p.1-8.

and practices that encourage risk reduction.<sup>40</sup> TASO<sup>41</sup> has not only provided care and support to more than 50 000 People Living With AIDS (PLWAs) and extensive AIDS education in communities, but has also trained hundreds of community workers to provide basic care and health education about AIDS.<sup>42</sup> The Church of Uganda, the Catholic Church and other religious groups have been active in community education and the training of religious leaders and lay workers, but it has also encouraged changes in attitudes and behaviours.<sup>43</sup> Different groups such as Young Men's Christian Association (YMCA), Young Women's Christian Association (YWCA), the Rakai AIDS Information Network and many others have developed projects to educate special groups and to extend education efforts throughout local communities.<sup>44</sup> Formal agencies and institutions, such as the Federation of Uganda's Employers, local businesses, the police and the national army developed "AIDS in the Workplace" projects for their employees.

What is outstanding about Uganda that also differentiates it from many of its neighbours and other countries in the sub-Saharan Africa is that it adopted several strategies to slow down the spread of HIV; in essence it tried available strategies and did not pick on a particular strategy. Thus, assistance was sought from both governmental and non-governmental organisations, including WHO, UNICEF, USAID, UNDP, and Save the Children Fund. These agencies immediately offered their help to expand the AIDS control programme.<sup>45</sup> As a result, many international organisations and western countries were so impressed by Uganda's efforts and success, as well as its HIV/AIDS transparency, that they funded more extensive HIV/AIDS education and treatment programmes.<sup>46</sup>

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<sup>40</sup> See Alwano-Edyengu and Marum, footnote 23 above.

<sup>41</sup> *Ibid.* Noerine Kaleeba and fifteen colleagues founded The AIDS Support Organisation (TASO) of Uganda with the purpose of eliminating the stigma, ignorance, and discrimination surrounding HIV/AIDS. Initially, the founders met informally to provide physical, mental and social support to each other, but the group quickly developed into an extensive volunteer organisation. Researchers and journalist flocked to Uganda to learn more about TASO, the first indigenous HIV/AIDS self-help group in Africa. TASO is the largest indigenous, non-governmental organisation in Uganda and has supported over 200 000 people since its creation.

<sup>42</sup> *Ibid.*

<sup>43</sup> Green; Halperin; Nantulya; Hogle; "Uganda's HIV prevention success: The role of sexual behaviour change and the national response", *AIDS and Behaviour Journal*, Vol. 10:4, 2006, p.335-346.

<sup>44</sup> *Ibid.*

<sup>45</sup> Ankrah, "The Impact of HIV/AIDS on the family and other significant relationships: The african clan revisited," *AIDS Care*, Vol. 4:1, 993, p. 17.

<sup>46</sup> Epstein, *The Invisible Cure*, New York: Farrar, Stause and Giroux 2007.

The population of Uganda reacted strongly to these campaigns and each campaign reached the masses one way or the other. The increase of deaths of close relatives and friends in each family or community promoted behavioural change among individuals. The percentage of Ugandan women of all ages in urban areas who reported having abstained from sexual intercourse over the year increased from 19 per cent in 1989 to 31 per cent in 1995.<sup>47</sup> These sexual behaviour changes coincided with the emergence of Uganda's women's rights movements<sup>48</sup>, which spoke openly of the HIV/AIDS issues and rape. Epstein points out that prior to Museveni's presidency, rape was often considered an excusable crime but, as HIV/AIDS spread, women's rights activists began speaking out against rape. Miria Matembe, then a member of the Ugandan parliament, declared that:

rapists, defilers and all those who, in one way or another commit sexual offenses are in possession of potentially dangerous instruments which must be taken away from them if they can't use them properly.<sup>49</sup>

It is clear that women's rights activism on criminalisation of rape was an important development in the law of Uganda in the fight against HIV/AIDS.

The Museveni presidency contended that the success of the government's programme had a bearing on the promotion of family values.<sup>50</sup> The use of condoms was initially doubted and not highly recommended. President Museveni and some of his ministers made speeches that denounced the use of condoms as un-African and raised doubts about their efficacy as a form of protection.<sup>51</sup> It should, however, be noted that the promotion of the use of condoms at an early stage proved to be counter-productive in Botswana as it resulted in an increase in HIV infections, whereas the lack of condom protection during the 1980s and early 1990s contributed to the relative success of behaviour change strategies in Uganda.<sup>52</sup> It is clear that

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<sup>47</sup> Uganda Demographic and Health Survey 2006, available at, <http://www.measuredhs.com/pubs/pdf/SR126/SR126.pdf>, (accessed 24 September 2012).

<sup>48</sup> Other movements include the Action for Women in Development which is one of the largest women's rights organisations established in 1985 by Maxine Ankrah. They discussed women's rights with regard to AIDS and encouraged wives to divorce their husbands if they were unfaithful and sick with HIV/AIDS. See Epstein 2007.

<sup>49</sup> See Epstein footnote 46 above, p. 164.

<sup>50</sup> Museveni condoms condom distribution to pupils, New Vision May 2004, available at, <http://www.newvision.co.ug/D/8/12/360669>, (accessed 29 August 2012).

<sup>51</sup> Allen and Heald, "HIV/AIDS Policy in Africa: What has worked in Uganda and what has failed in Botswana", *Journal of Development Vol 16*, 2001, p. 1141-1154.

<sup>52</sup> *Ibid.*



non-promotion of condom usage in Uganda played a role in ensuring social acceptance of sexual behavioural change messages.

In the 1980s and early 1990s hundreds of community-based AIDS groups sprang up throughout Uganda and spread to the Kagera district in Tanzania to comfort the sick, provide care for orphans, warn people about the dangers of casual sex, and address the particular vulnerability of women and girls to the virus.<sup>53</sup> Across the border there were also massive campaigns by Nyerere on the AIDS devastation reform which had left behind many orphans. In the nearby districts of Kagera and Bukoba USAID, UNAIDS and UNICEF estimated that the per cent of Tanzania's orphans that could be attributed to AIDS rose from 4.2 per cent in 1990 to 18.8 per cent in 1995; 42.3 per cent in 2001; 50.8 per cent in 2005; and 54.2 per cent in 2010.<sup>54</sup> This increase is a pointer that more still has to be done in the African region to manage the pandemic.

### 4.3 HIV Testing in Uganda

Recognising the vital role that testing plays in preventing the spread of HIV, Uganda was the first country in sub-Saharan Africa to open a voluntary counselling and testing (VCT) clinic.<sup>55</sup> A broad range of HIV/AIDS education and awareness campaigns in Uganda since 1986 resulted in many Ugandans asking the question 'Am I infected?' and this led to a growing demand for HIV testing.<sup>56</sup> In 1999 the Ugandan Ministry of Health started a voluntary door-to-door HIV screening programme using HIV rapid tests in an effort to reduce the spread of HIV. This effort was intended to make HIV screening services accessible to more people, especially in rural areas where there were neither modern laboratories nor electricity to run standard HIV tests.<sup>57</sup>

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<sup>53</sup> See Epstein footnote 46 above, p. 160.

<sup>54</sup> Joint United Nations Programme on HIV/AIDS, Global Report: UNAIDS Report on the Global AIDS Epidemic, Geneva, Switzerland 2010.

<sup>55</sup> Moodie; Aboagye-Kwarteng; "Confronting the HIV epidemic in Asia and the Pacific: developing successful strategies to minimize the spread of HIV", *Journal of the International AIDS Society*, Vol 7:12, 1993 p. 1543-155. A clinic called AIDS Information Centre and pioneered the concept of voluntary HIV testing centres. This was a landmark initiative that has been adopted by African countries such as South Africa, Zimbabwe and Nigeria, and has been noted for its success.

<sup>56</sup> See Alwano-Edyengu and Marum footnote 23 above p.10.

<sup>57</sup> Karobwa; Gati; Okello; Mukhone; Ali, "Health Policies in Uganda", Compilation of Working Papers 2011, available at, [http://www.kas.de/wf/doc/kas\\_4009-1442-2-30.pdf?110628155649](http://www.kas.de/wf/doc/kas_4009-1442-2-30.pdf?110628155649), (accessed 19 June 2013).

Uganda had also begun to implement routine or 'opt-out' testing (whereby anybody who enters a health care facility is tested for HIV unless they specifically ask not to be tested). This approach differs from voluntary counselling and testing, which is client-initiated; both testing standards are, however, on a voluntary basis.<sup>58</sup> Routine testing trials had overwhelmingly positive results, which indicate that this style of testing identified those who are infected at an early stage and, therefore, increased their survival rate. The use of routine testing emerged after a survey was made at Mulago hospital in Uganda and a finding that half of medical-in-patients with HIV related diagnosis left the hospital without having undergone HIV counselling and testing (HCT).<sup>59</sup>

It is clear that the Guideline on provider-initiated HCT at health care facilities, released by WHO in May 2007, recommended that testing should be part of a standard medical assessment for all persons during widespread HIV epidemics.<sup>60</sup> Uganda clearly had international support on the use of this comprehensive preventative care strategy and the number of people being tested clearly increased in urban hospitals, especially in Mbarara and Mulago. The latter hospitals demonstrated that provider-initiated free HCT was feasible and highly acceptable. Routine HCT identified a large number of undiagnosed HIV infections and HIV-discordant partnerships among patients and their families.<sup>61</sup> The United States Centre for Disease Control and Prevention (CDC) also revised HCT guidelines to recommend routine screening for HIV infection in health care settings for individuals aged 13-64 years.<sup>62</sup>

From November 2004, routine free HIV testing and counselling had been offered to improve testing coverage and the clinical management of patients. All patients in participating units who had not previously tested HIV-positive were offered HIV

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<sup>58</sup> Wanyenze; Kanya; Liechty; Ronald; Guzman; Wabwire-Mangen; Mayanja-Kizza; Bangsberg "Inpatient HIV counselling and testing practices at an urban hospital in Kampala, Uganda", *AIDS Behav*, Vol 10, 2006 p.361-7.

<sup>59</sup> *Ibid.*

<sup>60</sup> UNAIDS/WHO "Guidance on provider-initiated HIV testing and counselling in health facilities", Geneva 2007.

<sup>61</sup> Wanyenze; Nawavvu; Namale; Mayanja; Bunnell; Abang; Amanyire; Sewankambo; and Kanya; "Acceptability of routine HIV counselling and testing, and HIV seroprevalence in Uganda hospitals", *Bulleting of the World Health Organisation Vol 86*, 2008, p. 304.

<sup>62</sup> Branson; Handsfield; Lamp; Janssen; Taylor; Lyss; "Revised recommendations for HIV testing of adults, adolescents and pregnant women in health care settings", *MMWR Recomm Rep 55 RR14*, 2006, p.1-17.

testing and further family members of patients seen at the hospitals were also offered testing.<sup>63</sup> A study in two large Ugandan hospitals with a high HIV prevalence burden found a high rate of routine testing uptake with only 5 per cent of people refusing to take the test.<sup>64</sup> In 2007, HIV testing and counselling was available in 554 health facilities in the country. By the end of 2008, this number had risen to 812 and increased further to 1 904 in 2010.<sup>65</sup>

Uganda delivered HIV testing and counselling to an estimated 2 654 683 people aged 15 years and older in 2010.<sup>66</sup> It is thus without doubt that both counselling and testing are key components of HIV prevention and care programmes. This approach has more advantages as demonstrated by the Uganda situation which other African countries should be encouraged to emulate. Through HIV counselling and testing (HCT), uninfected individuals can take steps to avoid becoming infected, while infected individuals can avoid transmission of HIV to sexual partners or children.<sup>67</sup> Further, HCT is the first referral step to care and support service. It has also become important for preventing mother-to-child transmission and increasing access to HIV/AIDS care, including antiretroviral-therapy (ART).<sup>68</sup> The availability of HCT as a preventative measure cannot be over-emphasized as it is estimated that worldwide over 90% of HIV infected individuals are still unaware of their status.<sup>69</sup> In Uganda, 15% of the general population have received HCT, while more than 70% would like to be tested.<sup>70</sup>

A survey at Mulago hospital in Uganda found that half of the medical in-patients with HIV related diagnoses left hospital without HCT. It has thus been proposed that offering HCT routinely in health care settings will increase access to care.<sup>71</sup> Routine HCT is initiated by health care providers and offers testing to all patients irrespective

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<sup>63</sup> See Wanyenze, *et al*, footnote 61 above, p. 302-309.

<sup>64</sup> *Ibid.*

<sup>65</sup> *Ibid.*

<sup>66</sup> WHO/UNAIDS/UNICEF, "Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector" 2009.

<sup>67</sup> De Zoysa; Philips; Kamenga; O'Reilly; Sweat; and White; " Role of HIV counselling and testing in changing risk behaviour in developing countries", *AIDS Suppl (A)* 1995, p. 95-101.

<sup>68</sup> WHO/UNAIDS Report, "Emergency scale-up of antiretroviral therapy in resource limited settings: Technical and operational recommendations to achieve 3 by 5, Zambia consultation Geneva 2003.

<sup>69</sup> WHO/UNAIDS Policy Statement on HIV Testing: Geneva 2004, available at <http://www.who.int/hiv/pub/vct/en/hivtestingpolicy04pdf>, (accessed 26 March 2012).

<sup>70</sup> WHO/UNAIDS technician consultation on voluntary HIV counselling and testing: "Models for implementation and strategies for scaling of VCT services", July 2001, Harare, Zimbabwe 2001.

<sup>71</sup> Wanyenze; Kanya; Liechty; Ronald; Guzman; Wabwire-Mangen; "Inpatient HIV counselling and testing practices at an urban hospital in Kampala, Uganda", *AIDS Behav Vol. 10*, 2006, p. 361-7.

of their illness.<sup>72</sup> This approach differs from VCT which is client initiated. The guidelines on provider-initiated HCT at health care facilities, released by WHO in May 2007, recommended that testing should be part of standard medical care for all patients during widespread epidemics.<sup>73</sup>

A pertinent question that can be raised is whether routine HIV/AIDS prevention and care strategy is the ultimate testing policy that Africa can adopt. There is no question that it might have been the contributory factor to the Uganda HIV/AIDS success story. There is no legal obstacle to the state introducing a policy of routine HIV testing provided that the testing process meets the requirement of lawfulness and informed consent.<sup>74</sup> However, as pointed out by Strode, a key issue would be whether a routine offer for HIV testing with the option of opting in or out of testing will enable patients to act voluntarily. Consent may not be induced by fear, force, fraud, undue influence, perverse incentives or financial gain.<sup>75</sup> Careful consideration must then be given to gender issues, power imbalances and other subtle factors that may affect patient autonomy.<sup>76</sup>

It is important to note that in as much as routine testing might have been able to increase the number of people testing for HIV/AIDS in Uganda, thus combating the pandemic to an extent, the other side of the coin should also be considered. Patients could be abused if clear guidelines and procedures are not put in place and, further, patients may be coerced into taking an HIV test without having full knowledge of the procedure and its impact due to the imbalance of power between the provider and client.<sup>77</sup> For example, in Botswana organisations like the Botswana Network on Ethics, Law and HIV and AIDS (BONELA) have argued that the 'opt-out' policy has evolved into a policy of routine testing with minimal counselling but with subtle coercive pressures to deter people from opting out. Furthermore, although this policy might be reaping short-term benefits by identifying people in need of treatment, its

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<sup>72</sup> See Alwano-Edyegy; Marum, footnote 23 above.

<sup>73</sup> WHO/UNAIDS, "Guidance on provider-initiated HIV testing and counselling in health facilities" Geneva 2007.

<sup>74</sup> Strode, Van Rooyen and Heywood, "Scaling up HIV testing in resource constrained settings: Debates on the role of VCT and Routine 'Opt in or Opt out' HIV Testing" *The South African Journal of HIV Medicine* Vol. 2, 2005, p. 46-49.

<sup>75</sup> Van Oosten, "The Law and ethics of information and consent in medical research", *Journal of Contemporary Roman Dutch Law* Vol 63, 2000, p. 5-31.

<sup>76</sup> See Strode *et al*, footnote 74 above, p. 42.

<sup>77</sup> *Ibid* p. 46.

longer term consequences are likely to be poor adherence to treatment as well as continued misunderstanding about HIV.<sup>78</sup>

It has also been pointed out that many developing countries do not have the means to effectively apply new strategies like routine or opt-out testing which health care workers offer.<sup>79</sup> Taking the 'V' and 'C' out of VCT limits the prevention and risk reduction outcomes that are so critical within HIV and AIDS. Furthermore, there is little empirical evidence to support the belief that removing the voluntary informed consent and counselling components of VCT will lead to greater uptake of ARVs in developing countries.<sup>80</sup> VCT, in contrast, provides a significant prevention opportunity for dissemination of accurate information about HIV/AIDS, for risk assessment and risk reduction counselling (regardless of serostatus), and for information and referral to medical services specific to the treatment of associated infections such as sexually transmitted diseases or opportunistic infections such as tuberculosis.<sup>81</sup> The writer, therefore, submits that rights-based Voluntary Counselling and Testing is ideal for the African setting. More work still has to be done in terms of raising awareness and making the public understand the destruction HIV/AIDS has done to the African continent, and that more harm can still be done if people continue to be reckless, or pursue the ideology 'that it will never happen to me'; resent HIV testing; or stigmatise and discriminate against those infected.

Strode *et al.*, however, postulate that there is some synergy between models for HIV testing and these could be used to promote access to VCT. The latter authors further argue that a routine offer of HIV testing should be made to those considered at risk of HIV, e.g. those attending sexually transmitted infection clinics, pregnant women, and those presenting to health services with signs and symptoms of advancing HIV disease, including tuberculosis. The above authors recommended that in making public health policy decisions on models for HIV testing, governments should be:

- cognisant of the context;
- not compromise many gains that have been made over the years with regard to human rights;

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<sup>78</sup> *Ibid.*

<sup>79</sup> *Ibid.*

<sup>80</sup> UNAIDS Global Reference Group on HIV/AIDS and Human Rights: Issue Paper, "Current Debates on HIV Testing and Counselling", Geneva 2003 p. 2.

<sup>81</sup> See Strode *et al* footnote 74 above, p. 47.

- foster evidence-based decision-making which requires the establishment of the relationship between HIV testing and prevention outcomes; determine the relationships between VCT and ARV uptake and HIV testing and ARV uptake; and identifies whether the ‘V’ and the ‘C’ are really causing the bottleneck to testing;
- ensure that HIV testing is expanded to those who are asymptomatic;
- understand and address the reasons for the low uptake of VCT in developing contexts based on a thorough gender analysis; and
- compare the different models of HIV testing being provided to establish uptake through each, and understand better the decision-making process in each setting, the role of different levels of coercion or voluntariness on decisions to test; and the consequences thereof.

In Uganda VCT has been, and remains, the primary approach for the delivery of HIV/AIDS counselling and testing. This is not, however, the only approach practised in the country. VCT is supplemented by the Provider-Initiated Counselling and Testing (PICT) which is conducted routinely as part of the health services. Its major difference with VCT is that it shifts the burden of seeking services from the individual to the service provider.<sup>82</sup> HIV testing and counselling services are offered to a patient during the clinical evaluation of all patients along with any other tests or investigations being recommended to the patients.<sup>83</sup> In essence HIV testing will form part of the routine check-up, similar to blood pressure, temperature, sugar levels and urine tests. VCT as well as PICT comply with the 3 C’s principles, namely, voluntary counselling and testing.

#### **4.4 Barriers to Voluntary Counselling and Testing**

A joint study conducted by the US Centre for Disease Control and Prevention and the AIDS Information Centre of Uganda in 1997 reviewed a broad range of ethical, social policy, technical and economic issues that cause an impact on the HIV

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<sup>82</sup> Ministry of Health, Republic of Uganda, “National Policy on HIV Counselling and Testing” 2005. The introduction of the policy states that the policy is issued with a view to enhance diversification of HIV testing approaches that include Provider Initiated Testing and Counselling. These approaches are designed to remove the barriers to testing, treatment, care and support imposed by the VCT approach.

<sup>83</sup> *Ibid.*

prevention services.<sup>84</sup> The investigation established that some of the barriers that impact on or affect successful HIV prevention in developing countries include:

- widespread fear of taking an HIV test;
- potential for increased violence, loss of security, discrimination and isolation as a result of sharing information about HIV seropositivity;
- scarce economic resources and competing priorities; and
- lack of access to drug therapies and psychosocial clinical care.

There has been growing frustration about the failure of global efforts to address the spread of the HIV pandemic, and the focus should now shift towards considering other factors that seem to escalate the spread of the virus. The ARV needs of sub-Saharan Africa remain disproportionately high. About 4.2 million people in need of treatment were without access to ARV therapy.<sup>85</sup> In countries such as the Democratic Republic of Congo, Ghana and the United Republic of Tanzania, ARV therapy coverage was below 5%.<sup>86</sup> In contrast, about 70% of the estimated 15 310 people living with HIV in Australia in 2005 were receiving antiretroviral treatment.<sup>87</sup> Some individuals even without access to treatment may have incentives to know their HIV serostatus. However, the logic of undergoing testing when there is clear evidence of non-access to treatment may seem perverted at best to many people.<sup>88</sup> Hence scaling up access to treatment is a vital step towards encouraging testing in sub-Saharan Africa and dispelling the misconception that HIV/AIDS is a “death sentence”, a misconception that increases fear and obstructs testing.<sup>89</sup>

A second factor that has serious negative effects on HIV/AIDS testing in sub-Saharan Africa are the health systems which are abysmally weak and characterised by inadequate health workforces, poor management, and insufficient resource

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<sup>84</sup> Campbell; Marum; Alawano-Edyegu; Dillon; Moore; and Gumisiriza; “The Role of HIV Counselling and Testing in Developing World, *AIDS Education and Prevention Supplement 9(B)* 1997.

<sup>85</sup> Asante, National Centre in HIV Social, Research University of New South Wales, Sydney Australia, 2007.

<sup>86</sup> WHO “Progress on global access to HIV antiretroviral therapy, an update on “3 by 5”, Geneva 2005, available at, <http://www.catalegbeg.cultura.gencat.cat/.../C-Rb1291322-SGlobal%20Program>, (accessed 14 April 2012).

<sup>87</sup> Annual Surveillance Report, “HIV/AIDS, Viral Hepatitis and Sexually Transmitted Infections in Australia Sydney” National Centre in HIV Epidemiology and Clinical Research (NCHECR), University of New South Wales 2006.

<sup>88</sup> Schoepf, “Uganda: lessons for AIDS control in Africa, *Rev Afr Polit Econ Vol. 98*, 2003, p.553-72.

<sup>89</sup> *Ibid.*

allocation and utilisation, severely weakening their capacity to cope.<sup>90</sup> It has thus been pointed out that with such a health system, even if anti-retroviral drugs were available, distribution to all those in need of treatment still remains a problem in most countries.<sup>91</sup> Poor working conditions and low salaries have also triggered a wave of migration of health professionals from sub-Saharan Africa to the West. In Ghana, for example, about 61% of doctors trained locally between 1984 and 1995 left the country.<sup>92</sup> Data from Zambia and Zimbabwe show a similar trend of attrition from public sector health employment, with losses as high as 15-40% per annum.<sup>93</sup> It is clear that the issue of the brain drain has affected and undermined the HIV/AIDS prevention and care strategy and, as a consequence, mandatory testing may not be successful after all. It has been observed that African countries must nearly triple their current numbers of the health work force by adding the equivalent of one million health professionals through retention, recruitment and training if they are to come close to approaching the Millennium Development Goals set for health.<sup>94</sup>

Thirdly, the culture of health service utilization in Africa raises concerns about the feasibility of routine or mandatory HIV testing.<sup>95</sup> It is believed that Africans in general and the poor among them in particular do not resort to the use of health services unless they are very sick or there is a specific need.<sup>96</sup> Studies have shown that even in times of infirmity, self-medication and the use of traditional medicine are usually the first line of action.<sup>97</sup> A key consequence of this practice is the high incidence of late HIV/AIDS diagnosis across Africa and among African immigrants overseas.<sup>98</sup> Marum further suggests that in order for routine or mandatory testing or any other policy that focuses on health care settings to have the maximum impact in Africa, a

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<sup>90</sup> World Health report, "Health systems: improving performance" Geneva 2000, available at, <http://www.who.int/whr/2000>, (accessed 14 April 2012).

<sup>91</sup> See Alwano-Edyengu and Marum footnote 23 above, p. 644.

<sup>92</sup> Asante, "Scaling-up HIV prevention: Why routine or mandatory testing is not feasible for sub-Saharan Africa", *Bulleting of World Health Organisation*, Vol 85:8, 2007.

<sup>93</sup> *Ibid.*

<sup>94</sup> Chen; Evans; Anand; Boufford; Brown; and Chowdhury, "Human Resources for health: overcoming the crisis" *The Lancet Vol 364*, 2004, p. 1984-90, available at, <http://www.thelancet.com>, (accessed 14 August 2012).

<sup>95</sup> See Alwano-Edyegu and Marum footnote 23 above, p.645.

<sup>96</sup> Criel, "District based health insurance in Sub-Saharan Africa in studies in Health Services Organisation and Policy", *Institute of Tropical Medicine Issue 10*, 1998.

<sup>97</sup> WHO, "Promoting the role of traditional medicine in: Health system, a strategy for African Region" 2001-2010, Harare: 2000.

<sup>98</sup> See Marum and Alwano-Edyegu footnote 23 above.



massive educational effort on health care use is essential and, in addition, the removal of financial and other barriers to accessing health care.

Lastly, stigma and discrimination is another factor that is inseparable from the HIV/AIDS pandemic and it has seriously affected progress in combating this epidemic. A study in Botswana and Zambia revealed that the stigma against HIV positive persons and fear of discrimination were the key reasons for the low uptake of VCT to prevent mother-to-child transmission of the virus.<sup>99</sup> It is thus clear that the issue of stigma and discrimination must be addressed so that people can comfortably test in order to know their status without any fear of isolation and discrimination.

In as much as these barriers still persist and have a negative impact on the HIV/AIDS prevention and care strategies, experience in Uganda has shown that VCT has played, and still plays, an important role in that country's comprehensive HIV prevention strategy. This has clearly benefited both the HIV-negative and HIV-positive clients.<sup>100</sup> The major theme expressed by the AIDS Information Centre of Uganda which is quite interesting is that "*Knowledge is Power*".<sup>101</sup> The society has to come to an understanding that HIV/AIDS is not a death sentence; it can be prevented and controlled. It is high time that people believe in testing and knowing their status so that Africa can economically and socially grow with the influence of an HIV free generation.

An important fact is that Africa's AIDS epidemic spread in a different manner compared with the epidemic in the West. The Western epidemic was mainly contained in the male homosexuals and intravenous drug populations, while Uganda's epidemic was mostly driven by concurrent heterosexual relationships, gender inequalities, and high levels of sexually transmitted infections and decades of oppression. Africa's colonial history is perceived to have created an ideal environment for the spread of AIDS.<sup>102</sup> The decades of colonial rule created export-

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<sup>99</sup> Nyblade, Field, "Women communities and the prevention of mother to child transmission of HIV: Issues and findings from community research in Botswana and Zambia" 2002, available at, [http://www.icrw.org/publications\\_hivaids.htm](http://www.icrw.org/publications_hivaids.htm), (accessed 22 October 2012).

<sup>100</sup> This finding comes from the findings and experiences of the AIDS Information Centre of Uganda (AIC). AIC has played a profound role in Uganda as it is the organisation that facilitated testing, counselling and prevention of HIV/AIDS in Uganda.

<sup>101</sup> AIDS Information Centre of Uganda which was established in 1980.

<sup>102</sup> See Epstein footnote 11 above, p. 160.

oriented economies that resulted in an increasingly marginalised peasant labour force, the social disorganisation of rural society, a growing urban labour force and the emergence of squalid slums surrounding major cities with contingent high rates of unemployment and prostitution.<sup>103</sup> Further, Uganda's civil war, widespread urban and rural poverty and failure of the government and the health care system were some of the major factors that contributed to the spread of HIV in the country.

Data on HIV prevalence indicate that Africa's HIV and AIDS epidemic followed a sharp curve in the 1990s, followed by stabilization and small declines. The epidemic grew very fast but declined slowly while the number of people living with HIV and AIDS is still increasing. This is due in part to population growth offsetting the small declines in prevalence and partly due to the availability of treatment which prolongs the lives of people living with HIV and AIDS. In turn, this means that the number of people falling sick with AIDS related illness and dying from other diseases' is still rising.<sup>104</sup>

#### **4.5 Current Statistics and Position of HIV/AIDS Infections in Uganda**

Statistical data will be highlighted in this section since data suggests either signs of decline or increase in HIV prevalence among the population of Uganda. Subsequently it can be established which policies are in fact working or not working and this is extremely important in the fight against HIV/AIDS. Uganda's prevalence rate declined gradually to 18 per cent in 1992; 10,6 per cent in 1997; 6,7 per cent in 2001; and 6,4 per cent in 2008. The present statistics reflect that there is an estimated 1.2 million people living with HIV in Uganda, which includes 150 000 children.<sup>105</sup> An estimated 64 000 people died from AIDS in 2009 while 1.2 million children have been orphaned by Uganda's devastating epidemic.<sup>106</sup> However, the country's HIV/AIDS Strategic Plan bleakly predicts that the numbers of HIV infections will rise from 1.2 to 1.3 million in 2012 and the infection rate is predicted to increase from 6.4 to 7.3 per cent in 2012.<sup>107</sup> Abbas estimates that such a rise in the prevalence rate could cost Uganda 1.2 per cent of its Gross Domestic Product

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<sup>103</sup> *Ibid.*

<sup>104</sup> UNAIDS, "The Impact of Voluntary Counselling and Testing: A Global Review of the Benefits and Challenges Geneva, UNAIDS 2001.

<sup>105</sup> Government of Uganda , "UNGASS country progress report: Uganda", March 2010.

<sup>106</sup> UNAIDS "UNAIDS report on the global AIDS epidemic" 2010.

<sup>107</sup> Abbas, "Premier Thoughts" The CSUB Blog, Economic Research Centre, available at <http://www.csub.edu/kej>, (accessed 03 September 2012).

(GDP) in the next five years. This is yet another severe impact of the HIV/AIDS pandemic leading to a decline in productivity due to the shortage of an able-bodied workforce. People infected with the virus are either sick and bed ridden or dead. It has also been suggested that, “When AIDS patients eventually start falling sick, you don’t treat them once like you treat malaria and they recover; it is like you have incurred a debt, you must continue servicing the debt”.<sup>108</sup>

#### **4.6 Botswana Government’s Response to the HIV/AIDS Crisis**

Having examined the response and efforts of the Uganda government, we now turn to examine the response of the Botswana government to the HIV/AIDS pandemic. Botswana has the highest Gross National Product (GNP) per capita in sub-Saharan Africa and an impressive record of democratic governance and a relatively stable health infrastructure. Overall, 75 percent of Botswana’s citizens and 95 percent of its women receiving antenatal care have regular access to health care, a figure far higher than in many other developing countries.<sup>109</sup> Despite these positive factors, Botswana, with a population of 1.7 million people and with no medical school, has one of the highest HIV-prevalence rates in the world at over 35 percent, with at least 350 000 people estimated to be HIV infected, most of them in the 15-49 year old range.<sup>110</sup>

Prompted by the high prevalence of HIV infections, President Festus Mogae proclaimed that the government of Botswana has to respond assertively.<sup>111</sup> Of great significance is the fact that the government of Botswana recognised and supported the HIV/AIDS issue as soon as the first case was diagnosed in the country, which is very similar to the response of the Ugandan government.<sup>112</sup>

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<sup>108</sup> These were words spoken by Dr. Peter Okwero, Senior Health Specialist at the World Bank in Uganda, quoted in Abbas footnote 108, p. 3.

<sup>109</sup> Nieburg; Cannell; and Morrison, “Expanded HIV Testing: Critical Gateway to HIV Treatment and Prevention Requires, Major Resources, Effective Protections”, 2005, p. 7, available at, [http://www.csis.org/files/media/csis/pubs/0501\\_expandedhivtesting.pdf](http://www.csis.org/files/media/csis/pubs/0501_expandedhivtesting.pdf), (accessed 03 September 2012).

<sup>110</sup> Preliminary data from Gaborone, Botswana, suggest that the national HIV prevalence may be lower than previously thought. These data have yet to be completely analyzed and yet to be reconciled with earlier data.

<sup>111</sup> Botswana National Policy on HIV/AIDS approved and adopted by Government through Presidential Directive CAB: 35/93, 17 November 1993.

<sup>112</sup> Kasfir, “Addressing HIV/AIDS in South Africa and Uganda”, 1990, available at <http://wescholar.wesleyan.edu/cgi/viewcontent.cgi>, (accessed 14 October 2012).

A one year national emergency plan was set up in 1987, and this was followed by a series of 5 year strategic plans.<sup>113</sup> Various International Organisations also offered their assistance. WHO, United States Agency for International Development (USAID), inter-governmental organisations and NGO's collaborated with the Botswana Ministry of Health in setting up programmes aimed at disease surveillance and control.<sup>114</sup> HIV/AIDS awareness was promoted among the people as an attempt to change peoples' sexual behaviour. The first national campaign in 1988 used radio messages, car bumper stickers and T-shirts to get messages across.<sup>115</sup> However, by the mid-1990s, education campaigns were no longer pursued with much vigour and, by the end of the decade, there was minimal public discussion of the problem.<sup>116</sup> All that was seen around the capital, Gaborone, were white vans with 'Lovers plus Condoms' emblazoned on the side and large billboards which proclaimed that 'Avoiding AIDS is as easy as ABC, Abstain, Be faithful, Condomise'.<sup>117</sup> The population did not clearly understand the meaning of the latter concept and there was surprisingly little understanding or awareness of what was happening.<sup>118</sup>

Allen and Heald state that the failure of Botswana's strategies could be attributed to the manner in which the Government responded to the threat which meant that people had to believe in the health promotion messages before they had any experience of the disease in their own lives.<sup>119</sup> People thus became sceptical about what they were being told and AIDS became known as the 'radio disease'. In contrast, preventative strategies that were implemented by the government in Uganda seemed to work because people had seen fellow members of the society dying as a result of HIV and this induced change in people's behaviour in order to escape contracting the virus. It has also been suggested that in Botswana there is a

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<sup>113</sup> Averting HIV/AIDS, "HIV/AIDS in Botswana", available at <http://www.avert.org/aids-botswana.htm>, (accessed 29 September 2012).

<sup>114</sup> Allen, Heald, " HIV/AIDS Policy in Africa: What has worked in Uganda and what has failed in Botswana, *Journal of International Development Vol. 16, 2004*, p. 1141-54.

<sup>115</sup> Parkhurst, "The Ugandan success story: Evidence and claims of HIV-1 prevention" *The Lancet*, 360,2002, p.78-80, available at <http://www.thelancet.com> (accessed 14 April 2012)

<sup>116</sup> Ahmed; Lutalo; Wawer; Serwadda; and Sewankambo "HIV incidence and sexually transmitted disease prevalence associated with condom use: a population study in Rakai, Uganda" *AIDS Public Med Journal Vol. 15, 2001*, p. 2171-2179.

<sup>117</sup> See Allen and Heald, footnote 114 above, p.1141-48.

<sup>118</sup> *Ibid.*

<sup>119</sup> Allen and Heald further point out that the British campaign of 1988 met similar difficulties and has served since to undermine credence in Government health campaigns in areas of sexual health. The difference is that the British population at that time did not have any significant level of HIV infection. The tragedy is that Botswana did.

deep seated unwillingness to talk openly about sex. This is partly due to traditional rules of respect that lie at the heart of family and kinship structures which limit communication across generation and sexual divides.<sup>120</sup>

#### **4.7 HIV/AIDS Policy and Practice in Canada**

In early 2002, Canada introduced a mandatory HIV/AIDS policy which is an HIV policy that applied to all permanent and some temporary resident applicants to Canada over the age of 15 years.<sup>121</sup> This practice, however, had serious human rights implications as will be shown below in this section. However, there is no systematic documentation of the policy's implications on either the lives of persons who submit to mandatory testing or on health systems.<sup>122</sup> It is clear that the HIV testing policy and associated practices give rise to serious and significant challenges in the lives of HIV positive immigrant and refugee applicants, which must be understood as socially produced and set within the broader social and political contexts of which they are part.<sup>123</sup>

##### *4.7.1 Background to the Mandatory Screening Policy*

It must be pointed out at the outset that there is no reference to HIV/AIDS in the Canadian Immigration and Refugee Protection Act (hereafter referred to as the Act) or the Canadian Immigration and Refugee Protection Regulations (hereafter referred to as the Regulation).<sup>124</sup> In Canada, since 1991, people living with HIV/AIDS were not considered a danger to public health or safety by virtue of their HIV status.<sup>125</sup> There were, however, changes made to the Act and Regulations late in 2001 which took effect on 15 January 2002. They required all applicants for Canadian permanent residency to undergo serologic HIV testing. Tuberculosis and syphilis are the two

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<sup>120</sup> *Ibid.*

<sup>121</sup> Bisailon, "Human rights consequences of mandatory HIV screening policy of newcomers to Canada Health and human rights:" *An International journal Vol 12:2*, 2010. Bisailon points out that this HIV testing policy applies to all persons aged 15 years old who request Canadian permanent resident status (such as immigrant and refugee persons and temporary resident status (such as migrant workers, students and long term visitors from certain countries.

<sup>122</sup> *Ibid.*

<sup>123</sup> Bisailon, "Mandatory HIV screening policy and Everyday Life: A look Inside the Canadian Immigration Medical Examination", *Aporia The Nursing Journal Vol 3 Issue 4* 2010, p. 5-14.

<sup>124</sup> Immigration and Refugee Protection Act of 2001 and the Immigration and Refugee Protection Regulations (SOR/2002-227).

<sup>125</sup> Bailey; Caulfield; and Ries, "Public health law and policy in Canada" Lexis Nexis 2005.

other conditions for which applicants are mandatorily screened.<sup>126</sup> It is clear that there was no HIV testing prior to 2002, and this represented the first change to the immigration medical examination in approximately fifty years.<sup>127</sup>

Section 38(1) of the Act provides that an applicant for permanent or temporary residency can be deemed medically inadmissible and denied a Canadian visa based on medical conditions if 1) she/he is likely to be a danger to public health or public safety, or 2) she/he might reasonably be expected to cause excessive demand on public health and social services. Canada generally excludes people with HIV/AIDS only if they are expected to place an “excessive demand” on publicly funded health or social services. “Excessive demand” is defined to mean either more than the cost of such services for the average Canadian (calculated at \$4 078 per year in 2004), or a demand that would lengthen waiting lists for services so as to affect the mortality of Canadians.<sup>128</sup> There is no doubt that this legislation was carefully crafted to ensure Canada’s economic protection as well as protection of its citizens. A pertinent question that arises is whether immigrants who are HIV positive are ‘less human’ to such an extent that they cannot enjoy the same benefits of entry into another country as any other person who is HIV negative. The underlying factor is that such discrimination based on HIV status is unfair and unjustifiable in any country that claims to be democratic.

HIV screening, which takes place during the immigration medical examination carried out in Canadian foreign medical offices, is a mandatory component of Canada’s immigration policy process. This serologic screening programme is ‘unique’ because its public health goals are said to include health promotion rather than the exclusion of persons living with HIV/AIDS.<sup>129</sup> In as much as this policy might reduce the economic burden of the country, there are, however, serious human rights and ethical concerns at stake as coercion is clearly evident in two instances:<sup>130</sup>

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<sup>126</sup> Canadian HIV/AIDS Legal Network, “Canada’s immigration policy as it affects people living with HIV/AIDS, Toronto, Canadian HIV/AIDS Legal Network, 2011, p.1-8.

<sup>127</sup> See Bisailon, footnote 121.

<sup>128</sup> Canadian HIV/AIDS Legal Network, “Evolution of HIV testing policy and technology in Canada”, Canadian HIV/AIDS Legal Network 2007, available at <http://www.aidslaw.ca/testing>, (accessed 24 June 2012).

<sup>129</sup> Zencovich; Kennedy; MacPherson; Gushulak “Immigration medical screening and HIV infection in Canada”, *International Journal of STD and AIDS* 17, 2006 p. 813-820.

<sup>130</sup> *Ibid.*

- requiring HIV testing as a condition of obtaining a certain status, service or benefit, such as employment or health services (mandatory testing), or
- compelling or forcing a person or a group people to be tested, such that the person cannot choose to refuse testing and cannot legally avoid it (compulsory testing).<sup>131</sup>

The Canadian HIV/AIDS Legal Network promotes the human rights of people living with and vulnerable to HIV/AIDS in Canada and internationally through research, legal and policy analysis, education and community mobilisation. It further supports access to quality HIV testing and counselling and access to care, treatment and support for those who may be exposed to the risk of HIV infection, whether occupationally or otherwise.<sup>132</sup> Both globally and within Canada, human rights-based responses to HIV/AIDS have been broadly endorsed.<sup>133</sup> Human rights should thus be at the centre of all policy decisions relating to testing. It is clear that Canada is aware of this requirement, especially the concerns raised on its immigration mandatory HIV testing policy, which does not conform to the fundamental values of consent and counselling.<sup>134</sup>

Forced testing violates the legal and ethical principle of informed consent. The legal doctrine of informed consent reflects the fundamental principle of respect for persons and their autonomy. HIV testing without consent is never justified as consent. The latter is one of the underlying values for HIV testing, though it is argued that there are circumstances in which the protection of the public's health justifies mandatory testing but these circumstances appear in slim cases. Governments should always aim to maintain a balance between the realisation of human rights and the attainment of public health policies. The Supreme Court of Canada has repeatedly recognized that a person cannot be subjected to medical procedures without his or

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<sup>131</sup> Canadian HIV/AIDS Legal Network, "Evolution of HIV testing policy and technology in Canada", Canadian HIV/AIDS Legal Network 2007, <http://www.aidslaw.ca/testing>. (accessed 24 June 2012).

<sup>132</sup> Canadian HIV/AIDS Legal Network, "The proposed Mandatory Testing and Disclosure Act". An unjustified and Unnecessary Violation of Rights. A submission to the Yukon Department of Justice and members of the Legislative assembly, 2009.

<sup>133</sup> International Guidelines on HIV/AIDS and Human Rights, 2006 Consolidated Version, Geneva UNAIDS.

& Office of the UN High Commissioner for Human Rights 2006.

<sup>134</sup> The three C's approach has become the accepted rights based approach to HIV testing, shown to be effective and endorsed by the expert technical agencies of the United Nations, See UNAIDS/WHO Policy statement on HIV Testing, Geneva 2004.

her informed consent.<sup>135</sup> Informed consent means that sufficient information is provided to enable the patient to make an informed decision, and that the patient actually understands the information and implications of acting on that information.<sup>136</sup>

For a long period of time international guidelines repeatedly rejected the practice of restricting the mobility of people living with HIV/AIDS based on their health status.<sup>137</sup> However, to the surprise of many, in the 1990s Commonwealth countries such as the United Kingdom, New Zealand, Australia and Canada reviewed their domestic immigration policies and within a short space of time these countries and others worldwide, enacted various HIV specific legislation and policies that included restrictions on entry and immigration of people with HIV/AIDS.<sup>138</sup>

In the case of Canada the testing practice is managed by Citizenship and Immigration Canada (CIC) and it has been documented that the foreign and domestic medical offices carry out up to 550 000 examinations annually.<sup>139</sup> The overall number of HIV-positive applicants admitted to Canada is very small relative to the population increase through immigration and the resident HIV-positive population.<sup>140</sup> Since mandatory immigration screening was introduced in 2002, about 4 374 persons have tested HIV-positive during the Immigration Medical Examination (IME).<sup>141</sup> CIC agents deemed 453 of these people inadmissible for a Canadian visa based on a hypothetical estimate of costs for their care over a ten year period. However, most immigrants with HIV who end up acquiring a visa to remain in Canada are persons who cannot be excluded under the law on the basis that they will prove to be burden on the economy: they compromise those people who apply as refugees or family class applicants. For instance, it is revealed that in 2006-2007,

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<sup>135</sup> See for example, the ruling in *Reible v Hughes 1980 2 SCR 990*.

<sup>136</sup> VCT Toolkit, "HIV Voluntary Counselling and Testing A Reference Guide for Counsellors and Trainers", Family Health International 2004, available at, [http://www.pdf.usaid.gov/pdf\\_docs/PNACW801.pdf](http://www.pdf.usaid.gov/pdf_docs/PNACW801.pdf), (accessed 03 November 2012). See also Knobel 'Consent, with particular reference to HIV and AIDS' *South Africa's Continuing Medical Education Monthly* 79, 2006, p. 24.

<sup>137</sup> International guidelines on HIV/AIDS and Human Rights, Geneva UNAIDS, 2006, Available at [http://www.data.unaids.org/Publications/IRC-PUB07/JC252-internguidelines\\_en.pdf](http://www.data.unaids.org/Publications/IRC-PUB07/JC252-internguidelines_en.pdf), (accessed 24 September 2012).

<sup>138</sup> Coker, "Migration, public health and compulsory screening for TB and HIV", London Institute for Public Policy Research, 2006.

<sup>139</sup> Citizenship and Immigration Canada, in April 2010 documented these figures.

<sup>140</sup> Canadian HIV/AIDS Legal network, "Canada's Immigration Policy as it affects people living with HIV/AIDS", Toronto Canadian HIV/AIDS Legal Network 2011, p.1-8.

<sup>141</sup> Citizenship and Immigration Canada, Access to Information and Privacy Division, Health Management Branch Database on HIV as of 15 May 2010.



about 1050 HIV-positive applicants sought permanent residence of which 994 were refugee or family class applicants.<sup>142</sup>

In 2000 when Health Canada recommended that CIC automatically exclude HIV-positive applicants based on health status, including refugees and refugee applicants who were protected under international law, there was an assumption that HIV positive migrants would spread the HIV virus to at least one Canadian resident.<sup>143</sup> In as much as the government was in support of this policy, mandatory testing is an exception under Canadian law. However, the Canadian HIV/AIDS Legal Network, the country's leading HIV, law and human rights organisation opposed mandatory testing and a blanket exclusion of prospective immigrants.<sup>144</sup> Forced testing raises numerous human rights concerns under the Canadian Charter of Rights and Freedoms.<sup>145</sup> It infringes the rights to liberty and security of the person (section 7); and the right to be free from unreasonable seizure (section 8). A person's right to privacy and dignity is reflected in both of these constitutional guarantees.

The late Jonathan Mann and colleagues wrote that HIV testing models, policies and protocols rooted in human rights principles are in the best interest of individual and collective public health goals; since health inequities are subsets of inequalities, as are human rights integral subsets of public health.<sup>146</sup> It is without doubt that the rights of those infected with and vulnerable to HIV/AIDS need to be protected when addressing public health imperatives, through the use of the law as an instrument of social change.<sup>147</sup> The adoption of HIV/AIDS-relevant public health practices that exist within a sound human rights framework can achieve measurable gains, as can be witnessed by countries such as Brazil where human rights were at the centre of its national response to HIV/AIDS. As a result of putting human rights at the centre of its policy, Brazil now legislates a universal access to ARV treatment for persons in

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<sup>142</sup> See Bisailon footnote 123 above p. 6-8.

<sup>143</sup> Klein, "HIV/AIDS and Immigration: Final Report, Toronto: Canadian HIV/AIDS Legal Network, 2001, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=853> (accessed 03 October 2012).

<sup>144</sup> Jurgens, "HIV Testing and Confidentiality: Final Report", Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998.

<sup>145</sup> The Canadian Charter of Human Rights, Enacted as Schedule B to the *Canada Act 1982*, 1982, c.11 (U.K.), which came into force on April 17, Section 7.

<sup>146</sup> Mann; Gruskin; Grodin; Annas (eds), "*Health and Human Rights: A Reader*", London Routledge, 1999, p. 54-71.

<sup>147</sup> *International Guidelines on HIV/AIDS and Human Rights*, 2006 Consolidated Version <http://data.unaids.org/Publications/IRC-pub/07/jc1252-internationalguidelines-en.pdf>, (accessed 16 August 2011).

need.<sup>148</sup> Lawrence Gostin and the late Mann produced a seven-point methodology for evaluating the human rights consequences of public health interventions.<sup>149</sup> It is, however, submitted that this seven-point methodology forms an important guideline for countries to follow when they contemplate implementing testing policies in order to avoid violation of human rights as is the case with the current Canadian policy. In summary, the steps adopted by Gostin and Mann are as follows:

#### *4.7.1.1 Clarification of the public health purpose*

The first of the seven points proposed by Gostin and Mann is that for a testing policy to be effective, the public health goals of the policy should be specific and should be understood by the public. They further point out that a precise conceptualisation of the purpose will more likely lead to sound and properly conceived policies as opposed to overbroad or vague objectives.<sup>150</sup> In contrast, they point out that the objectives and goal of the Canadian testing programme are inferred rather than explicitly stated in legislation or in the HIV policy. This is so as there is no reference to HIV/AIDS in the Canadian Protection Act or the Refugee Protection Regulations. The Act provides that an applicant for permanent and temporary residency can be deemed medically inadmissible and the person denied a Canadian visa based on medical conditions if 1) she/he is likely to be a danger to public health or public safety, or 2) she/he might reasonably be expected to cause excessive demand on public health and social services. Testing of applicants for permanent residence in Canada is simply for economic reasons and other ethical implications are dismissed. However, respect for the rule of law, human rights, and democratic accountability are some of the fundamental elements of a successful HIV/AIDS strategy.

#### *4.7.1.2 Evaluation of likely policy efficacy*

These two writers quoted above propose that the second step in the framework should be to “[a]ssess the probable effectiveness of the proposed measures, alone and in comparison with other available options, with reference to such questions as

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<sup>148</sup> Galvio, “Brazil and access to HIV/AIDS drugs: A question of human rights and public health”, *American Journal of public Health* Vol. 9, 2005 p. 110.

<sup>149</sup> Gostin and Lazzarini *Human Rights and Public Health in the AIDS Pandemic* New York: Oxford Press 1997 p.110.

<sup>150</sup> Gostin *et al.* p. 55 have a strong standpoint that clearly articulated goals help to identify the true purpose of the intervention, facilitate public understanding and debate around legitimate health purpose, and reveal prejudice, stereotypical attitudes, or irrational fear.

the accuracy of screening programmes. It further requires a careful and impartial examination of the facts and expert opinion, as well as consultation with the groups affected. Field research from Montreal and Toronto revealed that pre- and post-test counselling does not routinely occur.<sup>151</sup> Upon being called back to receive a positive diagnosis by the Designated Medical Practitioner (DMP), the majority of study informants in Montreal reported that the post-diagnosis encounter consisted of the DMP providing them with a referral slip on which there was contact information and directions to a hospital with expertise in HIV/AIDS treatment.<sup>152</sup> This is a huge irregularity when it comes to HIV testing as counselling is one of the fundamental principles of testing. Counselling guidelines for HIV testing<sup>153</sup> point out that serological testing for HIV without counselling has a psychological, medical and social impact on patients, and, therefore, testing must be preceded by appropriate counselling carried out by trained and experienced professionals.

When evaluating the effectiveness of policy, Gostin *et al.* propose that three questions should be asked. Firstly, “*Is the screening program appropriate and accurate?*” They thus conclude that no screening test is 100 per cent sensitive; all people with a condition have a positive test and 100 per cent specific, that is all, people without a condition have a negative test. In addition to the inherent characteristics of testing methods, there are several important sources of potential problems which include human error, as well as improper manufacture and storage of laboratory reagents. The second question to be asked is, “*Is the intervention likely to be effective?*” If a government establishes an aggressive programme for screening such as partner notification or isolation, this alone does not necessarily mean that the government is doing something about the problem. The real issue is whether the policy leads to effective action. Thirdly, a major question suggested is that a government should ask, “*Is there a better approach of giving effect to the policy?*” This is a major question that governments should investigate before imposing a potentially damaging policy such as the one adopted by Canada. A hasty decision to pursue comprehensive programmes of screening, contact tracing, or coercive

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<sup>151</sup> See Bisailon footnote 123 above, p.125.

<sup>152</sup> Herder, Mandatory HIV Testing *Canadian Medical Association Journal (CMAJ)* Vol 184:1, 2012 (accessed 13 March 2012).

<sup>153</sup> Canadian Medical Association (CMA), “*Counselling Guidelines for HIV testing*”, 1995.

measures impose more than financial and human rights burden as there are also opportunity costs that may be forgone in favour of a better alternative.<sup>154</sup>

#### *4.7.1.3 Determination whether the public health policy is well-targeted*

The Gostin seven-point methodology propounds a very important and exciting factor, namely, that public health strategies are tailored for those who will benefit from them. Thus, every policy creates a class of people to whom the policy applies and a class to whom it does not. It can be deduced from this factor that the Canadian screening policy may not be well targeted. The Canadian policy imposed HIV/AIDS testing on potential immigrants and refugees. Policies that target individuals because of their race, sex, religion, national origin, sexual orientation, economic, disability or homeless status often stem from invidious stereotypes. Sound public health policies must avoid such actions, both under and over inclusiveness.<sup>155</sup> However, certain under-inclusive policies may mask discrimination, for example, when a government uses coercive powers to target the politically powerless and vulnerable groups but not others that engage in similar behaviour. In this case immigrants are vulnerable and powerless and they have been discriminated against by the Canadian government. The Canadian HIV/AIDS Legal Network has since argued that it was unfair and inconsistent with the 1948 Universal Declaration of Human Rights to test citizens of foreign countries for a stigmatized health condition where the only purpose was possible immigration.<sup>156</sup>

#### *4.7.1 4 Examination of each policy for possible human rights burdens*

This fourth point in the model is said to be the most complex step of Gostin and Mann's methodology because it is where collective/individual and domestic/international human rights interests fall.<sup>157</sup> The human rights impact assessment involves a meticulous balancing of the potential benefits to the health of

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<sup>154</sup> See Mann *et al* footnote 146 above p. 57.

<sup>155</sup> Mann *et al.* explains that a policy is under inclusive when it reaches some, but not all, of the persons it ought to reach. For example, a government's provision of disease prevention and treatment services (e.g., safe sex education, condom distribution and health care. The latter authors clarify that under inclusiveness of this policy does not, however, necessarily reflect discrimination; it may simply indicate that particular countries' public health problems and priorities.

<sup>156</sup> Klein, "HIV/AIDS and Immigration: Final Report, Toronto: Canadian HIV/AIDS Legal Network, 2001, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=853>, (accessed 03 October 2012).

<sup>157</sup> Bisailon footnote 121 above, p. 126.

the community with the human rights repercussions of the policy. A human rights impact assessment is thus the examination of the alternative policies that burden human rights to a lesser extent, while still protecting the health of the community.<sup>158</sup> Identifying all potential infringements of human rights and evaluating those likely to occur will contribute to sound government action. Bisailon<sup>159</sup> states that several key domestic questions relate to the federal immigration HIV screening programme and these include: firstly, in whose interest are prospective applicants tested? and, secondly, for what explicit public health aim is HIV mandated as an integral feature of medical examination?

In answering these questions, it must be considered that human rights are essential to the dignity and wellbeing of people and, therefore, they must not be infringed, even if the country is in a declared state of public emergency and the public health need is extraordinarily strong.<sup>160</sup> Since 1991, HIV/AIDS has been de-listed as a condition posing a threat to Canadian public health and safety. This means that harsh policies such as mandatory testing should be disregarded and more focus should be given to the respect for the promotion and protection of human rights.

#### 4.7.1.5 *Determination of whether the policy is the least restrictive alternative to achieve the public health objective*

The fifth principle which is referred to as the least restrictive alternative, seeks a policy that is least intrusive while achieving the public health objective as well as or better than the policy under consideration.<sup>161</sup> Hoffmaster and Schrecker,<sup>162</sup> as quoted by Bisailon, propound that there is no evidence to indicate that mandatory testing is the least restrictive way to pursue public health goals. The latter author further asserted that evaluating policy responses that fully consider and respect

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<sup>158</sup> See Gostin's model p. 65. The model goes ahead to explain that, "in general, broad or intrusive human rights violations are seldom, if ever warranted. At the extreme, a public health approach that uses an effective means to achieve a compelling public health objective may sometimes warrant a limitation of human rights.

<sup>159</sup> *Ibid.*

<sup>160</sup> Oloya and Salewi, "*Human Rights Issues Pertinent to the HIV Epidemic in Africa*", A briefing paper for submission to: The Committee on the Protection of Rights of People Living with HIV and those at Risk, Vulnerable to the Affected by HIV, Centre for Human Rights, University of Pretoria 2011.

<sup>161</sup> *Ibid.*

<sup>162</sup> Hoffmaster and Schrecker, quoted by Bisailon in "*An ethical analysis of the mandatory exclusion of refugees and immigrants who test HIV-positive*", Ottawa: Health Canada 2000, p. 23, available at <http://www.aidslaw.ca/publications/>, (accessed 03 December 2012).

human rights is possible when its objectives and public health goals are explicit and clearly communicated a factor which has not been taken into account in the case of Canada's HIV testing policy. The rationale, purpose and objective of mandatorily testing of immigrants for HIV are not even stated clearly in the Immigration Act. A less restrictive alternative that respects human rights should have been sought. The human rights community has a duty to ensure that governments find alternatives that achieve the public goal without unduly violating rights and dignity.<sup>163</sup>

#### *4.7.1.6 Whether or not a coercive public health measure is the most effective and least restrictive alternative: Factors for significant risk standard*

At times the most coercive public health policy might be the most appropriate one, for instance, in cases where a person is a serious risk to the public or the disease is contagious. The significant-risk standard permits coercive measures only to avert likely harm to the health or safety of others, and the determination of significant risk requires a public health inquiry.<sup>164</sup> The model points out that for infectious diseases such as HIV/AIDS or tuberculosis, the significant risk standard is based upon four factors, namely:

- the nature of the risk, that is, the mode of transmission of the disease. In this case the public health intervention must be based on epidemiology models of transmission;
- the probability of the risk, that is, how likely the transmission will occur;
- the severity of harm, that is, the harm to the person if the infection were transmitted; and, finally,
- the duration of the risk, that is, the length of time the person is infectious.

#### *4.7.1.7 Determination of significant risk to avert likely harm*

International human rights standards require that governments provide a fair public hearing before they deprive persons of liberty, freedom of movement or other fundamental human rights.<sup>165</sup> Ida Susser as quoted by Bisailon wrote that testing

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<sup>163</sup> De Cock; Mbori-Ngacha; Marum "Shadow in the continent: public health and HIV/AIDS in Africa in the 21<sup>st</sup> century", *The Lancet*, Vol 360, 2002, p. 67-72.

<sup>164</sup> See Mann *et al* footnote 146 above, p.66.

<sup>165</sup> Canadian HIV/AIDS Legal Framework, *Outcomes of the symposium on HIV testing and human rights* (2005) [http://www.genderhealth.org/pubs/testing\\_symposium.pdf](http://www.genderhealth.org/pubs/testing_symposium.pdf), (accessed 03 March 2012).

strategies that enhance the autonomy of individual decision-making achieve public health goals and respect human rights obligations.<sup>166</sup> Testing for HIV/AIDS in a consensual situation where there are treatment options available is consistent with ethical practice. The same, however, cannot necessarily be said about testing carried out in a context of power imbalances, where individuals denied entry to Canada following a positive HIV test may have been unprepared for the test; or where they may face considerable hardships and health-based stigmatization.

Further, studies show that while immigrants expect to be tested for HIV/AIDS as highlighted in their immigration applications, they were not informed that they were being tested for HIV/AIDS at the time of testing and given the required counselling.<sup>167</sup> This is a serious irregularity as the fundamental principles of testing clearly provide that individuals must be fully aware of the fact that they are being tested for HIV as a point of departure before anything else.<sup>168</sup> Where HIV/AIDS testing is done in the absence of informed consent, essentially the whole test should be declared null and void as testing is not to the benefit of the individual.

In summation HIV is not considered to be a danger to public health and safety. Therefore, having HIV does not, in itself, make one inadmissible to Canada. However, people are also considered medically inadmissible if they are expected to place an excessive demand on health and/or social services compared to the average Canadian.<sup>169</sup> Many people with HIV may be considered individuals of excessive demand due to the high cost of anti-HIV drugs. Costs are estimated over a 10-year projected period, which increases the likelihood that someone with HIV will start on anti-HIV drugs and incur the associated costs during that time period.

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<sup>166</sup> Susser, quoted in Bisailon "Women and AIDS in the second millennium", *Women's studies Quarterly* 35, 2007 p 336.

<sup>167</sup> Odongo, "Immigrant Women Living with HIV/AIDS: Their Barriers as Experience by Service Providers", Ryerson University 2008, available at, <http://www.digitalcommons.ryerson.ca/cgi/viewcontent.cgi?article=1101>, (accessed 28 September 2012).

<sup>168</sup> VCT Toolkit, "HIV Voluntary Counselling and Testing A Reference Guide for Counsellors and Trainers", Family Health International 2004, available at [http://www.pdf.usaid.gov/pdf\\_docs/PNACW801.pdf](http://www.pdf.usaid.gov/pdf_docs/PNACW801.pdf), accessed 03 November 2012. See also Knobel, "Consent, with particular reference to HIV and AIDS" *South Africa's Continuing Medical Education Monthly* 79 2006 p. 24.

<sup>169</sup> Canada's Source for HIV and Hepatitis C information, "Managing your health: a guide for people living with HIV, 2012, <http://www.catie.ca/en/practical-guides/managing-your-health/17>, (accessed 22 February 2013).

There is a contrast between the Canadian approach and that of Uganda. The Canadian approach is discriminatory and applies to a specific group of people, namely, immigrants. Uganda, however, has an HIV/AIDS testing practice that does not tolerate any form of HIV testing without complying with the three elements of consent, confidentiality and counselling.

#### **4.8 HIV Testing in South Africa**

According to UNAIDS, South Africa has the highest number of people living with HIV. In the past two decades (1990-2009), the South African Department of Health has produced good sentinel surveillance data that assists in monitoring the HIV epidemic prevalence trends in the 15-49 year old female population. Statistics show that there are about 1 500 new HIV infections a day and the important pertinent question that arises is whether mandatory HIV testing is what South Africa needs in order to fight the epidemic.<sup>170</sup>

There has been of late a call for mandatory testing which is now finding greater space in the public discourse. This stemmed from the former Western Cape Health Minister, Theuns Botha, who said mandatory testing would be a “major onslaught” on AIDS in South Africa, which has the largest number of people living with HIV in the world.<sup>171</sup> However, the South African Human Rights Commission said that forcing patients to take the test would be illegal because it violates their right to privacy. Universal testing and the immediate treatment of HIV-infected individuals could dramatically reduce, or even eliminate, HIV transmission, according to a mathematical model published in 2009 by Dr Reuben Granich of the WHO.<sup>172</sup> The question is how to get people to test. Due to the increase in infections, the society’s approach of managing HIV/AIDS becomes more aggressive and this is reflected by calls to make HIV/AIDS testing mandatory. Dr Maloko also pointed out that,

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<sup>170</sup> Ramothwala, “AIDS Law and Culture: Mandatory testing for HIV? No thanks”, Mail Guardian, 26 June 2007, p. 23:59, available at, <http://www.section27.org.za/wp-content/uploads/.../ALP-Review-2007-20081.pdf>, (accessed 28 March 2012).

<sup>171</sup> Alicestine, “AIDS testing plan illegal” News 24, 21 September 2009 at 0940hrs, <http://www.news24.com/SouthAfrica/AidsFocus/Aids-testing-plan-is-illegal>, (accessed 28 March 2012).

<sup>172</sup> Odendal, “Forced HIV Testing up for debate”, Mail Guardian, 20 May 2011, available at <http://mg.co.za/author/lesley-odendal>, (accessed 28 March 2012).



if we [South Africa] started having mandatory testing today, two years from now HIV/AIDS would be an old hat. Everybody would be testing and this entire human rights thing will be forgotten.<sup>173</sup>

South Africa is not really keen on the mandatory testing approach but prefers a more conservative and less radical approach. Dr Janet Giddy argued that HIV testing, with the use of pre- and post-test counselling, should be carried out as it is for other diseases, such as malaria. She argued that HIV testing should be offered at every visit of a person to a health facility with the option of refusing, instead of the current approach that requires people to come forward on their own accord if they wish to be tested.<sup>174</sup>

With the continuous rise of statistics, there have been various debates on the need to shift to a more aggressive testing policy which is mandatory testing. With almost 1000 people dying from HIV/AIDS related illnesses every day in South Africa, it is clear that society would wish to see radical policies that might bring the pandemic to an end. It has been suggested that by 2012 around 1.5 million people will still die from AIDS related causes with the treatment scale-up at the current rate.<sup>175</sup> However, if the target of 27 million people being tested in the next few years is not reached, there is need for change in attitude and this may justify a move towards mandatory HIV testing.<sup>176</sup> It is clear that there have been many talks to this effect. During the HIV/AIDS conference held in Durban in 2007, Venter suggested that the government and donors promulgate mandatory HIV/AIDS testing as a measure or a precondition in the management of HIV/AIDS in South Africa.<sup>177</sup>

The other rationale that proponents of mandatory testing have taken is that such testing would compel every man, woman and child to be tested. This means that no individual would be excluded either by sex, race, religion or financial status, and this would eliminate stigma and discrimination. Individuals found guilty of intentionally infecting others, after being made aware of their status, would be held criminally

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<sup>173</sup> Smart, "Does the Scale of the epidemic in South Africa call for compulsory HIV testing, *AIDS Map News*, June 2007, <http://www.aidsmap.com>, (accessed 24 September 2012).

<sup>174</sup> *Ibid.*

<sup>175</sup> Walensky, "Scaling up antiretroviral therapy in South Africa: The Impact of speed on survival", *Journal of Infectious Disease* Vol. 197, 2008.

<sup>176</sup> See Smart footnote 173 above.

<sup>177</sup> Venter, Make HIV tests compulsory to South Africans, *Sunday Times* June 2007, <http://www.suntimes.co.za>, (accessed 24 September 2012).

responsible in accordance with Section 29 and 32 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act.<sup>178</sup>

The provision of antiretroviral therapy can save lives and relieve the widespread suffering endured by people living with HIV/AIDS. However, providing treatment for AIDS patients is only one piece of the puzzle in changing the course of the epidemic in South Africa. The response to AIDS has to be commensurate with involving all sectors of society bound by a common vision.<sup>179</sup> South Africa has to have one common goal and one strategy to combat HIV/AIDS. There has to be an agreement on the use of voluntary counselling and testing or mandatory testing. It is unclear which testing policy is applicable in South Africa as it has been reported that a clinic in Mpumalanga has been practicing mandatory testing for the mere reason of making sure that patients know their status. This, however, is still a human rights violation due to the absence of informed consent. Preventing HIV transmission, providing good care for people who are already infected and adequately supporting individuals and communities affected by the HIV epidemic requires respect for human rights on the part of policy makers, programme managers, researchers and activists.<sup>180</sup>

The South African Constitution of 1996 states that everyone has the right to have access to health care services. The right to health care services is provided for in three sections of the South African Constitution. This right includes reproductive health and emergency services; basic health care for children, and medical services for detained persons and prisoners.<sup>181</sup> The Constitution further states that the state must take reasonable legislative and other measures within available resources to achieve the progressive realisation of these rights.<sup>182</sup> However, whether the South African government has ensured a progressive realization of these basic requirements is debatable, but it is significant that South Africa has attempted to

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<sup>178</sup> Criminal Law Sexual Offences and Related Matters Amendment Act 32 of 2007.

<sup>179</sup> Abdool Q; and Abdool K "The Evolving HIV Epidemic in South Africa", *International Journal of Epidemiology* Vol.31:1, 2002 p.37-40.

<sup>180</sup> Gruskin; and Maluwa, "AIDS in Africa", 2<sup>nd</sup> Edition, Kluwer Academic Publishers 2007.

<sup>181</sup> Sections 27 (1) (a), (b) and (c); Section 28 (1) (c) and Section 35 (2) (e) of the Constitution of the Republic of South Africa.

<sup>182</sup> Section 27 (1) and (2).

protect, promote and realise virtually every health related right in the Bill of Rights.<sup>183</sup> Much progress can be witnessed with access to ARV treatment country wide. ARVs have also been made accessible to prisoners though a number of obstacles are still being encountered.<sup>184</sup> The Constitution guarantees that everyone has the right to freedom and security of the person<sup>185</sup> and privacy<sup>186</sup>. Further, the National Health Act guarantees the right of confidentiality to everyone, which includes the right not to have privacy of one's communications infringed, information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment being confidential.<sup>187</sup> According to the Department of Health's National Policy on testing for HIV<sup>188</sup>, testing may only be done with informed consent and, in this regard, pre-test and post-test counselling must be given to the person before the test and after the person receives the test result, respectively.

The legal framework of South Africa's' health and HIV/AIDS was also tested in the case of *C v Minister of Correctional Services*<sup>189</sup> in which a prisoner was subjected to an HIV test without his consent and counselling. The court held that, in these circumstances, the deviation from the accepted norm of informed consent, including the fact that there was no pre-counselling, was of such a degree that it was material and wrongful. The court again submitted that these requirements for testing have become universal in South Africa. The state thus has a positive obligation to take legislative steps to provide access to health care services<sup>190</sup> and this has been buttressed by the landmark judgments in the *Grootboom*<sup>191</sup> and *Treatment Action Campaign*<sup>192</sup> cases. The Constitutional Court affirmed the principle that the measures taken by the state for the delivery of socio-economic rights must be

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<sup>183</sup> Singh; Govender; and Reddy" South Africa a decade after apartheid: Realising Health through human rights" *Georgetown Journal on Poverty Law and Policy* Vol. XII, 2005, p. 355-368.

<sup>184</sup> Vawda; and Madiba, "Compulsory testing of alleged sexual offenders, implications for human rights and access to treatment" available at, <http://www.sajbl.org.za/index.php/sajbl/article/view/91>, (accessed 26 September 2012). These two further opine that there is still a long way from ensuring the realisation of the human right to access to health care in the aspect of life in South Africa.

<sup>185</sup> The Constitution of South Africa 1996 section 12.

<sup>186</sup> The Constitution of South Africa 1996 section 14.

<sup>187</sup> The National Health Act 61 2003 section 14.

<sup>188</sup> Government of South Africa, Draft National Policy on HIV testing Act 116 of 1990, Ministry of Health, <http://www.doh.gov.za/aids/docs/policy.html>, (accessed 16 August 2012).

<sup>189</sup> *C v Minister of Correctional Services* 1996(4) SA 292 (T).

<sup>190</sup> Section 27.

<sup>191</sup> *The Government of the Republic of South Africa and Others v Grootboom and others* 2001(1) SA 46(CC).

<sup>192</sup> *Minister of Health and Others v Treatment Action Campaign and Others* (TAC) 2002 5 SA 721(CC).

reasonable, comprehensive and accessible. Guided by these principles, the Durban High Court ordered the government in the *Westville Prisoners case*<sup>193</sup> to provide forthwith ARV treatment to the affected prisoners.

The South African government respects and promotes the commands of the Bill of Rights since all policies are measured against the values and principles of this fundamental law. From what has been stated above, it is clear that testing policies ought to be rights-based as exemplified by the voluntary counselling and testing practice. What is questionable about this testing policy as postulated by proponents of mandatory testing is its ability to mobilise the masses to voluntarily test for HIV. It is, however, important for the government to maintain a human rights-based approach as it is also important in combating the increasing number of infections.

However, more work has to be done to create alertness and knowledge of the HIV virus. In the 1990s when HIV policies were implemented, awareness campaigns were undertaken and ARV treatment was made available to citizens. In essence there was a lot of focus on HIV/AIDS as everyone feared it. Presently, due to the fact that it can be managed by ARV treatment, citizens and governments have been lax on the assumption that, since the epidemic is 'manageable', one can survive for more than 30 years with the virus. This state of mind will have a serious impact because, if the rate of infection increases, this will have a spiral effect on the country's health care system and economy. It is clear that mandatory testing is still not the answer to the end of HIV. What makes sense is to counsel (that is, pre-and post-test counselling); to educate those who test negative (and society generally) so that they can pursue lifestyle changes; to avoid the spread of HIV; and to manage the virus in terms of CD4 count and viral load.

It can be deduced from the discussion on Uganda that everything at the time was about HIV/AIDS and awareness groups multiplied in an effort to educate young boys and girls, adults and those in rural and remote areas. It should be understood that HIV testing and counselling services of a satisfactory quality must involve development and support efforts to improve awareness and the benefits of HIV

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<sup>193</sup> *EN v Government of South Africa* 2007 1 All SA 74(D).

testing and counselling. This helps to normalize HIV and the corresponding testing and counselling services and to reduce stigma and discrimination.<sup>194</sup>

HIV testing and counselling services are a gateway to HIV prevention, care and treatment. The benefits of knowledge of HIV status can be seen at the individual, community and population levels. They include the following:<sup>195</sup>

- For the individual: it enhances ability to reduce the risk of acquiring or transmitting HIV; access to HIV care, treatment and support; and protection of unborn infants.
- For the community: a wider knowledge of HIV status and its links to interventions can lead to a reduction in denial, stigma and discrimination and to collective responsibility and action.
- At the population level: knowledge of HIV epidemiological trends can influence the policy environment, normalize HIV/AIDS and reduce stigma and discrimination.

#### **4.9 Brief Outline of Recognised Types of Testing in Africa and Beyond**

The UNAIDS and WHO recommend that the following types of HIV testing be clearly distinguished:<sup>196</sup>

##### *4.9.1 Voluntary counselling and testing*

Client-initiated HIV testing, which is intended to learn one's HIV status provided through voluntary counselling and testing, remains critical to the effectiveness of HIV prevention. UNAIDS/WHO promotes effective testing and counselling and the knowledge of HIV status among any population that may have been exposed to HIV through any mode of transmission. Pre-testing counselling may be provided either on an individual basis or in group settings with individual follow ups. UNAIDS/WHO encourage the use of rapid tests so that results are provided in a timely fashion and

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<sup>194</sup> Scaling up HIV Testing and Counselling Services: A toolkit for programme managers, World Health Organisation, available at, <http://www.who.int/hiv/pub/vct/counsellingtestingtoolkit.pdf>, (accessed 24 August 2012).

<sup>195</sup> *Ibid.*

<sup>196</sup> *International Guidelines on HIV/AIDS and Human Rights*, 2006 Consolidated Version <http://data.unaids.org/Publications/IRC-pub/07/jc1252-internationalguidelines-en.pdf>, accessed 16 August 2011.

can be followed immediately with a first post-test counselling session for both HIV positive and HIV-negative individuals.

#### *4.9.2 Diagnostic HIV testing*

This is a form of testing that is done whenever a person shows signs or symptoms that are consistent with HIV related disease or AIDS to aid clinical diagnosis and management. This includes HIV testing for all tuberculosis patients as part of their routine management. Diagnostic and routine testing allow the patient the right to refuse testing, that is, to 'opt-out' of testing, a procedure notably made popular in Botswana.<sup>197</sup>

#### *4.9.3 A routine offer of HIV testing by health care providers also known as provider-initiated testing and counselling (PITC)*

This form of testing should be made to all patients assessed in a sexually transmitted infection clinic or elsewhere for a sexually transmitted infection in order to facilitate tailored counselling based on knowledge of HIV status. Secondly, routine testing should be made to patients seen in the context of pregnancy so as to facilitate and offer antiretroviral prevention of mother-to-child transmission. Lastly, it should be made to all patients being seen in clinical and community based health settings where HIV is prevalent and antiretroviral treatment is available. The guidelines emphasize that explicit mechanisms are necessary in provider-initiated HIV testing to promote referral to post-test counselling services, emphasising prevention for all those being tested, and medical and psychosocial support for those testing positive.

With this type of testing whether for purposes of diagnosis, the offer of antiretroviral prevention of mother-to-child transmission or for encouragement to learn HIV status, patients retain the right to refuse testing, i.e. to 'opt-out' of a systematic offer of testing. PITC has already been implemented in a range of clinical settings in several low-middle income countries, including Botswana, Kenya, Malawi, Uganda, Zambia, Thailand, and the United States.<sup>198</sup> A key issue would be whether a routine offer of HIV testing with the option of opting in or out of testing enables patients to act

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<sup>197</sup> Smart, "Does the Scale of the epidemic in South Africa call for compulsory HIV testing, *AIDS Map News*, June 2007, available at, <http://www.aidsmap.com>, (accessed 24 September 2012).

<sup>198</sup> UNAIDS 2008.

voluntarily. In this regard, careful consideration must be given to gender issues, power imbalances and other subtle factors that may affect patient autonomy.<sup>199</sup>

#### 4.9.4 *Mandatory HIV screening*

UNAIDS/WHO support mandatory screening for HIV and other blood borne viruses of all blood that is destined for transfusion or for the manufacture of blood products. UNAIDS/WHO, however, does not support mandatory testing of individuals on public health grounds. Mandatory testing is the testing of individuals without their consent and without counselling being provided and, in some instances, without their knowledge. This type of testing is often described as compulsory or involuntary testing.<sup>200</sup> It is recognised that many countries require HIV testing for immigration purposes on a mandatory basis and that some conduct mandatory testing for pre-recruitment and periodic medical assessment of military personnel for the purposes of establishing fitness. UNAIDS/WHO recommend that such testing be conducted only when accompanied by counselling for both HIV-positive and HIV-negative individuals and referral to medical and psychosocial services for those who receive a positive test result. International agencies working on HIV and public health authorities continue to reject mandatory testing as unethical and a violation of human rights and ineffectual in public health terms.<sup>201</sup>

#### 4.9.5 *Compulsory HIV testing*

Compulsory testing, also known as involuntary testing, is defined as testing without a voluntary element, i.e. without informed consent at the behest of someone or some institution other than the person being tested and, in some cases, with neither the knowledge of having been tested nor the result being communicated to the person tested.<sup>202</sup> In South Africa compulsory HIV testing of alleged sexual offenders is thought to be one of the new, progressive services for rape complainants. It has been concluded that compulsory testing for alleged sexual offenders through the

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<sup>199</sup> See Strode *et al* footnote 74 above p. 45-49.

<sup>200</sup> Richter, "Different models of HIV testing: What are the considerations in South Africa", Johannesburg AIDS Law Project 2006.

<sup>201</sup> UNAIDS/WHO Policy Statement on HIV Testing 2004, available at <http://www.who.int/hiv/pub/vct/en/hivtestingpolicy04.pdf>, (accessed 26 March 2012).

<sup>202</sup> Canadian HIV/AIDS Legal Framework, "Prevention and Protection: Enhancing both HIV testing and Human Rights in Canada", 2007.

Sexual Offences and Related Matters Amendment Act<sup>203</sup> might provide a feeling of reassurance to victims/survivors. However, this does not necessarily protect them from infection since they have to take all the necessary precautions that they would otherwise have taken had they not demanded the HIV test of the perpetrator.<sup>204</sup>

Compulsory testing of sexual offenders has been a topical issue in South Africa over the years. Since 2003, the Portfolio Committee on Justice and Constitutional Development has deliberated on legislation providing for the compulsory HIV testing of accused sexual offenders.<sup>205</sup> The South African Law Reform Commission (SALRC) made an investigation on the need for compulsory testing and concluded that there is, in fact, a need for a statutory intervention for compulsory HIV testing of alleged sexual offenders at the instance or on behalf of the victim. As a result, the SALRC laid out a first draft of a Criminal Procedure Amendment Bill in the Fourth Interim report on aspects of the law relating to AIDS. This Bill envisioned compulsory HIV testing of arrested persons for non-evidentiary purposes.<sup>206</sup> In 2006, the compulsory HIV Testing Bill was incorporated into the Criminal Law (Sexual Offences and Related Matter) Amendment Bill (hereafter referred to as the Sexual Offences Bill). Since the inclusion of the compulsory HIV testing, the provisions allow not only the victims of sexual offences but also investigating officers to apply for a mandatory HIV test of the alleged offender.<sup>207</sup>

Countries such as Nigeria, through religious groups like the Orthodox and Pentecostal churches, have also introduced a form of mandatory testing known as mandatory pre-marital testing in an effort to combat the HIV/AIDS epidemic. Calls for mandatory pre-marital testing were necessitated by the escalation in figures of HIV infections, as Nigeria currently has about 3.4 million people living with HIV.<sup>208</sup> The controversial practice of mandatory pre-marital HIV testing which originated from the states of Louisiana and Illinois in the United States has also been documented in

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<sup>203</sup> Sexual Offences and Related Matters Amendment Act 32 Of 2007.

<sup>204</sup> Madiba, Vawda, "Compulsory testing of alleged sexual offenders-implications for human rights and access to treatment", *SAJBL Vol.3:1*, 2010.

<sup>205</sup> Roehrs, "Positive or negative: Compulsory HIV testing of alleged sexual offenders", *SA Crime quarterly No 20*, 2007.

<sup>206</sup> *Ibid.*

<sup>207</sup> Memorandum on the Objects of the Compulsory HIV Testing of Alleged Sexual Offenders Bill ,B10-2003.

<sup>208</sup> Uma, Oche, "Knowledge of HIV/AIDS and use of mandatory premarital HIV testing as a pre-requisite for marriages among religious leaders in Sokoto, North Western Nigeria", *Pan African Medical Journal Vol. 11:27*, 2012.



Nigeria, the Democratic Republic of Congo (DRC), Ghana, Burundi and Uganda<sup>209</sup>. The spokesman of the Anglican Church in Nigeria, Rev. Akintunde Popoola, stated that the aim of the mandatory testing was to help intending couples make a more informed decision because the church does not want anyone to remain in the dark about their partners. However, the church reiterated that where one or both of the intending couple are HIV positive, they would be allowed to make the choice as to whether or not to go on with the ceremony.<sup>210</sup>

HIV testing is also compulsory for all who are preparing to get married in Eritrea. As a result, seropositive individuals are not allowed to have their marriages officially recognized by public or religious entities.<sup>211</sup> The policy of the Eritrean government can be explained as a desperate bid to halt the spread of the deadly virus, though mandatory testing is contrary to at least one of the five strategic directions adopted by the WHO on the attainment of universal access to HIV prevention, treatment, care and support through the provision of confidential HIV testing and counselling.<sup>212</sup>

It is without doubt that mandatory premarital HIV testing barring HIV positives from marrying is a gross violation of the rights of people living with HIV: right to family life, privacy, confidentiality and to freedom from discrimination.<sup>213</sup> Ifemeje calls for the formulation of a uniform global policy to address this volatile issue and also makes a case for urgent legislative reforms in Nigeria, banning mandatory premarital HIV testing and other forms of discrimination often meted out on people living with HIV.<sup>214</sup> Any approach that aims to achieve a comprehensive prevention strategy must be consistent with respect for human rights, as enshrined in regional and international human rights law. In the same vein, Durojaye points out that even if the public health

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<sup>209</sup> Open Society Institute, "Women and HIV testing: Policies Practices and the impact on Health and Human Rights" available at <http://www.soros.com> (accessed 24 October 2012).

<sup>210</sup> Majau, "Mandatory Premarital Testing in Nigeria" 2011, available at, <http://www.thelwayerschronicle.com/index.php?option>, (accessed 24 October 2012).

<sup>211</sup> Mekonnen, "Mandatory Premarital HIV Testing as a challenge to Human Rights", *Interdisciplinary Journal of Human Rights Law Vol.5:1* 2007.

<sup>212</sup> WHO, Fifty-Ninth World Health Assembly, Provisional Agenda Item 11.3, UN/Doc/A59/39, (4May 2006).

<sup>213</sup> Durojaye, " Addressing Human Rights concerns raised by mandatory HIV testing of pregnant women through the protocol of the African Charter on the rights of women", *Journal of African Law Vol. 52:1*, 2008, p. 43-65.

<sup>214</sup> Ifemeje, "Mandatory premarital HIV testing policy in Nigeria: a gross violation of the rights of people living with HIV/AIDS", *The International Journal of Human Rights Vol. 16:3*, 2012.

policy is effective, proportionate or necessary; it is the duty of policy makers to seek to minimize the infringement of human rights by reason of such policy.<sup>215</sup>

#### **4.10 A Comparison between Uganda's and South Africa's Response to HIV/AIDS**

South Africa and Uganda clearly responded to the epidemic differently though the impact or devastation was the same. The virus, firstly, spread throughout the two countries in very different political and economic environments. Secondly, Uganda's government took a proactive stance to fight the disease while, initially, South Africa's leaders failed to recognize and address the threat of HIV. Thirdly, upon learning of the dangers of HIV, Ugandans spoke openly amongst each other in order to increase awareness and decrease discrimination.<sup>216</sup>

The other major difference is that the Western world and international organisations played a role in slowing down the spread of the virus in both countries, but they have distributed the aid in different ways. Since Museveni assumed power in 1986, Uganda has implemented a series of economic reforms, and the government received outside funding for extensive HIV/AIDS education and treatment programmes. In South Africa, before the end of apartheid in 1994, most international aid flowed through non-governmental organisations because the Western world did not support the government's apartheid and racist policies.<sup>217</sup> Clearly this political situation slowed down the efforts to fight back the epidemic. The political situation that is, apartheid; gave room for the spread of HIV/AIDS while Uganda tackled the epidemic head on.

#### **4.11 Lessons that South Africa can Learn**

What is outstanding about Uganda and what differentiates it from other countries in sub-Saharan Africa is the fact that it made several moves to slow down the spread of HIV; in essence it tried everything and did not pick on a particular strategy.

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<sup>215</sup> See Durojaye footnote 213 above.

<sup>216</sup> Low-Beer, "HIV-1 incidence and prevalence trends in Uganda", *The Lancet Vol. 360*, 2002, p. 1788.

<sup>217</sup> "Aspects of HIV/AIDS and the Law", Gender Health and Justice Research Unit, University of Cape Town, South Africa 2007.

The South African political leaders should also shift their attention towards educating and finding ways to combat this pandemic. Political rallies and meetings should be used as a platform to address HIV/AIDS issues, including testing.

It is also high time that the community put the HIV pandemic into their hands. Such co-operation between the community and government will definitely make a remarkable difference. Encouraging community members to talk about HIV testing and counselling is also a very important part of community action on HIV/AIDS. Increasing the acceptance of HIV as a community issue also mobilizes community members to respond to HIV/AIDS intervention.<sup>218</sup> Organisations such as TASO in Uganda focused on raising awareness of communities in rural and urban areas and ensured that the population understood what had to be done in order to manage the HIV crisis. The population condomised, followed the one man policy that is faithfulness to one partner and, finally, engaged in HIV/AIDS testing. It is time for the South African communities to take HIV into their own hands and educate each other about this crisis.

Perceptions and benefits of HIV testing and counselling ought to be addressed. Increasing the demand for HIV testing and counselling services is critical for normalizing HIV, increasing acceptance of HIV as a community issue, reducing denial, stigma and discrimination, and increasing the uptake of ARV treatment and prevention. However, because of the stigma and discrimination associated with HIV/AIDS, many people do not wish to know their status.<sup>219</sup> This is the problem that the South African community has to face. Stigma and discrimination stand as a roadblock against initiatives to combat HIV/AIDS. Perceptions have to be changed in order to allow for testing. The issue of perception was a success in Uganda as the deaths of family members and friends made people come to the realisation that HIV/AIDS is a reality; it will kill and it can attack anyone and, therefore, it was essential to change behaviour.

Perceptions of the South African population have to change. It is clear that in some settings mass media and marketing approaches have proved to be quite successful

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<sup>218</sup> Ministry of Health Uganda, "Voluntary Counselling and Testing (VCT)" ,*A Guide for Mobilisation of Communities* 2001.

<sup>219</sup> International Centre for Research on Women (ICRW), "Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia" 2003.

in improving people's perceptions about the benefits of knowing their status and increasing the uptake of HIV and counselling.<sup>220</sup> During the prime years of the epidemic in South Africa marketing approaches and awareness campaigns were utilised and visible efforts were made by the government and NGO's. However, such energy to combat HIV/AIDS has slowed down as people are of the impression that HIV can now be managed by anti-retroviral therapy. This poses a great challenge since new infections are still occurring and the population is still perishing as a result of this deadly virus. More work still has to be done to make people aware of the HIV/AIDS virus.

#### **4.12 Conclusion**

It is crystal clear that Uganda's success story was necessitated by perseverance and hard work from the government, NGOs, the population and communities at large. A number of strategies were implemented so as to cater for different people with different preferences. This factor contributed in raising awareness among the masses which successfully changed the behaviour of the population. An important strength that South Africa and other African countries can emulate from Uganda is the endurance the country had, right from its leaders, including the President himself, to boys and girls in the fight against HIV. The fight against HIV should not stop as a result of the availability of anti-retroviral therapy. With the economic and health instability in Africa, these drugs are not available to every individual in need. The solution is to stop the onset of new infections and eradicate this disease in the country and over the continent.

Respect for the rule of law, human rights, and democratic accountability are some of the values displayed by Uganda and these are fundamental elements of a successful HIV/AIDS strategy. Africa should not despair or try to implement radical and coercive measures such as mandatory testing to combat HIV/AIDS. This is not the answer to end this epidemic. As it has been proven by Uganda, public health programmes that respect human rights will encourage individuals and communities to trust and

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<sup>220</sup> Academy for Educational Development (AED), "Understanding and Challenging HIV Stigma" A Toolkit for Action 2003.

cooperate with public health authorities. This is virtually true in all successful models such as that of Botswana which implemented routine HIV testing.<sup>221</sup>

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<sup>221</sup> See Mekonnen footnote 211 above.

## CHAPTER 5: RIGHTS THAT INFORM HIV/AIDS AND THE PUBLIC HEALTH

### 5.1 Introduction

*All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.*<sup>1</sup>

*Respecting, protecting and fulfilling the full range of human rights of all individuals is indispensable to reducing the rates of HIV infection, expanding access to care and treatment, and mitigating the impact of the epidemic, including acts of discrimination and violence.*<sup>2</sup>

This chapter discusses the rights to dignity, freedom and security of a person and privacy without overlooking other rights that may be violated by a compulsory HIV/AIDS testing policy. The chapter will explore the extent to which these rights are affected if a compulsory HIV/AIDS testing policy is implemented. The essentials of HIV/AIDS testing, which are consent, confidentiality and counselling, will also be discussed as their protection has a firm impact on the rights to be discussed. The last part of the chapter will deal with the limitation of rights. South African law as well international human rights law make it clear that rights are not absolute; they can be limited provided certain conditions are met.

In the early years of the HIV/AIDS epidemic, aggressive calls for punitive, forcible testing sparked widespread concern about the effects of such strategies on individual rights and the spread of the epidemic. In recent years, an international consensus has emerged that access to HIV testing must be scaled up urgently and, in addition to the traditional model of client initiated voluntary counselling and testing (VCT), new approaches to HIV testing and counselling must be implemented in more settings and on a much larger scale than hitherto fore.<sup>3</sup> However, the debate about how to access HIV testing is not occurring in a vacuum; rather, it takes place in an environment in which evidence-based and human rights-based policies and

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<sup>1</sup> Universal Declaration of Human Rights of 1948, Article 1.

<sup>2</sup> The International Guidelines on HIV/AIDS and Human Rights 2006, Consolidated version, available at <http://www.familywatchinternational.org>, (accessed 28 May 2012).

<sup>3</sup> Jurgens, "Routinizing: HIV testing in-low and middle income countries", New York Public Health Program of the Open Society Institute Background paper 2007, p. 12-23, available at <http://www.unaids.org.cn/pics/20120821114907.pdf>, (accessed 28 May 2012).

programmes are being undermined. This thesis is persuasive on the notion that public health is a human right, whilst acknowledging the complex and ever changing relationship between public health, social control and human rights.<sup>4</sup>

Mandatory HIV testing occurs in many countries and contexts in violation of ethical principles and the basic rights of consent, privacy and bodily integrity.<sup>5</sup> Wynia also supports this notion and adds that the use of compulsory measures to achieve public health goals is problematic such that international law and, in particular, human rights law, imposes on governments the duty to promote and protect human rights.<sup>6</sup> Jurgens contends that, under international law, any public health action by the state that limits human rights must be justified by demonstrating that it is rationally connected to achieving a pressing objective, infringes human rights as little as possible, and the benefits achieved are proportional to the harm done to individuals' human rights.<sup>7</sup>

An interesting analysis was made in Manuel's<sup>8</sup> cost-benefit analysis, which led her to conclude that the interests of the community and the individual can be viewed as being one and the same, and that public health considerations actually require the respect of individual rights. Manuel argues that those coercive measures, such as mandatory testing which at first blush may appear aimed at protecting the interests of the community, may well jeopardize prevention opportunities and so produce the opposite of the desired effect. He adds that to prevent this, voluntary testing, confidentiality and anti-discrimination must be preferred.

The premise of this research is that HIV testing must be voluntary and that informed choice is central to creating a climate of confidence and trust between the person being tested and the service providers. Three underpinning principles of HIV testing, also known as the "*the three Cs*", were established as norms by UNAIDS/WHO and

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<sup>4</sup> Parmet, "Public Health and Social Control: Implications for Human Rights", Northern Public Law and theory faculty working paper series No. 4, 2010, p. 23, available at <http://www.ssrn.com/abstract=1546654>, (accessed 18 October 2012).

<sup>5</sup> With the exception of HIV screening for blood, blood products, and before all procedures involving transfer of bodily fluids or body parts, compulsory or mandatory testing is also ineffective for public health purposes. Jurgens, "Routinizing: HIV testing in-low and middle income countries" 2007, p. 9

<sup>6</sup> Wynia, "Ethics and Public Health Emergencies: Restrictions on Liberty", *The American Journal of Bioethics* Vol. , 2007, 1-5.

<sup>7</sup> See Jurgens footnote 5 above, p. iv.

<sup>8</sup> Bennet and Erin, "*HIV and AIDS: Testing, screening, and confidentiality*", (Eds) *Issues in biomedical ethics*, Oxford University Press 2003, p. 1-19.

these are: counselling and attainment of information about HIV/AIDS before and after the test; consent to be given in an informed, specific and voluntary way by the person to be tested; and confidentiality of test results and of the fact of seeking a test.<sup>9</sup> More importantly, it should be understood that testing alone is not the answer: many studies suggest that more tests alone are not a sufficient achievement and solution to combating the epidemic. For instance, studies have shown that many of the pregnant women who accept HIV testing in antenatal settings and in resource poor settings do not obtain their results or take up perinatal HIV interventions.<sup>10</sup> The implication is, however, that HIV testing is randomly done for the mere sake of testing and for statistical purposes without actually providing the necessary treatment and support required.

Jurgens points out that informed consent protects the human right to security of the person as well as the right to receive information. Clearly pre-test counselling contributes to the protection of these same human rights. Post-test counselling also imparts information to which people have a right.<sup>11</sup> Confidentiality of test results and seeking an HIV test are part of protecting and respecting the right to privacy.<sup>12</sup> Beyond the components of the testing process itself, governments have a responsibility to ensure that HIV testing is not offered or provided in a way that discriminates against any person or group of people. The right to be free of discrimination and the right to security of the person also require that in setting HIV testing policy and overseeing its practice, governments take into account the outcomes of HIV testing for people and do all they can to prevent human rights violations associated with HIV testing.<sup>13</sup>

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<sup>9</sup> Jurgens, "Increasing access to HIV testing and counselling while respecting human rights" Background paper New York: Public Health Program of the Open Society Institute 2007, p. 12, available at <http://www.unaids.org.cn/pics/20120821114907.pdf>, (accessed 28 May 2012).

<sup>10</sup> Parmet, "Public Health and Social Control: Implications for Human Rights", Northern Public Law and theory faculty working paper series No. 4, 2010, p. 23, available at <http://www.ssrn.com/abstract=1546654>, (accessed 18 October 2012).

<sup>11</sup> Csete, Elliot, "Scaling up HIV testing: human rights and hidden costs", *HIV/AIDS Policy Review Vol 11:1*, April 2006, p. 5.

<sup>12</sup> Canadian HIV/AIDS Legal Network., "Evolution of HIV Testing policy and technology in Canada", 2007, p. 23, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1076>, (accessed 23 September 2012).

<sup>13</sup> World Health Organisation (WHO ) Policy Framework, "Scaling up HIV testing and counselling in the WHO European region: as an essential component of efforts to achieve universal access to HIV prevention, treatment care and support", 2010, available at [http://www.euro.who.int/\\_data/assets/pdf\\_file/0007/85489/E93715.pdf](http://www.euro.who.int/_data/assets/pdf_file/0007/85489/E93715.pdf), (accessed 26 September 2012).



The European Council Assembly recognises that the global HIV/AIDS pandemic constitutes a formidable challenge to human life and dignity and to the full enjoyment of human rights, and that the full realisation of human rights and fundamental freedoms for the people affected is an essential element in the global response to the pandemic.<sup>14</sup> The last two decades have witnessed the gradual evolution of a doctrine of patient autonomy, fully endorsed in the writings of most ethicists and at least partially now recognized and enforced by law and in medical practice.<sup>15</sup> Further, Richards propounds that patient autonomy is increasingly perceived as a manifestation of the individual's rights of self-determination and privacy, universally regarded as pillars of the civil liberties enjoyed by citizens of the European Union.

Governments across Africa should ensure and make it mandatory that their laws, policies and practices respect human rights in the context of HIV/AIDS, in particular the rights to education, work, privacy, dignity, protection and access to prevention, treatment, care and support, protect people living with HIV/AIDS from all forms of discrimination in both the public and the private sectors, promote gender equality, ensure privacy and confidentiality in research involving human subjects, and provide for speedy and effective judicial, administrative and civil remedies in the event that the rights of people living with HIV/AIDS are violated.<sup>16</sup>

## 5.2 The Basis for a Human Rights Approach

A rights-based approach to development describes situations not simply in terms of human needs, or of developmental requirements, but in terms of society's obligations to respond to the inalienable rights of individuals.<sup>17</sup> It empowers people to demand justice as a right, not as a charity, and gives

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<sup>14</sup> Parliamentary Assembly Council of Europe, "HIV/AIDS in Europe" Report Social, Health and Family Affairs Committee Rapporteur 2007, Doc. 10307 Reference N° 3005 of 08.10.2004, available at <http://assembly.coe.int/main.asp?Link=/documents/workingdocs/doc06/edoc11033.htm>, (accessed 28 September 2012).

<sup>15</sup> Richards, "HV Testing, Screening, and Confidentiality: An American Perspective", in Bennet and Erin, *"HIV and AIDS: Testing, screening, and confidentiality"*, (Eds) *Issues in biomedical ethics*, Oxford University Press 2003, p. 61-75.

<sup>16</sup> *Ibid.*

<sup>17</sup> Albertyn, "Prevention, Treatment and care in the context of human rights" Expert Group Meeting on The HIV/AIDS Pandemic and its Gender Implications 13-17 November 2000 Windhoek, Namibia, available at <http://www.un.org/womenwatch/daw/csw/hiv aids/albertyn.html>, (accessed 24 September 2012).

communities the moral basis from which to claim international assistance where needed.<sup>18</sup>

Human rights are inherent to each person and this also means locating the needs of those infected with and affected by HIV/AIDS in a human rights context so that rights can be claimed and asserted.<sup>19</sup> Alvertyn also adds that;

The human rights approach entails an acceptance that there are certain claims or entitlements (often derived from basic human needs and enshrined in rights) that are universal and that any person has over other individuals, groups, societies or states.<sup>20</sup> It thus involves a corresponding set of responsibilities and obligations on the part of the state (and increasingly of non-state actors) to ensure that those claims are met. Human rights also have a moral and normative content as universally recognized standards for ensuring human development, wellbeing and dignity.<sup>21</sup>

Importantly therefore, a human rights approach entrenches the principle of accountability of governments to people. Governments have a responsibility (derived from international legal frameworks and, to differing degrees, from national constitutions) to ensure these rights are met. Civil society, if it is sufficiently empowered to do so, may assert these rights to improve the quality of human lives. The value of the human rights approach lies not only in principles such as state accountability and popular participation, but also in the transformative potential of rights to alleviate injustice, inequality and poverty.<sup>22</sup>

Human rights impose positive and negative obligations on states. These include refraining and preventing third parties from interfering with human right-holders, the

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<sup>18</sup> *Ibid.*

<sup>19</sup> Zuberu, "HIV/AIDS stigma and human rights: A localised investigation of Hammanskraal communities", A report of the Tswelopele Research Project of the Centre for the Study of AIDS 2012.

<sup>20</sup> See Alvertyn footnote 17 above, p. 2.

<sup>21</sup> *Ibid.*

<sup>22</sup> *Ibid.*

enjoyment of the rights and enacting positive measures so that rights holders are in a position to enjoy their rights.<sup>23</sup>

Mann asserts that “the human rights framework offers public health a more coherent, comprehensive, and practical framework of analysis and action on the societal root causes of vulnerability to HIV/AIDS than any framework inherited from traditional health or biomedical science.” Until these root causes are addressed, the HIV/AIDS pandemic would continue.<sup>24</sup> The protection and promotion of human rights is, therefore, essential in preventing the spread of HIV and in mitigating the social and economic impact of the pandemic. The reasons for this are threefold.<sup>25</sup> First, the promotion and protection of human rights reduces vulnerability to HIV infection by addressing its root causes. Second, the adverse impact on those infected with and affected by HIV is lessened. Third, individuals and communities have greater ability to respond to the pandemic. An effective international response to the pandemic, therefore, must be grounded in respect for all civil and political rights and economic, social and cultural rights and the right to development, in accordance with international human rights standards, norms and principles.

### 5.3 The Fundamental Values of Voluntary HIV/AIDS Testing

Voluntary Counselling and Testing (VCT) is when a person chooses to undergo HIV/AIDS counselling so that she/he can make an informed decision about whether or not to be tested for HIV.<sup>26</sup> VCT is, therefore, suggested to be an HIV intervention that includes both *voluntary pre- and post-test counselling* and *voluntary HIV testing*.<sup>27</sup> People, of their own free will, opt for VCT, and it provides them with an opportunity to confidentially explore and understand their HIV risks.<sup>28</sup> VCT is

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<sup>23</sup> Boggio; Zignol; Jaramillo; Nunn; Pinet; Raviglione “Limitations on Human Rights: Are they Justifiable to reduce the Burden of TB in the Era of MDR and XDR-TB”? *Health and Human Rights Journal Vol 10:1*, 2009, p. 121.

<sup>24</sup> Mann, “Human Rights and AIDS: The Future of the Pandemic”, in Mann; Gruskin; Grodin; Annas (eds) *Health and Human Rights: A Reader*, New York: Routledge; 1999,p. 223.

<sup>25</sup> United Nations Human Rights Office of the High Commissioner for Human Rights, “HIV/AIDS and Human Rights, 2012, available at [http://www.data.unaids.org/publications/irc-pub03/3797\\_en.html](http://www.data.unaids.org/publications/irc-pub03/3797_en.html), (accessed 3 November 2012).

<sup>26</sup> Department of Health Province of Kwazulu-Natal, “Voluntary Counselling and Testing” 2001, available at <http://www.kznhealth.gov.za/testing.htm>, (accessed 18 September 2012).

<sup>27</sup> Common Wealth Regional Health Community Secretariat “HIV/AIDS Voluntary Counselling and Testing: Review policies, programmes and guidelines in East Central and Southern Africa”, 2002, p. 4, available at [http://www.who.int/hiv/topics/vct/toolkit/components/policy/review\\_of\\_policies\\_pdf](http://www.who.int/hiv/topics/vct/toolkit/components/policy/review_of_policies_pdf), (accessed 22 November 2012).

<sup>28</sup> *Ibid.*

becoming increasingly recognised as a component of effective HIV prevention initiatives.<sup>29</sup> Key components of VCT policy include access to counselling, consent, confidentiality, and overcoming discrimination against people who have undergone testing and are found HIV positive.<sup>30</sup>

In Canada, a broad consensus has emerged that except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent, when counselling and education - before and following testing - are available and offered, and when confidentiality of results or anonymity of testing can be guaranteed.<sup>31</sup> Similar rules also apply in South Africa, that is, in principle a person may only be tested at his or her own request. However, the South African Medical Association (SAMA) encourages medical practitioners to urge their patients to undergo HIV testing for the purpose of good patient care<sup>32</sup> and, in terms of the Employment Equity Act of 1998;<sup>33</sup> medical practitioners may not test (prospective) employees at the request of employers. In general, the same principle applies: no medical testing without the employee's free and informed consent.

Mandatory screening can be done in so many different ways but at the end of the day it results in unnecessary human rights violations. For instance, in many health institutions across Africa and in South Africa, mandatory HIV screening can be done through anonymously testing blood that has been drawn for other reasons, in which case it is known as unlinked anonymous testing (UAT).<sup>34</sup> UAT has routinely been conducted at many antenatal clinics worldwide and although it might not violate a woman's right to confidentiality, it may violate her right to informed consent, a right that WHO and UNAIDS have identified as central to a "rights based-approach" to

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<sup>29</sup> United Nations Population Fund [UNFPA], 2002.

<sup>30</sup> WHO, "Scaling up HIV Testing and Counselling Services: A Toolkit for programme managers, 2005, p. 6 available at, <http://www.who.int/hiv/pub/vct/counsellingtestingtoolkit.pdf>, (accessed 27 August 2012).

<sup>31</sup> Canadian HIV/AIDS Legal Network., "Evolution of HIV Testing policy and technology in Canada", 2007, 23, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1076>, (accessed 23 September 2012).

<sup>32</sup> South African Medical Association, Human Dignity, Law and Ethics Unit, A Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners of South Africa 2001, available at <http://www.chr.up.ac.za/undp/domestic/docs/policies03.pdf>, accessed 17 January 2012.

<sup>33</sup> Employment Equity Act 55 of 1998, Section 7. This section specifically states that, testing of an employee to determine that the employee's HIV status is prohibited unless such testing is determined to be justifiable by the Labour Court in terms of Section 50(1) of this Act.

<sup>34</sup> Parmet, "Public Health and Social Control: Implications for Human Rights", Northern Public Law and theory faculty working paper series No. 4, 2010, 23, available at <http://www.ssrn.com/abstract=1546654>, (accessed 18 October 2012).

HIV/AIDS.<sup>35</sup> Parmet<sup>36</sup> points out that in certain cases some clinics offered syphilis testing in order to conduct UAT for HIV. This effectively deceives patients thus jeopardizing their right to informed consent and threatens to undermine trust between patients and health care providers.<sup>37</sup> Because it is anonymous, a different form of human rights violation arises as individuals who test positive for HIV are not identified and treated as data is collected without supporting the health needs of those from whom they obtain the information.<sup>38</sup>

The voluntariness of testing must remain at the heart of all HIV policies and programmes in order to comply with human rights principles and to ensure sustained public health benefits.<sup>39</sup> Self-initiated HIV testing and prevention counselling allow people to voluntarily learn their status and reduce the risk of acquisition or transmission of HIV infection. It is clear that such pro-action or rather self-imitativeness sends a clear message that a person wants to take control of his/her health and subsequently improve it, if need be. It is opined that mandatory testing does not yield the same result as it is unexpected and due to the lack of voluntariness individuals might not quickly accept their new status and make changes to their lifestyle.

The UNAIDS Global Reference Group on HIV/AIDS AND Human Rights has recommended that the following key factors, which are mutually reinforcing, should be addressed simultaneously: These include:<sup>40</sup>

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<sup>35</sup> WHO & UNAIDS, "The UNAIDS /WHO Policy Statement on HIV Testing", June 2004, available at [http://www.who.int/ethics/topics/en/hivtesting\\_policy\\_who-un aids\\_en\\_2004.pdf](http://www.who.int/ethics/topics/en/hivtesting_policy_who-un aids_en_2004.pdf), (accessed 24 August 2012).

<sup>36</sup> Parmet quoting Rennie in, "Conducting Unlinked Anonymous HIV Surveillance in Developing Countries: Ethical, Epidemiological, and Public Health Concerns", *PLoS Medicine journal Vol 6(1)*, 2009, p. 31, available at <http://www.plosmedicine.org/article/info:doi/10.371/journal.pmed.1000004>, (accessed 18 October 2012).

<sup>37</sup> Parmet, "Public Health and social Control: Implications for Human Rights to the International Council on Human rights policy", Project on social control and Human Rights Research paper (final draft) 2009, p. 46, available at [http://www.ichrp.org/.../public\\_health\\_and\\_social\\_control.](http://www.ichrp.org/.../public_health_and_social_control.), (accessed 03 November 2012).

<sup>38</sup> *Ibid.*

<sup>39</sup> UNAIDS Reference Group on HIV and Human Rights, "Statement and recommendations on scaling up HIV testing and counselling", 2007, available at , [http://www.unaids.org/en/Issues/Impact\\_HIV/20070601\\_reference\\_group\\_HIV\\_human\\_rights.asp](http://www.unaids.org/en/Issues/Impact_HIV/20070601_reference_group_HIV_human_rights.asp)(accessed 29 September 2012).

<sup>40</sup> *Ibid.*

- ensuring an ethical process for conducting the testing, including defining the purpose of the test and benefits to the individuals being tested; and assurances of linkages between the site where the test is conducted and relevant treatment, care and other services, in an environment that guarantees confidentiality of all medical information;
- addressing the implications of a positive test result, including non-discrimination and access to sustainable treatment and care for people who test positive;
- reducing HIV/AIDS-related stigma and discrimination at all levels, notably within health care settings;
- ensuring a supportive legal and policy framework within which the response is scaled up, including safeguarding the human rights of people seeking services; and
- ensuring that the healthcare infrastructure is adequate to address the above issues and that there are sufficient trained staff in the face of increased demand for testing, treatment, and related services.

The act of voluntariness lies at the heart of the HIV epidemic because of its nature. Firstly, there is the often intimate and private nature of the transmission routes, several of which lean crucially on what may broadly be termed an individual's lifestyle. Secondly, there is the age in which we live, and upon which AIDS has impacted, to take into account: it is not an overstatement of the truth to say that we live in an age of human and civil rights, and thus we must be far more cautious now than we have been in the past when it comes to the implementation of policies which infringe upon the liberties of the individual citizens.<sup>41</sup> It is thus against this background that practical issues of testing and screening for HIV and questions over the confidentiality of the results of such testing and screening must be examined and understood.<sup>42</sup>

### 5.3.1 Confidentiality

Patient confidentiality is one of the cornerstones of the medical profession. It ensures that a patient divulges all the information relevant to his or her health care to the

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<sup>41</sup> Bennet, Erin, *"HIV and AIDS: Testing, screening, and confidentiality"*, Issues in biomedical ethics, Oxford University Press 2003, p. 1-20.

<sup>42</sup> *Ibid.*

practitioner, thereby ensuring the best appropriate health care.<sup>43</sup> Confidentiality thereby refers to the keeping of medical records, including HIV test results or even seeking an HIV test in ways that protect people's privacy.<sup>44</sup> It is further an ethical and legal duty that flows from the individual's human right to privacy. The South African Law, that is, the Constitution and common law, clearly guarantees the right to privacy and confidentiality. It is to this effect that the privacy and confidentiality of status of those infected by HIV should be protected.

The counselling session prior to obtaining informed consent should be provided in a confidential situation, preferably in a private room and on a one-to-one basis.<sup>45</sup> Confidentiality means that doctors, nurses, psychologists, dentists and other health care workers have a moral and legal duty to keep all information about patients confidential. Any information about the patient's illness or treatment must be held in trust and cannot be given to another person unless:<sup>46</sup>

- the patient gives consent;
- the information is about the illness or treatment of a child - then health workers can tell others but only with the permission of the child's parent or guardian;
- the patient is dead - then the doctor must get permission from the next-of-kin (the person's closest family).

Respecting confidentiality is ethically required out of respect for the dignity of the patient so that the patient's most personal physical and psychological secrets are kept confidential in order to minimize a sense of vulnerability or shame. The nature of transmission of HIV/AIDS is associated in many African communities with promiscuity and, therefore, confidentiality is an important value that can reduce stigma and discrimination. It must be emphasized that professional health care

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<sup>43</sup> "Compendium of key documents relating to human rights in East and Southern Africa", PULP 2008, p. 208, available at, <http://books.google.co.za/books?id=NwvAOKGrRAcC&dq=Patient+confidentiality>, (accessed 04 November 2012).

<sup>44</sup> Canadian HIV/AIDS Legal Network., "Evolution of HIV testing policy and technology in Canada", 2007, p. 23, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1076>, (accessed 23 September 2012).

<sup>45</sup> Cohen, Ankus, "Counselling and testing for HIV", 2009, available at, [http://www.ashm.org.au/images/publications/.../isithiv/chapter\\_15.pdf](http://www.ashm.org.au/images/publications/.../isithiv/chapter_15.pdf), (accessed 15 October 2012).

<sup>46</sup> Aidsbuzz, "Rights and HIV", 2012, available at <http://www.aidsbuzz.org/index.php?option=com> (accessed 15 October 2012).

givers have a crucial role to play, that is, they ought to promote confidentiality as this gives the patients trust and faith in the health care system. Effective health care requires that patients feel confident and free to come forward to seek medical advice or treatment, rather than feel inhibited from entrusting physicians with personal information without being confident that their privacy will be protected.<sup>47</sup> Loss of that trust could lead people to avoid the health system, with serious consequences for the health of those individuals and for public health more broadly.<sup>48</sup>

An individual's control of who should have access to his or her medical information affirms, emphatically, respect for individual autonomy. Vedder explains that there is a special character associated with personal medical information, so that any breach of medical confidentiality which is not sanctioned by the individual concerned may cause him/her emotional and material harm, and it is the individual who is best positioned to judge the harm that may be done.<sup>49</sup> As further noted by Vedder, discrimination against those who are HIV positive is a fact, and is likely to disincline those who consider themselves to be at risk from voluntarily seeking an HIV test if confidentiality is not maintained.

Holm and Rossel<sup>50</sup> analyse a cluster of moral rights which afford a person protection from unsanctioned interference by others: the right to personal integrity, the right to autonomy, and the right to privacy. In their analysis, Holm and Rossel's understanding is that the right to personal integrity may be understood as a person's right to be the person he/she is and this right will only be infringed by unauthorized disclosure of personal information in unusual cases. They add that an extensive right to the control of personal information can only be founded on the right to privacy. It can be deduced from the analysis above that in order to protect the right to privacy and confidentiality, together with real informed consent, is a necessity especially

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<sup>47</sup> See Bennet *et al* footnote 41 above.

<sup>48</sup> *Ibid.*

<sup>49</sup> Vedder, "HIV/AIDS and the Point and Scope of Medical Confidentiality", in Bennnet and Erin (eds) *HIV and AIDS: Testing, Screening, and Confidentiality Issues in Biomedical Ethics*, Oxford University Press 2003, P.140-154.

<sup>50</sup> Holm and Rossel, " Ethical Aspects of the Use of 'Sensitive Information' in Health Care Research", in Bennnet and Erin,(eds) *HIV and AIDS: Testing, Screening, and Confidentiality Issues in Biomedical Ethics*, Oxford University Press 2003, p. 200-216.



when dealing with HIV cases. The nature of the illness requires trust between the patient and the health care giver and, subsequently, secrecy of the test results.

It will be unjust to give an outright assertion that HIV test results should only be known by the person being tested where the result is positive, as attempts to gain information about the HIV status of an individual are motivated by the considerable value that this information is perceived to have upon other people. It is without doubt that information of this kind may be valuable not only to the subject of the test, but may allow others to avoid risk and these people may include sexual partners, insurance companies and even the employer.<sup>51</sup> The latter are instances where the human rights to autonomy, privacy, dignity and bodily integrity can be limited since rights are not absolute. Such limitations are necessary for the protection of the public at large.

The question that quickly arises is whose rights should be curtailed in this regard and which are of paramount importance, and can confidentiality be breached? It is easy to see the value of information about HIV status to insurance companies, for instance, so that they can calculate risk, but, again, does this interest justify insistence on disclosure? These questions are not clearly addressed by Sorell and Draper<sup>52</sup> who further question the supportable grounds for overriding the principle of respect for personal autonomy of an individual or group of individuals. Can it ever be morally justified to obtain information about a person's HIV status irrespective of her wishes in the matter?<sup>53</sup> It is thereby submitted that confidentiality lies at the heart of a rights-based approach to voluntary counselling and testing. The intended results of control of the epidemic might not be reached as the African community is still ashamed of this disease so much that exposing those infected does not do any good to the individual's self-esteem and dignity; instead what it does is to expose them to more stigma and discrimination.

For the reason that HIV/AIDS is not an open issue, communities need to be educated about HIV and AIDS and the supportive role they can play in the lives of

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<sup>51</sup> *Ibid.*

<sup>52</sup> Sorell, Draper, "AIDS and Insurance", in Bennet and Erin, (eds) *HIV and AIDS: Testing, Screening, and Confidentiality Issues in Biomedical Ethics*, Oxford University Press 2003, p. 216.

<sup>53</sup> See Bennet and Erin footnote 41 above, p. 16.

people living with the disease. In this way people may be encouraged to be open about their HIV status so that they can get the necessary treatment and practice a healthy standard of living without fear of being judged. Some people choose to be open about their status to certain people but this does not mean they lose their right to confidentiality with a doctor, nurse, health care worker, employer or friend.<sup>54</sup> Patients, their contacts, doctors and their staff, and the common good are most likely to be best served if medical confidentiality continues to be honoured.<sup>55</sup> More so, real consent is only possible where patient confidentiality is respected, so that the testing values of confidentiality and consent are inter-related. Ultimately, a person's personal right to privacy and confidentiality must always be respected.

### 5.3.2 Informed consent

Informed consent has been part of South African law. A patient must provide informed consent for all medical treatment (diagnostic or therapeutic) performed on him or her. This notion was laid down in the famous case of *Stoffberg v Elliot*.<sup>56</sup> Everyone has the right to make their own decisions about their bodies. Therefore, no patient can be given medical treatment without his/her consent.<sup>57</sup> Informed consent means that sufficient information is provided to enable the patient to make an informed decision, and that the patient actually understands the information and implications of acting on that information. Informed consent relates to a person's right to human dignity and autonomy.<sup>58</sup> Consenting to medical treatment or an HIV test has two parts to it: information (understanding) and permission (agreeing). The critical element of informed consent or the agreeing element is the fact that consent cannot be presumed or implied. Thus, this means that individuals subjected to the

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<sup>54</sup> The AIDS Law Project and the AIDS Legal network, "HIV and AIDS and the Law": A Resource Manual, 2<sup>nd</sup> edition, 2003, available at <http://www.paralegaladvice.org.za/docs/chap09/03.html>, (accessed 18 October 2012).

<sup>55</sup> Canadian HIV/AIDS Legal Network. "Privacy Protection and the Disclosure of Health Information: Legal Issues for People Living with HIV/AIDS in Canada". 2004.

<sup>56</sup> *Stoffberg v Elliot* 1923 CPD 148 at 150.

<sup>57</sup> South African Medical Association, Human Dignity, Law and Ethics Unit, "A Human Rights and Ethical Guideline on HIV: A Manual for Medical Practitioners of South Africa" 2001, available at, [http://www.chr.up.ac.za/undp/domestic/docs/policies\\_03.pdf](http://www.chr.up.ac.za/undp/domestic/docs/policies_03.pdf), (accessed 17 August 2012).

<sup>58</sup> VCT Toolkit, "HIV voluntary counselling and testing a reference guide for counsellors and trainers", Family Health International 2004, available at [http://www.pdf.usaid.gov/pdf\\_docs/PNACW801.pdf](http://www.pdf.usaid.gov/pdf_docs/PNACW801.pdf), (accessed 03 November 2012). See also Knobel "Consent, with particular reference to HIV and AIDS", *South Africa's Continuing Medical Education Monthly* 79, 2006, p. 24.

test ought to sign consent forms or, in other circumstances, affirmatively allow having these tests conducted.<sup>59</sup>

Consent is, however, a straight forward concept though normally taken for granted due to the imbalance of the relationship between the client and the health care provider. A vital element necessary for an HIV test to be conducted is that an individual must know what the test is about, why it is being done, and what the implications of the results are before agreeing to the blood sample being taken. This is essentially what is termed pre-test counselling.<sup>60</sup> After the HIV test results have been received, patients must be counselled again to help them understand and accept the effect that a negative or a positive result will have on their lives.

#### *5.3.2.1 Exceptions to the rule of informed consent*

The following are the only exceptions to the rule that a person must give his/her consent to treatment or an operation:<sup>61</sup>

- if a patient needs emergency treatment;
- testing is done on blood donations;
- Mentally ill patients - in this case the mental hospital must get permission from one of the following people: the patient's husband or wife, parent, child (if the child is 21 or older), brother or sister; and
- HIV tests routinely done on the blood of all pregnant women for health research, but the name of the woman is not attached to the blood sample, so no-one knows whose blood it is.

#### *5.3.3 Counselling*

WHO defines HIV counselling as a “confidential dialogue between a client and a counsellor aimed at enabling the client to cope with stress and make personal

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<sup>59</sup> Canadian HIV/AIDS Legal Network, “Prevention and protection: Enhancing both HIV testing and human rights in Canada”, 2007, available at <http://www.aidslaw.ca/testing>, (accessed 14 October 2012).

<sup>60</sup> *Ibid.*

<sup>61</sup> See Erin and Bennet footnote 41 above.

decisions related to HIV/AIDS.<sup>62</sup> The counselling process includes evaluating the personal risk of HIV transmission and discussing how to prevent infection. It is the only way that an individual can acquire the relevant information needed in order to make an informed decision whether to test or not. It concentrates specifically on emotional and social issues related to possible or actual infection with HIV and AIDS. With the consent of the client, counselling can be extended to spouses, sex partners and relatives (family-level counselling, based on the concept of shared confidentiality).<sup>63</sup> HIV counselling has as its objectives prevention and care as well as emotional support to those who are tested positive.

The goal of pre-test counselling is to determine the parameters of the session, describe the roles and responsibilities of the participant and counsellor, and establish an agreement with the participant about the objectives of the session.<sup>64</sup> Corbitt is careful to make it clear that such counselling is not only aimed at providing technical information regarding HIV and the test; it is also essential if the person undergoing a test is to be optimally and psychologically prepared in order to deal with the implication of the test result, whether positive or negative. It has been postulated that serological testing for HIV without counselling has a psychological, medical and social impact on patients.<sup>65</sup> Therefore, testing must be preceded and followed by appropriate counselling by trained or experienced professionals.<sup>66</sup>

HIV counselling plays two important roles: preventing HIV infection by promoting behaviour change, and providing psychosocial support to people infected with and affected by HIV. These roles are fulfilled by:<sup>67</sup>

- giving information about HIV/AIDS to clients and their partners;
- encouraging preventive behaviours;

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<sup>62</sup> UNAIDS technical update, "Counselling and HIV/AIDS" 1997, available at, [http://www.unaids.org/en/media/unaids/.../dataimport/.../irc.../counstu\\_en.](http://www.unaids.org/en/media/unaids/.../dataimport/.../irc.../counstu_en.), (ccessed 16 November 2012).

<sup>63</sup> *Ibid.*

<sup>64</sup> Anderson, Louw- Potgieter, " An implementation evaluation of a voluntary counselling and testing programme for the human immunodeficiency syndrome(AIDS)", *SA Journal of Industrial Psychology Vol 38:1*, 2012 p. 10.

<sup>65</sup> Corbitt, "HIV Testing and Screening: Current Practicalities and Future possibilities", in Bennet and Erin,(eds) *HIV and AIDS: Testing, Screening, and Confidentiality Issues in Biomedical Ethics*, Oxford University Press 2003 p. 21-37.

<sup>66</sup> Canadian Medical Association, "Counselling Guidelines for HIV Testing ", 1995, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1076>, (accessed 02 November 2012).

<sup>67</sup> *Ibid.*

- helping HIV-positive clients and those close to them cope with the diagnosis;
- discussing decisions that need to be made according to the client's life circumstances; and
- referring clients to appropriate treatment and care.

Internationally, the benefits of counselling linked to HIV testing have been demonstrated in several countries. A widely cited 2000 study in Kenya, Tanzania, and Trinidad and Tobago showed that people who received well-supported and individualized counselling with HIV testing were more likely to reduce HIV risk behaviours than those who received health information without the chance to talk with a counsellor.<sup>68</sup> A major concern raised by many academics is that, although there is a consensus that counselling is desirable, in many cases the quality of counselling provided is not given a high enough priority and that there is little consistency, regulation or evaluation of counselling and counsellors in this area. Sherr contends that testing should not be seen as an end in itself, but rather as one of the many tools in the fight against HIV/AIDS.<sup>69</sup> Both research studies and anecdotal evidence revealed serious inadequacies in counselling practices in Canada over the years. At a 2006 national consultation in Canada on HIV testing, some health professionals expressed concern that inadequate compensation for physicians for counselling time may lead to poor-quality HIV counselling, a concern that has been raised repeatedly over the years.<sup>70</sup>

#### **5.4 Specific Rights that can be potentially violated**

A lot of human rights are applicable to the HIV/AIDS discourse and may potentially be violated by HIV/AIDS testing. Testing alone without respecting the three fundamental values of testing violates a wide range of human rights and these include the following rights to: non-discrimination and equality before the law; life; health; liberty and security of the person; freedom of expression; freedom from

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<sup>68</sup> Canadian Medical Association, "Counselling Guidelines for HIV Testing ", 1995, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=1076>, (accessed 02 November 2012).

<sup>69</sup> Sherr, "Counselling and HIV Testing: Ethical Dilemmas", in Bennet and Erin (eds) *"HIV and AIDS: Testing, Screening, and Confidentiality Issues in Biomedical Ethics"*, Oxford University Press 2003, p. 39-61.

<sup>70</sup> See the Canadian Medical Association footnote 66.

inhuman or degrading treatment or punishment; freedom of movement; privacy; marry and have a family; education; work; an adequate standard of living; social security; assistance and welfare; seek and enjoy asylum; share in scientific advancement and its benefits; and participate in public and cultural life.<sup>71</sup> However, this section will discuss three rights which are human dignity, privacy, and the right to freedom and security of the person.

## 5.5 The Right to Privacy

International law specifically preserves the right to privacy in some of its instruments. The International Convention on Civil and Political Rights states that no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, or to unlawful attack on his honour and reputation.<sup>72</sup> Article 17(2) of this covenant further guarantees that, “Everyone has the right to the protection of the law against such interference or attacks”. The European Convention on Human Rights also guarantees the right to respect for private and family life in Article 8. It postulates that, “Everyone has the right to the respect for his private and family life, his home and his correspondence.”<sup>73</sup>

### 5.5.1 The right to privacy under South African Law

Research has pointed out that South African scholars largely refrain from examining and discussing the right to privacy and its limitations in the context of HIV/AIDS.<sup>74</sup> However, the right to privacy is preserved by both the common and constitutional law in South Africa.<sup>75</sup> The common law recognises the right to privacy as an independent personality right that the courts consider being part of the concept of *dignitas* as expounded in the case of *Bernstein v Bester*.<sup>76</sup> As common law,<sup>77</sup> the breach of a

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<sup>71</sup> United Nations Human Rights Office of the High Commissioner for Human Rights, “HIV/AIDS and Human Rights, 2012, available at [http://www.data.unaids.org/publications/irc-pub03/3797\\_en.html](http://www.data.unaids.org/publications/irc-pub03/3797_en.html), (accessed 3 November 2012).

<sup>72</sup> International Convention on Civil and Political Rights of 1976 Article 17.

<sup>73</sup> The European Convention on Human Rights of 1950.

<sup>74</sup> Roehrs, “Privacy, HIV/AIDS and public health interventions”, *South African Law Journal Vol 126:2*, 2009, p. 360. Roehrs points out that until the Constitutional Court’s decision in *NM and Others v Smith and Others* 2005 (5) SA 250(CC), the lack of literature was accompanied by a scarcity of case law regarding the importance of the protection of privacy of HIV-infected people.

<sup>75</sup> *Bernstein v Bester* NO 1996 (2) SA 751 (CC) para 68.

<sup>76</sup> *Ibid.*

<sup>77</sup> The common law of South Africa is made up not only of decided cases but also of views expressed by celebrated Roman Dutch writers of the the 17<sup>th</sup> and 18 Centuries, together with certain statutes that were in force in the province of Holland. See Palmer and Poulter *The Legal System of Lesotho*

person's privacy constitutes an *injuria* and for this to occur, the following three elements must be proved: an invasion of privacy; wrongfulness; and fault.<sup>78</sup> A breach of a person's privacy constitutes an *injuria* and it occurs when there is an unlawful intrusion on someone's personal privacy or an unlawful disclosure of private facts about a person.<sup>79</sup> Under the South African Constitution<sup>80</sup> fault is not a requirement when establishing whether the right to privacy has been violated. However, a two stage analysis is employed to decide whether the right to privacy has been violated.<sup>81</sup> First, the scope of the right must be assessed to determine whether it has been infringed. If it is established that the right has been violated, this violation will prima facie be regarded as unlawful. In the second leg of the analysis, the person or body breaching the right must show that the infringement was justifiable.<sup>82</sup>

The National Health Act of South Africa (NHA)<sup>83</sup> is a comprehensive piece of medical legislation that applies to both public and private health care facilities. It entails detailed provisions for the protection of confidentiality, emphasising that *all* information concerning a user of a health facility, including information relating to his or her health status, treatment or stay in a health establishment is confidential.<sup>84</sup> Confidential information may be disclosed only with the patient's informed consent, and in writing.<sup>85</sup> The legislation does, however, allow breaches of confidentiality in certain circumstances. If, for instance, a court orders or any law requires the disclosure of specific health information, the consent of the patient is not required for such disclosure.<sup>86</sup>

Before an analysis is made of how the right to privacy can be violated by mandatory testing, it is important to clearly set out or define what privacy is. Ackermann J's reasoning in the *Bernstein case* can be summarised as follows: a) privacy is a subjective expectation of privacy that is reasonable; b) it is reasonable to expect

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The Legal System of Africa Series. Michie Company, Law Publishers, Charlottesville, Virginia, USA, 1972, p. 73.

<sup>78</sup> McQuoid-Mason, "Invasion of privacy: common law v constitutional delict - does it make a difference?" *Acta Juridica* 2000, p. 247.

<sup>79</sup> *Financial Mail v Sage Holdings* 1993(2) SA 451(A).

<sup>80</sup> The Constitution of South Africa 1996, section 14.

<sup>81</sup> Roers, "Privacy, HIV/AIDS and public health interventions, p. 362.

<sup>82</sup> Currie, De Waal, "*The Bill of Rights Handbook*", 5<sup>th</sup> Edition 2005, p. 316.

<sup>83</sup> National Health Act 61 of 2003.

<sup>84</sup> *Ibid* section 14.

<sup>85</sup> Section 14 (2).

<sup>86</sup> *Ibid*.

privacy in the 'inner sanctum', in the truly personal realm.<sup>87</sup> The inner sanctum of a person as referred to in the *Bernstein case* refers to family life, sexual preference and home environment.<sup>88</sup> The case concerns a dispute between Mr Bernstein and other partners and employees of Kessel Feinstein, a partnership of chartered accountants (the Applicants) and Mr Bester and other liquidators of Tollgate Holdings Limited (the Respondents). The essence of the dispute between the parties is whether the Respondents are precluded by the Constitution from continuing with the examination of the Applicants in terms of sections 417 and 418 of the Companies Act 61 of 1973 (as amended).

Fagan DJP in the Cape Provincial Division of the Supreme Court submitted that these sections of the Act are inconsistent with the Constitution and are consequently invalid and of no force and effect. As part of their attack on the constitutionality of section 417 and 418 of the Act, the Applicants submit that a witness's privacy is clearly invaded when he is forced to disclose his books and documents that he wants to keep confidential and to reveal information that he wants to keep to himself. In addition, the Applicants contend that the compulsory production of documents under section 417(3) constitute a seizure within the meaning of the right not to be subject to seizure of private possessions in terms of section 13 of the Constitution. Ackermann J warned that caution must be exercised when attempting to project common-law principles onto the interpretation of fundamental rights and their limitation. He drew a distinction between the two-stage constitutional inquiry into whether a right has been infringed and whether the infringement is justified, and the single inquiry under the common law, as to whether an unlawful infringement of a right has taken place. It is therefore important to evaluate the right to privacy in the light of both the common law and the Constitution.

The issue in the Constitutional Court case of *National Media Ltd and Another v Jooste*<sup>89</sup> was whether the Appellants (the publisher of two weekly magazines, the Huisgenoot and You, and the news editor of the former) have wrongly breached the respondent's right to privacy by publishing details of private affairs for "public delectation". The respondent, at the time an unmarried postgraduate student, was

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<sup>87</sup> Currie, De Waal, "The Bill of Rights Handbook", 5<sup>th</sup> ed 2005 p. 319.

<sup>88</sup> *Bernstein case* para 67.

<sup>89</sup> *National Media Ltd and Another v Jooste*. 1996 (3) SA 262 (SCA)



thrust into the public eye during September 1988. The Daily Press had discovered that she had, some six months earlier, given birth to a child. A well-known rugby player, Mr Naas Botha, was alleged to be the father. The court held that a right to privacy encompasses the competence to determine the destiny of private facts, and the individual concerned is entitled to dictate the ambit of disclosure, e.g. to a circle of friends, a professional adviser or the public.<sup>90</sup>

The court defined 'private facts' as affairs, the disclosure of which will cause mental distress and injury to anyone possessed of ordinary feelings and intelligence.<sup>91</sup> Privacy was also defined as an individual's condition of life characterised by exclusion from the public and from publicity.<sup>92</sup> This condition embraces all those personal facts which the person concerned has determined himself to be excluded from the knowledge of outsiders and in respect of which he has the will that they be kept private. Charles Ngwena, a profound writer on HIV/AIDS and the law, also submits that privacy serves to protect the individual's dignity and personality by proscribing unjustifiable intrusions into the private sphere.<sup>93</sup>

O 'Regan J in the case of *NM and others v Smith and Others* also characterises privacy, liberty and dignity as the key constitutional rights which construct our understanding of what it means to be a human being.<sup>94</sup> In *NM & Others v Smith*, the Constitutional Court of South Africa was required to strike a balance between the right to freedom of expression and the protection of individuals' privacy interests. The Applicants were three HIV positive individuals who had participated in clinical research concerning possible HIV treatments. The Respondents published a book which discussed those clinical trials. A passage in the book referred to the Applicants by their real names and disclosed their HIV status. The Applicants argued that the disclosure of this information without their consent had violated their fundamental rights to privacy, dignity and psychological integrity. The Constitutional Court held that there had been a violation of their fundamental rights. The right to free expression had to give way to the fundamental right of human dignity.

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<sup>90</sup> *Jansen van Vuuren and Another NNO v Kruger* 1993 (4) SA 842.

<sup>91</sup> *NM and Others v Smith and Others* 2007 (5) SA 250 (CC) para 34.

<sup>92</sup> See footnote 88 above para 645.

<sup>93</sup> Ngwena, "HIV in the Workplace: protecting rights to equality and privacy", *South African Journal on Human Rights* Vol 15, 1999, p. 533.

<sup>94</sup> Roehrs, "Privacy, HIV/AIDS and Public Health Interventions", p. 368, See also *NM and Others v Smith*, par 40.

People living with HIV/AIDS often invoke this right when dealing with issues around disclosing their HIV-positive status. Most people would consider their HIV status to be a private affair, as it is referred to as a taboo in most societies and no one wants to be associated with HIV/AIDS. This is also supported by Roers who says HIV is a condition related to sex, death and disease, topics that allude to the most existential aspects of life and are, therefore, perceived as highly intimate. Stefanie Roehrs in his elegant and analytical work adds that a person's HIV status is a private fact as confirmed in *NM and Others v Smith and Others* where Madala J acknowledged that an individual's HIV status deserves protection against indiscriminate disclosure due to the nature and negative social context the disease has, as well as the potential intolerance and discrimination that results from its disclosure.<sup>95</sup>

Protection of privacy is also emphasized in order to encourage individuals to seek treatment and divulge information encouraging disclosure of HIV and to initiate improvement of public health policies on HIV/AIDS.<sup>96</sup> HIV/AIDS is not a notifiable disease and, except in rare instances, HIV-positive people cannot be forced to disclose his/her HIV status to anyone.<sup>97</sup> People have a constitutional right to privacy and, therefore, they do not have to disclose their status to their families. A problem, however, arises in issues of partner notification, that is, when and how a person can disclose his/her status to avoid infecting the other person. The counselling process has an active role in dealing with this issue as individuals are advised and are taught how to inform their partners of their status. However, the Criminal Law (Sexual Offences and Related Matters Act) makes the intentional non-disclosure of HIV/AIDS by a person to his/her sexual partner a criminal offence.<sup>98</sup> It is the responsibility of the HIV positive individual to inform his/her partner of the HIV test result. It is clear that such advice is given during counselling, but if mandatory testing is effected and proper counselling is omitted, HIV/AIDS will continue to spread.

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<sup>95</sup> See *NM and Others v Smith and Others* footnote 91 above.

<sup>96</sup> Canadian HIV/AIDS Legal Network, "HIV/AIDS and privacy of health information: The importance of privacy of health information for people living with HIV/AIDS, 2004, available at <http://www.aidslaw.ca/publications/interfaces/downloadFile.php?ref=187>, (accessed 15 September 2012).

<sup>97</sup> *Ibid.*

<sup>98</sup> Criminal Law (Sexual Offences and Related Matters Amendment Act 32 of 2007, sections 29-32.

The types of infringements that may apply in the context of HIV/AIDS as expounded by Roehrs<sup>99</sup> include, firstly, unauthorized blood tests. This takes place where insurance companies, employers or others perform an HIV test on a blood sample without the informed consent of the person whose blood is being tested. This issue was dealt with in the case of *C v Minister of Correctional Services* and the High Court found out that such a test violated the prisoners' right to privacy.<sup>100</sup> In this case, the Department of Correctional Services had taken a blood sample from an inmate which was later used for an HIV test without the Plaintiff's informed consent. This does not only infringe the right to privacy but also infringes the 3' C's - the foundations of any HIV testing practice advocated and laid down by the UNAIDS guidelines. It cannot be reiterated strongly enough that testing must be done where informed consent and counselling have been given, and confidentiality observed. In this case none of the above principles were observed and the right to privacy as set out by section 14 of the South African Constitution was also infringed. The court ruled that testing for HIV in prisons must be undertaken in accordance with the relevant Correctional Service protocol which rightfully required informed consent for an HIV test.<sup>101</sup>

The second type of infringement that may apply in the context of HIV/AIDS is the non-consensual HIV disclosure.<sup>102</sup> The same principles as above also apply. It is clear that one's consent is required and this consent must be informed, implying that people must have the full knowledge as to the reason their blood is being taken and for what purpose. Such protection in HIV testing is still required to date as the infection still carries the two serious elements of HIV/AIDS which are stigma and discrimination.

The Constitutional Court made its first ruling on HIV disclosure and its implications in the case of *NM and Others v Smith*.<sup>103</sup> This case concerned three plaintiffs who had participated in clinical trials conducted at the Medical Faculty of the University of Pretoria, designed to determine the efficacy of a combination of drugs developed for the fight against the HIV virus. All three had signed consent forms indicating that

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<sup>99</sup> See Roehrs footnote 94 above, p. 370.

<sup>100</sup> *C v Minister of Correctional Services* 1997 JOL 407(T).

<sup>101</sup> *C v Minister of Correctional Services*, para 5.

<sup>102</sup> See Roehrs footnote 94 above.

<sup>103</sup> See *NM and Others v Smith* footnote 91 above.

they were informed of the nature, benefits, side effects and risks entailed by the clinical trials. The issue in this case was that their HIV status was revealed in a book without their authorization.

The justices hearing the case were in agreement regarding the private nature of any information concerning a person's medical condition in general and particularly because they are HIV positive. They also agreed that the disclosure of such information establishes a basis for an invasion of privacy complaint. It was held that the defendants were negligent in publishing information of such a nature as consent was not given. Justice O' Regan expounds that the right to privacy recognizes the importance of protecting the sphere of our personal daily lives from the public. In so doing, it highlights the inter-relationship between privacy, liberty and dignity as the key constitutional rights which construct our understanding of what it means to be a human being.<sup>104</sup>

The third potential infringement of the right to privacy as postulated by Roers is the imputation of HIV infection. A potential example of an infringement of privacy that magistrates often have to deal with is where one person publicly accuses someone of being infected with HIV or having AIDS, although such person is not infected with the virus.<sup>105</sup> McQuoid-Mason's understanding of a violation of privacy includes placing a person in a false light, in cases where the law of defamation does not cover the conduct.<sup>106</sup> Publicly imputing that a person is infected with HIV/AIDS would constitute an invasion of privacy.<sup>107</sup>

In relation to disclosure of HIV-related information, the court upheld and enforced the common law right to privacy when a medical practitioner unjustifiably disclosed his patient's HIV status in the case of *Jansen van Vuuren NNO v Kruger*.<sup>108</sup> The court held that the disclosure by one medical practitioner to another regarding a patient's HIV status was a breach of the patient's privacy.

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<sup>104</sup> *Ibid* para 131.

<sup>105</sup> See Roehrs footnote 94 above p.371. The latter author came to this conclusion that infringement could occur in cases where there is imputation of HIV infection after he facilitated discussions around HIV/AIDS, and privacy and HIV/AIDS and *crimen iniuria* between magistrates at workshops in various South African Provinces. A very high number of magistrates had heard cases where one person had accused another person of being infected with HIV or having AIDS.

<sup>106</sup> Roehrs quoting McQuoid-Mason, "Invasion of privacy: common law v constitutional delict, does it make a difference?", *Acta Juridica* 2000, p. 229.

<sup>107</sup> *Ibid*.

<sup>108</sup> *Jansen van Vuuren NNO v Kruger* 1993 4 SA 842 (A).

## 5.6 The Right to Human Dignity

Rapidly increasing numbers of people infected with HIV and people with AIDS will be accompanied by intense political, social and economic stresses. Further, threats to and interference with the human rights and dignity of those infected, those who are ill and those most vulnerable will increase substantially.<sup>109</sup> On the brighter side human rights and, of particular interest, human dignity is inherent in humans, and it arises from the very nature of a human being as a social animal.<sup>110</sup> The concept of human rights is grounded in concepts of human dignity and equality, which can be found in most cultures, religions and traditions that are today reflected in many legal systems. It is thus important to realize that PLHAs have the same fundamental, civil, political, social and cultural human rights as any other person by virtue of their humanity.<sup>111</sup>

### 5.6.1 What really is human dignity?

Botha states that dignity is “notoriously difficult to define” and it seems that the meaning of the term is seldom explained and it is assumed that everyone instinctively knows what it means.<sup>112</sup> Goolam notes that only human dignity is presented as an unqualified constitutional value.<sup>113</sup> Human dignity is the most fundamental value and thus it lies at the root of the Constitution, which also resonates well with all the other values. Each of the other values emerging from the constitutional text can, therefore, be seen as derivative from human dignity.<sup>114</sup> Wood expounds that “human dignity” represents the highest possible social status or worth and it belongs to all human beings simply because of their humanity. “Human dignity” equates to the irreplaceable non-fungible worth of each human being as an end in itself and as the principle that every person has self-determination.<sup>115</sup>

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<sup>109</sup> Mann and Tarantola *AIDS in the World* Oxford Press 1996, p. 616

<sup>110</sup> Mc Crudden, “Human Dignity and Judicial Interpretation of Human Rights”, *European Journal of International Law Vol 19:4,2008*, p. 655.

<sup>111</sup> Centre for the Right to Health for the policy project, “HIV/AIDS and Human Rights in Nigeria”, Background Paper for HIV/AIDS Policy Review in Nigeria, 2003.

<sup>112</sup> Botha, “Human Dignity in Comparative Perspective”, *Stell LR 2*, 2009, p. 207-208.

<sup>113</sup> Goolam, “The cartoons controversy: a note on freedom of expression, hate speech and blasphemy” *CILSA* 333, 2006.

<sup>114</sup> *Ibid.*

<sup>115</sup> Wood, in Bernard-Naude(eds) *Dignity, Freedom and the Post-Apartheid Legal Order* Cape Town: Juta 2008.

The US Supreme Court and constitutional courts around the world regularly use the term “human dignity”<sup>116</sup> when deciding cases about freedom of speech, reproductive rights, racial equality, gay marriage and bioethics.<sup>117</sup> Judges and scholars treat dignity as an important legal value, but they usually do not explain what it means and often imply that it has one obvious core meaning.<sup>118</sup> There has been so much debate and disagreements about the meaning of human dignity. During the start of international efforts to protect human dignity, the drafters of the Universal Declaration of Human Rights disagreed about its meaning. Neomi, espouses that the world community chose dignity in the Universal Declaration of Human Rights precisely because the term was open enough to hedge controversial judgements between different cultural values.<sup>119</sup>

The Universal Declaration of Human Rights<sup>120</sup> in its preamble provides that, “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world”, and it declares in Article 1 that “All human beings are born free and equal in dignity and rights”, and that “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment”<sup>121</sup>. The International Covenant on Civil and Political Rights<sup>122</sup>, Article 5, also buttresses these provisions and states that, “everyone shall be free from torture and other cruel, inhuman or degrading treatment or punishment”. Clearly both the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights<sup>123</sup> proclaim in their preambles that human rights derive from the inherent dignity of the human person.

In the African context, Article 5 of the African Charter on Human and Peoples’ Rights (ACHPR) article 5 provides that,

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<sup>116</sup> The word itself human dignity has its roots in Latin, but the Romans primarily used it in a context that referred to the respect due to those who were of elevated social status or *dignitas* and this status was not accorded to women, slaves and common men.

<sup>117</sup> Neomi Rao, “Three Concepts of Dignity in Constitutional Law”, *Notre Dame Law Review*, Vol.86:1, 2011, p. 183-271.

<sup>118</sup> *Ibid.*

<sup>119</sup> *Ibid.*

<sup>120</sup> The Universal Declaration of Human rights of 1948.

<sup>121</sup> Universal Declaration of Human Rights Article 5.

<sup>122</sup> International Covenant on Civil and Political Rights of 1976.

<sup>123</sup> International Covenant on Economic, Social and Cultural Rights of 1976.

Every individual shall have the right to the respect of the dignity inherent in a human being and to the recognition of his legal status. All forms of exploitation and degradation of man particularly slavery, slave trade, torture, cruel, inhuman or degrading punishment and treatment shall be prohibited.<sup>124</sup>

Also in the preamble to the Constitutive Act of the African Union all members of the Organization were made conscious of the fact that dignity is one of the essential objectives for the achievement of the legitimate aspirations of the African people. All the above stated instruments are in support of the dignity and worth of those affected by HIV/AIDS, as this status and the accompanying medical conditions do not make them short of being human beings.

### *5.6.2 The right to dignity and the South African Constitution*

Section 10 of the South African Constitution states that, “Everyone has inherent dignity and the right to have their dignity respected and protected.”<sup>125</sup> Human dignity is a central value of the objective, normative value system established by the Constitution.<sup>126</sup> According to section 1, the Republic of South Africa is founded on the values of ‘human dignity, the achievement of equality and the advancement of human rights and freedoms.’<sup>127</sup> Chief Justice Chaskalson, one of the noted Constitutional Court Judges in South Africa, points that:

the affirmation of inherent human dignity as a foundational value of the constitution order places our legal order in line with the development of constitutionalism in the aftermath of the Second World War.<sup>128</sup>

This important remark reflects on South Africa’s constitutional environment in that it is in line with international standards as well as modern constitutions that put human dignity as a value and is used to interpret other rights. In support of the latter remark, Judge O’Regan also postulates that recognising a right to dignity is an acknowledgement of the intrinsic worth of human beings; human beings are entitled

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<sup>124</sup> African Charter on Human and Peoples’ Rights (ACHPR) of 1986.

<sup>125</sup> The Constitution of South Africa 1996.

<sup>126</sup> *Carmichele v Minister of Safety and Security* 2001(4) SA 938(CC) para 56.

<sup>127</sup> Currie, De Waal, *The Bill of Rights Handbook* 5<sup>th</sup> Edition, Juta Law 2005.

<sup>128</sup> Chaskalson, “ Human Dignity as a foundational Value of our Constitutional order, *South African Journal of Human Rights* Vol 16, p. 193, 2000.

to be treated as worthy of respect and concern. This right, therefore, is foundational of many other rights that are specifically entrenched in the Bill of Rights.<sup>129</sup>

The South African Constitution places so much emphasis on the right to dignity and it is a value of high regard in South Africa. Chaskalson points out that;

the rights to life and dignity are the most important of all human rights, and the source of all other personal rights in the Bill of Rights. By committing ourselves to a society founded on the recognition of human rights we are required to value these two rights above all others.<sup>130</sup>

Human dignity is not only a justiciable and enforceable right that must be respected and protected, it is also a value that informs the interpretation of possibly all other fundamental rights and that is of central significance in the limitation enquiry.<sup>131</sup> For instance, when balancing rights under the limitations clause, one must ask how the central constitutional value of dignity is affected.<sup>132</sup>

Dignity is invoked as a supreme value, an interpretive *leitmotiv*, a basis for the limitation of rights and freedoms, and a guide to the principled resolution of constitutional value conflicts as it is used in the interpretation of all other rights.<sup>133</sup> South Africa is one of the countries which have recently embraced dignity as a constitutional right, a supreme value and a guide to constitutional interpretation.<sup>134</sup> Dignity exists merely by virtue of a person's humanity and does not depend on intelligence, morality or social status. Intrinsic dignity is a presumption of human equality and each person is born with the same quantum of dignity.<sup>135</sup> In essence

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<sup>129</sup> *S v Makwanyane*, 1995, (3) SA 391 (CC) para 328. This case also stated that the respect for dignity of all human beings is particularly important in SA, because during apartheid there was a denial of a common dignity. Black people were refused respect and dignity and thereby the dignity of all South Africans was diminished. The new Constitution rejects this past and affirms the equal worth of all South Africans. Thus recognition and protection of human dignity is the touchstone of the new political order and is fundamental to the new Constitution.

<sup>130</sup> *National Coalition for Gay and Lesbians Equality v Minister of Justice* 1999 (1) SA 6 (CC). In this case the common law criminalisation of sodomy was said to be in violation of the right to dignity. The court held that the constitutional protection of dignity requires us to acknowledge the value and worth of all individuals as members of our society. Punishing a form of sexual conduct which is identified by the broader society with homosexuals is inconsistent with human dignity.

<sup>131</sup> *Dawood v Minister of Home Affairs* 2000(3) SA 936(CC) para 35.

<sup>132</sup> *Christian Education South Africa v Minister of Education* 2000(4) SA 757 (CC) para 15.

<sup>133</sup> Botha, "Human Dignity in Comparative Perspective", *Stellenbosh Law Review* 2, 2009, p. 171.

<sup>134</sup> *Ibid.*

<sup>135</sup> Roas, "The concept of dignity in international law: Inherent dignity", *Notre Dame Law Review* Vol 86, p. 187, 2011. He further expounds that this type of dignity arises in each individual simply by virtue of being human and, stripped down, this dignity does not confer any status, actual intelligence,



everyone is equal in worth irrespective of race, colour, social status, income or HIV or any other health status.

An interesting aspect of human dignity is the fact that inherent/intrinsic dignity focuses on human potential and not the exercise of such potential; this means that it does not judge whether a person's reasoning, choices or criteria for self-worth are "dignified".<sup>136</sup> Intrinsic dignity reflects the idea that personhood requires a certain degree of respect.<sup>137</sup> It is thus different from other forms of substantive dignity as it does not depend on the good opinion of others or the community; it does not require policies to enforce how one is respected.<sup>138</sup> On the other hand, substantive conceptions of dignity are related to the traditional understanding of dignity that requires judging the worth or honour of a person. This common social understanding of dignity requires comparisons of people as being more or less worthy or excellent by some community standard.<sup>139</sup> Fundamental rights such as the right to be free from cruel, inhuman or degrading treatment or punishment, the rights to privacy, to equal treatment and to security of the person are so closely linked to the concept of the intrinsic dignity of all human beings that they cannot be treated separately.

The right of a PLHA to human dignity is violated where such a person is mistreated by a fellow human being as a result of his/her HIV/AIDS status. Thus, where a health worker refuses to treat a person infected by HIV/AIDS, an employer denies him/her employment, or his/her movement is restricted or insurance cannot be covered are all tantamount to the violation of human dignity. It can be summarized that an act of discrimination against a person living with HIV/AIDS that directly relates to his status is an infringement to his right to human dignity.<sup>140</sup> According to the court in the South African case of *Hoffman v South African Airways (SAA)*<sup>141</sup>, "it was held that the heart of the prohibition of unfair discrimination is the recognition that under our constitution

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achievement, capability, morality, or social standing, but simply identifies the individual as a bearer of human dignity.

<sup>136</sup> *Ibid.*

<sup>137</sup> Kant, *Grounding for the metaphysics of morals*, 1785, p. 41.

<sup>138</sup> See Roas footnote 135 above, p. 188.

<sup>139</sup> *Ibid.*

<sup>140</sup> Centre for the Right to Health for the policy project, "HIV/AIDS and Human Rights in Nigeria", Background Paper for HIV/AIDS Policy Review in Nigeria, 2003, available at <http://www.heart-intl.net/HEART/030106/HIVAIDSandHumanRights.pdf>, accessed 27 August 2012.

<sup>141</sup> *Hoffman v South African Airways* 2000(2) SA 628.

all human beings, regardless of their position in society, must be accorded equal dignity and that dignity is impaired when a person is unfairly discriminated against.”

Examples of infringement on the right to dignity include:<sup>142</sup>

- denial of access to HIV/AIDS information and education to people living with HIV/AIDS;
- mandatory HIV testing without proper counselling would amount to degrading treatment in breach of the right to human dignity;
- ejecting a person with HIV/AIDS from his accommodation solely because of his status;
- conducting clinical trials using people with HIV/AIDS as subjects without their consent; and
- denying the right to information or testing institutionalized individuals such as prisoners without benefiting from counselling and without their consent.

Mandatory testing violates human rights recognized in many international and regional human rights agreements. One of the most important of these rights is the right of an individual to be free from non-consensual medical treatment or experimentation, the right to personal autonomy. According to Durojaye this right is broadly associated with other fundamental rights such as liberty, privacy, dignity, security of the person and bodily integrity.<sup>143</sup> Violations of the above stated rights emanate from the fact that a positive result may expose the patients to stigma and discrimination, as well as denial of access to health care, employment, travel, insurance and other services.<sup>144</sup>

In the South African case of *Minister of Home Affairs and Another v Fourie*, Sachs J, held that a democratic, universalistic, caring, aspirationally egalitarian society embraces everyone and accepts people for whom and what they are.<sup>145</sup> To penalize people for being who and what they are is profoundly disrespectful of the human personality. This exposes one of the main issues in this dissertation, namely that

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<sup>142</sup> United Nations Human Rights Office of the High Commissioner for Human Rights, “HIV/AIDS and Human Rights, 2012, available at [http://www.data.unaids.org/publications/irc-pub03/3797\\_en.html](http://www.data.unaids.org/publications/irc-pub03/3797_en.html), (accessed 3 November 2012).

<sup>143</sup> *Ibid.*

<sup>144</sup> Cook, Dickens, Fathalla, “Reproductive Health and Human Rights: Integrating Medicine” *Ethics and the Law*, p. 168, 2003.

<sup>145</sup> *Minister of Home Affairs and Another v Fourie* 2006 (1) SA 524 (CC), Para 59.

discriminating those infected with HIV/AIDS is certainly not accepting people for who and what they are; it certainly takes away their birthright as humans which is inherent dignity. Further, mandatorily testing them goes far beyond violating the right to human dignity; it takes away their status as human. There should thus be respect as well as fair accommodation of differences in our societies, as human rights involves caring for the more vulnerable, disadvantaged members of society.

Human dignity is relevant, in determining whether discrimination on an unspecified ground exists, whether discrimination is unfair and, finally, whether unfair discrimination so found is justifiable in terms of section 36.<sup>146</sup> In *Khosa v Minister of Social Development*, the Constitutional Court employed the concept of dignity to find out whether the denial of social benefits to permanent residents who were non-citizens constituted a breach of the equality provision, in that the exclusion “almost inevitably creates the impression that permanent residents are in some way inferior to citizens and less worthy of social assistance”. This is also synonymous to those affected by HIV/AIDS. HIV is treated as a different and dangerous infection which requires harsh policies that are not rights based such as mandatory testing. The same rules do not apply to other serious or more chronic illnesses such as cancer. Testing for cancer, for instance, breast cancer, is voluntary. There is, however, an unfair differentiation of HIV/AIDS which has a negative impact on human rights.

Discrimination on the basis of HIV status, thereby infringing on the right to dignity, was also witnessed in the case of *Hoffman v South African Airways*.<sup>147</sup> Mr Hoffman applied for a job as a cabin attendant with South African Airways (SAA) and was asked by SAA to go for an HIV test. The test showed that he was HIV positive. SAA refused to give Mr Hoffman the job because, they said, part of his job involved travelling to different countries and he would need to have a yellow fever vaccination. It is not advisable for someone with HIV to have these vaccinations. SAA said that this was an inherent requirement of the job in the airline.

The case was referred to the Constitutional Court. The court was asked to decide if SAA had violated Hoffman's rights to equality, dignity and fair labour practices. The court decided that:

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<sup>146</sup> *Khosa v Minister of Social Development* 2004(6) SA 505 CC.

<sup>147</sup> *Hoffman v South African Airways* 2000(2) SA 628.

- SAA had discriminated against Hoffman;
- discrimination was unfair and infringed his dignity;
- being HIV negative was not an inherent requirement of the job of being a cabin attendant; they should have taken greater steps to investigate how Hoffman's immune system could have dealt with travelling and the possibility of getting a strange disease.

At the heart of the prohibition of unfair discrimination is the recognition that, under the Constitution, all human beings, regardless of their position in society, must be accorded equal dignity.<sup>148</sup> The determining factor regarding the unfairness of the discrimination is its impact on the person discriminated against.<sup>149</sup> Relevant considerations in this regard include the position of the victim of the discrimination in society, the purpose sought to be achieved by the discrimination, the extent to which the rights or interests of the victim of the discrimination have been affected, and whether the discrimination has impaired the human dignity of the victim.<sup>150</sup>

The Court held that the state and public corporations like the South African Airways cannot take a ruthless and inhuman stand that they will not employ a person unless they are satisfied that the person will serve during the entire span of service from the employment till superannuation.<sup>151</sup> It is evident that the most important thing in respect of persons infected with HIV is the requirement of community support, economic support and non-discrimination of such persons.<sup>152</sup> This is also necessary for the prevention and control of this terrible disease. Taking into consideration the widespread and present threat of this disease in the world in general and in South Africa in particular the State cannot be permitted to condemn the victims of HIV infection, many of whom may be truly unfortunate, to certain economic death. This is not in the general public interest and is impermissible under the Constitution. The interests of the HIV positive persons, the interests of the employer and the interests of the society will have to be balanced in such a case.”<sup>153</sup>

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<sup>148</sup> *President of the Republic of South Africa and Another v Hugo* 1997 (4) (CC); at para 41.

<sup>149</sup> *Harksen v Lane NO and Others* 1998 (1) SA 300(CC) para 50.

<sup>150</sup> *Ibid* para 51.

<sup>151</sup> *Hoffman v South African Airways*, para 38.

<sup>152</sup> *Ibid*.

<sup>153</sup> *Ibid*.

## 5.7 Freedom and Security of a Person

Section 12 of the South African Constitution combines the right to freedom and security of the person with the right to bodily and psychological integrity. The right to freedom and security of the person protects the physical and psychological integrity of human beings. Section 12(1) protects a person's ability to control his/her bodily movement. Section 12(1) states the right to freedom and security includes the right:

- not to be deprived of freedom arbitrarily without just cause;
- not to be detained without a trial;
- to be free from all forms of violence;
- not to be tortured; and
- not to be treated in a cruel and inhuman and degrading way.

Of much interest is section 12 (2) which goes further to state that everyone has the right to bodily and psychological integrity, which includes the right:

- to make decisions concerning reproduction;
- to security in and control over their body; and
- not to be subjected to medical or scientific experiments without their informed consent.

The first provision in subsection 12(2) concerns reproductive decisions. This provision makes it legal for a woman to undergo abortion in South Africa. Section 12(2)(b) relates to consent which is necessary before any surgery or medical treatment can be performed on a person. It is without doubt that the cluster of interests now protected by s 12(2) were protected under the umbrella right to security of the person in s 7 of the Canadian Charter of Rights and Freedoms and it included protection of personal autonomy, at least in respect of medical treatment<sup>154</sup> and decisions concerning reproduction.<sup>155</sup> Section 12(2) removes any doubts in this regard and it expressly delineates the ambit of the right to security of the person so as to include protection of physical integrity, and extends it to the protection of psychological integrity.<sup>156</sup>

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<sup>154</sup> Currie and De Waal, *The Bill of Rights Handbook* 5<sup>th</sup> Edition, Juta Law 2005, p. 308.

<sup>155</sup> *R v Morgentaler* (No2) [1988] 1 SCR 30.

<sup>156</sup> See Currie and De Waal footnote 154 above, p.308.

Currie and De Waal reiterate that the specific inclusion of this right is recognition that the power to make decisions about reproduction is a crucial aspect of control over one's body. It can be clearly exposed that mandatory testing of HIV/AIDS can violate this right. People have to choose whether they want to go through testing as it is an issue that concerns their body, and mandatory testing certainly violates their physical integrity. Proper informed consent and counselling are thus needed to protect both that physical and psychological integrity as guaranteed by this right.

#### *5.7.1 Bodily Integrity defined*

According to Nussbaum, bodily integrity is a feature of basic human capabilities, and the basic human capabilities are meant to define characteristics of the human being. Bodily integrity is understood to include, among others, freedom of movement, respect of bodily boundaries and opportunities for sexual satisfaction and reproductive choice.<sup>157</sup> The definition of bodily integrity as postulated by Nussbaum has an important feature which is basic human capabilities. He formulated a list of aspects of human capabilities which include:<sup>158</sup>

- Life (the ability to have a life of normal length).
- Bodily health (the ability to have good health).
- Bodily integrity (the ability to have freedom of movement, security against violence, sexual satisfaction, and reproductive choice).
- Senses, imagination and thought (the ability to imagine, think and reason).
- Emotions (the ability to have attachments to things and people out-side of oneself).

The basis of Nussbaum's thinking is an idea of the autonomous, integrated subject who is the bearer of rights. Allowing an individual to make a decision about his/her body is essential, in this case to allow him/her to accept or decline an HIV test protects the ability to make choices which is an important aspect of being a human being.<sup>159</sup> In essence it can be deduced from this formulation that a person ought to

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<sup>157</sup> Nussbaum, " *Women and Human Development: The capabilities approach*", 2000, p. 78.

<sup>158</sup> *Ibid* p. 77-78. Her interest in this concept of bodily integrity is the ability to move freely from place to place; having one's bodily boundaries treated as sovereign, i.e. being able to be secure against assault, including sexual assault, child sexual abuse, and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.

<sup>159</sup> Patosalmi, "Bodily Integrity and conceptions of subjectivity", *Hypatia Vol 24:2, Spring 2009*, p. 124.

be in control of his or her body and that body should be treated as sovereign. This is essentially part of being a human being; thus the control of one's body works parallel with the right to dignity and humans possess inherent dignity. It thus makes sense that the value placed on human bodies and that placed to the dignity and worth of a person is of such importance that mandatorily testing human beings for HIV is a pure violation of these boundaries. Cornell views<sup>160</sup> bodily integrity as not just an idea of physical inviolability, but refers to a person's imaginings and understandings of her or his body, its limits and characteristics. Cornell adds that bodily integrity is not something that the person possesses, but a process that needs protection and recognition from others, including the state and the legal system<sup>161</sup> Better still, the body is understood to be a physical entity that has certain fixed boundaries which should be respected.<sup>162</sup>

Victims of HIV/AIDS have the right to take their own decisions about medical treatment and cannot be forced to have an HIV test. They may not be treated in a cruel or degrading way by any person or institution. The rights of people living with HIV/AIDS are often violated because of their presumed or known HIV status which causes them to suffer both the burden of the disease and the burden of discrimination. From the discussion above, it can be deduced that the bottom line or the most important element is the sovereignty of the body. Individuals should do what they please with their own bodies. There are, however, some instances that warrant control of people's bodies or where the right to freedom and security of the person and bodily integrity can be curtailed. This was dealt with in the case of *Minister of Health, Western Cape v Goliath & others*<sup>163</sup>.

In this case the Cape High Court authorized the forced isolation of four patients infected with extreme drug-resistant tuberculosis at Brooklyn Chest Hospital. The court accepted that compulsory isolation of the respondents amounted to a deprivation of their freedom as envisaged by s 12 of the Constitution. The court held that such deprivation was neither arbitrary nor without just cause, nor incapable of

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<sup>160</sup> *Ibid* p.125.

<sup>161</sup> *Ibid* p. 126.

<sup>162</sup> Nussbaum, "Women and human development: The capabilities approach", The Press Syndicate of the University of Cambridge, 2000, p. 78-79. Her theorizing is based on the straight forward idea that a person is in control of her or his own body and should be the sole authority in making decisions about the body.

<sup>163</sup> *Minister of Health, Western Cape v Goliath & others*, 2009 (2) SA 248 (C).

justification under section 36 of the Constitution.<sup>164</sup> Reference was also given to section 7 of the Canadian Charter of Rights and Freedoms which regarded the forced isolation of a TB patient as a justifiable infringement.<sup>165</sup>

The isolation of TB patients and mandatory HIV/AIDS testing policy are both public health measures that restrict the freedom and security of the person. A pertinent question that arises is whether and to what extent it is justifiable to limit the right to freedom of security of the person. Forced isolation can be justified to a greater extent as failure to do so will lead to the spread of TB which is an airborne and contagious disease. HIV/AIDS differs essentially from TB and its control measures. For starters, mandatory testing public health policy does not essentially stop the spread of the virus, especially in poor health settings where there is the unavailability of antiretroviral therapy.<sup>166</sup> Testing alone, especially on a mandatory basis, might not be a worthy cause because it does not change or stop the deterioration of a positive person's immune system. It thus might not be a just cause to override the autonomy of individuals to make informed decisions about their bodies. With TB, isolation is of paramount necessity. Not only does it isolate patients to stop the disease from spreading, it also enables patients to be treated at the same time. Therefore, after the disease is treated they will earn back the right to freedom and security. Isolation of patients with infectious diseases is universally recognized in open and democratic societies as a measure that is justifiable in the protection and preservation of the health of citizens, even though it necessarily involves some intrusions upon the individual liberty of the patients concerned.<sup>167</sup>

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<sup>164</sup> *Ibid* paras 39-43.

<sup>165</sup> Section 7 of the Canadian Charter of Rights and Freedoms Part I of the *Constitution Act, 1982*, being Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11. This section provides that everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice. This section has a broad application and it guarantees fundamental justice to 'everyone,' not only Canadian citizens. This includes persons not legally in Canada, participants in immigration proceedings, and individuals making refugee claims may all benefit from the application of section 7. See also Canadian Foundation for Children, Youth and the Law v. Canada, [2004] 1 S.C.R. 76 (CanLII).

<sup>166</sup> My emphasis. The majority of African countries which include South Africa, Mozambique and Zimbabwe rural hospitals do not have antiretroviral drugs such that their availability should be made a priority, so as to thoroughly fight the epidemic. Testing alone is not enough without the required and necessary treatment thereof.

<sup>167</sup> *Minister of Health, Western Cape v Goliath & others*, para 19.



## 5.8 Limitations of Human Rights

Following the discussion above it is clear that the rights of those affected by HIV/AIDS should be protected, promoted and fulfilled. However, on the other side of the coin, it is a well-known phenomenon that constitutional rights and freedoms are not absolute. A limitation is, however, a 'justifiable infringement: in this regard a law that limits a right infringes the right.<sup>168</sup> The infringement will not be unconstitutional, though, if it takes place for a reason that is accepted as a justification for infringing rights in an open and democratic society based on human dignity, equality and freedom; thus not all infringements of fundamental rights are unconstitutional.<sup>169</sup> The limitation of rights does not only apply to the rights and freedoms in the South African Constitution, but is also provided for worldwide in most constitutions as well as under international conventions.

With regard to limitation of human rights in the context of a democratic setting, further guidance is to be drawn from the ICCPR and the General Comments adopted by the Human Rights Committee (UNHRC) in relation to the interpretation of the ICCPR.<sup>170</sup> It is common practice in most democratic legal systems for the limitation of human rights to require special procedures and mechanisms which are compliant with the requirements stipulated under the ICCPR.<sup>171</sup> An example close to home is that of the South African Constitution where a general limitation section 36 sets out a specific criteria for the justification of restrictions of the rights in the Bill of Rights. Section 36 will be discussed in detail under section 5.8.1.

There are situations where it is considered legitimate to limit a right in order to achieve public good. The ICCPR points out that the public good can take precedence to, "secure due recognition and respect for the rights and freedoms of others; meet the just requirements of morality, public order, and the general welfare; and in times of emergency, when there are threats to the vital interests of the nation."<sup>172</sup> It can be deduced that in situations where the public at large is at risk of,

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<sup>168</sup> See Currie and De Waal footnote 154 above, p. 164.

<sup>169</sup> *Ibid.*

<sup>170</sup> UN Human Rights Committee, General Comment 29, States of Emergency article 4, UN Doc CCPR/C/21/Rev 1/Add1, 2001), available at <http://www.umn.edu/humanrts/gencomm/hrc29.html>, (accessed 19 September 2011).

<sup>171</sup> Mekonnen, "Mandatory Premarital HIV Testing as a challenge to Human Rights", *Interdisciplinary Journal of Human Rights Law* Vol.5:1 2007, p. 8.

<sup>172</sup> International Covenant on Civil and Political Rights, Art 22.

for example, an infection or epidemic, it may be necessary to compromise individual rights in favour of those of the community at large. In such a situation, the infringement of an individual may be deemed justifiable. Interference with the right to freedom of movement when instituting quarantine or isolation for a serious communicable disease, for example, Ebola fever, syphilis, typhoid or untreated tuberculosis, are examples of limitations on rights that may be necessary for the preservation of the public good and, therefore, may be considered legitimate under international human rights.<sup>173</sup>

The United Nations has developed a well-defined criteria or framework for analysing the human rights impact of health policies through the Siracusa principles.<sup>174</sup> In terms of their binding and non-binding nature, the Siracusa principles are not different from the General Comments of the Human Rights Committee or the Committee on ESCR; they are guiding interpretative principles meant to provide insights to the signatories on how to implement the covenants.<sup>175</sup> Therefore, the protection afforded to an individual's human rights is subject to limitations, and international human rights law authorizes restricting rights in order to protect public health when necessary. In this regard, the Siracusa principles provide that measures restricting human rights should be legal; neither arbitrary nor discriminatory; proportionate; necessary for the least restrictive means that are reasonably available under the circumstances; and based on sound science.<sup>176</sup> In accordance with these principles, the enjoyment of human rights can be limited in the following circumstances, namely where:<sup>177</sup>

- The restriction is provided for and carried out in accordance with the law. In practical terms, this requires that substantive and procedural safeguards are

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<sup>173</sup> Tarantola, "Building on the synergy between health and human rights: A global perspective", Boston, Massachusetts, Harvard School of Public Health, François-Xavier Bagnoud Center for Health and Human Rights, 2000, p.10.

<sup>174</sup> The United Nations Economic and Social Council (UNECOSOC), *The Siracusa Principles on the Limitations and Derogation Provisions in the International Covenant on Civil and Political Rights*, UN Document E/CN.4/1985/4, Annex. Geneva: UNECOSOC.

<sup>175</sup> Mekonnen, "Mandatory Premarital HIV Testing as a challenge to Human Rights", *Interdisciplinary Journal of Human Rights Law* Vol.5:1 2007, p. 8.

<sup>176</sup> Boggio; Zignol; Jaramillo; Nunn; Pinet; Raviglione, "Limitations on human rights: Are they justifiable to reduce the burden of TB in the era of MDR- and XDR-TB?" *Health and Human Rights: An International Journal*, Vol 10:1, 2008, available at <http://hhrjournal.org/blog/perspectives/limitations-on-human-rights-are-they-justifiable.pdf>, (accessed 08 Nov 2012).

<sup>177</sup> Mekonnen quoting Durojaye in, "Mandatory Premarital HIV Testing as a challenge to Human Rights", *Interdisciplinary Journal of Human Rights Law* Vol.5:1 2007.

put in place. Thus from a substantive perspective, governments that intend to enforce mandatory HIV/AIDS testing must enact a law of general application that states the conditions and precautionary measures that should be put in place for testing. Procedurally rules regulating testing should be put in place.

- The restriction is in the interests of a legitimate objective of public interest.
- The restrictions are strictly necessary in a democratic society to achieve the objectives.
- There are no less intrusive and restrictive means to reach the same goals. The least restrictive measure should be considered first and should only be adopted if dictated by necessity.
- The restrictions are not imposed arbitrarily, in an unreasonable or discriminatory manner.

#### *5.8.1 Limitation of rights in the South African Constitution*

The limitation of rights in the South African Constitution is provided for in section 36(1) which states that:

The rights in the Bill of Rights may be limited only in terms of law and general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including:<sup>178</sup>

- (a) the nature of the right;
- (b) the importance of the purpose of the limitation;
- (c) the nature and extent of the limitation;
- (d) the relation between the limitation and its purpose; and
- (e) less restrictive means to achieve the purpose.

(2) Except as provided in subsection (1) or in any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights.

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<sup>178</sup> The Constitution of South Africa 1996 section 36. Section 36 has a textual similarity to section 1 of the Canadian Charter which states that, “the rights and freedoms set out in the [Charter are] subject only to such reasonable limits prescribed by law as can be demonstrated justified in a free and democratic society”. It is clear that that the Canadian model had an influence in the drafting of s 36 of the South African limitation clause.

The general limitation highlighted above applies to all the rights in the Bill of Rights and provides that all the rights may be limited according to the same criteria.<sup>179</sup> To establish whether the limitation clause should be implemented, a two stage analysis is employed, firstly to identify the infringement of the right and, secondly, to find out whether the infringement can be justified as a permissible limitation of the right.<sup>180</sup> This second stage draws on the factors listed in section 36(1) to determine whether the infringement of the right is justifiable.<sup>181</sup> The result of such a two stage approach is that, as state interests are accommodated at the second justification stage, courts can afford to interpret rights generously and broadly at the first stage and reserve any qualification of the right for the second stage of the analysis.<sup>182</sup> However, the question whether an infringement of a right is a legitimate limitation of that right frequently involves a far more factual enquiry than the question of interpretation. Therefore, appropriate evidence must be submitted to justify the limitation in accordance with the criteria set out in s 36.<sup>183</sup>

To balance public health concerns and human rights protection is a difficult proposition but it cannot be ignored and a balance between the two has to be sought. However, international law provides that public health may be invoked as a ground for limiting *certain rights*, as human rights are generally not absolute.<sup>184</sup> The key word is 'certain' rights, which can imply that there are some rights that may not be easily limited, dignity being one of them. Another pertinent issue that arises is the debate between individual and community rights. Public health measures in essence focus on the rights of the community or society as a whole. This is synonymous with HIV/AIDS as it is clear that the motive for mandatory HIV/AIDS testing is to eradicate the virus in all societies, thus community rights are given more weight as opposed to individual rights.

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<sup>179</sup> See Currie and De Waal footnote 154 above, p. 165.

<sup>180</sup> *Ibid.*

<sup>181</sup> Cheadle, "Limitation of Rights" in Cheadle, Davis, Haysom (eds) *South African Constitutional Law: The Bill of Rights* 2002, p. 693.

<sup>182</sup> *S v Zuma* 1995 (2) SA 642 (CC) para 21-22 and *S v Makwanyane* 1995 (3) SA 391 (CC) paras 105-107.

<sup>183</sup> *Ibid.*

<sup>184</sup> World Health Organization, "WHO Guidance on Human Rights and Involuntary Detention for XDR-TB Control", [http://www.who.int/tb/xdr/involuntary\\_treatment/en/index.html](http://www.who.int/tb/xdr/involuntary_treatment/en/index.html), (Accessed on 18 November 2012).

A close comparison can be made between patients of tuberculosis - hereafter referred to as TB - and multi-drug-resistant tuberculosis (MDR-TB)<sup>185</sup> and those with HIV or AIDS. Are limitations of human rights to this group of patients necessary and justifiable? Another pertinent question that always arises is whether it is justifiable to implement compulsory involuntary measures to control the epidemic given the high death rate caused by the above two epidemics. These measures include a compulsory medical examination, compulsory quarantine, and compulsory isolation or detention of infected persons.<sup>186</sup> The conflict now arises between protecting the rights of those infected, such as the rights to dignity and freedom of movement, and the public health measure to isolate these patients in order to stop the spread of this disease since it is contagious.

What is distinctive in TB patients is the fact that Extreme Drug Resistant TB (XDR-TB)<sup>187</sup> is highly contagious and therefore it has a potential to cause harm to a great number of people. In such a case, compulsory measures may be justifiable under international law to protect healthy individuals and the public interest.<sup>188</sup> Health being a public good, individuals with TB have a duty to limit the spread of TB and the development of drug-resistant TB. Preventing harm to third parties is a sufficient ground for limiting the autonomy of a person whose actions may lead to harming innocent parties.<sup>189</sup> In terms of international law, the need to prevent healthy individuals from getting sick may provide a sufficient reason to override individual considerations.<sup>190</sup>

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<sup>185</sup> Tuberculosis is among the most widespread communicable diseases and world's second most important cause of death from an infectious agent - see World Health Organization, *The World Health Organisation Report Changing History* Geneva 2004.

<sup>186</sup> Gostini, *Public Health Law: Power, Duty and Restraint*, University of California Press, 2000.

<sup>187</sup> TB in South Africa has posed a challenge to public health in South Africa due to its prevalence among poor and malnourished populations subjected to substandard living conditions. The systems failure to treat TB effectively has, over the years, resulted in the emergence of drug-resistant, multi-drug resistant (MDR) and, latterly, extreme drug-resistant (XDR) strains of TB. See London, "Confinement in the management of drug-resistant TB: The unsavoury prospect of balancing individual human rights and the public good", *South African Journal of Bioethics & Law* 11:1, 2008, p.12.

<sup>188</sup> Centers for Disease Control and Prevention, "Emergence of Mycobacterium Tuberculosis with extensive resistance to second-line drugs worldwide 2000-2004", *Morbidity and Mortality Weekly Report* 55, 2006, p.301.

<sup>189</sup> Gostini, Berkman, "Project on Addressing Ethical Issues in Pandemic Influenza Planning", Geneva WHO 2007, available at, [http://who.int/eth/ethics/PI\\_Ethics\\_draft\\_paper\\_WG2\\_6\\_pdf](http://who.int/eth/ethics/PI_Ethics_draft_paper_WG2_6_pdf), (accessed 18 Nov 2007).

<sup>190</sup> *Ibid.*

Having discussed the fact that rights are not absolute and can be limited, it should be cautioned that enshrining fundamental rights in a Constitution and in international treaties grants them a special status: it involves an assertion that such rights are higher-level norms with which other parts of the law and policy must conform.<sup>191</sup> This, in turn, implies that such rights must have a particular importance for the individual or society as a whole and, therefore, grant protection to individuals or society for interests that are of a fundamental importance to them.<sup>192</sup>

Dworkin has conceptualised rights as 'triumphs' over utilitarian considerations. He, however, postulated that collective interests may, in certain circumstances, prevail over rights where there are particularly strong reasons to do so. He put forward an interesting view, namely that the very nature of rights means that they cannot be overridden simply on the basis of a routine calculation of costs and benefits.<sup>193</sup> According to Alexy, rights are principles rather than rules: rules are norms that are always either fulfilled or not; whereas principles are norms which require that something be realised to the greatest extent possible given the legal and factual possibilities.<sup>194</sup> Such categorisation has implications when dealing with conflict and whether one principle may outweigh the other, hence the principle of proportionality. Proportionality therefore relates to the fact that the benefits to be derived from the proposed public health policy, in this case mandatory testing, must outweigh its implications for deprivation of rights.<sup>195</sup>

Following the theoretical formulation of Childress *et al.*, Durojaye points out that mandatory testing does not justify the resulting violations of human rights. However he draws an illustrative comparison between HIV/AIDS and avian influenza or bird flu contending that, although the latter is a deadly virus, the mode of transmission of HIV is less threatening than other similarly dangerous ailments such as avian flu. Further with the advancement of medical technology since the discovery of the HIV virus, AIDS has become a manageable chronic disease and is less threatening in

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<sup>191</sup> Michelman, "Justice as fairness, legitimacy and the question of judicial review: A comment", *Fordham LR* 1412, 2004.

<sup>192</sup> Bilchitz, "Does balancing adequately capture the nature of rights", *SAPL* 25, 2011, p. 425.

<sup>193</sup> Dworkin, "Rights as triumphs" in Waldron, *Theories of rights*, 1984, p. 153

<sup>194</sup> Alexy, *A theory of constitutional rights* Oxford Press 2002, p.342.

<sup>195</sup> Durojaye, "Addressing Human Rights concerns by Mandatory HIV testing of Pregnant Women through the Protocol to the African Charter on the rights of Women", *Journal of African Law Vol 52:1*, 2008 p. 43-65.

terms of transmission.<sup>196</sup> Moreover, Durojaye suggests that the argument that compulsory testing can effectively halt HIV transmission remains doubtful in the sense that individuals may avoid testing at all.<sup>197</sup>

The bottom line is that in most sub-Saharan African countries, HIV/AIDS is highly stigmatized and the health care system is acutely under-funded. Forcing people to undergo HIV testing fuels the stigma and discrimination and aggravates attendant problems. Instead, Africa should re-direct its focus and shift the energy and debates from more radical and damaging public health policies, such as mandatory HIV testing, to developing a voluntary HIV/AIDS testing policy buttressed by availability and access to antiretroviral therapy. Mekonnen emphasizes that these are core factors in fighting discrimination and stigma. A balance ought to be maintained between public health imperatives and human rights. Such a balance is often depicted as a trade-off between human rights and public health with individual rights having to give way where their enforcement would undermine the achievement of public health goals. Human rights advocates correctly insist that harmonization of the interests protected by public health measures and individual rights is both called for and possible.<sup>198</sup> In fact, it is argued that respect for fundamental rights in this context will not only ensure fairness towards affected individuals and communities, but will also serve to advance and reinforce public health.<sup>199</sup>

In accordance with the necessity principle, given two equally suitable means, the one which interferes less intensively with a right should be chosen.<sup>200</sup> Further, if rights are norms that must be optimised to the greatest extent possible then, when engaged in proportionality analysis, courts should adopt a stringent approach of ensuring that any limitation of a right that is being proposed should, strictly speaking, be necessary to realise the purpose sought to be achieved. This means that no other

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<sup>196</sup> Durojaye quoted by Mekonnen in, Mandatory premarital HIV testing as a challenge to human rights: A case study of Eritrea, *Interdisciplinary Journal of Human Rights Law* Vol 5:1, 2010-2011.

<sup>197</sup> *Ibid.*

<sup>198</sup> Pieterse, Hassim, "Placing human rights at the centre of public health: A critique of Minister of Health, Western Cape v Goliath, *The South African Law Journal*, Vol 126:2, 2009, p. 231.

<sup>199</sup> Childress, Bernheim, "Beyond the liberal and communitarian impasse: A framework and vision for public health", *Florida Law Review* 55, 2003, p. 1195-7.

<sup>200</sup> Lamptey, Gayle, "HIV/AIDS prevention and care in resource constrained settings: A Handbook for the design and management of programs 2001, available at [http://www.pdf.usaid.gov/pdf\\_docs/PNACY892](http://www.pdf.usaid.gov/pdf_docs/PNACY892), (accessed on 17 October 2012).

alternative must be available that can equally realise the purpose and be less intrusive of the right in question.<sup>201</sup>

The South African Constitutional Court's approach to the interpretation of rights is a clear reflection that rights can be limited and this is just not a technical constitutional law doctrine, but goes to the heart of what is a fundamental right.<sup>202</sup> The South African Constitution contains a general limitations clause which outlines the circumstances under which a limitation is reasonable and justifiable within an open and democratic society based on the values of human dignity, equality and freedom.<sup>203</sup> However, a range of factors must be taken into account which includes the requirement that the limitation must be related to the purpose and also a consideration by the courts as to whether there are less restrictive means to achieve the purpose in question. The Constitution of South Africa is in line with Alexy's principle of necessity which requires that, "less" restrictive means ought to be used as opposed to "least restrictive" means.<sup>204</sup>

In *S v Manamela*,<sup>205</sup> the constitutionality of a reverse onus provision that required an accused person who was in possession of stolen goods to prove that s/he had reasonable cause at the time of acquiring the goods to believe that they were not stolen was at issue. Despite the differing conclusions, both the majority and minority judgements agreed on the approach to be adopted towards the less restrictive means requirement: the minority judgement agree with the proposition that the 'less restrictive means' component is an important part of the limitation analysis'.<sup>206</sup> In his analysis of the case Bilchitz notes the famous quotation of the US Judge Blackmun who postulates that , "a judge would be unimaginative indeed if he could not come up with something a little less 'drastic' or a little less 'restrictive' in almost any situation, and thereby enable himself to vote to strike the legislation down."<sup>207</sup>

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<sup>201</sup> See Bilchitz footnote 192 above, p. 425.

<sup>202</sup> *Ibid.*

<sup>203</sup> *Ibid.*

<sup>204</sup> *Ibid.*, p. 438.

<sup>205</sup> *Sv Manamela* 2000 3 SA 1 (CC).

<sup>206</sup> *Ibid.*

<sup>207</sup> *Illinois State Board of Elections v Socialist Workers Party* 440 US 173 (1979) p. 188-189.



Judge Kriegler also points out that;

where section 36(1)(e) speak of less restrictive means it does not postulate an unattainable norm of perfection. The standard is reasonableness. And in any event, in theory less restrictive means can almost invariably be imagined without necessarily precluding a finding justification under the section.

It is but one of the enumerated considerations which have to be weighed in conjunction with one another, and with others that may be relevant.<sup>208</sup> However the foundational values of the South African Constitution which are human dignity, equality, and freedom play a major part in determining whether the limitation of a right is justifiable or not. This is a crucial point as it places at the heart of the enquiry to be conducted under the limitations clause the very values that underlie fundamental rights.<sup>209</sup> Already integrated into the limitations enquiry itself is a systematic bias in favour of rights: for the very considerations underlying the recognition of rights in the first place are a crucial part of determining whether a limitation will itself be justifiable or not.<sup>210</sup>

### **5.9 Impact of Limitations on those Infected by HIV/AIDS**

Having concluded that human rights ought to be limited in a proportionate and in the least restrictive manner, the bottom line is that the human rights of those affected by HIV/AIDS are of paramount importance and they ought to be respected and justified when limited. The harmonization of public health and human rights in South Africa is often the task of the courts and as guardians of a Supreme Constitution that obliges the state to respect, protect, promote and fulfil the rights it enshrines.<sup>211</sup> Public health scholars in South Africa and elsewhere argue that individual rights should be limited in the interest of public health only when this is the least invasive option available.<sup>212</sup> They further agree on the notion that such limitation should only pass constitutional muster where public health measures adhere to the principle of legality and are clearly conceptualized, effective, well targeted, linked to realistic risk-assessment and applied according to fair and transparent administrative

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<sup>208</sup> *Ibid.*

<sup>209</sup> See Bilchitz footnote 192 above, p. 443

<sup>210</sup> *Ibid.*

<sup>211</sup> Section 2 read with section 7 of the Constitution of South Africa 1996.

<sup>212</sup> Hodges, Svoboda, Van-Howe, "Prophylactic interventions on children: Balancing human rights with public health" *Journal of Medical Ethics* 2002 Vol 28, o. 10-16.

procedures.<sup>213</sup> The mandatory testing policy does not follow these requirements. HIV/AIDS is clearly not a contagious disease and has since been contained through the introduction of antiretroviral therapy. It is thus not justifiable to violate dignity, privacy and freedom and security of the person as this disease does not pose an immediate threat to the community. The writer of this dissertation advocates not only for a human rights based approach to be followed in HIV/AIDS cases but also consistent awareness to be raised in schools and communities so as to prevent loss of lives in Africa through this disease.

Human rights are inextricably linked with the spread and impact of HIV on individuals and communities around the world. Lack of respect for human rights fuels the spread and exacerbates the impact of the disease, while at the same time HIV/AIDS undermines progress in the realisation of human rights.<sup>214</sup> Women are vulnerable and are a disadvantaged sex when it comes to HIV/AIDS. This is as a result of the unequal status of women in the community; it means that their capacity to negotiate in the context of sexual activity is severely undermined. People living in poverty often are unable to access HIV care and treatment, including antiretroviral and other medications for opportunistic infections.<sup>215</sup>

In addition to stigma and discrimination, the rights of people living with HIV often are violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigmatisation and discrimination may obstruct their access to treatment and may affect their employment, housing and other rights. This, in turn, contributes to the vulnerability of others to infection, since HIV-related stigma and discrimination discourages individuals infected with and affected by HIV from contacting health and social services. As a result, those most in need of information, education and counselling will not benefit even where such services are available.

Efforts to increase access to HIV testing and counselling are not occurring in a vacuum; they take place in an environment in which evidence-informed and human rights-based policies and responses to HIV are being widely undermined.

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<sup>213</sup> Mann; Gruskin; Grodin; Annas (eds), *Health and Human Rights: A Reader*, 1999, P. 54-71.

<sup>214</sup> United Nations and Human rights, "HIV and Human rights" available at, <http://www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx>, (accessed on 14 Nov 2012).

<sup>215</sup> *Ibid.*

Furthermore, even as vastly increased funding for HIV has become available, those most vulnerable to HIV and its impact continue to receive the least access to HIV prevention, care and treatment services.<sup>216</sup> A UNAIDS reference group found that in a number of countries there are many abuses around the manner in which HIV testing and counselling are conducted.<sup>217</sup> It is thus a concern that if the issues it raises are not addressed; the implementation of the Guidance may lead to further abuses rather than to increased benefits for human rights and public health. For instance, UNAIDS suggest that provider-initiated testing cannot be implemented in Africa because of the following factors:

- There are high levels of stigma and discrimination and there is insufficient programmatic attention to protecting people from stigma and discrimination.
- Access to HIV prevention, care and support services, including reasonable expectation that access to antiretroviral therapy will become available in the near future, is not possible in most parts of Africa.
- There is an insufficient capacity of health care providers to implement provider-initiated testing and counselling under the conditions of informed consent, confidentiality and counselling.

The factors above make it very difficult to implement provider initiated testing which, to a greater extent, is rights-based. The implementation of mandatory HIV testing programmes is appalling and potentially disastrous as it does not comply with any of the factors stated above. It can also be drawn from the guidance above that the health environment in most African countries, including South Africa, does not permit this type of testing practice due to lack of resources, which are health care workers and antiretroviral drugs. Mandatory testing is thus not suitable for the African environment. A voluntary HIV/AIDS testing policy is suitable and can further be improved to scale up testing.

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<sup>216</sup> UNAIDS Reference Group on HIV and Human Rights, “ Statement and recommendations on scaling up HIV testing and counselling”, 2007, available at [http://www.unaids.org/en/Issues/Impact\\_HIV/20070601\\_reference\\_group\\_HIV\\_human\\_rights.asp](http://www.unaids.org/en/Issues/Impact_HIV/20070601_reference_group_HIV_human_rights.asp), (accessed 29 September 2012). This paper makes it clear that the views of the reference group do not necessarily reflect the views or positions of the UNAIDS Secretariat or the Co-sponsors of UNAIDS. The UNAIDS Reference Group on HIV and Human Rights is an independent advisory body, established in in 2002 to advice the Joint United Nations Programme on HIV/AIDS (UNAIDS) on all matters relating to HIV and human rights.

<sup>217</sup> *Ibid.*

Public health ethicists have articulated a variety of principles to mediate the tensions between coercive public health interventions and human rights. For example, Gostin and Berkman argue that compulsory measures are justified only when government has good faith, for which it can give supportable reasons, that a coercive approach is necessary.<sup>218</sup> They also assert the importance of community participation, transparency, proportionality, and respect for distributive justice.<sup>219</sup> In accordance with Parmet's findings, public health officials have a pressing need to obtain up to date surveillance data on HIV through mandatory HIV/AIDS testing. This would enable them to track the epidemic and allocate prevention and treatment programmes where they are needed. This information can also be obtained via voluntary, confidential testing, especially when it is well-integrated into a nation's health care delivery system.<sup>220</sup>

It should, however, be noted that health and human rights are co-related. Thus, in a ground breaking work on HIV/AIDS, Jonathan Mann, the former head of WHO's AIDS programme, argued that human rights were supportive of population health. Mann added that, because human rights articulate the societal preconditions for human well-being, they offer a form of guidance for public health efforts to analyze and respond directly to the societal determinants of health.<sup>221</sup>

## 5.10 Conclusion

Respecting, protecting and fulfilling the full range of human rights of all individuals is indispensable in order to reduce the rate of HIV infection, expand access to care and treatment, and mitigate the impact of the epidemic, including acts of discrimination and violence in the fight against HIV/AIDS.<sup>222</sup> HIV testing is not occurring in a vacuum; rather it takes place in an environment in which evidence-based and human rights-based policies and programmes are being undermined. Among other rights,

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<sup>218</sup> Childress, "Public health ethics: Mapping the terrain", *Journal of Law, Medicine & Ethics* Vol 30:2, 2002 p. 173

<sup>219</sup> *Ibid.*

<sup>220</sup> Parmet, "Public health and social Control: Implications for human rights", Northern Public Law and theory faculty working paper series No. 4, 2010, p. 23, available at <http://www.ssrn.com/abstract=1546654>, (accessed 18 October 2012).

<sup>221</sup> Mann, "Medicine and public health", *Hastings Center Report*, 27:3, 1997, p. 6-14.

<sup>222</sup> Amnesty International.

dignity and privacy of those infected by HIV/AIDS are being violated and these individuals are regarded as less human. For instance, social exclusion through stigma, violence and discrimination, which have been highlighted throughout this chapter, continue to happen. This can result in further damage through implementation of mandatory HIV testing. In order to have zero new infections in South Africa, a rights-based approach which is voluntary counselling and testing ought to take priority.

People should be tested only with their informed, voluntary and specific consent, when counselling and education before and following testing are available and offered, and when confidentiality of the results or anonymity of testing can be guaranteed. These are non-debatable fundamental values of HIV/AIDS testing. They have to be honoured and respected as the human rights of those affected by HIV/AIDS can only be effected and applied if these values are complied with. The interests of the community and of individuals should be viewed as one and the same, and these public health considerations actually require the respect of individual rights.

## CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

### 6.1 Introduction

In recent years an international consensus has emerged that access to HIV testing must be scaled up urgently and that, in addition to the traditional model of client-initiated voluntary counselling and testing (VCT), new approaches to HIV testing and counselling must be implemented in more settings and on a much larger scale than has so far been the case.<sup>1</sup> HIV/AIDS testing is a focal point in HIV/AIDS prevention. This is because information that is provided by an HIV-test is crucial if an individual is to protect himself or herself from exposure to situations that create risks because her or his immune system is compromised; to protect others by avoiding the types of contact implicated in transmitting the virus; to notify others with whom he or she has had contact or exposure; to make informed reproductive decisions, including whether to continue or terminate pregnancy; to decide whether or not to breast-feed; and to avail himself or herself of early treatment, including monitoring of immune system function.<sup>2</sup>

Testing for HIV has become one of the thorniest aspects of a health debate that is fraught with human rights implications.<sup>3</sup> It is without contention that there is need to scale up access to HIV testing and counselling as this is essential for an effective global response to HIV/AIDS. There is also consensus among AIDS and human rights activists, public health officials and policy makers alike in favour of vastly scaled up access to affordable and high quality HIV testing.<sup>4</sup> Central to the debate about scaling up access to HIV testing is the submission that voluntary counselling has done little to increase uptake of HIV testing as opposed to mandatory HIV testing which forces everyone who visits a health centre to be tested, thus increasing the uptake of HIV testing. Such a move creates problems which this study exposes,

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<sup>1</sup> Jurgens, "Routinizing HIV testing in low and middle income countries", New York public health program of the Open Society Institute Background paper 2007, p iii-v.

<sup>2</sup> UNAIDS Technical Update, "Voluntary Counselling and Testing", Best Practice collection, 6 2000,. See also Stein, *The Social Welfare of women and children with HIV/AIDS: Legal protections, policy and programs* New York Oxford Press 1998, p. 90.

<sup>3</sup> The South African Institute of International Affairs Special Feature, "AIDS experts tests boundaries of HIV testing", available at <http://www.saiia.org.za/modules.php?op=modload&names=News&file> (accessed 23 March 2011).

<sup>4</sup> See Jurgens footnote 1 above.

which are human rights violations. These would be more defined if mandatory or compulsory testing is implemented in South Africa.

The study examined the extent to which coercive government policies aimed at controlling the AIDS pandemic infringe on the human rights of individuals known or suspected to be living with HIV/AIDS.<sup>5</sup> Mandatory HIV/AIDS testing threatens the three key principles of HIV testing, namely that the individual freely *consent* to testing; that *counselling* is provided before and after testing; and that the results be kept *confidential*.<sup>6</sup> Failure to respect these core principles of HIV testing will certainly undermine the human rights of those being tested for HIV.

The AIDS pandemic has made it clear that a complex relation exists between the fields of Human Rights and Public Health which historically have remained largely separate. Public health and human rights have common goals. The only human rights based approach to HIV/AIDS testing, VCT, has to be promoted and scaled up in the fight against HIV/AIDS.<sup>7</sup>

Chapter 1 outlined the research goals and objectives. Chapter 2 subsequently provided a theoretical background of groups and scholars in favour of or against compulsory HIV/AIDS testing policy. The debate over compulsory HIV testing, that is the pros and cons of this policy, also emerged. Stronger arguments supported the contention that there are no benefits either to the individual or for public health arising from testing without informed consent.”<sup>8</sup>A balance between community rights and individual rights were also explored, highlighting where and when human rights can be curtailed in favour of society or individual rights.

Chapter 3 discussed the regulatory framework laid down under various international and regional conventions that have a bearing on human rights and health. The chapter examined the extent to which international and regional instruments protect the human rights of those infected with HIV/AIDS. Most provisions do guarantee the right to health and this includes the rights of those infected by HIV/AIDS. However,

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<sup>5</sup> Gostin and Lazzarini *Human Rights and Public Health in the AIDS Pandemic* New York: Oxford press 1997 p. 16 -17.

<sup>6</sup> *Ibid.*

<sup>7</sup> Strode, Van Rooyen, Heywood, “Scaling up HIV testing in resource constrained settings: Debates on the role of VCT and routine ‘Opt-in or Opt-out’ HIV testing, *The South African Journal of HIV Medicine*, Vol 1, 2005, p. 25.

<sup>8</sup> Bennet, Erin, *Issues in Biomedical Ethics: HIV AND AIDS, Testing, Screening and Confidentiality*, Oxford University Press 2003, p. 1-19.

though the human rights of those infected by HIV/AIDS are not expressly provided for in other instruments such as the ICCPR, it is, however, the duty of African states to use the framework set up by different conventions discussed above and develop a strong base of legislation on HIV/AIDS which is tailor-made for Africa. This is imperative because the African continent, especially sub-Saharan Africa, has the highest number of people affected by the virus. It has also been contended that “lack of evidence and documentation (whether epidemiological, social or legal) of the value of integrating human rights in the response to HIV/AIDS is increasingly proving to be an obstacle in ensuring the integration of human rights in governmental and UN HIV/AIDS efforts”.<sup>9</sup>

Chapter 4 comprised of case studies of the law and practice obtained in South Africa, Uganda and Canada. The examination of HIV/AIDS testing practices assisted in informing South Africa what successful approach to testing should be pursued. Chapter 5 concentrated on closely connected rights, namely, dignity, freedom and security of the person, and privacy without denying that other rights may be violated by the compulsory HIV/AIDS testing policy. The chapter explored the extent to which these rights are affected if the compulsory HIV/AIDS testing model is implemented. Limitation of these rights is also discussed in line with the Bill of Rights and the Constitution.

The study also realized that policy makers should know that when conceiving public health policies they should have in mind the implications of such policies on human rights. Every public health policy<sup>10</sup> should be viewed as a potential threat to human rights, unless proved otherwise. In designing any public health policy, particularly in the context of HIV/AIDS, the respect, protection and fulfilment of human rights should be one of the primary considerations of governments.

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<sup>9</sup> UNAIDS Global Reference Group on HIV/AIDS and Human Rights, “Statement and Recommendations on Scaling up HIV testing and counselling”, 2007 p. 6-7, available at <http://www.unaids.org/en/Issues/ImpactHIV/20070601referencegroupHIVhumanrightsasp> (accessed 29 September 2012)

<sup>10</sup> Mann, Statement at an Informal Briefing on AIDS to the 42<sup>nd</sup> Session of the United Nations General Assembly.



The study submits that the law should be used as an instrument of social change and protection of the rights of those infected and vulnerable to HIV/AIDS.<sup>11</sup> This is so because there is a widely held perception that in cases of public emergencies human rights may become a secondary concern. The perception that human rights can be swept aside in cases of emergencies is not new and this is clearly represented by public health officials or proponents who favour mandatory HIV/AIDS testing.

## 6.2 Findings

Human health cannot be maintained without respect for the dignity and rights of persons. Equally, human rights cannot be deemed adequate and comprehensive without ensuring the health of individuals and populations. The two problems are, as it were, two sides of the same coin. It should be recognised that HIV/AIDS is not just a medical problem in need of a medical solution: the people who are most susceptible to infection are those who are most vulnerable to human rights violations and in need of protection.

The promotion of voluntary counselling and testing (VCT) is an essential element in the response to the HIV epidemic.<sup>12</sup> This research found out that VCT would demystify HIV/AIDS, place the responsibility for avoidance of acquiring or transmitting HIV on every individual, and empower the community to take charge of its own health.<sup>13</sup> Forcing people to get tested often frequently results in increased vulnerability for the affected groups. Ultimately, this would breed resentment against testing, resulting in individuals not knowing their status or even receiving treatment.<sup>14</sup> For this reason, the pandemic can never be controlled and, therefore, South Africa and other Southern African countries will still experience continuous deaths as a result of HIV/AIDS and HIV/AIDS related illnesses.

The study has revealed that mandatory models of HIV testing are contrary to human rights norms, and with the exception of mandatory HIV screening for blood and blood

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<sup>11</sup> *International Guidelines on HIV/AIDS and Human Rights*, 2006 Consolidated Version, available at, <http://data.unaids.org/Publications/IRC-pub/07/jc1252-internationalguidelines-en.pdf>, (accessed 16 August 2011).

<sup>12</sup> Baggaley, "Voluntary Counselling and Testing (VCT)", Paper for the UNAIDS expert panel on HIV testing in the United Nations peacekeeping operations, 17<sup>th</sup>-18<sup>th</sup> September 2001.

<sup>13</sup> *Ibid.*

<sup>14</sup> Heywood, "The Implication of AIDS Notification for Human Rights and HIV/AIDS Prevention in South Africa", Johannesburg: AIDS Law Project 1999.

products, mandatory testing cannot be justified. There is, however, a need to step up the fight against compulsory and mandatory testing. In the final version of the WHO and UNAIDS guides, it is stressed that both “do not support mandatory or compulsory testing of individuals on public health grounds”.<sup>15</sup>

A shift has to be made so that counselling is mandatory and testing voluntary. A pertinent observation that has been made throughout this research is that there is lack of understanding of the reasons for the low uptake of VCT in developing countries. It is, to a greater extent, unclear whether VCT has failed as a policy approach or VCT has not been well supported. This study, therefore, supports VCT as a successful rights-based approach that is suitable in resource constrained settings such as South Africa. However, more can be done to raise awareness of this model to the citizens of South Africa and a lot still has to be done in terms of alertness and awareness of HIV/AIDS infection as a whole. VCT still has room for improvement and for this reason there is no need for radical approaches such as the mandatory testing model to be put in place.

The study also established that though there are policies and legislation that guarantees the protection of human rights in HIV testing, violations still occur. For instance, the Immigration Offices of Canada conduct HIV tests without informed consent from immigrants, and both pre- and post-test counselling do not occur. In Canada, a broad consensus has emerged that except in a few well-defined circumstances, people should be tested only with their informed, voluntary and specific consent, when counselling and education are available before and following testing and where the confidentiality of results or anonymity of testing can be guaranteed.<sup>16</sup> This is also applicable in South Africa: in principle a person may only be tested at his or her own request.<sup>17</sup> Despite the existence of these regulations and legislation, testing still occurs randomly. This poses a challenge to governments to ensure that clear guidelines and policies are put in place to protect the rights of those infected by HIV.

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<sup>15</sup> See Jurgens footnote 1 above, p. iii.

<sup>16</sup> Canadian HIV/AIDS Legal Network, “Evolution of HIV testing policy and technology in Canada”, 2007, available at <http://www.aidslaw.ca/testing>, (accessed 24 June 2012).

<sup>17</sup> South Africa Medical Association, Human Dignity, Law and Ethics Unit, “A Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners of South Africa 2001, available at, <http://www.chr.up.ac.za/undp/domestic/docs/policies03.pdf>, (accessed 17 August 2012).

### 6.2.1 *The role of a rights-based approach in combating HIV/AIDS*

A human rights based approach to HIV/AIDS is one that protects, respects and fulfils as opposed to restricting human rights.<sup>18</sup> The protection and promotion of human rights is necessary not only for the protection of the inherent dignity of persons affected by HIV but also for the achievement of the public health goal of reducing vulnerability to HIV infection, lessening the adverse impact of HIV and AIDS on those affected, and empowering individuals and communities to respond to HIV.<sup>19</sup>

A rights-based approach to HIV testing means that HIV testing shall be undertaken in compliance with the 3C principle that is pre- and post-test counselling, informed consent, and confidentiality of the test results. These principles are embedded in human rights documents which guarantee the highest attainable standard of health, the right to dignity, privacy, freedom and security of person and freedom from discrimination. Human rights, however, are neither illimitable nor absolute. Therefore, a public health action by the state that limits human rights must be justified by demonstrating that it is rationally connected to achieving a pressing objective, infringes on human rights as little as possible, and the benefits achieved are proportionate to the harm done to individuals' human rights.<sup>20</sup>

A human rights-based approach is relevant and is an essential element in the fight against HIV/AIDS. Human rights are now understood to offer a framework for action and it is through a human rights based approach that gaps in the public health system can be identified. Similarly, a human rights approach entrenches the principle of accountability of governments to its people. Governments have a responsibility (derived from international legal frameworks and, to differing degrees, from national constitutions) to ensure that these rights are met. Civil society, if it is sufficiently empowered to do so, may assert these rights in order to improve the quality of human lives. The value of the human rights approach lies not only in principles such

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<sup>18</sup> UN Office of the High Commissioner for Human Rights, "A human rights-based approach to HIV/AIDS: UN General Assembly Special Session on HIV/AIDS 2001, para 4.

<sup>19</sup> UNAIDS/OHCHR *International Guidelines on HIV/AIDS and Human Rights: 2006 Consolidated Version* 2006, available at [http://www.ohchr.org/english/issues/hiv/docs/consolidated\\_guidelines.pdf](http://www.ohchr.org/english/issues/hiv/docs/consolidated_guidelines.pdf), (accessed 15 October 2011).

<sup>20</sup> See Jurgens footnote 1, p. iv.

as state accountability and popular participation, but also in the transformative potential of rights to alleviate social injustice, inequality and poverty.<sup>21</sup>

Respect for the rule of law, human rights, and democratic accountability are some of the values pursued by Uganda and these are fundamental elements of a successful HIV/AIDS strategy. South Africa should not despair or attempt to implement radical and coercive measures such as mandatory testing to combat HIV/AIDS. This is not the answer to end the epidemic. Uganda has proved that public health programmes that respect human rights will encourage individuals and communities to trust and cooperate with public health authorities.

HIV/AIDS and human rights activists have taken the position that infringing the right to privacy by, for example, making HIV/AIDS testing mandatory will effectively drive the AIDS epidemic further underground, particularly where being infected is followed by persecution, ostracism, violence and destitution.<sup>22</sup> In the absence of public health strategies that loudly encourage VCT among the population generally, it is bound to have limited impact. However, the study clearly observed that every public health policy, no matter how good it may seem, is potentially a threat to the enjoyment of human rights.<sup>23</sup> Mann *et al.*<sup>24</sup> reiterate that every public health policy should be viewed as a potential threat to human rights, unless proved otherwise. In designing any public health policy, particularly in the context of HIV/AIDS, the duty to respect, protect and fulfil human rights should be the primary considerations of governments.<sup>25</sup>

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<sup>21</sup> Albertyn, "Prevention, treatment and care in the context of Human Rights" Expert group meeting on the HIV/AIDS pandemic and its gender implications 13-17 November 2000 Windhoek Namibia, p. 2, available at, <http://www.un.org/womenwatch/daw/csw/hiv/aids/albertyn.html>, (accessed 24 September 2012).

<sup>22</sup> Canadian HIV/AIDS Legal Framework, "Outcomes of the symposium on HIV testing and human rights" 2005, available at <http://www.genderhealth.org/pubs/testing.pdf>, (accessed 22 August 2011).

<sup>23</sup> Durojaye, "Addressing human rights concerns raised by mandatory HIV testing of pregnant women through the protocol of the African Charter on the Rights of women" *Journal of African Law Vol 52(1)* 2008 p. 46.

<sup>24</sup> Mann, Statement at an Informal Briefing on AIDS to the 42<sup>nd</sup> Session of the United Nations General Assembly, *Journal of the Royal Statistical Society. Series A (Statistics in Society) Vol. 151, No. 1, 1988*, p. 131-136.

<sup>25</sup> Gruskin, Tarantola, *Health and Human Rights*, New York Routledge 2005, p. 3-58.

### *6.2.2 Stigma and discrimination*

Since its inception, HIV/AIDS has been associated with being promiscuous and people viewed as such have been regarded as outcasts by the community. Society viewed HIV/AIDS as being different from other diseases due to the intimate and private nature of the transmission routes, several of which lean crucially on what may broadly be termed an individual's lifestyle.<sup>26</sup> For this reason, HIV/AIDS has been associated with stigma and discrimination. The rights of people living with HIV often are violated because of their presumed or known HIV status, causing them to suffer both the burden of the disease and the consequential loss of other rights. Stigma and discrimination may obstruct their access to treatment and may affect their employment, housing and enjoyment of other rights. HIV-related stigma and discrimination thereby discourages individuals infected with and affected by HIV from obtaining health and other social services. The result is that those most needing information, education and counselling will not benefit even where such services are available.<sup>27</sup>

It is a futile exercise to increase the number of people who test positive for HIV/AIDS without, firstly, preparing them for the stigma and discrimination which might follow and, secondly, without giving them the treatment that they need for the future. This, therefore, requires a continuous supply of antiretroviral therapy. Testing alone has little or no effect on behaviour;<sup>28</sup> mandatory testing will in fact increase stigmatisation and this would be counter-productive.

### *6.2.3 Gender dimensions of the AIDS pandemic*

HIV and AIDS should cease to be seen as a medical problem but as one that cuts across gender, development and human rights issues.<sup>29</sup> The solution to the HIV/AIDS crisis is not as simple as testing every person and disclosing their status. Not effecting changes such as gender equality and putting an end to violence

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<sup>26</sup> See Bennet and Erin footnote 8, p 1.

<sup>27</sup> Office of the High Commissioner for Human Rights, "HIV/AIDS and Human Rights", available at <http://www.ohchr.org/EN/Issues/HIV/Pages/HIVIndex.aspx>, (accessed on 23 November 2012).

<sup>28</sup> The Lancet, "Compulsory testing and falling incidence", The Lancet Vol 367 Issue 9517, 2006, p. 1118.

<sup>29</sup> Statement by Crewe, Director of the Center for the study of AIDS at the University of Pretoria, during her presentation 'AIDS democracy development and human rights', given at stakeholder consultation on gender, human rights and HIV and AIDS: A UNDP-OHCHR joint initiative for Southern and Eastern Africa, Rosebank hotel, Johannesburg 27-29 June 2006.

against women will further drive these efforts underground. Ignoring these factors in the short term will only delay reversing the epidemic, cost more money and, most importantly, cost more lives<sup>30</sup>. Women are exposed to violence after exposing their HIV status or even sexually transmitted diseases and infections to their partners. Mandatory HIV testing inevitably runs up against the gender dimensions of the pandemic. The subordinate status of girls and women may exacerbate the spread of HIV/AIDS, because girls and women are often blamed for bringing the virus into the house, and, as such, they suffer from violence or discrimination of various kinds upon disclosing their HIV status.<sup>31</sup>

Women are vulnerable when it comes to HIV/AIDS. The unequal status of women in the community also means that their capacity to negotiate safe sex is severely undermined. Not only women are vulnerable to infection, people living in poverty often are also unable to access HIV care and treatment, including anti-retroviral and other medications for opportunistic infections.<sup>32</sup> “HIV/AIDS has brutally exposed all the fault lines of our society: poverty, gender inequality, violence, lack of access to education, health care, social service, employment and social security.”<sup>33</sup> The HIV pandemic should not only be seen as a medical problem but also as a problem that cuts across gender, development and human rights. This issue should, therefore, be clarified and addressed in plain language by governments and in international and regional human rights instruments.

#### *6.2.4 Change of attitude of African communities is imperative*

HIV/AIDS in South Africa is beyond testing. Mind sets have to be shifted and focus has to be given to education and awareness of the disease. The study has shown that the approach that Uganda followed should be emulated as there was a 100 percent commitment towards the fight against HIV/AIDS from the President to members of rural communities. Lip service to human rights principles by governments is dangerous and only leads to cynicism and derision of international

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<sup>30</sup> Coercive measures such as mandatory testing which at first blush appear to be protecting the interests of the community may well jeopardize prevention opportunities and so produce the opposite of the desired effect.

<sup>31</sup> Canadian HIV/AIDS Legal Framework, “Outcomes of the symposium on HIV testing and human rights” 2005, available at <http://www.genderhealth.org/pubs/testing.pdf> (accessed August 2011)

<sup>32</sup> *Ibid.*

<sup>33</sup> See Crew footnote 29.

human rights.<sup>34</sup> The government and society have to act together in this fight against HIV. Implementation of policies is the greatest challenge faced by Africa. The responsibility of HIV infected people to learn about their status and act accordingly has to be balanced by that of society in providing a supportive environment that offers strong protection against discrimination.<sup>35</sup> A massive government involvement, open communication about HIV/AIDS, and extensive campaigns should be put in place as these are some of the factors that contributed to Uganda's success story.<sup>36</sup>

#### 6.2.5 *Scaling up treatment and human resources in health care centres*

Another finding that affects HIV/AIDS testing in sub-Saharan Africa is that health systems are abysmally weak; there are inadequate health workforces, poor management, and insufficient resource allocation and utilisation which have severely weakened the capacity of most health systems on the continent to respond to the pandemic.<sup>37</sup> Given such a health system, even if antiretroviral drugs were available, distribution to all those in need of treatment still remain a problem in most countries.<sup>38</sup> On the other hand, poor working conditions and low salaries have also triggered a wave of migration of health professionals from sub-Saharan Africa to the West. In Ghana, for example, about 61% of doctors trained locally between 1984 and 1995 have left the country.<sup>39</sup> Scaling up access to treatment is a vital step towards encouraging testing in sub-Saharan Africa and dispelling the misconception that HIV/AIDS is a "death sentence."<sup>40</sup>

Provider-initiated HIV/AIDS testing and compulsory testing models cannot be implemented in a country or community where there are high levels of stigma and discrimination or low capacity of health care providers. It is thus clear that the status of the African health systems requires a testing model that is in line with its capacity.

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<sup>34</sup> International Symposium, "The ethics of State Involvement in Woman's Health" University of California 2010.

<sup>35</sup> Epstein *The Lessons of Uganda*, The New York Review of books 2001, available at <http://www.nybooks.com/articles/14309>, (accessed 18 August 2012).

<sup>36</sup> *Ibid.*

<sup>37</sup> World Health report, Health systems: Improving performance: Geneva 2000, available at <http://www.who.int/whr/2000>, (accessed 14 April 2012).

<sup>38</sup> Alwano-Edyegu, Marum, "Knowledge is power: Voluntary HIV counselling and testing in Uganda", UNAIDS Case study June 1999, p. 644.

<sup>39</sup> Asante, "Scaling-up HIV Prevention: Why Routine or Mandatory Testing is not feasible for sub-Saharan Africa", *Bulleting of World Health Organisation*, Vol 85: 2000.

<sup>40</sup> *Ibid.*

VCT is not only appropriate but it also shows that individuals are taking charge of their own health and bodies despite the deficiencies of the health system.

While efforts to increase the uptake of HIV testing are important, studies have shown that tests alone are not sufficient to contain the disease. For example, many pregnant women who accept HIV testing in antenatal and resource-poor settings do not obtain their results or take up perinatal interventions.<sup>41</sup> This thus buttresses the argument that there is an urgent need for an increase in ART and other support resources in Africa before efforts are made to increase the number of people who test. In essence, HIV testing policies should be linked with technologies that allow rapid testing and the subsequent availability of ART.<sup>42</sup>

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<sup>41</sup> See Jurgens footnote 1.

<sup>42</sup> *Ibid.*



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