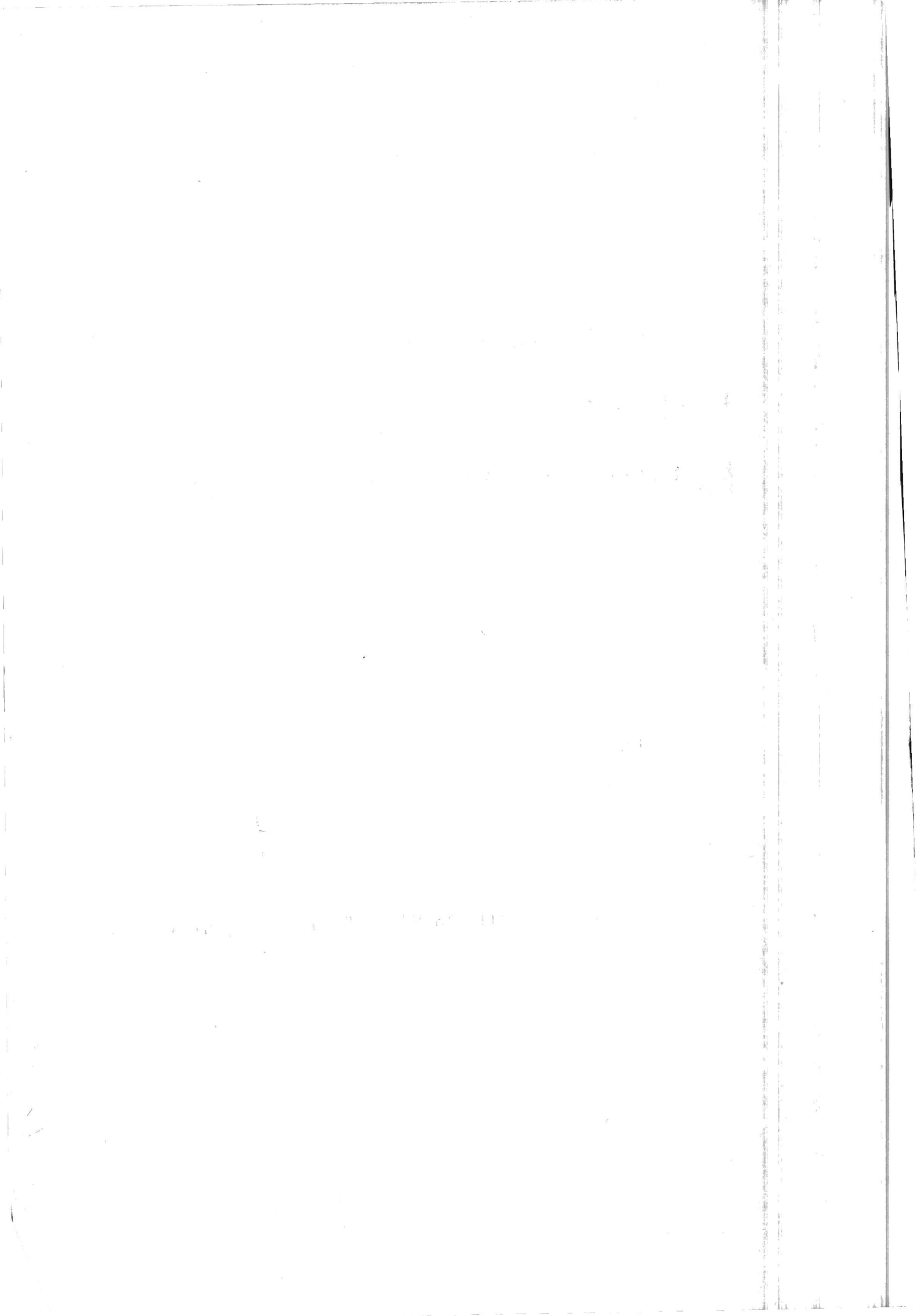


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# Report of the Task Force on Legal Issues Relating to HIV and AIDS



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## LIST OF ABBREVIATIONS/ACRONYMS

ACU	-	AIDS Control Unit
AIDS	-	Acquired Immune Deficiency Syndrome
AKI	-	Association of Kenya Insurers
ARVs	-	Anti-Retrovirals
CACC	-	Constituency AIDS Control Committee
CBO	-	Community Based Organization
CEDAW	-	Convention on the Elimination of All Forms of Discrimination Against Women
CRC	-	Convention of the Rights of the Child
CRRF	-	Children Relief and Rescue Fund
FGM	-	Female Genital Mutilation
GIPA	-	Greater Involvement of People Living With HIV And AIDS
GOK	-	Government Of Kenya
HIV	-	Human Immune-Deficiency Virus
HMO	-	Health Management Organization
ILO	-	International Labour Organization
KANCO	-	Kenya AIDS NGOs Consortium
KEFRI	-	Kenya Forestry Research Institute
KELIN	-	Kenyan Ethical and Legal Issues Network On HIV And AIDS
KEMRI	-	Kenya Medical Research Institute
KICC	-	Kenyatta International Conference Centre
KICOSHEP	-	Kibera Community Self Help Project
KIPO	-	Kenya Industrial Property Office
MOEST	-	Ministry of Education, Science and Techonology
MOH	-	Ministry of Health
MTEF	-	Medium Term Expenditure Framework
MTP	-	Medium Term Plan
NACC	-	National AIDS Control Council
NASCOP	-	National AIDS And STD Control Programme
NGO	-	Non Governmental Organizations
PACC	-	Provincial AIDS Control Coordinator
PLWHA	-	People Living With HIV/AIDS
PMTCT	-	Prevention of Mother to Child Transmission
PTCT	-	Parent To Child Transmission
STD	-	Sexually Transmitted Disease
VCT	-	Voluntary Counselling and Testing
WHO	-	World Health Organization
WIPO	-	World Intellectual Property Organisation
WOFAK	-	Women Fighting AIDS In Kenya

## **The Terms of Reference of the Task Force on Legal Issues relating to HIV and AIDS**

- (a) To consider the challenges posed by HIV and AIDS to all laws with a view to making appropriate recommendations for the reform of our laws with a view to better prevention, management and control of the HIV and AIDS disaster in Kenya;
- (b) To advise on the adoption of guidelines, rules, regulations and procedures immediately required to address the HIV and AIDS disaster;
- (c) To look into the human rights issues affecting widows and widowers, orphans, employees and other workers and people living with HIV and AIDS among others and make recommendations thereon;
- (d) To address legal matters concerning HIV and AIDS and related to marriage, research, insurance and drug access matters and make recommendations thereon;
- (e) To review offences under the Penal Code and other offences in the laws of Kenya in the light of the HIV and AIDS pandemic and make recommendations on how the penal laws can be strengthened;
- (f) To make any other recommendations that are incidental to foregoing.

## Members of the Task Force on Legal Issues Relating to HIV and AIDS

Mr. Ambrose D. O. Rachier - **Chairman**

### **Members**

Bishop Philip Sulumeti  
Dr. J. B. Okanga  
Rev (Dr) Jones Kaleli  
Mr. Abdulhamid Slatch  
Mrs. Violet Wainaina  
Mr. P. L. O. Lumumba  
Dr. Mtana Lewa  
Mr. Sammy K. Kirui  
Dr. J. G. Wasonga  
Mr. Philip Wangalwa  
Mrs Dorothy Odhiambo  
Ms. Grace Madoka  
Mr. Hassan Haji

### **Ex-Officio Members**

Dr. Margaret Gachara - Director, National AIDS  
Control Council

Mrs. Margaret Nzioka - Chief Parliamentary Counsel,  
Attorney-General's Chambers

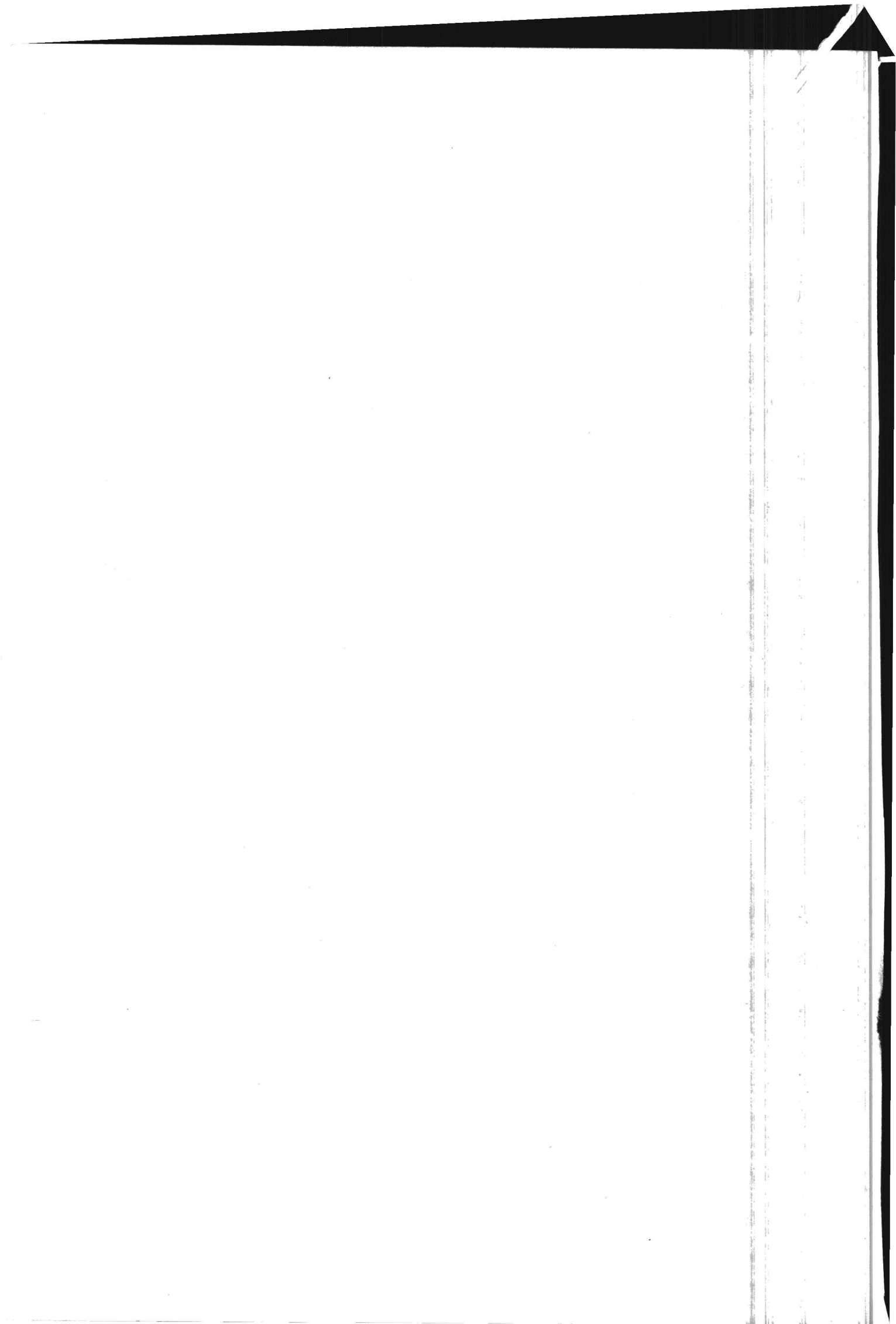
Mr. P. J. Kamau - Administrator-General,  
Attorney-General's Chambers

Mr. Allan Ragi - Kenya AIDS NGOs Consortium

### **Joint Secretaries**

Mrs. Catherine Mumma - Senior State Counsel  
Attorney-General's Chambers

Mr. Otiende Amollo



## 1.0 FOREWORD

When the first case of HIV infection was identified in Kenya in the early 1980s, hardly anyone would have reckoned that this was the beginning of a public health catastrophe, a pandemic and a national disaster — a devastation indeed not just for Kenya but for the developing world at large and particularly for Africa.

The debilitating effects of HIV and AIDS have taken a major toll on the social and economic life of the Kenyan people — with the frequent death of family members, and of those in active economic and social production and development such as the workers, the health-care givers, and many categories of professional service-providers. The effect has been to sap the country's strength for economic productivity, and to severely undermine the standards of living and the stability of the social system. Indeed the economic gains of the last decades have been reversed.

As of July 1, 2002 the following HIV and AIDS statistical estimations had been made: (i) HIV infections: 2.2 million; (ii) actual AIDS cases: 200,000 every year; (iii) cumulative deaths: 1.7 million; (iv) deaths due to AIDS per day: 500-700; (v) number of AIDS orphans: 1.1 million.

Kenya, like other developing countries, but unlike the technologically advanced developed countries, has been hard-hit by the HIV and AIDS scourge. In the developing countries, poor technologies of economic production dictate that the critical factor of production is *labour*. When this factor of production is wholly negated by the ravages of HIV and AIDS, the national capacity in production necessarily falls, with serious implications for both domestic food sufficiency and the capacity to participate in international trade, i.e., the capacity to make wealth. The effect is that the nation and its people become poorer, and their pace of social and economic progress is considerably slowed down.

Technological poverty has yet another dimension on the impact of HIV and AIDS, in the developing countries. While better clinical assessments and access to retrovirals and prophylactic treatment are more or less taken for granted in the developed countries, they are hardly ever available to the HIV and AIDS-afflicted of Africa. The consequence is that life expectancy has sharply fallen in Africa, and infection by HIV and AIDS are virtually a pointer towards impending death. Such is not the case in the developed countries, where life expectancy is constantly kept relatively high.

HIV and AIDS, in these circumstances, is a fundamental item of agenda in governance strategies in Kenya and in Africa generally. In the quest for good governance, we must squarely address the issue.

Thus in 1999 the President declared HIV and AIDS a national disaster. This was the policy-priority basis for moving into action to put in place institutions and resource commitments, for fighting the scourge.

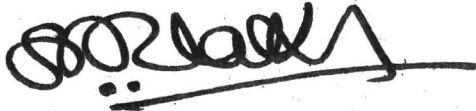
Any challenges or changes in society inevitably result in the need to re-examine and reform the law to meet the needs of the society. Consequently, by Legal Notice No. 4015 of June 12, 2001, I established the Task Force on legal Issues Relating to HIV/AIDS. The immense problems posed by HIV/AIDS cannot be addressed comprehensively in all their aspects unless the legal issues are delved into and dealt with. The object was to review Kenya's existing legal framework, and to consider all possibilities within the capacity of legal instruments, with a view to making the best possible contribution to the fight against the HIV and AIDS scourge. It was a quest for appropriate recommendations for the establishment of a legal framework of supportive initiatives for combating HIV and AIDS, a framework that was at the same time germane to the observance of human rights, as well as the normal legal rights of the individual regardless of the fact of afflictions occasioned by HIV and AIDS.

Since its establishment in 2001, the Task Force has been able to conduct a substantial amount of work; involving the definition of all the critical legal relationships and issues; visiting different parts of the country and conducting interviews with stakeholders and responsible persons; conducting workshops and seminars; and formulating a comprehensive report. The Report has delved into critical issues such as: the issue of HIV AND AIDS and the protection of the right to confidentiality and privacy; HIV AND AIDS and questions of succession and inheritance and in particular property rights in relation to AIDS orphans; the law of insurance in relation to HIV and AIDS; the rights of workers in the workplace, in relation to the HIV and AIDS scourge; the protection of human rights, in relation to HIV and AIDS infection; the issue of consent, in sexual relations that lead to HIV and AIDS infection; the scope for using criminal law to discourage willful infection; legal safeguards for biomedical research involving human subjects; the role of the law in relation to access to retroviral medication, etc.

I commend this Report as a serious study initiative in the law's possible contribution to the struggle against the HIV and AIDS pandemic. This is, at the moment, the most authoritative indication of the path that the legal process should take in making its contribution to the struggle. This

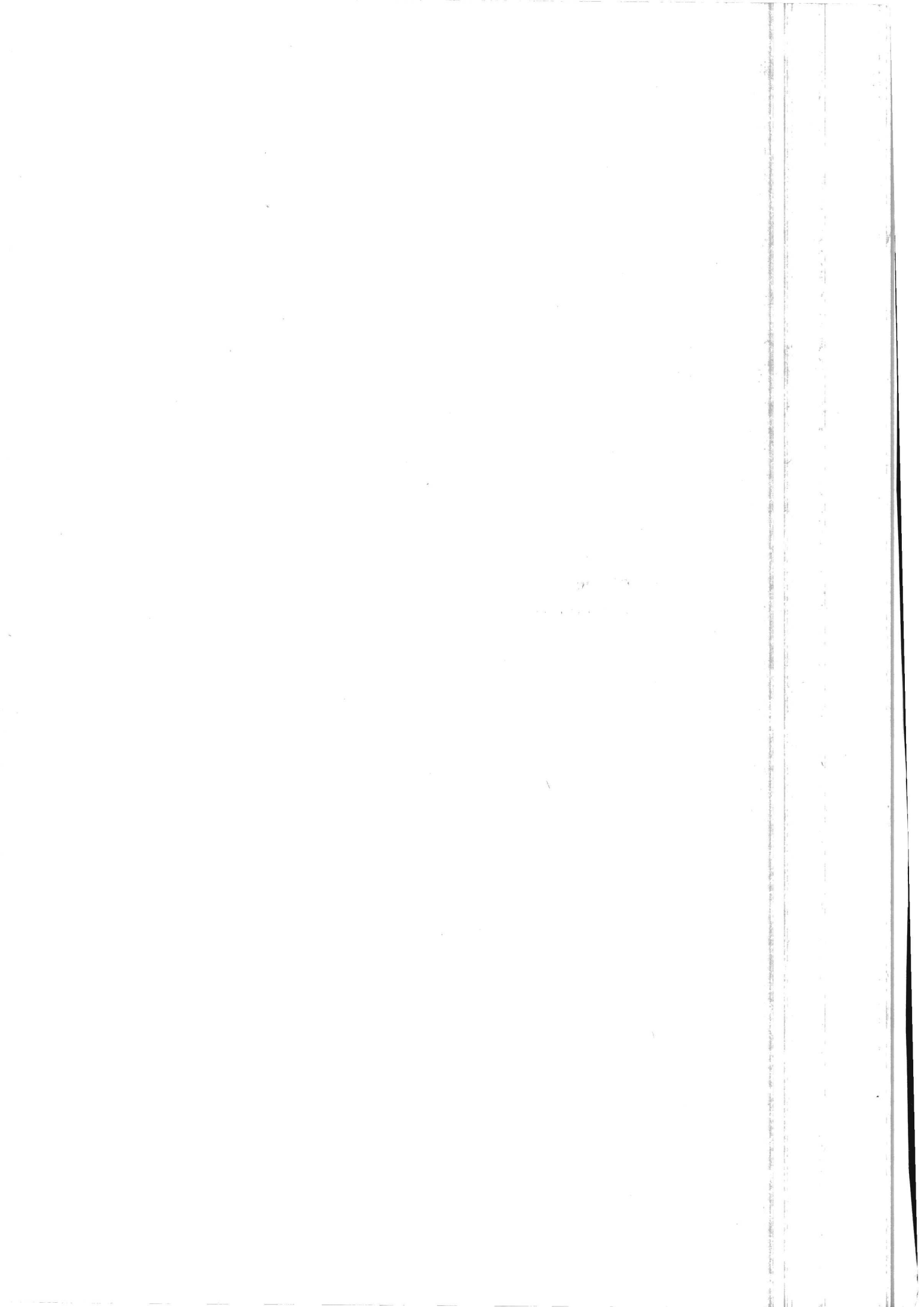
**report** will also be extremely useful as resource material for those engaged in informed discussion, consultation or dialogue on some of the sensitive issues that have to be addressed in this area of HIV/AIDS pandemic. For my part, I will promptly take up every individual recommendation, and pursue it vigorously at the level of legislation and implementation.

I congratulate the members of the Task Force on their great achievement, which is a remarkable contribution to the cause of good policy direction and the management of public affairs in our country.



**(S. AMOS WAKO) EGH, EBS, MP.**  
**ATTORNEY - GENERAL**

28<sup>TH</sup> JUNE 2002



## 1.1 ACKNOWLEDGEMENT

The Task Force on Legal Issues Relating to HIV and AIDS would not have completed its task in time without the generous help of a number of people and organisations.

We would first like to thank the Honourable the Attorney-General, S. Amos Wako for giving us the opportunity to participate in this noble exercise which we believe will contribute to the fight against HIV and AIDS in Kenya.

We particularly wish to thank him for the flexible working time frame that he allowed us, notwithstanding the disaster status of HIV and AIDS. The Attorney-General was always available for consultations at the various stages of the work of the Task Force, and made the considerate decision to publish this report, in this way enabling all Kenyans to participate in the fight against HIV and AIDS even after the Task Force has finalised its work.

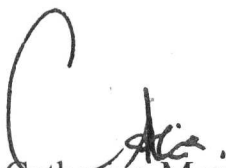
We also wish to thank the National AIDS Control Council, in particular the Chairman, Dr. Mohammed Abdullah and the Director, Dr. Margaret Gachara for facilitating the work of the Task Force by hosting the Secretariat. NACC also provided support to the Secretariat by seconding some of its personnel to assist the Joint Secretaries in their onerous task. The Provincial AIDS Control Co-ordinators, in liaison with the Office of the President through the Provincial Commissioners and their officers in the Provincial Administration also assisted by giving logistical support for the consultations with members of the public.

The Council also helped to secure funding for all the activities that were undertaken. In this regard, gratitude goes to the Government of Kenya, the United Nations Development Programme (UNDP) Policy Project, and the World Bank, which not only provided the funding, but also showed a keen interest in the work of the Task Force.

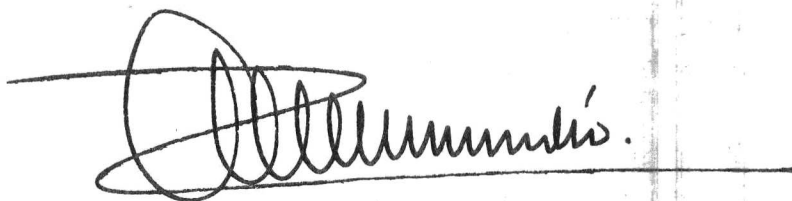
The report draws from library and internet research, interviews, consultations undertaken at public meetings all over the country, memoranda submitted by various institutions and individuals, exchange of views with local and international experts, workshop deliberations and from retreats organised to synthesise the views and issues. We wish to thank all those who turned up for these meetings and consultations and who chose to play a role and participate in the process.

We acknowledge the special support from the Consultants, Quality Controllers, Research Assistants and the NACC staff who participated in the research for the various identified subjects and who helped in the compilation of the report.

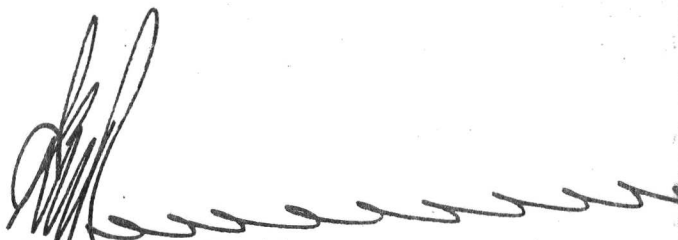
Special thanks goes to Professor J. B. Ojwang (Dean, Faculty of Law, University of Nairobi), Prof. G. Muriuki (Pharmacy Department, University of Nairobi), Dr. Christine Saadia (UNIFEM), Dr. Sobbie Mulindi (Kenyatta National Hospital), Mr. Tom Odhiambo Ojienda (Faculty of Law, Moi University), Mr. Fredrick Sisule Musungu (The South Centre, Geneva), Mrs. Rose Ayugi-Masinde (Faculty of Law, University of Nairobi), Ms Kagwiria Mbogori (Executive Director, International Commission of Jurists, Kenya Chapter), Mr. Jotham Arwa (Advocate), Mr. David Otieno (Advocate), Mr. Michael Angaga (Network of Africa People Living With HIV and AIDS), Mr. Lucas Sese (Kenya Industrial Property Institute), Mrs. Tina Ojuka (Kenya Alliance for Advancement of Children), Mrs. Winfred Lichuma (NACC), Mr. A.K.B. Muthama, Ms. Lilian Abishai, Ms. Rosemary Odoyo, Ms. Jane Miano, Mr. Boniface Auma, Mr. Wilson Maina, Mrs. Grace Wetindi, Ms. Mercy Karanja, Mr. Francis Chesang, Mr. Joseph Mbugua, and Mr. Mohammed Adan.



Mrs. Catherine Mumma  
Joint Secretary  
**Task Force on Legal Issues  
Relating to HIV and AIDS**



Mr. Otiende P. Amollo  
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**Task Force on Legal Issues  
Relating to HIV and AIDS**



Mr. A.D.O. Rachier  
Chairman,  
**Task Force on Legal Issues  
Relating to HIV and AIDS**

## 1.2 INTRODUCTION

Since 1981 when the first case of HIV (Human-Immune Deficiency Virus) was diagnosed in the United States of America, HIV and AIDS have become the twin vehicles of doom and gloom, ravaging families and leaving nothing but death and despair in their wake.

Currently, over 36.1 million people worldwide have been diagnosed as having the HIV virus, while 21.8 million have succumbed to AIDS. The majority of the people living with HIV and AIDS are concentrated in developing countries, with 75% living in Sub-Saharan Africa.

In 1998, UNAIDS estimated that HIV and AIDS would erase 17 years of potential gains in life expectancy in nine African countries, including Kenya. In essence, this represents a reversal of several decades of development gains in these countries.

As people, networks of people and communities affected by the pandemic emerge and develop innovative responses to contain the spread of HIV and AIDS, the individual rights of People Living With HIV and AIDS (PLWHAS) and those affected have sometimes become the sacrificial lamb. Initial responses to the pandemic were often reactionary, invoked in the name of public health and frequently, at the expense of human rights. In some countries, strong walls were built separating the "healthy" from the people living with HIV and AIDS, and discriminatory treatment of PLWHAS was common on the ground of protecting the greater society from contagion. In this thinking, when the first case of HIV was diagnosed in Kenya in August 1984, hospital staff literally abandoned the person. Other patients were moved from the ward, and nobody would serve the PLWHA food. Similar experiences are the tales of many a place elsewhere in the world.

With hindsight and experience however, it has become clear internationally that such extreme measures as segregation and isolation, have not served to prevent infection. It has come to be appreciated that any measures taken in the name of control of infection, which are not informed by human rights, are bound to be negative. It has been recognized that measures proposed to be taken for any special category of people, or confined populations, may not be effective unless they would be effective for the free population. It has been acknowledged that the responsibility to control HIV infection lies with both the HIV-positive and HIV-negative, and that only by engagement and consultation with people living with HIV and AIDS can the war against the virus be won.

According to the official record released by the National AIDS and STD Control Programme (NAS COP) in the Ministry of Health in the year 2001 (AIDS in Kenya booklet), it was estimated that 2.2 million Kenyans were living with the HIV infection, and about 200,000 have AIDS. Of these, only a few know that they are infected, or that they are living with HIV or AIDS.

Since the beginning of the epidemic in Kenya, over 1.5 million have died of AIDS. About 300,000 are likely to be infected with the HIV virus every year. About 80,000 will die of AIDS in every year. In a number of selected sites in Kenya, the Sentinel Surveillance System indicated that about 20% of the pregnant women and girls are living with the HIV virus. Indeed the percentage has been placed as high as 35% in some sites in Kisumu.

The prevalence of HIV infection among those aged between 15 and 49 years is estimated to be 13.5%. The prevalence in urban areas is estimated to be 17% to 18%.

Even if the prevalence of HIV is higher in urban areas, the total number of people living with the virus is still fairly high in the rural areas since about 80% of the population lives in these areas. Coupled with the fact that most of those infected are unaware of their status, and of the fact that many of the infected will not develop the symptoms of AIDS for 5 to 10 years, and also from the fact that the general prevalence of HIV is only visible through those with AIDS who are a very small percentage of people living with HIV or AIDS (PLWHAs), it is clear that the HIV and AIDS scourge is ahead of us and we have to do all in our capability to catch up, overtake it, and control it.

It is important, however, to note that the impact of HIV and AIDS in the developing countries, and particularly those in Africa, is a lot more severe than it is in the developed countries. In the poorer countries dependent on rural farm production to support their economy. The debilitating impact of HIV and AIDS on rural populations invariably undermine the labour basis of the economy. This is unlike the position in the technologically advanced, urbanized nations in which human labour does not play such a critical role in economic productivity. Besides, the availability of pharmaceutical technology and of large varieties of prophylactic medicine in the industrialized countries have made HIV and AIDS normal ailments there, rather than public health and economic disasters as in the developing countries.

In the circumstances, Kenya and indeed all other African countries must take a hard look at their situation and, in the context of progressive lessons from

elsewhere, work out their own best approaches for addressing the HIV and AIDS scourge.

### **1.3 BACKGROUND**

#### **EVOLUTION OF KENYA POLICY ON HIV AND AIDS**

At the initial stages of the diagnosis of the first cases of HIV and AIDS in Kenya in 1984, the focus of the strategy was to deal with the scourge in terms of blood safety. However, as more came to be known about the condition, various bodies were set up to assess the situation of HIV and AIDS, and make recommendations for an appropriate policy framework. The evolution of Kenya's policy on HIV and AIDS may be summarized as follows:

- Since diagnosis of HIV and AIDS in Kenya in 1984, the Kenya Government saw it fit to centralize the National AIDS response within the Ministry of Health. The initial reaction was to deal with HIV and AIDS as a medical problem. The Government's response was in three phases.
- The 1<sup>st</sup> phase spanned through 1984 – 1987. The phase did not regard HIV and AIDS as a pandemic, but as an epidemic. Any discussion of HIV and AIDS by the media was highly sensationalized and stigmatized. During this phase, the Government created the National AIDS Council (NACC).
- The years spanning through 1987 – 1991 saw the launch of the first five-year Medium Term Plan (MTPI) with the support of the World Health Organization. The National AIDS Committee within the Ministry of Health established an AIDS Programme Secretariat (APS) to control the spread of HIV and AIDS. The MTPI (1987-91) focused on blood safety, mass awareness creation, promotion of safer sex and control of STDs. To this end, National Guidelines were developed to help in prevention and reduction of infection and in ensuring blood safety. NASCOP began to reach out to the general public, which was starting to be confused by different views on HIV and AIDS.
- Towards the end of 1987, the National AIDS Committee was changed to the National AIDS Control Programme, which merged with the STD Control Programme to become the National AIDS and STD Control Programme (NASCOP). (NASCOP remains the department

within the Ministry of Health for co-ordinating HIV and AIDS programmes in the Ministry among others and is also the AIDS Control Unit for the Ministry).

- The 2<sup>nd</sup> phase (1988-91) saw the government appraise the HIV and AIDS situation and acknowledge it as a key public health problem. While there still existed public ignorance in the area of HIV and AIDS transmission and prevention, religious organizations preached against the use of condoms.
- The national HIV and AIDS surveillance system was put into place in 1999 to provide information to policy makers and programme planners for action.
- In the 2<sup>nd</sup> phase, the government response was still driven by the Ministry of Health, which relied heavily on general public education to address the epidemic.
- The 3<sup>rd</sup> phase (1992-95) made significant changes in Kenya's HIV and AIDS policy as the first surveillance data was released in 1992. A Socio-Economic Impact Assessment was commissioned by the Government and a second MTP (MTPII) spanning five years (1992-96) was developed focusing on strengthening inter-sectoral collaboration in responses to HIV and AIDS. At this stage it was recognized that the problems relating to HIV and AIDS were not confined to the health sector.
- Much of the national HIV and AIDS activities began to focus on strengthening District-level co-ordination of activities. Between 1995-97, the Government put in place a national structure of consultation to identify relevant policies to drive the response to the scourge, culminating in the Sessional Paper No. 4 of 1997.
- The Sessional Paper recommends two key strategies namely,
  - (i) Prevention of transmissions
  - (ii) Reduction of the impact of AIDS in society.
- Under prevention the strategy is to address:
  - (i) Prevention of sexual transmission
  - (ii) Prevention of mother-to-child transmission

- (iii) Prevention of transmission through invasive procedures
  - (iv) Prevention of infection through blood
- Under reduction of the impact of AIDS in society, it is suggested that national capacity to respond to the epidemic be enhanced. In this regard the following are suggested:
    - (i) Enhancing the co-ordination of a multisectoral prevention and control programme
    - (ii) Having an advocacy and networking strategy at the national level.
    - (iii) Mobilisation of resources from all potential sources.
    - (iv) Enhancing research, training and treatment of HIV and opportunistic infection.
    - (v) Monitoring the trends of AIDS.
  - The principal recommendation of the Sessional Paper is the setting up of an entity to effectively co-ordinate a multisectoral approach in this fight. It recommends the establishment of the National AIDS Council for this purpose.
  - Another marked development in the phase was the Five-Year Strategic Plan developed by the Ministry of Health through NASCOP spanning the period 1999-2004. The strategic plan was not multi-sectoral as HIV and AIDS was still squarely within the health domain. Nevertheless the problem was widely acknowledged as crosscutting and was included in the various national policy documents.
  - The HIV and AIDS priority activities and implementation arrangements were spelt out in the strategic plan 1997-2001 and the National Poverty Eradication Plan 1999-2015.
  - The Declaration of HIV and AIDS as a National Disaster on November 25<sup>th</sup> 1999, and the formation of the National AIDS Control Council (NACC) by His Excellency the President on 26<sup>th</sup> November 1999 provided the beginning of a stronger co-ordination mechanism to tap the full potential of all sectors. In a nutshell, NACC was to mobilize all sectors and co-ordinate a multi-sectoral approach to the

fight against HIV and AIDS pandemic. NACC is appropriately set up in the Office of the President, for a better undertaking of its mandate.

- As all sectors were mobilized to play their part in the fight on HIV and AIDS, a lot of issues have been and are being raised on law and human rights. The Sessional Paper does promise that the legal and ethical issues on HIV and AIDS shall be addressed.
- It was after the Declaration of HIV and AIDS as a National Disaster and the establishment of the National AIDS Control Council that the Attorney-General established the Task Force on Legal Issues Relating to HIV and AIDS, through Gazette Notice No. 4015 of 22<sup>nd</sup> June, 2001.

The Attorney General felt that there was a need to set up a Task Force to examine the legal questions that arise in the wake of the scourge and, where possible, address these in the spirit of the Declaration of Disaster status. The Task Force membership was drawn from various stakeholders and experts in various fields in the Kenyan Society.

The Task Force was formally launched on 6<sup>th</sup> August, 2001 and begun its main activities in September 2001. It was to report by 31<sup>st</sup> December 2001 but this was not possible given the schedule of work necessary for the satisfactory completion of the tasks relevant to its work. In this regard the date for reporting for the Task Force was extended to 30<sup>th</sup> June, 2002.

#### **1.4 LEGAL ISSUES RELATING TO HIV AND AIDS**

As the HIV and AIDS pandemic continues to ravage humankind, a number of issues have come up engendering many difficult questions relating to the link between the law and human rights and the strategies and policies put in place to combat the scourge.

The noble principle of confidentiality in doctor – patient relationships has raised a dilemma in the developing countries where the need to encourage HIV testing and the need to prevent transmission are central to the strategy for control of the scourge.

The predominant mode of transmitting HIV (through sexual intercourse) has attached a stigma to the scourge, and many would rather not know their status, and where they know, they would not disclose their status because of the discrimination and stigmatisation that is likely to follow. People who are known to

be living with HIV and those with AIDS have suffered discrimination at all levels; in the family, in schools, in employment in treatment facilities, in social places and in other places and situations.

With the need to find a scientific solution to the HIV and AIDS pandemic, researchers are frantically searching for solutions. In the process, a number of vulnerable people find themselves involved in research studies without fully appreciating the guiding policy relating to such research. At the local level, local researchers working with international researchers have found themselves in need of laws to govern such relationships.

There are those who have been accused of knowingly infecting others, thus eliciting much hue and cry from members of the public. Many would want to see the Criminal Law System address itself to such situations.

Transmission of the HIV virus from parent-to-child has raised many questions, and various suggestions have been made on the correct policy to help prevent such transmission. The issue of conflicting rights between the parent, or mother, and the child, has been a thriving one in discussions on appropriate policy in the provision of antiretroviral treatment for purposes of preventing Parent-to-Child Transmission (PTCT). Should the treatment be provided to expectant mothers free of charge? And should it be mandatory or upon the mother to decide whether or not to take the therapy? What is the role or place of the other parent in this case?

The Sessional Paper on AIDS in Kenya, in Chapter 4, itemised the Legal and Ethical Issues On HIV and AIDS as follows:

- Ensure voluntary testing for individuals;
- Enhance enforcement of ethical codes as they pertain to confidentiality in relation to AIDS;
- Ensure legal provisions regulating circumstances in which notification to partner, or to those at risk of HIV infection may be made without the consent of the infected person, in the interest of public health;
- Develop codes for counselling that have the force of law, taking into account the requirements for voluntary testing and confidentiality as they relate to home/community-based care of HIV-infected persons and people living with AIDS;

- Institute legislation to deal with isolation of and discrimination towards HIV-infected persons and people living with AIDS;
- Regulate the conduct of biomedical research involving human subjects and provide penalties for those engaging in unethical research;
- Ensure drug trials are regulated by clear legal provisions, and that sanctions are provided against those peddling, cutting up for sale or advertising substances which have no proven curative value against HIV;
- Ensure that insurers do not decline compensation to those insured who were not infected prior to the issuance of insurance policies;
- Ensure provisions for the protection of children orphaned by AIDS and people infected with HIV;
- Uphold criminal sanctions against those who deliberately infect others.

## **2.0 METHODOLOGY**

### **2.1 INAUGURAL AND PREPARATORY MEETINGS**

Following their appointment in June 2001 and the official launching held on 2<sup>nd</sup> August, 2001, Members of the Task Force on Legal Issues Relating to HIV and AIDS held a number of preparatory meetings to develop a workplan.

Members agreed to identify the issues that would need to be addressed in accordance with the Terms of Reference for the Task Force. The following were identified as the issues to look at:

- (i) Privacy and confidentiality
- (ii) Declaration of HIV and AIDS as a National Disaster
- (iii) HIV and AIDS, and the Patent Question
- (iv) HIV and AIDS in the Workplace
- (v) Testing
- (vi) HIV and AIDS in the Insurance Sector
- (vii) Ethics of Research
- (viii) HIV and AIDS in Prisons
- (ix) Euthanasia in the Wake of HIV and AIDS
- (x) HIV AND AIDS and Human Rights
- (xi) HIV, AIDS and Criminal Law
- (xii) Cultural Issues in the wake of HIV and AIDS
- (xiii) HIV and AIDS in Inheritance and Succession Issues

Members also agreed on the best way to ensure exhaustive consultations with as many stakeholders and experts as possible for purposes of accomplishing the mandate of the Task Force. In this regard it was agreed that we work through:

- i) Consultations with members of the public in all the regions of the country.
- ii) Consultations with stakeholders in the identified subject areas.
- iii) Discussions of the subject areas in fora like workshops and seminars where local and international experts would be invited to present their views.
- iv) Desktop, library and internet research on the topics including comparative analysis of situation in other countries.

- v) Visits to special institutions like children's homes and the prisons.
- vi) Consultations with special groups where possible.

The National AIDS Control Council hosted the Secretariat and sourced for the funding that enabled the Task Force to undertake the activities it did.

Initially, the Task Force had been given upto 31<sup>st</sup> December, 2001 to hand in it's report but this was not possible because the Task Force activities began over two months after it's appointment. Once the work begun, however, the Council generously support it and enabled the work to be finished on time in the extended period until 30<sup>th</sup> June, 2002.

In total 2 workshops were organized by the Task Force in the 1<sup>st</sup> half of it's work and 2 retreats were held at the beginning of the last quarter of its term to synthesize the various papers prepared by a selection of Consultants on the various identified subjects.

### **Provincial Visits**

In order to cover the Provinces as much as possible in the limited time available, the Task Force divided itself into two groups of ten persons each to travel and collect views from the public simultaneously. The first group visited Nyanza (Kisumu) and Western (Kakamega) Provinces between 30<sup>th</sup> October and 2<sup>nd</sup> November 2001, while the second group visited Coast Province, Mombasa and Malindi, between the same dates.

In the second phase of the Provincial Visits, the first group visited North Eastern Province (Garissa), Eastern Province (Embu) and Central Province (Nyeri) between 20<sup>th</sup> and 24<sup>th</sup> November 2001, while the second group visited the South Rift Valley (Nakuru), North Rift Valley (Eldoret) and Nairobi Provinces in the same period.

Each of the Provincial visits was preceded by advertisement in the print media, giving details of the place, venue and time for the consultations.

In each of the Provinces, the Task Force consulted first with the Provincial Commissioner and other administrators within the province between the hours of 8.00 a.m. and 10.00 a.m. Immediately thereafter, public hearings proceeded, some going on as late as 7.00 p.m.

At the Provincial hearings, members of the public were allowed to make contribution on subjects touching on legal or ethical issues. Those who had written submissions were invited to submit their documents either at the venue or subsequently. (The list of the documents submitted are annexed to this report as appendices).

The Provincial hearings recorded a high turnout in some instances by senior citizens of the age of 90 years and above, and by the youth. The meetings were useful in raising new issues, giving new approaches to known issues, and in securing consensus. In total, the number of people consulted during provincial visits including the confined prisoners, remandees and prison officials, was in excess of 4000.

### Consultations with Stakeholders

Having identified the preliminary list of stakeholders, the Task Force set out to hold focused consultations with these groups; these were held as follows:

	ISSUES/STAKEHOLDERS	VENUE	DATE	TIME
1	Consultations with H.E. President Daniel Toroitich Arap Moi, C.G.H. MP.	State House	25 <sup>th</sup> June, 2002	9.00 a.m.
2	HIV and AIDS, Labour & Employment Concerns	KICC Room 7	26 <sup>th</sup> October 2001	8.45a.m.–10.45 a.m.
3	HIV and AIDS and the Insurance Sector	KICC Room 7	26 <sup>th</sup> October 2001	11.00a.m.– 1.00 p.m.
4	HIV and AIDS and the Medical Practitioners	KICC Room 7	26 <sup>th</sup> October 2001	2.30 p.m. – 4.30 p.m.
5	Legal Task Force Meeting with ACU Heads in the Ministries	The Chancery	21 <sup>st</sup> January 2002	9.00 a.m.
6	HIV and AIDS and the rights of Women	KICC Room 7	30 <sup>th</sup> January 2002	9.00a.m. – 11.00 a.m.
7	Religious Organisations	KICC Room 7	30 <sup>th</sup> January 2002	11.00a.m. – 1.00 p.m.
8	People Living with HIV and AIDS (PLWHAS)	KICC Room 7	30 <sup>th</sup> January 2002	2.30 p.m. – 4.30 p.m.
9	HIV and AIDS and the rights of the child (Children living with HIV and AIDS, Orphans, Children's Institutions)	KICC Room 7	31 <sup>st</sup> January 2002	9.00a.m – 11.00 a.m.
10	HIV and AIDS in Employment, Ministry of Labour	KICC Room 7	31 <sup>st</sup> January 2002	11.00a.m–1.00 p.m
11	Public Health and HIV and AIDS Ministry of Health	KICC Room 7	31 <sup>st</sup> January 2002	2.30p.m.–4.30 p.m.
	Visits to Children's Home	i. Nyumbani Children's Home ii. Children's Relief & Rescue Foundation iii. New Life Children Home iv. KIKOSHEP	19 <sup>th</sup> February 2002	9.30a.m–12.30 p.m 9.30a.m–12.30p.m. 2.30p.m.–4.30 p.m. 2.30p.m.-4.30 p.m.
12	Courtesy Call to Commissioner of Prisons	Prisons Headquarters	6 <sup>th</sup> March 2002	

13	Visits to Prisons and Borstal Institutions	i. Kamiti Maximum Prison ii. Langata Women Prison iii. Industrial area G.K. Prison iv. Approved School in Kabete	7 <sup>th</sup> March 2002	
14	Association of Kenya Insurers	KICC	7 <sup>th</sup> March 2002	10.00a.m-1.00 p.m.
15	Commercial Sex Workers	Stima Club	12 <sup>th</sup> March 2002	9.30a.m-12.30p.m.
16	Research Stakeholders	Stima Club	12 <sup>th</sup> March 2002	2.30p.m- 4.30 p.m.
17	The Disciplined Forces	KICC Room 7	13 <sup>th</sup> March 2002	9.00a.m-11.00a.m.
18	The Disabled	KICC Room 7	13 <sup>th</sup> March 2002	11.00a.m-1.00p.m.
19	University Students and Youth Groups	KICC Room 7	13 <sup>th</sup> March 2002	2.30p.m- 4.30 p.m.
20	Ministry of Education	KICC Room 7	14 <sup>th</sup> March 2002	9.00a.m-11.00a.m.
21	Media	KICC Room 7	14 <sup>th</sup> March 2002	11.00a.m-1.00p.m.
22	Judiciary	KICC Room 7	14 <sup>th</sup> March, 2002	2.30p.m- 4.30 p.m.
23	Stakeholders on herbal medicines	KICC Room 7	15 <sup>th</sup> March, 2002	9.00a.m-11.00p.m.
24	Stakeholders on Access to Drugs	KICC Room 7	15 <sup>th</sup> March 2002	11.00a.m-1.00p.m.
25	Office of the Vice-President, Ministry of Home Affairs and National Heritage	KICC Room 7	15 <sup>th</sup> March 2002	2.30p.m- 4.30 p.m.
26	International Vaccine Initiative	KANCO		3.00 p.m. - 4.00 p.m.
27	Gay Community	KANCO	30 <sup>th</sup> April 2002	10.00 a.m.
28	Meeting with Director of Medical Services	Afya House	14 <sup>th</sup> May 2002	2.30 p.m.
29	Meeting with Chairman, Director and Senior Officials of National AIDS Control Council	Chancery Building	6 <sup>th</sup> June, 2002	11.30 a.m.

### Focus-group Meetings

While the Task Force had met various groups during the Stakeholders' meetings as above, and whereas the Task Force had also received various written recommendations and presentations, the Task Force still found it necessary to hold further meetings with certain stakeholders to amplify some issues or seek consensus on areas of radically inconsistent proposals. Some of the persons and entities met by prior request included:

- (a) The Commissioner of Prisons and Senior Prisons Officials, on 6<sup>th</sup> March, 2002.
- (b) The Director of Medical Services and Senior officials of the Ministry of Health, on 14<sup>th</sup> May, 2002.
- (c) The Association of Kenya Insurers, on 7<sup>th</sup> March, 2002
- (d) The Chairman, Director and Senior Officials of the National AIDS Control Council, on 6<sup>th</sup> June, 2002.
- (e) A representative of the Law Society of Kenya on 3<sup>rd</sup> May, 2002.

While the Task Force met the above-mentioned groups at its initiative, two groups of stakeholders took the initiative and specifically requested to meet the Task Force. These were the Commercial Sex Workers and the Association of Gays and Lesbians. Having considered the request in light of its mandate, the Task Force members agreed to meet these groups.

The Commercial Sex Workers who were all women raised many legal issues on HIV and AIDS. These are dealt with elsewhere in the report.

The Association of Gays and Lesbians also specifically sought such consultations and the Task Force met with them at the Kenya AIDS NGOs Consortium (KANCO) offices and listened and recorded their concerns, issues and proposals.

What clearly emerged from these two meetings is that both groups comprise a large number of well-organized individuals with interest in various issues relevant to HIV and AIDS, even if some of the issues exceeded the ambit of the Task Force's mandate.

### **Specialised Visits**

Because of the serious issues that arise on HIV and AIDS in Prisons, the Task Force deemed it necessary to visit a select number of Prisons in order to gather the views of the prisoners and prisons officials, and to assess the situation and practicability of certain suggestions on the ground. The Task Force visited the following Prisons.

- (a) Mombasa
  - (i) Shimo la Tewa Prison Main Prison
  - (ii) Shimo la Tewa Women's Prisons
  
- (b) Nyanza
  - (i) Kodiaga Men's Prison
  - (ii) Kodiaga Women's Prisons
  - (iii) Kibos Prison
  
- (c) In Nairobi
  - (i) Kamiti Maximum Prison

In order to better address and understand the concerns raised on HIV and AIDS vis-à-vis orphans and on the establishment, regulation and workings of Children's Homes, the Task Force visited the following Children's Homes:

- (i) Nyumbani Children's Home
- (ii) Kibera Community Self Help Project (KIKOSHEP in Kibera)
- (iii) Children Relief and Rescue Centre – Buruburu
- (iv) New Life Children's Home in Hurlingham

## **2.9 NATIONAL CONFERENCE ON LEGAL AND ETHICAL ISSUES ON HIV AND AIDS**

The Task Force found it necessary to call a National Conference in December 2001 to discuss all the issues on HIV and AIDS. The theme of the Conference was "Laying a Basis for HIV and AIDS Legislation". The conference took place between 5<sup>th</sup> and 9<sup>th</sup> December, 2001 at the Safari Park Hotel, Nairobi.

It was attended by a total of ninety-five (95) persons of varied experience and from various sectors. The Conference benefited from presentations by experts from Canada, the United States and South Africa.

The National Conference was highly informative and immensely beneficial in guiding the Task Force in appreciating some of the more difficult questions.

### **3.0 IDENTIFIED AREAS OF CONCERN**

#### **Introduction**

With the process of public and focus-group hearings completed, and having rethought the legal and ethical questions, the Task Force identified the following issues which were now accorded due consideration as outlined:

#### **3.1 HIV AND AIDS, AND THE RIGHT TO PRIVACY AND CONFIDENTIALITY**

##### **Issues**

The question on when to test for the HIV virus, whom to test, in what circumstances to allow testing, and what to do with the test results presents considerable difficulty. Should the entire population be mandatorily tested; should only prisoners, commercial sex workers, students, surgical patients or immigrants be mandatorily tested? Should testing be mandatory or purely voluntary? Should any group of persons, for instance those in the Armed Forces, be tested as a precondition to employment? How about mandatory testing of pregnant mothers? How important is the necessity of consent to an HIV test? What is informed consent? Should counselling be a mandatory requirement before and after testing? What is counselling anyway? Should mandatory testing of couples intending to marry be effected? How much would this impact on the transmission of the virus.

Life Assurance companies have often routinely had their doctors test prospective insured for the HIV virus, many times without their consent. The question surrounding this practice include an examination of the rationale, legal and constitutional legitimacy of such actions.

Even if testing was to be purely consensual and voluntary, are there not forms of indirect testing which are allowable on grounds of necessity? Testing of donated blood and donated fluids and organs has been argued to be necessary in all instances, with or without the consent of the donor. Whether, and how, to inform donors of the test results, and how to deal with donors who do not wish to know their status, are matters to be addressed with care.

The time-honoured doctrine of doctor-patient confidentiality is one that has been much discussed and criticized. The call to limit confidentiality has ranged from calls to publicly disclose the names and identities of all who have tested positive, to the more moderate suggestions to disclose only to those at risk of infection.

Even then, the question “*who is at risk*”, is one to be considered carefully. Does it include only the husband or wife; or all sexual partners including concubines, girlfriends or boyfriends?

In any case, should the doctor have **the duty** to disclose or merely **a liberty** to disclose in certain circumstances? And how should the doctor tell when it is right to make the disclosure? What factors should the doctor take into account?

The extent of the duty, in terms of who is covered, is another issue. Does, and should, the duty fall only on doctors and dentists? Or should it cover clinical officers, nurses, counsellors and others?

The issue that raised the greatest furore was the question of disclosure of cause of death as a result of AIDS. A majority of stakeholders called for a public disclosure and pronouncement of the fact of AIDS – related death during the burial. In many instances, however, the proponents would not specify **how** the fact of the death having been AIDS-related and the **mode** of disclosure, should be expressed. They are also not clear on **who** is to make the disclosure.

### **Comparative Lessons and Recommendations**

Issues of protection of privacy and confidentiality no doubt arise in the course of testing for HIV and AIDS. Throughout the consultation with various stakeholders, it was stated that while testing is important so as to enable persons to make informed decisions on their lives, it should be conducted through laid-down procedures. Confidentiality and privacy ought to be maintained in all cases.

In terms of the guidelines recommended by the Ministry of Health, confidentiality must be maintained in line with existing professional medical ethics. However, this requirement must also be weighed against the need and necessity of others at risk to know the status of an individual. Consequently, health-care providers should be able to disclose the HIV status of their patients to persons considered at risk of infection after such patient have been given sufficient opportunity to disclose his/her HIV status to the relevant persons, especially spouses and sexual partners. Disclosure by people living with HIV and AIDS of their status is relevant for purposes of reducing the stigma associated with HIV and AIDS, and eventually assisting in the management of the pandemic. This view was supported by a majority of the stakeholders and other persons consulted. Although it was suggested that local administrators be allowed to disclose the cause of death if it is AIDS related, and that such cause be publicly pronounced and shown in the relevant certificates, it was the view of the Task Force that such measures may

adversely affect the family and relatives of the deceased, in view of the stigma that HIV and AIDS generate.

In terms of the Sessional Paper No. 4 of 1997 on AIDS in Kenya, informed consent of a patient must be obtained prior to testing. The paper recommends that the law should safeguard against testing without informed consent, except under special circumstances such as during emergencies, or in situations where a patient is so incapacitated as not to be able to make a decision, or where it is required by a court order. Informed consent refers to authority given by a person to be tested for HIV and AIDS or other medical condition where such authority is based on the full understanding of the process implication and consequence of such test.

The majority of stakeholders from all the Provinces agreed that shared confidentiality towards relevant people, e.g. spouses and close relatives, ought to be encouraged. However, that should not mean that the public is entitled to such knowledge unless the patient wishes it to be so. This does away with the stigma and the discrimination that usually emanate from disclosure.

In the case of marital arrangements, the various stakeholders stressed that it was important that intending spouses be encouraged to take voluntary testing upon counselling. In the final analysis, it is the view of the Task Force that the denial of a person's right to marry and found a family on the basis of HIV and AIDS status, or for refusing to be tested for such a condition, is inimical to the rights-based approach for managing the pandemic. Pre-marital testing should not be used as a basis for prohibiting couples from being married but rather to empower them to make informed choices about their future. Some faith-based organisations, however, insisted on pre-marital testing after which a decision would be made whether or not to solemnize the relationship, depending on the test results. This view was criticized by many who felt that it amounts to an intrusion into the privacy of those affected. One cleric opposed the practice, admitting that when they attempted to enforce it, they went through long "*dry spells*" without conducting any marriage ceremony. The other view expressed was that the role of pre-marital testing should not be to prohibit couples from getting married, but to empower them to make informed choices. In the case of couples already married, it was felt that the law ought to compel disclosure but that couples should be encouraged to bear the responsibility for informing their partners.

Mandatory testing is generally reprehensible and ought not be encouraged, as it was felt to be an infringement on human rights. However, situations may arise in which exceptions may need to be made, e.g., during emergencies where the patient cannot make a decision; before blood donation, or donation of body organs; or as a

legal requirement, e.g., by virtue of a court order. A large majority of prisoners interviewed were of the view that all prisoners should be mandatorily tested.

Whereas mandatory testing is not acceptable, with regard to the insurance sector, one has to consider the competing interests of companies to get returns on their businesses. Stakeholders from the insurance sector confirmed that the high mortality rate associated with AIDS led to its being classified as an exclusion, since medical cover for clients with HIV and AIDS is not economically viable; hence the insistence on testing. However, testing for HIV and AIDS in the course of insurance must take issues of privacy and confidentiality of clients into consideration. Disclosure of the HIV status of a client to the insurance company without the consent or knowledge of the client and without pre-and post-test counselling is objectionable on moral and ethical grounds. As regards denial of benefits in cases of death resulting from AIDS, members of the public felt that this was not justifiable especially when it was a condition subsequent to the contract of insurance. It was also suggested that the government should come up with specific programmes of insurance for persons with HIV and AIDS. A comparative overview of the Canadian approach disclosed that any pre-insurance testing must adhere to the general principles of confidentiality and privacy.

The subjection of persons to testing prior to employment or in the course of employment is generally reprehensible and should not be condoned. Indeed, pre-employment testing is unnecessary and irrelevant in light of measures that need to be taken to control the pandemic. At the global level, the International Labour Organisation, in conjunction with the World Health Organisation, have devised guidelines that disapprove pre-employment testing as being unnecessary. This is justified by the fact that people with HIV and AIDS pose no risk to their colleagues at work. In South Africa, guidelines formulated by different stakeholders such as the AIDS Law Project, in conjunction with the AIDS Consortium on Employment Code of Conduct, recommend against generalized HIV testing. The case law available on this subject indicates that the HIV sero-status is not of itself a *bona-fide* ground of disqualification from employment.

The South Africa Chamber of Business and Employment's Code of Conduct for Employers recommends screening for life-threatening conditions and fitness for work, but proscribes discrimination grounded on an applicant's sero-status. The South African Society for Occupational Medicine's Guidelines on AIDS at the workplace do not recommend pre-employment HIV and AIDS examination. Members of the public disapproved pre-employment testing, especially when used to discriminate against a prospective employee. Testing in the course of employment, with a view to discriminating against those found to be HIV-positive, was also **deprecated**. Some members of the public seemed to support non-

consensual testing and publication of results. However, this is felt to be contrary to the rights-based approach in the fight against HIV and AIDS. As regards prisons, it was suggested by the prisoners themselves that they be subjected to testing prior to and after incarceration. The general principles of privacy and confidentiality must be adhered to and tests should not to be done for discriminatory purposes. With respect to commercial sex workers, it was felt that since it was something in which they could exercise a choice, testing must be insisted upon, but the basic safeguards of consent, privacy and confidentiality must be adhered to. This suggestion is challenged by the fact that commercial sex work is an illegal trade in Kenya. The alternative view was expressed that the practice be legalised if only for purposes of regulation.

## **Recommendations**

### **Testing for HIV**

- (i) Except as may be provided under this Act, mandatory testing for HIV is unlawful.
- (ii) Testing for HIV may be conducted only with the specific, prior and informed consent of the person tested.
- (iii) Every person or organization that undertakes HIV testing must:
  - (a) have a qualified counsellor recognized as such by the Ministry of Health or by such other body as may be nominated by the Ministry of Health;
  - (b) afford the person being tested counselling, both prior and subsequent to the test;
  - (c) communicate with the person being tested in a language best understood by him/her;
  - (d) seek and obtain consent through individual interview, except in the case of minors, mentally deficient persons or persons otherwise incapacitated, where parents, guardians or the next of kin may give such consent;
  - (e) explain to the person being tested the details and procedures involved before the test is conducted;

- (f) carefully and strictly follow the methods and procedures approved and expected of him/her under rules of medical practice and ethics.
- (iv) Testing without express consent may be permitted in the following instances:
  - (a) where a patient is without the ability to consent within the period available, and it is in the patient's health interest to determine his/her HIV status;
  - (b) where the person being tested has been convicted of a sexual offence.

### **Indirect Testing**

- (i) The requirement of specific informed consent may not apply to donors of blood, semen or body parts.
- (ii) Every blood, semen or body part sample donated shall be tested for the HIV virus before the transfusion, transplantation or use.
- (iii) In all cases of donation of blood, semen or other body parts, prospective donors shall be informed before the performance of the procedure that an HIV test will be conducted, and given adequate information about the nature and purpose of the test.
- (iv) In such instances as mentioned in (iii) above, the prospective donors may elect whether they wish to know the results of such tests, and through whom, should they choose to know.
- (v) Anonymous and unlinked tests for HIV of blood donations, populations or groups, for purposes of blood safety, epidemiology or surveillance will not constitute a breach of rights. Every epidemiological and surveillance testing shall be sanctioned by a recognized ethical review committee.

### **Pre-Marital Testing**

Testing for HIV as a pre-condition to the celebration of marriage is unlawful.

## **Pre-Natal Testing and Testing of Newborns**

- (i) All individuals or health institutions, which offer HIV testing to pregnant women and girls, shall routinely counsel them about the advantages and benefits of HIV testing.
- (ii) In every instance, pregnant women and girls may only be tested with their consent.
- (iii) Every person conducting pre-natal testing on the mother, or a post-natal testing to the new born shall fill a Testing Requisition form declaring that counselling was provided and informed consent sought and obtained in a language best understood by the pregnant woman or girl. In such instance, the woman or girl so tested shall affix her signature or thumb print to the form.
- (iv) Girls and young persons between the age of 13 and 18 years and who are pregnant, married, are parents, or are otherwise engaged in behaviour that puts them at risk may consent for testing directly. It shall be the responsibility of the person testing to make an independent assessment of the person's maturity.
- (v) Testing of girls and young persons under the age of 13 years, or between 13 and 18 years who do not fall under (iv) above, shall be done with the knowledge and participation of their parents or guardians.
- (vi) Newborn babies may be tested for the HIV virus with the consent of their parents, guardian or other persons standing in *loco parentis*.

## **Pre-Insurance Testing**

Every HIV test conducted for purposes of insurance must only be conducted with the prior and informed consent of the proposer.

## **Testing in Special Situations**

- (i) Except voluntarily, with his or her free and informed consent, no suspect, remandee or prisoner may be subjected to the HIV test.
- (ii) No person shall be subjected to a mandatory HIV test as a precondition to travel outside the country or re-entry.

## Policy Recommendations

- (i) HIV testing must be carried out with the specific, prior and informed consent of those being tested, with pre-counselling and post-counselling, and with the guarantee of confidentiality.
- (ii) Counselling should be culturally and appropriate, sensitive to issues of sexual identity and orientation, and ought to be conducted in a language best understood by the person(s) counselled.
- (iii) Recognizing the fundamental ethical and legal principle of autonomy as the basis of the doctrine of informed consent, every human person has the right to determine what should happen to, or to be done with, his/her body in accordance with his/her chosen values and priorities, even in poor physical health.
- (iv) The doctrine of prior and informed consent both in the conduct of research and vaccine trials, and in the care and treatment of PLWHAS is to be observed, with the result that every individual acquires the right of election whether to decline the test or participate in research.
- (v) Mandatory pre-marital testing infringes the rights of the parties to marry and found a family.
- (vi) Mandatory pre-marital testing also constitutes discrimination and an affront to the parties' freedom of association.
- (vii) To ensure that informed consent is provided and counselling preferred, Pre-Natal Testing Requisition Forms should require the doctor/medical attendant to declare that counselling was provided and informed consent sought and obtained in a language best understood known by the person, and that she understood or appeared to understand.
- (viii) Routine and compulsory testing of newborns is improper and unlawful. Pregnant women and girls who freely undertake the HIV test and test positive should be encouraged to take treatment that will benefit them and reduce the risk of transmission to their infants.
- (ix) As far as possible, every pregnant woman tested shall be asked to bring their spouse for voluntary counselling and testing.

- (x) Pre-travel mandatory testing would offend International, Bi-lateral and National legal instruments enabling the free movement of persons otherwise possessed of the basic travel documents. Such testing is ineffective in controlling incidences of HIV and AIDS.
- (xi) Every person has the right to work and to just and favourable conditions of employment. The right to work entails the right to access employment without discrimination except the necessary occupational qualifications and abilities. This right accrues to people with HIV and AIDS, like every other citizen.
- (xii) Mandatory pre-employment testing is discriminatory, stigmatizes prospective employees and violates their human rights by excluding them from productive employment for reason only of their health status. This constitutes unfair discrimination and offends the International Labour Organisation Conventions.
- (xiii) A prospective employee is under no moral or legal obligation to inform the employer of his/her serostatus, except in very rare and exceptional circumstances where the nature of the engagement might expose co-workers and customers to a demonstrable risk of infection.
- (xiv) Mandatory Pre-employment testing for HIV is unimportant and improper to the extent that the person's productivity does not necessarily depend on his/her sero-status.
- (xv) Prospective employees should be given the normal medical tests of current fitness for work in terms of the national legislation and normal employment contracts.
- (xvi) Information regarding the sero-status of an employee such as might come into the employer's hand must not be disclosed without the employee's express consent.
- (xvii) No employee shall be dismissed merely on the basis of his/her sero-status, nor shall HIV and AIDS influence retrenchment procedures. In this respect, due regard would be had only to individual productivity and continued capability to do the job.
- (xviii) In every instance of termination, the employer will use the "Work Ability Index" to determine the person's ability. This shall be established on the

basis of the ability of the employee to perform in employment before the Employment Equity Tribunal.

- (xix) Every medical personnel conducting tests for HIV and AIDS is required to keenly follow the procedures and employ methods approved and expected of him/her by medical practice and ethics. Negligent and reckless conduct of a test, resulting in misdiagnosis, should invite legal actions for damages against the persons and the institution under which he/she operated.
- (xx) Subjection of international travellers and immigrants to mandatory testing, and insistence on AIDS Free Certificates as a pre-condition for entry, is irrational and offends basic norms of International human rights law.
- (xxi) Testing of returnees for HIV and AIDS offends their constitutional right to privacy and freedom of movement. Such actions serve no useful purpose in controlling HIV and AIDS.

#### **Privacy and Confidentiality: Recommendations**

- (i) Save as may be prescribed under legislation, the right to privacy and confidentiality of people living with HIV and AIDS shall be observed.
- (ii) Health-care providers and other institutions, which handle HIV and AIDS-related data, will ensure the information is kept in the greatest confidence.

#### **Doctor-Patient Confidentiality**

- (i) Health-care providers and medical institutions should not disclose the HIV status of patients to any other person except with the express consent of the patient.
  - (a) provided however that if a health care provider attending to a person living with HIV and AIDS reasonably believes he/she has failed to disclose his/her status voluntarily to other people at risk of infection from him/her and continues to expose them to the risk of infection, and;

- (b) a reasonable period has elapsed since the date when the person living with HIV and AIDS was so requested to share the information;
- (ii) The health care provider may be exempt from the duty of confidentiality and be allowed to disclose the information to such persons at risk as may be known to the health care provider or such of them as may seek information.
- (iii) The term "health-care provider" shall mean medical practitioners, dentists, pharmacists, laboratory technicians, nurses, clinical officers and counsellors who come by such information and who are otherwise bound by the legal duty of confidentiality.
- (iv) For minors and patients in an advanced stage of AIDS infection, a health care provider may inform the closest or most appropriate family member.
- (v) Information requested by a patient about his/her HIV status should not be withheld, provided that provision of the information is attended with counselling and confidentiality is observed.
- (vi) In exceptional circumstances, the duty of confidence may be waived in the interest of Public Health and public safety.

### **Privacy and Confidentiality at the Work Place**

- (i) Except as may be permitted by law, no employer may subject prospective employees to mandatory testing for HIV and AIDS or to disclosure of the results as a pre-condition to employment.

This provision shall apply with equal force to protect employers from disclosure of their status to employees.

- (ii) Information regarding the sero-status of an employee such as might come into the employer's hands, should not be disclosed without the express consent of the employee.

### **Privacy and Confidentiality in Prisons**

- (i) Test results should be communicated to prisoners as they request by health care providers who shall observe confidentiality.

- (ii) Information on health status and medical treatment of prisoners is confidential and shall only be available to health care providers who may release this information at the prisoner's request, or where authorized by law.
- (iii) Information regarding prisoners' HIV status may only be disclosed to the Prison Superintendent or if the health care provider considers, with due regard to medical ethics, that this is warranted to ensure the safety and well-being of prisoners and staff, applying the general principles on disclosure such as apply to the free community.

### **Confidentiality and Insurance**

- (i) Subject to such other provisions as may be prescribed under this Act, any doctor or other health care provider who conducts an HIV test for purposes of insurance will respect and uphold, to the fullest extent possible, the patient's right to privacy and confidentiality.
- (ii) In every instance where the information is requested by any insurance company or other entity for purposes of insurance, the doctor or other health care provider will cause the patient to authorize this disclosure by signing a disclosure authorisation form before the test is conducted.
- (iii) In every instance where disclosure is so authorized, the information will only be released to a health care provider in the employ of the entity or insurance company seeking the information.

### **Privacy, Confidentiality and Disclosure of Cause of Death**

- (i) In case of death occurring in Kenya of any person who has been attended during his last illness by a medical practitioner, that practitioner shall sign a certificate stating to the best of his knowledge and belief the cause of death.
- (ii) In every instance where the death is caused by an AIDS-related illness or condition, the medical practitioner shall, in addition to indicating the cause of death also disclose that the same was AIDS-related.

## **Notification of HIV Diagnosis**

It is necessary to adopt the provisions of the **Public Health Act (Cap 242)** regarding notification, with strict observance of confidentiality of the person.

## **Privacy and Confidentiality in Specific Contexts**

- (i) It shall not be lawful for any educational institution to undertake or insist on disclosure or ascertainment of sero-status as a pre-condition to admission.
- (ii) It shall not be lawful for any bank, building society or other financial establishment to require a disclosure of a person's HIV status as a pre-qualification for mortgages, advances, loans or other financial accommodation.
- (iii) It shall not be lawful to require refugees, returnees or asylum seekers to demonstrate their sero-status, as a pre-condition to admission into Kenya.

## **Constitutional Protection of the Right to Privacy and Confidentiality**

The phrase "health status" should be added to S.70 and 82 of the Constitution, so that no person may be discriminated against on grounds only that he or she is HIV-positive or is living with AIDS.

## **Additional Policy Proposals**

- (i) Every medical practitioner or registrar issuing a certificate of death or permit for burial or interment shall encourage the person to whom the same is issued to share out the information.
- (ii) In all instances, steps shall be taken to encourage spouses and relations to disclose publicly every HIV and AIDS-related death.
- (iii) The right to privacy constitutes a restriction of others' right to personal information. Confidentiality restricts the further disclosure of that information once it has been given limited disclosure. Breach of privacy or confidentiality should be unlawful and actionable.
- (iv) In the context of HIV and AIDS, the right to privacy and confidentiality is comprised in the right of the individual to whom the AIDS-related

information relates, to determine when, to whom, and under what circumstances such information will be divulged.

- (v) Of fundamental necessity, a doctor should be required not to disclose such information regarding a patient as might come to his/her knowledge in the course of attendance upon the patient, to assure continued trust and openness for fuller medical assistance - this being the foundation of the Hippocratic Oath.
- (vi) People living with HIV and AIDS should be encouraged to share information about their sero-status with their sexual partners, and with those demonstrably at risk of infection by them.
- (vii) In exceptional circumstances, the duty of confidence may be waived in the public interest, if it can be demonstrated that a greater public good would be served by disclosure than by maintaining the confidence.
- (viii) Information on the health status and medical treatment of prisoners is confidential, and information that will assist in treatment and care of the prisoner may only be provided to the prison authorities with the prisoner's consent. No mark, label, stamp or other visible sign should be placed in the prisoner's file, cells or papers to indicate their HIV status.
- (ix) Prisoners who by reason of the nature of the charge, recidivism or other circumstances, must be imprisoned shall not be isolated, segregated or otherwise discriminated against unless they present actual danger threatening to put other inmates at risk of HIV infection. Their confidentiality shall be respected by the courts, health authorities and prison personnel, or any of them who may come to learn of their status.

## **3.2 HIV AND AIDS IN THE WORKPLACE**

### **Issues**

The question of HIV and AIDS at the workplace has always presented competing claims and rights. Other than the question of mandatory testing as a pre-condition to employment, the issue of disclosure of test results to the prospective employer simultaneously raises the question of privacy and confidentiality.

Does a prospective employer have any right to know the HIV status of a prospective employee? On the other hand, does the prospective employee have a right to know the HIV status of the prospective employer or senior managers? Are

there instances of employment where the status of an employee puts either co-workers or customers at risk of infection? Does productivity of an employee necessarily decline, for the fact only of being HIV positive? Would pre-employment HIV discrimination fall within the ambit of freedom of contract or would this be unacceptable discrimination within the letter or spirit of the Constitution and the universally accepted human rights instruments?

Other than the pre-employment stage, there is the question of screening and testing of employees after employment. Does this serve any purpose? Would this include stigma and discrimination in inter-personal relations between the employees themselves, and with customers? Should the HIV status of the employee be a factor in promotion and transfers? Should an employee be dismissed, retrenched or otherwise have their employment terminated on the ground only that they are HIV-positive? If the answer were in the negative, is there a stage after development of full-blown AIDS when an employer may legitimately terminate the employment relationship? What index is to be used by the employer in this situation?

Are there specialized considerations to be given to members of the Armed Forces, employees in the hotel industry, those in the medical and nursing profession or other specialized categories? Is prior or periodic testing in these cases allowable?

In the event of termination on grounds of one's HIV status, what practical remedies are available to an aggrieved party? Can the Courts order reinstatement or otherwise quash the decision? And how is this jurisdiction to be created and exercised in the event?

By the Legal Notice No. 3539 of 31<sup>st</sup> July 1987, the Minister for Health at the time declared that Acquired Immune Deficiency Syndrome(AIDS) is a notifiable infectious disease under the **Public Health Act (Cap 242)**. A number of employers have interpreted this gazette notice to describe AIDS as a communicable disease and by virtue of section 47 of the Public Health Act some have adopted a policy to test prospective employees and current employees, in the hotel industry, for HIV. Some of those who have tested HIV positive have as a result been bared or dismissed from employment. The Ministry of Health on the other hand indicates that the gazette notice No. 3539 of 31<sup>st</sup> July 1987 does not make AIDS a communicable Diseases and that the notification was for purposes of epidemiological and statistical purposes. The Federation of Kenya Employers contents that this gazette notice has caused confusion and some employers feel that it prohibits them from employing HIV positive people.

## **Views Received**

The Task Force, at its consultations with the public, received a number of views relating to legal and ethical issues on HIV and AIDS, as summarized below.

It was thought mandatory testing for HIV and AIDS was desirable to encourage responsible living and change of behavior. Those who are living with HIV and AIDS should be issued with identity cards. Mandatory testing should be carried out on the Disciplined Forces, hotel workers and commercial sex workers. Those admitted in hospitals should also be tested.

Many thought voluntary testing should be encouraged, but those under 18 years should not be tested. Voluntary pre-employment testing should be encouraged.

On breach of privacy, it was noted that the spouse and close family members should be informed of the sero-status of an employee who refuses to give this information, and AIDS-related deaths should be indicated in Death Certificates and Burial Permits. Chiefs should be empowered to declare the cause of death in public at the funeral. Law should be enacted to compel certain people to undergo HIV and AIDS tests. Disclosure of the HIV and AIDS test results should be made with the person's consent.

On employment, the sero-status of an individual should not be a pre-condition for employment except as regards certain types of jobs. Those persons who test positive should be employed on a short-term basis and only denied employment where a person is found to be wanting in terms of ability to perform the job. A law should be enacted to prohibit dismissal on grounds of sero-positivity. Health and safety considerations should be the only reasons for dismissal, but only where it is proved by medical evidence to be a threat or to be able to cause substantial harm in the work place. In this case, occupational hazards should be eliminated to avoid workplace infection.

The law should be used to stop discrimination against PLWHAS in the course of employment, by drafting a Kenyan code on HIV and AIDS in employment. Sero-positive staff should not be isolated, and where necessary they should be transferred and given light duties in the interest of their health. Promotions should be based on the employee's ability to perform, weighed on the same scale, to promote equality and remove discrimination.

The **Workman's Compensation Act (Cap 236)** should be amended to provide compensation for health workers who contract HIV and AIDS in the workplace.

Commercial sex workers should be empowered to enable them to get jobs. Commercial sex workers should be tested for HIV and AIDS and given certificates, and their trade should be legalized, regulated and allocated operating zones. On the other hand other members proposed that commercial sex work should not be legalized because if it is legalized, then the trade in drugs and other psychotropic substances might also claim the protection of the law.

Insurers should cover those with HIV and AIDS, and the National Social Security Fund should pay early retirement benefits to those living with HIV and AIDS without discrimination. Medical schemes should be put in place by the Government to help Kenyans deal with HIV and AIDS.

There is need to create a Special Court and Desks in every district to receive complaints of discrimination on the basis of sero-positivity. Remedies, including monetary penalties, should be set for discriminatory treatment. Legislation needs to be reviewed to give effect to International Conventions and International Labour Organisation standards on labour and HIV and AIDS.

The informal sector ought to be taken into account in discussions on HIV and AIDS in the workplace, and socio-economic causes and effects of HIV and AIDS should be broadly considered.

Employment policies and programmes should be designed and implemented to enhance the technological basis of productivity, as a short-to-medium-term coping mechanism. A new tax should be introduced to fund HIV and AIDS control and management.

Licensing regulations should be reviewed to deal with high-risk establishments such as bars in the residential estates, and the media encouraged not to promote immorality through sensationalised programmes and advertisements.

### **Comparative Analysis**

According to the Ministry of Health/National AIDS Control Council report on AIDS in Kenya, the socio-economic impact of HIV and AIDS has been felt in various sectors including the military, transport, agriculture, as well as the informal sectors. AIDS is shown as having caused a reduction in the size and experience of the labour force. In the case of companies, there is reduced productivity through AIDS-related deaths. Increased expenditure on staff recruitment and training, funeral expenses, medical costs and employee benefits have meant a reduced profitability in company production. The need to come up with specific policy and legal interventions in the labour sector cannot be gainsaid.

Most of the people consulted reiterated their opposition to pre-employment HIV testing. The general rule is that pre – employment testing is not necessary though it may be relevant in certain cases. As regards privacy and confidentiality at the workplace, though it is important to safeguard these two aspects, yet for the sake of containment and prevention measures, it may be necessary to disclose such information to those who “need to know”, e.g. spouses and sexual partners and, to some extent, close family members. Generally, employers were not considered as being in that category of those who need to know. In some cases, the employer may need to be informed for purposes of making the necessary accommodation at the workplace. Generally it was felt that disclosure of sero-status may eventually have an influence on the trends of infection and spread. It was suggested, however, that regard must be had to the discrimination that undue publicity may induce against the PLWHAS.

It was felt that, though an employer may, under certain circumstances, be entitled to require a pre-employment test for HIV and AIDS, yet such test should not be used to deny employment to the prospective employee, nor should it be a condition to a decision whether or not to employ a person. It was felt that employment decisions ought to be based on a person’s fitness to do a job rather than their HIV status. Further, dismissal on the grounds of sero-positivity was said to be not justifiable. Dismissal can only be based on health and safety considerations, which should be shown by medical evidence indicating that a person poses a direct threat and can cause substantial harm in the workplace. This evidence would need to be presented to the Employment Equity Tribunal.

Stigmatisation and discrimination by clients, workmates and management on the basis of one’s sero-status was felt to be a reprehensible act, which should not be encouraged. Such discrimination was said to be not compatible with containment and management strategies and ultimately, was detrimental to the interests of the person being discriminated against.

However, the stakeholders conceded that mandatory pre-employment testing may be required in the case of specialised employment situations where the inherent nature of the work in question required that an employee be in a particular state of health, e.g. the disciplined forces or some health-care providers. The notion that workers in the hotel industry, and handling food may need to be tested is not justified since they do not pose a danger of infecting anyone through the handling of food. The Legal Notice of 1990 making AIDS a notifiable disease should be repealed.

For purposes of enforcement, it was noted that the civil court system may not be conducive to the needs of people living with HIV and AIDS, since it encourages publicity that may generate stigma and hostility against them. The creation of a tribunal to deal with discrimination in the employment sector was recommended. In the alternative, it was felt that the Industrial Court could be adapted to fit such a role.

Stakeholders also felt that the informal labour sector needs to be considered in any discussions on HIV and AIDS. People working in the informal sector also have a right to information regarding appropriate measures of prevention and care.

Reference was made to the United Nations Commission on Human Rights - promulgated International Guidelines on HIV and AIDS and Human Rights (1996), which adopted the approach that an effective response to HIV and AIDS must involve the protection of human rights. Stakeholders also noted that public health goals and human rights norms touching on HIV and AIDS are compatible and both can be achieved alongside each other.

As regards public health law, certain elements of the guidelines were deemed to be relevant in relation to labour and HIV and AIDS. These include:

- (i) The requirement for informed consent prior to testing. Exceptions would require specific judicial authorisation given after evaluation of the considerations involved such as privacy and liberty.
- (ii) Proper Counselling should be ensured both prior to and subsequent to testing.
- (iii) Prohibition of isolation and quarantine on the basis of HIV status.
- (iv) Protection of HIV-related information from unauthorised collection, use or disclosure in health care and other settings, and requirement for informed consent for such use.
- (v) Laws should authorise but not require that health-care professionals decide on the basis of each individual case, and of ethical considerations, whether to inform their patients' sexual partners or spouses, of the HIV status of their partner.

As regards HIV and AIDS and discrimination, guideline 5 on anti-discrimination and protective laws calls on states to:

“Enact or strengthen antidiscrimination and other protective laws that protect vulnerable groups, people living with HIV and AIDS and people with disabilities from discrimination in both the public and private sectors, that will ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation and provide for speedy and effective administrative remedies.”

The Guidelines also recommend the following anti-discrimination measures:

- (i) Enactment of disability laws to include HIV and AIDS, prohibiting discrimination in social security, welfare benefits, employment etc.
- (ii) Enactment of laws to proscribe indirect discrimination, e.g., where HIV and or AIDS is only one of the reasons for a discriminatory act.
- (iii) Establishment of procedures for redress, which are speedy and independent.

As regards privacy and confidentiality the guidelines provide as follows:

- (i) Laws should be enacted to regulate the use and publication of personal data.
- (ii) Individuals should be able to have access to and control of the use of data relating to themselves.

As regards the workplace, the guidelines require that laws, regulations and collective agreements should be enacted to guarantee the following rights:

- (i) Freedom from HIV screening for employment, promotion, training and benefits;
- (ii) Confidentiality regarding all medical information including HIV status;
- (iii) Employment and early retirement for workers living with HIV and AIDS until they are no longer able to work, including reasonable alternative management;
- (iv) Defined safe practices for first aid and adequately equipped first aid kits;

- (v) Protection of social security and other benefits for workers living with HIV and AIDS, including life insurance, pension, health insurance, termination and death benefits;
- (vi) Adequate information on preventive measures and facilities including supply of condoms free to workers at the workplace;
- (vii) Adequate health care in or near the workplace;
- (viii) Workers' participation in decision making in workplace issues related to HIV and AIDS;
- (ix) Access to information and education programmes, Counselling and referral
- (x) Protection from stigmatisation and discrimination by colleagues, union, employers and clients;
- (xi) Appropriate inclusion in workers' compensation legislation of the occupational transmission of HIV testing Counselling and confidentiality;

On the other hand, the United Nations has set out a **United Nations HIV and AIDS Personnel Policy** (1993), which has provisions that seek to regulate HIV and AIDS issues with regard to UN employees. Though restricted as such, useful lessons can be drawn from it. Employers in Kenya can come up with their policy statements and codes to contribute to the prevention and control of HIV and AIDS among their staff. Critical aspects of the UN policy document are:

A requirement for the provision to UN Staff and their families, of sufficient updated information to protect them from infection and enable them to cope with incidences of HIV and AIDS. To this end all UN bodies are encouraged to develop and implement an active staff education strategy for HIV.

Assurance of voluntary testing with pre- and post-counselling, with attendant confidentiality to UN staff and their families.

As regards terms of appointment, the following guidelines are pertinent:

- (i) The only medical criterion for recruitment is fitness to work;
- (ii) HIV infection does not, in itself, constitute a lack of fitness to work;

- (iii) HIV screening of candidates for recruitment shall not be performed;
- (iv) AIDS will be treated as any other medical condition in considering medical classification;
- (v) HIV testing with the specific and informed consent of the candidate may be required if AIDS is clinically suspected;
- (vi) Nothing in the pre-employment examination should be considered as obliging any candidate to declare his status;
- (vii) HIV infection or AIDS should not of itself be considered as a basis for termination of employment;
- (viii) If fitness to work is impaired by HIV-related illness, reasonable alternative work arrangements should be made;
- (ix) UN staff members with AIDS should enjoy health and social protection in the same manner as other serious illness;
- (x) HIV and AIDS screening, whether direct (HIV testing) or indirect (assessment of risky behaviour or asking questions) should not be required;
- (xi) Confidentiality regarding all medical information including HIV and AIDS status must be maintained;
- (xii) There should be no obligation on the part of the employee to inform the employer of his/her HIV and AIDS status.
- (xiii) Persons in the workplace affected by or perceived to be affected by HIV and AIDS must be protected from stigmatization and discrimination by co-workers, unions, employers or clients.
- (xiv) Employees living with HIV and those with AIDS should not be discriminated against, with regard to access to statutory social programmes and occupationally related schemes;
- (xv) Health insurance coverage should be made available for UN employees regardless of HIV and AIDS status and the premiums payable by them should not be affected by such status.

There are various instruments promulgated under the auspices of the International Labour Organisation and which are of relevance to the protection of the rights of employees with HIV and AIDS.

The **Discrimination (Employment and Occupation) Convention**, 1958 (No.111) bans any distinction, exclusion or preference which has the effect of nullifying or impairing equality or opportunity or treatment in access to training, access to jobs, promotion processes, security of tenure, remuneration, conditions of work including leave, rest periods, occupational safety and health measures and Social Security benefits.

The convention lists seven situations of prohibited discrimination, and allows states to stipulate additional checks. The Committee of Experts on the Application of Convention No. 111 has made recommendations suggesting that an Additional Protocol to Convention No. 111, be promulgated to include discrimination on grounds of disability, which should cover HIV and AIDS as well.

The **Termination of Employment Convention**, 1982 (No.158) sets out the position as regards dismissals. Article 4 specifies that termination can only occur when there is a valid reason connected with the capacity or conduct of the worker, or based on the operational requirements of the undertaking, establishment or service. Article 6 provides that temporary absence from work owing to sickness or injury – whether occupationally related or not – is not a valid reason for dismissal. Both these provisions are relevant to HIV infection and affliction with AIDS. The 1995 General Survey of the Committee of Experts on Convention (No.158) expands on how law and practice treat temporary absences due to illness, and extends the anti-dismissal protection of the Convention to cases of HIV and AIDS.

The **Vocational Rehabilitation and Employment (Disabled Persons) Convention**, 1933 (No.159) bans discrimination based on disability. Article 4 seeks to promote special protective measures, such as workplace accommodation and transfers, to enable people with disability to continue earning a living until such time as their disability affects their capacity to perform a particular kind of work. The text has clear relevance for HIV and AIDS in the workplace.

The **Right to Organise and Collective Bargaining Convention**, 1949 (No.98) and the **Promotion of Collective Bargaining Convention**, 1981 (No. 154), which establish labour standards dealing with negotiations and collective bargaining, could be used to address HIV and AIDS in collective bargaining and labour relations pacts. These instruments require the promulgation of policies that encourage free negotiations, and this may include negotiations touching on HIV and AIDS.

The **Occupational Safety and Health Convention**, 1981 (No.155) sets out basic requirements to protect workers, such as the provision of protective clothing at no cost to the worker; the right to be transferred to less strenuous jobs; and the right to leave a situation of imminent danger to the worker - all these are relevant in the field of HIV and AIDS.

The **Occupational Health Services Convention**, 1985 (No. 161) requires ratifying states to adopt a comprehensive, co-ordinating national policy in the area of occupational health. Its accompanying Recommendation No. 171 lists a number of measures that would be of specific relevance in the HIV and AIDS context. These include an assurance that health surveillance is not used for discriminatory purposes; confidentiality of medical examination data; collaboration in finding alternative employment where transfer is required for health reasons; worker counselling on the results of health examination; and the principle of no-cost to the workers for the health-related facilities provided for such services. The recommendation favours members securing occupational health services for self-employed persons, such as informal sector workers.

The **Employment Injury Benefits Convention**, 1964 (No. 121) and the **Social Security (Minimum Standards) Convention**, 1952 (No. 102) are social security instruments that provide guidelines on HIV and AIDS issues with respect to benefit entitlements, for occupational injury and non-discrimination in coverage respectively.

Other ILO Conventions address specific groups of workers who by the nature of their work, are groups at risk of HIV infection. The **Nursing Personnel Recommendation**, 1977 (No. 157) required the provision of protective clothing, and temporary transfer away from jobs placing staff at risk. The **Migration for Employment Convention (Revised)**, 1949 (No. 97) and the **Migrant Workers (Supplementary Provisions) Convention**, 1975 (No. 143) address the inequalities that migrant workers face generally. The former's technical requirements such as medical testing to assess migrants and their family members' state of health, merit attention from the point of view of HIV and AIDS.

The 1994 **Maritime Conference Resolution** specifically refers to the need to include information on prevention of HIV infection in the medical examination of seafarers.

There are other non-binding ILO and UN instruments that seek to provide specific guidelines in relation to HIV and AIDS in the workplace. In 1988, the ILO and the WHO co-signed the **Statement from the Consultation on AIDS and the**

**Workplace**, which sets out policy components for persons applying for employment and persons in employment. There is prohibition of screening, assurance on confidentiality of all medical data, non-discrimination, access to services and benefits, reasonable changes in working arrangements when fitness for work is impaired and a ban on termination of service on account of HIV infection. In 1996 ILO, member states adopted a Code of Practice on The Protection of Workers' privacy, which declares that personal medical data should not be collected except in conformity with national legislation, medical confidentiality and the general principles of occupational safety and health and only as needed.

It was suggested that labour laws should be reviewed to give effect to international conventions and ILO standards on labour and HIV and AIDS.

The comparative jurisprudence shows that a number of countries are increasingly adopting legislation that specifically covers HIV and AIDS issues with regard to labour relations.

### **Zimbabwe**

The **Labour Relations (HIV and AIDS) Regulations**, 1998, ban non-consensual testing, outlaws discrimination at the workplace, requires wide dissemination of the Regulations and provide penal sanctions for violations.

A **National AIDS Council of Zimbabwe Bill** was gazetted in October, 1999 with the aim of establishing a national co-ordinating body, which incorporates representatives of trade union and industry and commerce.

### **South Africa**

The **Employment Equity Act**, 1998 prohibits discrimination based on HIV status and bans pre-employment testing. However, an employer is allowed to file a request for pre- or post-employment testing, in which case the burden lies on such employer to demonstrate that such testing would be necessary.

The **South African Development Community (SADC) Code on HIV and AIDS and Employment** also states that there should be no direct or indirect pre-employment testing for HIV and requires member states to adopt national legislation to give effect to the code.

The **Draft Business South Africa National HIV and AIDS Employment Code of Conduct** recommends against pre-employment testing.

The **South African Chamber of Business's HIV and AIDS and Employment Code of Conduct for Employers**, states that HIV status alone should not be a motivation to exclude recruits.

### **The Philippines**

The **AIDS Prevention and Control Act (No. 8504)** declares that the state shall extend to every person suspected or known to be living with HIV and AIDS full protection of his/her human rights and civil liberties. It bans compulsory testing and declares HIV-related discrimination "in all its forms and subtleties" to be inimical to individual and national interest. Termination of employment on the sole basis of actual or perceived HIV status is unlawful.

The Act provides for the creation of modalities for training for livelihood and self-help co-operative programmes for PLWHAS, to enable them to continue to contribute to their economic upkeep.

It requires written informed consent for testing, and prohibits compulsory HIV testing in cases of employment.

It guarantees the right to confidentiality, subject to exceptions enumerated.

It prohibits discrimination on the basis of actual, perceived or suspected HIV status in the areas of employment, schooling, health and social services.

### **United States of America**

The **Americans With Disabilities Act, 1990** has been interpreted to extend protection to people with HIV and AIDS by deeming HIV and AIDS a disability. People with HIV and AIDS have to be recognised as otherwise qualified, i.e. capable of fulfilling the essential requirements of their work with or without accommodation at the workplace. The Act obliges employers, within the scope of their financial capacities, to make reasonable accommodation and adjustment at the workplace for an employee who has HIV or AIDS. These would, for example, include job restructuring, reassignment, adjustment of equipment and devices, modification of examinations and training modules, flexible working hours and additional sick leave. Complaints of violations are heard by the Equal Employment Opportunities Commission.

The **Rehabilitation Act** of 1973 (29 U.S.C 793 – 794) prohibits discrimination based on disability in the areas of employment and the provision of services or benefits by any programme or activity of an entity receiving federal financial

assistance (section 504). This section provides in part that no "otherwise qualified" handicapped individual shall be excluded from participation in or be denied the benefits of any such programme or activity. This section has been interpreted to include HIV and AIDS as handicaps, for the purpose of protection under this statute.

The **Family Medical Leave Act** guarantees eligible employees the right to take unpaid leave from a job for family or medical reasons. It requires covered employees to provide eligible employees with unpaid leave of up to 12 weeks in any 12 months period, for a variety of health-related reasons, including the birth or adoption of a child or the care of a child, spouse or parent of the employee with a serious health condition or because of a serious health condition of the employee which prevents the employee from performing the functions of his or her position.

The **Employee Retirement Income Security Act** (29 U.S.C 510) prohibits an employer from taking action against an employee, which is designed to deprive him/her of benefit under plans protected by the Act.

The **Ticket to Work and Work Incentives Improvements Act** of 1999 is intended to provide social security to recipients who want to return to work while guaranteeing continued access to rehabilitation services and public health care benefits.

## **Recommendations**

The basic principles that would need to be embraced by proposed legislation are as follows:

- (i) Every person has the right to work, and to just and favourable conditions of employment.
- (ii) Mandatory pre-employment testing is a violation of the right to work and hence unlawful; it is irrational and ineffectual in containment and prevention measures directed at HIV and AIDS.
- (iii) No moral or legal obligation attaches to a prospective employee to disclose his or her health status or medical condition to an employer.
- (iv) Similarly, an employer has no moral or legal right to require an employee to disclose his or her health status or medical condition.

- (v) An employer who claims such a legal right is under duty to prove that it exists and to establish it under law. He may do so by showing that the inherent requirements of the particular work demand that a person be in a particular state of health or medical or clinical condition.
- (vi) Where an employer establishes as a fact that the inherent qualities of the relevant work require that the employee should be in a particular state of health or medical or clinical condition, he or she may be authorised to conduct a test or to direct that a test be conducted for HIV or any other medical condition.
- (vii) It is proposed that an Employment Equity Tribunal be set up to deal with issues arising from disputes involving employees' right to work and propriety of dismissals and terminations.
- (viii) Such authorisation may be granted by the Employment Equity Tribunal upon terms and conditions including conditions relating to:
  - (a) provision of counselling
  - (b) maintenance of confidentiality
  - (c) period during which authorisation applies
  - (d) category or categories of jobs or employees in respect of which the authorisation applies
- (ix) Every aggrieved person may seek redress in the Employment Equity Tribunal on:
  - (a) The Jurisdiction of the Tribunal
  - (b) Propriety of Pre-employment Testing
  - (c) Questions of ability to continue in employment (to be determined using the Work Ability Index)
  - (d) Appropriate remedy including compensation or reinstatement to employment.
- (x) The Employment Equity Tribunal as established or authorised should have the power to punish violations of the provisions.
- (xi) Post-employment testing is equally unlawful and ineffectual in the containment of HIV and AIDS.
- (xii) No employer shall accord negative exclusionary treatment to employees on the basis of their HIV status in terms of job status, promotion transfer,

work benefits, pension benefits, health insurance or other forms of Social Security.

- (xiii) Every employee has the right to the protection and safeguard of data and information relating to his or her HIV status and the right to decide and authorize the use and publication of such data.
- (xiv) The unauthorised or non-consensual use of information relating to a worker's HIV status should attract punitive sanctions.
- (xv) There is need for the ministry to officially state the proper interpretation of gazette notice No. 3539 of 31<sup>st</sup> July 1987. If necessary this notice should be repealed and replaced with a clearer one.

### **Policy Recommendations**

- (i) The Ministry of Labour should issue Guidelines on HIV and AIDS and the Workplace which would provide direction on testing, privacy, confidentiality, non-discrimination, fair labour practices, containment and management of HIV and AIDS at the workplace.
- (ii) Disclosure of medical data and information relating to an employee as between Health Care Provider and the employers can only be done upon the written and informed consent of an employee.
- (iii) An employee should freely access information relating to his/her HIV status.
- (iv) Employers should maintain a work atmosphere that is conducive to all workers including those living with HIV and AIDS. Generally employers should provide safe working conditions inclusive of protective clothing and on serve universal protective measures that would minimise the risk of transmission at the workplace.
- (v) There should be an obligation on the part of employers to provide HIV and AIDS awareness and education to employees.
- (vi) Employers should provide information and promote practices that are aimed at stemming the spread of HIV and AIDS.

- (vii) Employers should have sufficient scope for work adjustment, and accommodation in the case of employees living with HIV and AIDS, as would be necessary and practicable in any given instance.
- (viii) Employers should take measures to eliminate discrimination against employees known or suspected to be living with HIV and AIDS.
- (ix) The Government should consider introducing tax breaks for employers who implement measures aimed at assisting employees living with HIV and AIDS, or otherwise implement a special tax for assisting those affected and infected by HIV or AIDS.
- (x) That in instances of termination of employment on account of HIV and AIDS would be in regard to the work ability index of the employee.

### **3.3 HIV AND AIDS IN PRISONS, AND OTHER PLACES OF CONFINEMENT**

#### **Issues**

The high rate of prevalence and spread of the HIV virus in prisons has given rise to difficult questions, with proposals varying from radical to mild. What can the law do to check the high rates of HIV infection in Prisons?

Should testing of prisoners be mandatory or voluntary? How would this be done in light of the window period? Would testing serve any legitimate purpose? What measures are to be taken regarding those who test positive? Should they be released from Prisons or segregated? Is it possible to adopt policies for prisoners and other persons in confinement, which cannot work or are not adoptable for the free population?

Should we adopt a policy of segregation and isolation for inmates living with HIV or AIDS? Would such policy serve to reduce the rate of infection in Prisons? How would it be possible to implement such policy, in light of the high turnover in most Prisons? Is it possible to create facilities to give effect to such segregation?

Conjugal visitations have not usually been allowed in Kenyan prisons. Would these serve to reduce instances of sodomy in prisons? Are the prison facilities equipped to handle such an arrangement? Should a policy decision on the point depend on availability of funds?

Are there other practices in prisons, which put inmates at risk of infection? How is caning effected? What of shaving and handcuffing of two prisoners together, or with prisons officials?

Do the inmates get sufficient AIDS education and information? Should this be a right to be incorporated into a statute, or merely a privilege and a practice to be promoted by conscious but non-legislative policy?

How effective have Community Service Orders been in decongesting Prisons? Are these Orders a positive step to be encouraged in the war against HIV and AIDS in Prisons? And how is this to be done?

The question of the provision of condoms to inmates has raised much heat. Should prisoners be provided with condoms as a policy? How is this to be formally validated in light of the illegality of sodomy and such unnatural acts? Would provision of condoms bring a false sense of security? Or would it encourage instances of sodomy? Even if condoms were to be provided, how would their use be ensured, when most inmates interviewed themselves rejected these?

The position of refugees, asylum seekers, remandees and detainees calls for attention. Should refugees be tested as a pre-condition to admission to the refugee status? What policy is to be adopted for remandees, in light of their short duration of confinement? How is this to be addressed where male and female remandees, and sometimes also children of tender years are kept together?

### **Summary of Views and Analysis**

HIV prevalence in prisons has been thought to be much higher than in the general community. The risk and actual incidence is much greater because of the potentially unsafe behaviour occurring during sex between male inmates (consensual and coerced). Accordingly, any effort to control the HIV pandemic will not bear fruit if it does not also aim at controlling the spread of HIV and AIDS in Prisons, Detention Camps, Borstal Institutions and other places of confinement. Because of high turnover, there is the likelihood of prisoners returning to the community when already infected, hence posing a risk to the rest of the members of the community.

Most people, including prisoners who gave their views to the Task Force felt that there should be compulsory and mandatory testing of prisoners, but the purpose of the tests and consequences thereof varied. While the free population advocated testing with recommendations that even those who test positive to remain in prisons, perhaps even beyond their sentence period. The prisoners, on the other

hand, wished to be tested so that those who test positive may be segregated, or released to go home immediately. The prisoners also wished to be tested when leaving and their partners tested also. Many feared the prevalence of AIDS in the free world.

There was a sharp polarity of opinion on whether HIV-positive prisoners should be given a custodial sentence. The view was expressed that HIV-positive prisoners should be given non-custodial sentences, or better still, be discharged. Another view was that HIV status *per se* should not be a basis for granting a non-custodial sentence or unconditional discharge, as this would have the effect of creating an AIDS exception. The preferred view was that HIV-positive prisoners were criminals nonetheless, and any release or discharge should be based on legal principles and the general health (clinical) condition without reference to HIV status.

Many respondents seemed to support the isolation and segregation of HIV-positive prisoners. This approach would seem to be harsh and unduly punitive, and the Task Force adopted the view that segregation and isolation are measures that can only be taken when based on sound medical evidence and when a prisoner puts others at real risk of substantial harm.

It was felt that women prisoners have unique problems not shared by their male colleagues. Underlying the many problems that women encounter in prisons is the fact that they belong to a social group that has traditionally been marginalised on the basis of gender. Many HIV-positive women do not receive the diagnostic and treatment services that could benefit them as easily as do HIV-positive men. It was reported to the Task Force by women prisoners and the wardens that there is no contact between the female prisoners and their male counterparts or male prison warders.

It was established that various forms of sexual relationships especially male-to-male sexual relations are prevalent in the prisons set-up, whether they are consensual or not. The entire prison population including their handlers are no doubt affected. Other risk factors were thought to include shaving and caning.

It was established that most prison staff and inmates are not adequately educated on vital information on HIV and AIDS. Some prisoners, having been incarcerated long before public knowledge of the HIV pandemic, may not have any knowledge in that regard, as access to relevant reading materials, including newspapers is restricted.

Another recommendation popular amongst the respondents was the need to permit conjugal visitations in Prison. It was felt that the risky behaviour in prisons underscored the need for conjugal visits and that this may serve to reduce instances of homosexuality.

Although not core to the Task Forces work, there was universal hue and cry from inmates and even prisons officials, that the prisons food rations should be increased, having been last reviewed decades ago.

The Kenyan Ethical and Legal Issues Network on HIV and AIDS (KELIN) has developed guidelines of relevance on HIV and AIDS infection in prisons and other places of confinement. The following general principles are outlined:

- (i) Mandatory testing is prohibited at any stage of incarceration. Testing should at all times be consensual and based on a compelling need to avert significant harm to others.
- (ii) Sentencing of convicts should also take into account their health status.
- (iii) The human rights of prisoners should be respected and decisions on isolation and segregation should be based on the need to avert significant harm to others.
- (iv) Health care is a requisite in the prison set-up if the pandemic is to be addressed effectively.
- (v) Prison authorities have a responsibility to create a safe environment for all prisoners to minimise risk of transmission and eliminate those factors that encourage illicit sexual encounters.
- (vi) Prisoners who are living with HIV or AIDS should not be discriminated against and should be entitled to receive all amenities equally with other people.
- (vii) Confidentiality and privacy in respect of the health and medical status of prisoners must be maintained at all times.
- (viii) Prisoners are entitled to receive adequate and up-to-date health-care services.
- (ix) The special needs of women prisoners must be taken into account.

- (x) Special needs of juvenile prisoners must be taken into account.

The World Health Organisation has also devised guidelines on HIV and AIDS in Prison, the general import of which is similar to those outlined above.

The Probation of Offenders Act allows a Court to release an offender on probation when, in its opinion, and having regard to youth, character, antecedents, home surroundings, health or mental condition of the offender, or to the nature of the offence, or to any extenuating circumstances, it is so expedient. It appears, therefore, that a Court may take the HIV status of an offender into account at the time of sentencing.

The provisions of the Criminal Procedure Code relating to bond and bail are relevant in the circumstances of HIV and AIDS.

The **Prisons Act (Cap 90)** has provisions that are of direct relevance to HIV and AIDS in prison. The Act regulates the management of prisons and hence touches on all aspects of prisoners' lives, including health. It also regulates the dealings between staff and prisoners. It deals with hospitalisation of sick prisoners, release of prisoners on parole, corporal punishment and segregation of prisoners.

### **Recommendations**

- (i) The **Prisons Act (Cap 90)** should be amended to specifically outlaw searches and examinations of women prisoners by male prison staff.
- (ii) The Prisons Act (S.21) should also be amended to specifically prohibit sexual relationships with or between prisoners and to impose more severe penalties for prison staff found to be engaging in such a relationship.
- (iii) The Act (S.28) should be amended as follows:

The Act should specifically require that female officers employed in women's prisons be persons trained to deal with psychological, psychosocial and special medical problems associated with female inmates.

- (iv) The Act should impose a responsibility on prison authorities to provide the following facilities:
- (a) Family planning and counselling services oriented to the specialized needs of female prisoners.

- (b) Gynaecological consultations at regular intervals.
  - (c) Pre - and post – natal care for pregnant women prisoners
  - (d) Care of children born to HIV-infected mothers in prisons.
- (v) The Act (S.29) should be amended to impose a duty on the Prison authorities to provide prisoners in general with the following:
- (a) appropriate psycho-social treatment
  - (b) medical and counselling services to take care of the special needs of the asymptomatic HIV-infected prisoners.
  - (c) HIV and AIDS information and education for both the prisoners and the prison staff.
- (vi) Subsection (3) and (4) of Section 29 of the Act should be repealed.
- (vii) Section 39 of the Act should be amended to provide that the decision to hospitalise a prisoner with HIV or AIDS should be made on medical grounds by qualified health personnel and access to adequately equipped services should be availed.
- (viii) Section 55 of the Act should be, altered, to abolish corporal punishment generally, and especially for prisoners with HIV or AIDS.
- (ix) The Act or other legislation should be amended specifically/ outlaw isolation or segregation of prisoners with HIV or AIDS from the rest of the prison community except in the following cases:
- (a) Where the prisoner is suffering from an infectious or contagious disease that poses significant risks to other prisoners.
  - (b) Where such isolation or segregation is necessary to ensure better care and support for the prisoner himself/herself.
  - (c) Where the prisoner has exhibited excessive and unreasonable tendencies of physical assault or abuse of fellow prisoners as to put those others at risk.

- (x) Rule 49 of the Prisons Rules should be amended to impose an obligation on Prison authorities to make special and appropriate dietary provisions for prisoners with HIV or AIDS having regard to their specific health needs. It should also require the prison authorities to improve the quantity of food rations to prisoners in general.
- (xi) Rule 51 of the Prisons Rules should require that shaving be done only with sterilised equipment and that prisoners may be allowed to bring their own shaving equipment to be kept by the Prison Administration except when required by the prisoner.
- (xii) Rule 57 should allow prisoners with HIV or AIDS to be visited and attended to by their own special physicians.
- (xiii) All prisoners should be allowed conjugal visitation. The Commissioner of Prisons shall make rules governing this right, including restriction or how often, one may be visited per month, and restricting such relations between prisoners and prisons staff.
- (xiv) Rule 63 of the Prisons Rules should make provision for:
  - (a) Appropriate educational programme for prisoners and prison staff.
  - (b) Provision of relevant HIV and AIDS literature to both prisoners and prison staff.
- (xv) A new provision should be introduced in the Prisons Act to deal specifically with the housing conditions for both prisoners and the prison staff, with a view to improving them and to also make provisions regarding sanitary conditions in prisons.
- (xvi) Sections 36 and 37 of the Borstal Institutions Act should be amended in tandem with the proposed amendments to sections 55 and 56 of the Prisons Act. So too should the Borstal Institutions Rules.
- (xvii) Mandatory screening of prisoners should be specifically outlawed. Testing of prisoners for HIV shall be purely voluntary and only with their specific and informed consent, attended with pre and post-counselling.
- (xviii) Every prisoner who develops full-blown AIDS, and whose sentence is not one that arises from a capital offence, shall be considered for early release on compassionate grounds.

- (xix) In every **case** for consideration for early release, an assessment shall be forwarded to the Commissioner of Prisons who, with the assistance of a Board, shall make a decision expeditiously, and in any event, within thirty days.
- (xx) Every prisoner with HIV who develops AIDS, as ascertained by a qualified doctor, and who, for any reason, is not available for early release, shall be exempt from hard labour.

### **Policy Recommendations**

- (i) Methods used in combating HIV and AIDS in prisons should be similar to those applied to the free population.
- (ii) In order to decongest prisons and other correctional facilities, Courts should apply the Community Service Orders especially when dealing with petty crimes, and avoid custodial sentences unless it is extremely necessary.
- (iii) The condom policy applied to the general population should be extended to prisons and other correctional institutions.
- (iv) Preventive measures for HIV and AIDS in prisons should be based on risky behaviour actually occurring in prisons.
- (v) Information and education should be provided to prisoners to promote achievable attitude and behaviour change, both within and outside prisons.
- (vi) The needs of prisoners and others in the prison environment should be taken into account, primary health-care services should be provided.
- (vii) Active involvement of prisoners and prison staff, and adoption of non-discriminatory and humane attitudes towards prisoners with HIV or AIDS, is necessary for the achievement of an HIV and AIDS prevention strategy in Prisons.
- (viii) Prison authorities have the responsibility to implement policies and practices that create a safer environment for prisoners and prison staff, so as to reduce the risk of HIV transmission.

- (ix) Prisoners may be incorporated in research activities relating to HIV and AIDS, but only with their specific and informed consent.
- (x) Prison authorities should provide proper sanitary conditions within the prison facilities.
- (xi) Prison authorities should employ sufficient personnel to ensure provision of adequate security for prisoners within the cells to avoid instance of sexual assault.
- (xii) An appropriate drug policy should be developed and applied uniformly both within and outside prisons.
- (xiii) Special attention should be given to the needs of women prisoners. Prison staff dealing with women in confinement should be trained to deal with psychosocial and medical problems associated with HIV infection in women and the proper provisions made for women with children.
- (xiv) Health education programmes adopted to the needs of juvenile prisoners should be organised to foster attitudes and behaviour change conducive to avoidance of HIV transmission.
- (xv) The peculiar needs of foreigners who become prisoners should be respected to avoid discrimination and trauma.
- (xvi) As far as possible prisoners with AIDS should be granted compassionate release, in order to facilitate contact with their families for home based care, and friends and to allow them to face death with dignity and in freedom.
- (xvii) The nutritional needs of prisoners must be addressed adequately and promptly.
- (xviii) The Chief Justice, in conjunction with the Commissioner of Prisons and the Attorney-General, should organize joint sensitization meetings for Judges, Magistrates, State Counsel and Prosecutors. These categories of personnel should also be encouraged to view the scales of justice more broadly, and in particular to accept greater use of Community Service Orders for certain classes of criminals.

### 3.4 HIV AND AIDS, AND THE CRIMINAL LAW

#### Issues

The role of criminal law in the fight against HIV and AIDS is one that has raised much controversy and led to varying proposals. The critical issue is what to do about persons living with the HIV virus and who, while being well aware of their status, intentionally, knowingly or recklessly put others at risk of infection. Those who may intentionally infect others, other than in the course of sexual contact have invited less controversy, but still left open the issue of the possible application of criminal sanctions.

Proponents against resort to criminal law have argued that it would amount to a criminalisation of the virus, and would also entail serious difficulties of proof.

Discussions on whether to invoke criminal law must be alive to the delicate nature of consensual sex. Should the husband or wife who transmits the virus in the course of normal marital relations be penalized? Is it the **fact of actual transmission**, or the mere fact of **non-disclosure** of one's status that should attract sanctions?

How should the law address instances of undue influence by female house helps and others, with young boys? How is the law to address commercial sex workers who despite knowing their status, continue to ply their trade?

Considerations of the HIV status of the accused by the Court, in granting bail or sentencing, also come to mind. Should the fact of the accused being a person living with HIV or AIDS predispose the court to grant bail? Should this fact incline the court to enhance sentence in offences of a sexual nature? Should there be a policy in favour of non-custodial sentences for persons living with HIV or AIDS? Most important, should such a policy be legislated, or left to the discretion of the Court.

Finally, if the possibility of applying the some criminal law were to be entertained, should it be left to the Courts to apply pre-existing common law and statutory offences? Or should new and special provisions be made to address the HIV and AIDS phenomenon? If the latter is preferred should such new provisions be inserted into the Penal Code, or the Public Health Act, or other penal legislation? Or should the penalties be applied in the context of a new Act specifically on HIV or AIDS? Should the offences be HIV-specific, or generic and equally applicable to other related afflictions.

## Summary of Views and Analysis

Apart from the public health measures designed to contain the rate of HIV infection, it is arguable that the coercive power of the law should be brought to bear on persons who deliberately cause the transmission of HIV to other persons. Criminal law being the regime of public law that is the monopoly of the state as public protector, has been pressed into service to discourage certain kinds of risky outrageous and despicable sexual behaviour.

The representations made to the Task Force throughout the consultations was that criminal sanctions be applied against those responsible for deliberate HIV infection. It has been recognised that Kenya's criminal law has at present no specific criminal provisions regarding HIV infection. Consequently, it was suggested that deterrent punishment be meted out against those who intentionally infect others with HIV. Extreme views were expressed which mostly called for capital punishment in cases of infection through rape; in the alternative, sanction by castration or at least some custodial sentence was proposed.

However, it was felt that such recommendations tended to be limited in perspective. They are overwhelmingly punitive and merely seek restraints on persons who have caused the HIV infection. They have a tendency to be reactive to the pandemic rather than proactive, on the scales of human behaviour in the social context. However, such calls have become so generalised that the government had embraced them in its policy framework e.g. Sessional Paper No. 4 of 1997 on AIDS in Kenya, in which the Ministry of Health commits itself to uphold criminal sanctions against those who deliberately infect others.

Whereas it is accepted that criminal law has a role to play in addressing the HIV and AIDS pandemic, reservations are expressed as to its appropriate mode of application due to a recognition of the fact that criminal sanctions may be inimical to the overall goal of containment of the spread of HIV and AIDS and preservation of human rights.

In terms of the **International Guidelines on HIV and AIDS**, states are called upon to ensure that their criminal laws and penal institutions are consistent with international human rights obligations, and that they are not misused in the context of HIV and AIDS, or targeted against vulnerable groups. Punishment under criminal or public health law is to be reserved for the most serious culpable behaviour. In that event, the general criminal or public health law should be applicable. There is need to guard against legislative preoccupation with HIV and AIDS, by dealing with criminal matters through the general law.

Therefore, it was felt that HIV and AIDS ought to be treated in a similar manner to other health conditions, and the existence of the pandemic should not be used as an occasion for violating the human rights of individuals, or to apply draconian penalties against individuals. Consequently, it may be argued that there is no justification for a special regime of penal law.

A well designed set of public health, education and awareness measures is the most effective way of addressing the HIV and AIDS scourge. Criminal law should only come in as an exception, and within the framework of the general laws to deal with particularly outrageous and unacceptable, intentional acts designed to cause infection.

### **Comparative Jurisprudence**

A study of the experience of the developed countries with HIV and AIDS Criminal law shows the following trends:

A reluctance to enact special criminal law provisions for HIV and AIDS as such. There is a preference for juristic principles from time-honoured rules of law to deal with the extraordinary situation of HIV and AIDS infection.

Adherence to the principle of causing minimum harm to PLWHAS

A reluctance to regard HIV and AIDS as a crisis so monumental as to justify compromise to ordinary enjoyment of human rights, especially rights to social amenities, to work, and to supportive social relationships.

Application of the criminal law only against persons who have evinced abuses of trust and fraudulent conduct at the time of infecting other persons with HIV and AIDS.

Application of moderate sentencing where criminal law is applied.

Within these guiding principles, the courts in various countries have attempted to mould the wrongs associated with HIV to fit in the following categories:-

- assault;
- sexual assault;
- aggravated assault;
- common nuisance;
- reckless endangerment;

- grievous bodily harm;
- reckless transmission of disease;
- knowingly exposing a person to HIV;
- criminal transmission;
- reckless conduct;
- aggravated reckless endangerment;
- criminal exposure to HIV;
- infected sexual battery;
- recklessly endangering safety;
- attempted manslaughter;
- causing serious bodily harm;
- criminal negligence causing bodily harm.

The developed countries have used their established legal systems to define the parameters of the law as regards HIV and AIDS. Generally, the common law and civil law are grounded on the rights of the individual, as enjoyed within the context of general laws that do not target any category of individuals. They have sought to uphold these principles even with respect to new and emerging challenges such as HIV and AIDS.

### **Canada**

In *R v. Cuerrier* 1998, a Canadian Court in finding wilful infection to be a perpetration of fraud sought to apply those principles of the law that had historically been applied in parallel scenarios.

In *R v. Holliham* (1988) a man was charged with the offence of common nuisance for having unprotected sex without disclosing his HIV – positive status. The applicable law provided that a person who does an “unlawful act or fails to discharge a legal duty and thereby endangers the lives, safety, health, property or comfort of the public commits a common nuisance”; in which case the prescribed penalty was up to two years imprisonment.

In *R v. Mitchell* (1998) a Canadian Court (in Ontario) ruled that an HIV-positive woman had committed aggravated assault by biting a police officer, thereby endangering life.

### **Australia**

In *R v. Mutemeri* (1997) an Australian Court sentenced the accused to six months imprisonment on 12 counts of reckless endangerment, for having been found to

have had unprotected sex with his former girlfriend. The applicable law was the Victoria Crimes Act, 1958, S.22 of which provided:

“a person who, without lawful excuse, recklessly engages in conduct which places or may place another person in danger of death is guilty of an indictable offence”.

### **Recommendations**

- (i) Laws should be enacted or the Penal Code should be amended to expressly provide for penalties for intentional as well as reckless transmission of infection.
- (ii) Such law should not confine itself to sexual transmission but should also address transmission through contaminated implements, through unlawful or fraudulently-achieved physical contacts, and through contaminated health-care supplies.
- (iii) The prohibitions of the criminal law against HIV transmission should be based on fault rather than strict liability. It is however to be noted that this principle can only serve true social purpose if there is full knowledge of an individual's sero-status. There would, therefore, be a public duty resting on the state to secure much better access to blood testing for members of the public.
- (iv) Intention or recklessness should, therefore, be cardinal elements in a finding of criminal responsibility.
- (v) Risky contacts may or may not lead to actual HIV infection in any particular case. However, it is desirable that criminal sanctions should be applied whether the mischief actually comes to pass, or the victim has only been exposed to high risk.
- (vi) The Criminal law should be founded on the principle that HIV and AIDS is not an exceptional mischief requiring exceptionally rigorous penalty. The pattern of sentencing for offences should take the general approach adopted over time by the Courts.
- (vii) Ultimately, the fact of knowing ones HIV-positive status, yet putting another person at risk by non-disclosure, should be punished.

## **Policy Recommendations**

- (i) Persons found guilty of HIV and AIDS-related offences should be awarded punishment on the basis of one general principle: minimisation of the harm caused to others.
- (ii) The mode of trial and punishment for such offenders should clearly avoid tendencies towards discrimination or stigmatisation.
- (iii) There is need to sensitise judicial officers on the social dimensions of HIV and AIDS, and on the special hardship experienced by PLWHAS in society.
- (iv) Criminal sanctions should only be resorted to as a last resort, and only in exceptional and outrageous instances.

### **3.5 HIV AND AIDS, AND ISSUES OF SUCCESSION AND INHERITANCE**

#### **Issues**

The current law relating to succession and inheritance is a product of law reviews conducted in the last two decades. The object of the initiative was to unify and standardize succession laws, while accommodating certain religious and cultural considerations, especially with regard to Muslims. Yet, this initiative has not dealt with administration of estates in the context of HIV and AIDS, which sometimes wipes out the executors and possible administrators even before they could regularize their own status as such. Is the process too long? Too technical or just incompatible with reality? Or does the problem lie with societal attitudes and a disinclination towards the role of legal procedures?

Are children orphaned by AIDS to be dealt with separately from other orphans?

There are competing proposals on how to deal with orphans. Should we consider co-ordination through the District Welfare Office, or through the Constituency AIDS Committees established as part of the lower echelons of the National AIDS Control Programme? Should we simply ask the Provincial Administration to ensure all orphans under their respective jurisdiction are provided for materially and psycho-socially?

Other considerations have included establishment of independent trusts at Locational, Divisional or Constituency levels. Still, who would establish these and

what assurances are there that such trusts would not be abused? Should we consider an expansion of the Office of the Public Trustee to the Divisional level?

If establishment of Children's Homes was to be regulated, should these be standardized at the Village, Locational or Constituency levels?

Should there not be a national fund for the protection of children infected or affected by HIV and AIDS? How is this to be effected and where would the necessary funds be drawn from?

The position of widows and widowers also raises serious questions, the former more than the latter. What practical measures can we take to ensure widows and the estates of deceased persons are protected from unfair and exploitative manoeuvres by relations? How can the embedded cultural and traditional practices be curtailed to ensure an equitable disposal of succession matters? How are the penal sections of the succession laws, which make it criminal to deal with property comprising the estate before taking letters of administration, to be addressed without penalizing the ignorant widows? And how are similar problems facing widowers to be addressed?

### **Summary of Views and Analysis**

The view was expressed that the mechanism for the protection of inheritance rights of widows and orphans is usually out of their reach, in being, for example, too expensive and too complex. It was suggested that succession laws be made easier and more accessible, to protect such persons from other competing interests.

It was suggested that the office of the Public Trustee be made more accessible, so as to assist widows and orphans in matters of succession as it seemed that they were more vulnerable in situations of succession.

It was also felt that there was need to create special institutions to cater for the needs of children orphaned by AIDS.

The stakeholders expressed the need to co-ordinate issues of succession and inheritance to avoid disinheritance of widows and children. This co-ordination was thought possible through; the District Child Welfare Office, the Constituency AIDS Committees and the Provincial Administration.

Some of the people and organisations expressed the need to establish an institution to deal specifically with the needs of children infected and affected with HIV and AIDS or infected and orphaned by HIV and AIDS.

In line with propositions laid down in Sessional Paper No. 4 of 1997, the view was expressed that it was necessary to establish or strengthen the capacity of Children's Homes, to cater for children orphaned or infected by HIV and AIDS or also living with the virus. This would also be in line with the United Nations General Assembly Special Session Declaration of Commitment on HIV and AIDS, which urges member countries to provide a supportive environment for orphans, by giving appropriate counselling and access to shelter, good nutrition, health and social services on an equal basis with other children.

The Constitution of Kenya (Section 75) provides for protection from any form of deprivation, except by due process of the law, i.e. unless it is in the public interest or is justified by way of compulsory acquisition, but which deprivation is strictly subject to prompt payment of adequate compensation.

The Law of Succession Act (Cap 160) is one of the means by which the right to property is protected. The Act provides for adequate protection of the free property of a deceased person, by ensuring that the said property is lawfully transmitted to those who are legally entitled to inherit. The Act recognises the rights of a customary law wife at section 3(5), so that the inheritance rights of such a woman together with those of her children with the deceased are protected. The Act makes provisions for both testate and intestate succession. In the case of the former, Succession is based on a Will, written or made by a person prior to his death. It enables those people who consider themselves dependants but have been dispossessed to challenge the bequests (property given) made by the testator (deceased). In this regard, the Act provides safeguards for widows and children who have been dispossessed. In matters of succession, the Act gives priority to the widows and children of the testators, and then to other members of the family.

Under intestate succession, where a person does not leave behind a widow, it is possible to invoke the mechanisms of the Law of Succession Act to protect the inheritance rights of the dependants. Priority is given to surviving spouses and children and then other relatives.

The Act makes elaborate provisions for the appointment of persons to administer the estates of deceased persons. There are safeguards to ensure that such appointed persons act in accordance with instructions given to them in the will or otherwise in the best interest of the estate. Where personal representatives are appointed, certain obligations attach to that position, geared towards the protection of the estate.

For the Muslim community, succession is governed by the Holy Quran as prescribed in the Mohammedan Marriage, Divorce, and Succession Act. Although, the general principles of succession are highlighted, male heirs may appear to be given preference to female heirs, though both are entitled to inherit.

This contention was highly contested, by muslim members of the Task Force, who clarified that the female may well be entitled to more.

The judiciary is also an important institution in matters of succession. Its principal responsibility is to ensure due administration of justice within the framework of the laws enacted by the legislature. In addition, the Chief Justice has created a Family Division in the High Court to deal specifically with family matters, including succession and inheritance.

The office of the Public Trustee is especially relevant in succession matters, especially with regard to protection of the rights of those persons who have no capacity to protect their own rights. The Public Trustee is the administrator of last resort, and intervenes in most cases where nobody is able or willing to administer the estate. A Grant may be made to the Public Trustee to administer an estate where: a person has died intestate, no executor has been appointed in a will; executors are unable or unwilling to administer the estate; probate of will, or letters of administration has not been obtained within the requisite period; the testator has appointed the Public Trustee as an executor; and where executors or holders of letters of administration die or are unable or unwilling to complete the administration of the estate. There are instances when a grant may be made to the Public Trustee despite the existence of a person entitled to apply therefore. All these instances would be relevant for the protection of the rights of those dependants who for one reason or another are unable to protect their own rights. This would have particular significance to widows or orphans reduced to that situation by HIV and AIDS.

The Office of the President, through the Provincial Administration, is another important institution dealing with questions of succession and inheritance. Administrative officers may intervene under appropriate circumstances to protect the rights of intended beneficiaries (Section 46 of Cap 160). Under the Public Trustee Act, the District Commissioners, as ex-officio agents of the Public Trustee, are empowered to summarily administer estates whose gross value does not exceed Kshs.100,000/=. The advantage with the Provincial Administration being involved in succession matters is that they are easily accessible to members of the public right from the lowest level. This is advantageous to widows and orphans who may not have the means to access the legal system.

## Recommendations

- (i) The criminal penalties presently specified for intermeddling are insufficient and should be enhanced, to ensure that appointed administrators perform their duty as expected, in the interest of the beneficiaries. The fine should be pegged at Kshs.1 million, or the value of any loss occasioned by the intermeddling; in the alternative, or imprisonment for a maximum of 3 years.
- (ii) An Office of The Public Guardian (or a similar office) should be established to co-ordinate issues of guardianship, not only for children but also for adults who by reason of old age, health or otherwise are incapacitated and cannot make decisions concerning their property.
- (iii) The Constitution should be amended to prohibit discrimination on health status so as to curb discriminative tendencies against PLWHAS.
- (iv) The office of the Public Trustee should be mandated to be the custodian trustee in cases where both parents die leaving behind minor children. In the present state of affairs, minor children are often dispossessed by other older relatives who take advantage of that minority to take out Letters of Administration and proceed to misuse property to which such minors would be entitled as belonging to their deceased parents.
- (v) In the case of such an appointment, the custodian trustee would be able to exercise greater scrutiny over appointed Administrators
- (vi) Section 8(1) of the Public Trustee Act should be amended to enable the Public Trustee to administer through summary procedure an estate whose gross value does not exceed Kshs.500,000/-. This saves on the time spent in obtaining formal Grant.
- (vii) Section 8(2) should similarly be amended to enhance the gross value of the estate, so that the Public Trustee can issue a Summary Certificate to an interested party to administer an estate whose gross value does not exceed Kshs.100,000/=. This enables beneficiaries to enjoy the benefits of the estate without undue delay.
- (viii) There is need to revise the Law of Succession Act, to provide for the invalidation of the acts of Administrators that are in breach of trust.

- (ix) The criminal sanctions currently imposed by Sections 45 and 95 of the Law of Succession Act are too lenient and need to be enhanced.
- (x) There is need to establish the Office of Special Prosecutor to deal specifically with complaints under the Law of Succession Act or other complaints which arise on Administration of estates.
- (xi) There is need to authorise the Public Trustee to intervene in cases of inheritance by or for orphans.
- (xii) The definition of dependants needs to be reviewed, with a view to restricting it. **(See Comments by Task Force below)**
- (xiii) Islamic succession laws actually discriminate against the girl child and should be reviewed with the object of creating gender equality. **(See Comments by Task Force below)**
- (xiv) For purposes of better care of children orphaned by AIDS, and those otherwise living with the virus, a National Children's HIV and AIDS Tax should be levied to finance child care and welfare.

The parental responsibility clause in the Children's Act should be emphasised and effected.

### **Policy Recommendations**

- (i) There is need to make it easy for people to access the legal system for redress. For example the Law of Succession Act should be make more friendly to users especially the vulnerable ones such as women, children and disabled persons. The procedure for accessing the courts should be simplified at least so far as succession is concerned.
- (ii) There is need to expedite the implementation of the Family Courts throughout the country.
- (iii) There is need to disseminate knowledge to the public on the provision of the Law of Succession Act (Cap 160, Laws of Kenya).
- (iv) There is need to increase awareness on the Law of Succession, to relevant Government Departments and Public Officials.

- (v) Members of the legal fraternity should be able to provide free legal services to those in need, especially widows and orphans.
- (vi) All stakeholders and institutions should constantly be sensitized on the laws and policies touching on succession and inheritance. This will include PLWHAS and those affected by HIV and AIDS.
- (vii) There is need to encourage Kenyans to appreciate the value of writing wills, and planning for the survival of their dependants in their absence. Correspondingly, there is need to encourage PLWHAS to make wills.
- (viii) The Government should devise standard printed wills and avail them in Hospitals, Non-Governmental Organisations, Government Departments and other relevant institutions dealing with HIV and AIDS.
- (ix) People living with HIV and AIDS should, where possible, be encouraged to settle their properties during their lifetime as provided under the Act.
- (x) There is need to review the role of the Provincial Administration in succession matters, in addition to developing modalities for protecting the property rights of children, particularly those born out of wedlock.
- (xi) Children should generally be cared for by the community; but their institutionalization may be resorted to particularly in regard to abandoned and orphaned children.
- (xii) The Ministry of Culture and Social Services should develop clear guidelines on the registration, regulation, supervision and deregistration of Children's Homes.

### **3.6 HIV AND AIDS, AND INSURANCE**

#### **Issues**

Testing as a pre-condition to insurance, especially in the case of life policies, has raised issues of concern. Is insurance purely and entirely a private contract issue – one where utmost good faith reigns, and that therefore an insurer may insist on such tests? Would it drive insurers out of business if such pre-insurance testing were outlawed? Are there alternatives to consider, such as no-test limits or other forms of group covers?

Is it possible insurers insist on such tests because they do not have reliable statistics on HIV and AIDS infection? Is it otherwise possible for the insurance companies to develop or use available statistics in actuarial calculations to spread the risk, without need for testing? Would they use these in calculating the premiums payable?

In responding, some insurers have argued that HIV and AIDS are no different from other diseases for which they have usually examined proposers. Is HIV and AIDS any different? Is the exclusion driven by stigma, prejudice and discrimination or by legitimate reasons?

How have countries which have outlawed insurance discrimination addressed the issue? Is there overriding public interest or policy against insurance discrimination? Should such AIDS disclaimers come after death while premiums were accepted during the life of the individual?

Many health and medical organizations have cropped up in the country, and a dilemma of their regulation has arisen, with neither the Commissioner of Insurance nor regulators of medical practice being able to reach them. How are they to be regulated, and who are they to answer to? How is the exclusion of HIV and AIDS to be dealt with? Can they be compelled to cover people living with HIV and AIDS?

Noting insurance companies have sometimes based their exclusion of HIV and AIDS on the fact that Re-insurers have on their part excluded these, should these consideration extend to Pre-insurers, even those established under statute? What is to be the fate of insurers who re-insure abroad? Should there be state-owned insurance companies which would take on HIV and AIDS without discrimination?

### **Summary of Views and Analysis**

Insurance companies carry out significant responsibilities through medical and life policies. The HIV and AIDS pandemic has focussed debate on a number of issues hitherto not addressed by the Government and the insurance industry.

Insurance companies in Kenya do not usually cover people who are HIV-positive in life insurance, leading to the perception that insurance companies are merely profit-oriented. At the root of the debate is the question on how to strike a balance between the need to ensure that the necessary coverage is extended by insurance companies without them going bankrupt.

The view was expressed that HIV-positive people are entitled to receive an insurance cover upon application, and their estates to benefits of a policy in case of their demise. Discrimination on the basis of HIV or AIDS is reprehensible. Members of the public felt that pre-insurance testing should be prohibited or otherwise required to be done through a laid-down procedure. However, reservations were expressed as to whether it would make economic sense to compel insurance companies to underwrite those who are HIV-positive, in which case it was suggested that the Government should create a statutory body to do the underwriting, at subsidised rates, to help those living with the virus.

However, views from the insurance industry indicated that the measures taken by insurance companies are meant to protect their own interests as business concerns. Although the industry may not be averse to underwriting PLWHAS, they would be doing so at their own risk as business enterprises. The view was expressed that this would necessitate them charging a premium that the majority of policy-holders would not afford, and that this would only be possible if there was reliable statistics available.

The HIV and AIDS and insurance debate is premised on the argument that the industry cannot operate in isolation, and that it has a duty to contribute towards the socio-economic development of a nation.

On the other hand there is the argument that as a business, insurance companies must realise a return on their investments.

The lasting solution to this interplay of interests should then be one which reconciles economic interests, questions of public and policy and the principle of non-discrimination.

The requirement for an HIV test prior to insurance is prevalent in the country. It is discriminatory in itself and more so where positive test results are used to deny insurance to applicants. It also often comes with breach of privacy and confidentiality.

The freedom-of-contract argument cannot hold in insurance contracts, since, in most instances, the applicant has not had an input in the course of negotiations nor does he/she always have a choice as to the terms upon which to accept to be bound by the agreement.

The Insurance Act does not set minimum, uniform standard provisions applicable in all policy documents.

Insurance companies have generally had a free hand in requiring testing before granting insurance, and have denied insurance upon positive test results. Such tests are usually carried out without regard to the basic safety nets required, e.g. informed consent, counselling, confidentiality and privacy.

Insurance companies were also accused of denial of benefits in cases where deaths have occurred as a result of AIDS.

The view was expressed that insurance companies are not entitled to discriminate against people with HIV and AIDS, as discrimination in any such set-up is generally abhorrent.

The view was also expressed that payment of benefits should not be pegged on whether or not death was as a result of AIDS, more so when the condition was neither known to exist nor was it a condition necessary for the issuance of the policy.

The view was expressed that insurance companies resort to certain underwriting measures such as pre-insurance testing, policy limits, exclusion clauses, etc to protect their own interests.

Insurance companies were of the view that it would be possible to cover HIV and AIDS-related cases if only the reinsurance companies would follow suit, and also if statistics were more reliable.

Many people thought the Health Medical Organisations (HMOs) should be regulated and compelled to cover PLWHAS at reasonable rates.

## **Comparative jurisprudence**

### **United States**

On the basis of **the Americans with Disabilities Act 1990** and the Rehabilitation Act, the United States Courts have held that refusal to issue cover to people with disability without actuarial justification constitutes a violation of the right not to be discriminated against.

Several states in the United States have promulgated Uniform Policy Provisions law which requires that insurance contracts on health and life must contain standard policy provisions as prescribed. This limits the free hand with which insurance companies operate to draw up policies in their favour. This protects the

insured who often negotiate from a weak position and have no input in those contracts.

### **Australia**

The **Federal Disability Act**, 1992 makes discrimination on the basis of disability (which is defined to include HIV AND AIDS) illegal.

### **United Kingdom**

The **Disability Discrimination Act** prohibits discrimination on the basis of disability.

### **South Africa**

The **Medical Scheme Act** of 1998 seeks to address the problem of exclusion of those living with HIV and AIDS from insurance. The Act requires insurance companies under its medical scheme to insure any HIV positive person able and willing to pay premiums. The Act prohibits the deliberate setting up of high premiums in the case of insurance for HIV and AIDS. It requires prescribed minimum benefit schemes which include medical and surgical management for opportunistic infectious or localised malignancies, albeit not necessarily to cover the provision of anti-retroviral drugs.

### **Philippines**

The AIDS Prevention and Control Act of 1998 prohibits discrimination on the basis of actual perceived or suspected HIV status in various areas including insurance. It obligates the state to take measures to guarantee the human rights of all persons infected with HIV and AIDS or affected thereby.

### **International Law**

Whereas the major human rights instruments make no specific reference to HIV and AIDS, many of their provisions have been interpreted as according protection to all people irrespective of their condition.

It is clear that the current trend so far as HIV and AIDS and insurance law is concerned is the restriction of the freedom of contract in order to strike a balance between the rights of PLWHAS and the interests of insurance companies. Discrimination that is not based on reasonable actuarial data is generally outlawed.

## Use of Legislation

It is proposed that the anticipated legislation do provide as follows:

- (i) In this Act reference to the term "insurer" or "insurance company" shall include reference to Health Management Organizations.
- (ii) No person shall be denied insurance cover on the basis of his or her HIV status.
- (iii) Mandatory pre-insurance testing infringes the right of the Proposer to insurance and constitutes unjustifiable discrimination.
- (iv) Save as may be prescribed under this Act, the right to privacy and confidentiality of Proposers and Insureds living with HIV and AIDS shall at all times be observed.
- (v) Except as is otherwise provided under this Act, mandatory pre-insurance testing for HIV is unlawful, provided that Pre-insurance testing for HIV may be conducted upon pre and post-test and with the prior, specific and informed consent of the proposer.
- (vi) Except as may be otherwise provided under this Act, there shall be no disclosure of a Proposer's or Insured's HIV status, provided that an insurer shall be entitled to disclose a Proposers or Insureds HIV status where:
  - (a) The Proposer or Insured has with prior informed consent and in the prescribed form authorised the disclosure of his/her HIV status to specifically designated person or persons or;
  - (b) The Proposer or Insured has in the prescribed form, and with prior informed consent waived his rights under this Act. The breach of this provision by an insurer shall be an offence, provided that the prosecution of an insurer under this Section shall be without prejudice to the right of the insured to bring an action for damages.
- (vii) In addition to the foregoing:
  - (a) Subject to such other provisions as may be prescribed under this Act, any doctor or other health care provider who conducts an HIV test for insurance purposes will respect and uphold to the

fullest extent possible, the Proposer's or Insured's right to privacy and confidentiality.

- (b) In every instance where an insurer or other person or entity requests, for insurance purposes, information on the HIV status of a proposer or an insured, the doctor or health-care provider will cause the Proposer or the Insured, as the case may be, to authorise disclosure to specifically designated person or persons by signing the prescribed Disclosure Authorisation Form before the test is conducted. Provided that where there are no designated person or persons for purposes of disclosure, the information will only be released to a Doctor or a Health-Care Provider in the employment of the insurer, person or entity seeking the said information.
- (viii) Except as is otherwise provided under this Act, it shall not be lawful for any bank, building society or other financial institution to require the disclosure of a person's HIV status as a prequalification for mortgages advances, loans, or other financial facility or accommodation.
- (ix) No Insurer or Re-insurer may:
  - (a) Decline to issue or renew a policy of insurance of whatever class or description merely on the ground that the Proposer or the Insured is a person living with HIV or AIDS
  - (b) Levy unreasonable premiums on such policies merely on the ground that the proposer or the insured is a person living with HIV or AIDS.
  - (c) Repudiate claims on a policy of insurance merely on the ground that the policy holder was a person living with HIV and AIDS.

Provided that:

- (a) It shall be lawful for insurers for purposes of determining the amount of premium chargeable to devise a no test limit under which Proposers and Insureds will be allowed to elect to be tested for HIV or not to be tested, in consideration for being charged an appropriately reviewed premium. This option shall remain voluntary for PLWHAS
- (b) It shall also be lawful for an Insurer or Re-insurer to require a reasonable additional sum life assurance premiums for People Living with HIV or AIDS.

- (c) The question as to whether the additional premium charged by an insurer or a re-insurer is reasonable or unreasonable shall be determined by the Commissioner of Insurance on the basis of statistical and actuarial principles and other relevant considerations. Any party aggrieved may appeal to the Insurance Appeals Tribunal.
- (d) The provisions of this section shall apply *mutatis mutandis* to Health Management Organizations.

### **Policy Recommendations**

- (i) The Commissioner of Insurance should be able to exercise decision making powers so far as regards the limit of payable premiums.
- (ii) There is need to bring Health Management Organisations within the purview of the Insurance Act, and to generally monitor and regulate their operations.
- (iii) Insurance companies should adhere to the principle of promoting the human rights of their insured and prospective insured. Consequently, under circumstances where testing is shown to have been accepted the principles of voluntary and informed consent must be adhered to and Counselling provided. It should be upon the prospective insured to decide whether to disclose the test results to the insurers, as no doubt he is the one who bears the consequences. Unauthorised disclosure of test results by the person performing the test is reprehensible and unethical and should be discouraged.
- (iv) Insurance companies should develop their own policies to govern HIV and AIDS issues in their sector. Adherence to the principle of promoting human rights is most important.
- (v) The government should step in where insurance companies have failed to provide cover for PLWHAS, in pursuit of social welfare goals.
- (vi) The Insurance laws need needs to be reviewed to enable the government to exercise more control and scrutiny over business of insurance including the determination of the terms of policy documents or the provision of specific policy packages. Certain minimum provisions should be prescribed in the case of health and life insurance and generally

to seek to strike a balance between the insurers and prospective insureds who are generally in a weaker bargaining position.

- (vii) In order to address concern by the Insurance Industry on inaccuracy of HIV and AIDS statistics, the Association of Kenya Insurers should be involved in conduct and evaluation of HIV and AIDS data in Kenya.
- (viii) There is also need for the Association of Kenya Insurers to work closely with the Office of the Commissioner of Insurance for purposes of analysing how insurance discrimination laws have been operationalised in other jurisdictions, and in order to have realistic and reasonable calculations of additional premiums where this is necessary.

### **3.7 HIV AND AIDS AND BIOMEDICAL RESEARCH**

#### **Issues**

There has been much concern about the regulation of research, especially that involving human subjects. Is there any formula regulating such research? What body or bodies should co-ordinate and regulate research especially bio-medical research? Existing legislation appears to confer authority on the various Universities and other bodies to conduct research trials? How can we deal with the engagement of commercial sex workers as research subjects? How can it be ensured that research subjects benefit from such research?

How should the law address those who claim to have developed a cure for HIV and AIDS? Outside research institutions, how should doctors, pharmacists, herbalists or religious groups be dealt with, where they make such claims? Would this be an interference with the freedom of worship and of religion?

What international and regional instruments exist to regulate biomedical research, and what extent have these been locally incorporated? Should they be legislated in Kenya? Are there any peculiar or uniquely African issues that call for adjustments to the international provisions? Is it possible to encourage herbalists and traditional healers to ply their trade without legislation?

#### **Summary of Views and Analysis**

The view was expressed by stakeholders that there was need for a legal framework to guard against exploitation of people living with HIV and AIDS for research purposes. It was also felt that there was need to regulate experimentation with herbal medicine, so as to guard against false claims of cure. In all cases of

research on human subjects, it was considered that the consent of the subjects must be sought, and that they must be informed of the consequences of giving such consent.

The importance of herbal medicine in the fight against HIV and AIDS was recognised by stakeholders; and it was generally agreed that there was need to enact laws to regulate practice and research involving herbal medicine.

A suggestion was made for the development of a research protocol to regulate research, and to guard against the exploitation of human subjects.

The need to develop ethics of research on human subjects, as an approach to the protection of human rights and dignity was emphasised. Participation in research requires the making of an informed choice. Information given to the subject must include knowledge about the objective of the proposed research, the procedures to be adopted and the confidentiality of results.

The distinction between medical practice and research is understandably blurred, with the result that patients, including those with HIV and AIDS, are not readily able to draw a clear line between receiving treatment and participating in research.

Unethical biomedical research involving human subjects is an affront to the human rights of PLWHAS. A different approach is necessary, to give fulfilment to the rights of the subject.

While research for diagnostic and therapeutic purposes may be allowed under regulated circumstances, the human being should not be used for research for purely scientific purposes, with no practical benefits. Even in those areas where human experimentation may be tolerated, human subjects, do not lose their entitlement to the fundamental rights of the person. Conduct of research must pay greater regard to human rights.

The general public has a right to receive appropriate information about research results that are effective. False claims of discoveries should be deprecated.

It is recognised that whereas it is necessary to regulate scientific research on human subjects, a complete prohibition of the same is inimical to the objective of searching for a cure for HIV and AIDS. Consequently, what is required is a legal regime to regulate the conduct of experimentation.

In regulating the conduct of research three principles should be taken into account:

- (a) Interest of science – for scientific experiments to yield the desired results there are scientific procedures that must be followed:
- For individual human subjects: ethico-legal regulation of the conduct of experiments must give priority to the rights of the individual;
  - Public interest – while considering the interests of science and of the individual, the public interest must also be incorporated..

The Declaration of Helsinki, drawn up by the World Medical Association in 1964 and revised in 1975 provides that:

“Biomedical research involving human subjects must conform to generally accepted scientific principles and should be based on adequately performed laboratory and animal experimentation and on a thorough knowledge of scientific tradition.”

The third basic principle of the Declaration of Helsinki provides that:

“Biomedical researches involving human subjects should be conducted only by scientifically qualified persons”.

An ethical experiment depends on the free and autonomous participation of the subject. The ninth basic principle of the Declaration of Helsinki provides:

“In research on human beings, each potential subject must be adequately informed of the aims, methods, anticipated benefits and the potential hazards of the study and the discomforts it may enact. He or she should be informed that she/he is at liberty to abstain from participation in the study.”

It is therefore unethical to use PLWHAS patients as subjects of biomedical experiments on AIDS and HIV without seeking their informed consent.

In line with other issues arising in the wake of HIV and AIDS, principles of privacy and confidentiality must be upheld in all cases.

Biomedical research in Kenya is regulated by the Science and Technology Act, which established the Kenya Medical Research Institute to undertake research on biomedical sciences. The Act has several flaws e.g. it does not provide for the establishment of mechanisms to monitor ethical considerations in research. Institutions engaging in research are therefore not amenable to supervision by a centralised body.

The Act does not oblige researchers on human subjects to develop a protocol, or seek clearance from any ethical committee. Hence no sanctions can be imposed upon any researcher as there would be no basis for such a charge.

The Act does not provide for monitoring and evaluation once research has commenced. No mechanism exists to monitor researchers in their work. This means that subjects are left to be dealt with at the whims of the researcher.

It is unethical for researchers to make premature announcements of the results of a research or to advertise a particular drug in a manner that amounts to a claim that the drug can cure certain forms of disease when it cannot.

The First International Code on Ethics of Research, the Nuremberg Code, was promulgated in 1947, as a consequence of the trial of physicians who had conducted atrocious experiments on unconsenting prisoners and detainees during the Second World War. The code is designed to protect the integrity of the research subject. It sets out conditions for ethical conduct of research involving human subjects, emphasising the human subjects' "voluntary consent".

The Declaration of Helsinki promulgated in 1964 by the World Medical Association is the fundamental document in the field of ethics in biomedical research. It sets out ethical guidelines for physicians engaged in both clinical and non-clinical biomedical research, and provides for informed consent.

### **General Ethical Principles**

All research involving human subjects should be conducted in accordance with three basic principles namely; respect for the person, beneficence and justice.

*Respect for persons* incorporates respect for autonomy, which requires that those who are capable of deliberation about personal choices should be treated with respect for their capacity for self-determination. It also requires protection of persons with impaired or diminished autonomy, which dictates that those who are dependent or vulnerable be afforded security against harm or abuse.

*Beneficence* refers to the ethical obligation to maximize benefits and to minimise harms and wrongs. This principle gives rise to norms requiring that the risks of research be reasonable in light of expected benefits, that the research design be sound, and that the investigators be competent both to conduct the research and to safeguard the welfare of the research subjects. It further proscribes the deliberate infliction of harm on persons – sometimes expressed as the principle of non-maleficence.

*Justice* refers to the ethical obligation to treat each person in accordance with what is morally right and proper, to give each person what is due to him or her. In the ethics of research involving human subjects, the principle refers primarily to distributive justice which requires equitable distribution of both the burdens and benefits of participation in research.

Human research subjects should be afforded the opportunity to choose what shall or shall not happen to them. This entails giving them an opportunity to give informed consent. The process of informed consent contains 3 elements:

- (i) *Information* – Subjects should understand the research procedure, the purpose, risks and anticipated benefits. Subjects should be afforded the opportunity to ask questions and to withdraw from the research at any time. Subjects should be able to understand the range of risks and the voluntary nature of participation.
- (ii) *Comprehension* – presentation of information should be adopted to suit the subject's capacity for understanding. Cases of immaturity or mental disability would require special provision but there is a general need to test comprehension.
- (iii) *Voluntariness* – an agreement to participate in research constitutes a valid consent only if voluntarily given. There should be no coercion or undue influence. Coercion occurs through overt or covert threats of harm in order to procure participation while undue influence occurs through an offer of an excessive, unwarranted, inappropriate or improper reward or other act designed to obtain compliance.

## **Recommendations**

- (i) There is need to enact a specific legislation on Biomedical Research which would incorporate most of the recommendations proposed, while incorporating the international principles.

- (ii) There is need for legislation to incorporate the relevant principles of the various ethical guidelines on biomedical research, for the protection of human subjects. In this regard the functions and responsibilities of the research institute need to be expanded.
- (iii) The Act should further provide for :
  - (a) The establishment of an independent Ethical Review Committee specifying the composition, qualification of members, terms of service, functions and criteria for decisions, and procedural regulation governing evaluation of research and operation generally.
  - (b) Provision of counselling, protection from discrimination, and health support services before, during and after participation.
  - (c) Provision for obtaining informed consent.
  - (d) The privacy and confidentiality of research subjects.
  - (e) Guaranteed equitable access to the information and benefits of research.
  - (f) Non-discriminatory selection of subjects
  - (g) Mandatory submission of a scientific protocol addressing ethical issues to a Scientific Review Board and thereafter to an Ethical Review Board.
  - (h) The monitoring and evaluation of on-going research.
  - (i) Obligation on researchers to furnish both Review Boards and the research institutes with the results of research.
- (iv) Section 17 of the Science and Technology Act vesting discoveries and inventions in the research institute should be amended to accord with the provisions of the Industrial Property Act.
- (v) The law should specify the qualifications of a researcher, provide mechanisms for accreditation, and impose penalties for defaults.
- (vi) The law should provide for the regulation of the functions of the various bodies now concerned with biomedical research.
- (vii) Regulation and control of research institutions should also be specifically addressed.
- (viii) Before carrying out biomedical research on any person, the free informed and specific consent of the person must be obtained through interviews carried out in a language best understood by the person.

- (ix) No biomedical research involving administration of drugs or other concoctions to the subject should be undertaken until and unless approval is granted by the relevant bodies.
- (x) Biomedical Research must be preceded by consultation with and approval by the Government and the Principal Professional Medical Association. No one should engage in health research involving human subjects in Kenya without the authority of the Government and other recognized professional bodies. Breaches of this requirement should be sanctioned with prescribed penalties.

### **Policy Recommendations**

- (i) There should be a comprehensive document detailing the National Guidelines on HIV and AIDS research.
- (ii) Review Boards should be harmonized.
- (iii) Enhance/facilitate training of Review Board members.
- (iv) Educate the public so as to positively influence their attitude towards HIV and AIDS.
- (v) Encourage de-stigmatisation of HIV and AIDS, so as to enhance consultations and hence promote the principle of informed consent.
- (vi) Hold regular consultations/meetings for review of research principles and activities.
- (vii) Develop a framework to regulate biomedical experimentation and research on HIV and AIDS.
- (viii) To the extent that biomedical research aims to increase scientific knowledge of the human being with the specific goals of improving health; and given the fact that biomedical research relating to HIV and AIDS primarily seeks to find a cure, biomedical research even on human subject should be allowable, subject to observance of proper procedures.
- (ix) All experimentation involving human subjects should conform to the principles set out in the Helsinki Declaration of 1964, the International Code of Medical Ethics of 1949, municipal statutes on health and research, and other international and local codes that stipulate standards.

- (x) All projects must be studied by an Independent Ethical Committee.
- (xi) The object of each project must be clearly defined and previous studies must show the benefit of the project for public health and for the subjects.
- (xii) Discriminatory selection of participants is to be discouraged. Women, Children and minorities should as far as possible be encouraged to participate.
- (xiii) Personal information given by the participant should be treated as confidential.
- (xiv) Any benefit derived from research undertaken in a given community should accrue to that community in priority.
- (xv) Counselling, protection from discrimination, health and support services should be provided during and after participation.

### **3.8 HIV AND AIDS AND THE RIGHTS OF THE CHILD**

#### **Issues**

The effects of HIV and AIDS on children and young people is devastating. It is perhaps one of the greatest manifestations of the disaster occasioned by HIV and AIDS.

A high number of young people are infected with HIV and end up dying from AIDS. Young women are more vulnerable at earlier ages than men, particularly at the 20-24 year age range. The young men have the highest infection levels at ages 30 – 39.

A large number of young women particularly between ages 12 and 24 have their first sexual encounter through forced sex or sexual abuse. This makes them vulnerable to HIV infection as a result of such abuse. What can be done to root instances of sexual abuse?

The instance of children orphaned by AIDS is phenomenal, and has occasioned great social and legal difficulties. The number of children orphaned due to AIDS is estimated to be 900,000 and expected to rise to 1.5 million by 2010. How do we, as a society, ensure that children whose parents succumb to the scourge remain well provided for materially, emotionally, psychologically and socially?

HIV and AIDS have occasioned a new scenario where we now have “*Child-headed*” homes. Children are also taking on roles of adults during the lifetime of their ailing parents. How are we to address this problem? Have we equipped our children well enough for this?

Even as we plan for the care of orphans, is it better to care for them within the families and communities or should they be transferred to institutions? Generally, it has been suggested it is better to leave children in their community setting where possible, unless institutionalization is in the best interests of such children. Even then, who is to make this determination? And based on what considerations?

Even as we think of institutions as possible places of refuge for orphans and children in vulnerable situations, what body of law governs Children’s Homes? Does the Children’s Department, the Provincial Administration, the Ministry of Culture and Social Services, the Children’s Council or any of these bodies have jurisdiction? Is this jurisdiction sole or co-extensive? Who should supervise adoption of children from these homes? Is the existing framework adequate?

Who takes care of the estate of the deceased parents while the children are in the homes? Do we have provisions for such situations?

Perinatal transmission of the HIV virus is the key cause of HIV infection among infants and children. About 30 to 40% of babies born to HIV positive mothers will be positive. Currently about 150,000 children are living with HIV and AIDS. The transmission of HIV from a parent to a child (usually referred to as Mother-to-Child Transmission – MTCT), has presented difficult questions of balancing the rights of the HIV-positive parent against the rights of the unborn child. The key concerns that arise when focusing on possible ways of preventing Parent-To-Child Transmission include the following: Should all pregnant mothers be mandatorily tested in order to take the necessary measures to prevent HIV infection of the children to be born? In the alternative, do the pregnant mothers have access to the necessary reproductive health information to equip them to make prudent and informed decisions to prevent transmission of the HIV virus to their children? Should the Government provide, freely, the necessary anti-retroviral drugs that assist in the prevention of Parent-to-Child Transmission? Even then should HIV-positive pregnant mothers be forced to take this medication? Given the importance of encouraging breastfeeding for the benefit of the survival of the majority of children in Africa, what laws and/or policy would be appropriate on this issue? Even as we focus on the rights of the child not to be infected where possible, how about the rights of the mother to survival and for the benefit of the child?

Does a child or young person living with HIV and AIDS have a right to education? Reports have been received of education institutions that refuse admission to children and young persons living with HIV and AIDS. Is it entirely at the discretion of such institutions to elect whom to admit? Are private institutions exempted from any rule on this issue? Are there instances when pre-admission HIV testing in schools and other institutions of learning may be justified?

How about the involvement of children in biomedical research relevant for addressing problems relating to HIV and AIDS? Should this be acceptable? Even where it is acceptable, should vulnerable children in care institutions be involved in such research?

With many children needing care within families, how good is the legal framework governing the adoption of children? Do we have enough safeguards to ensure that only genuine adoptions take place from children's homes? How about inter-country adoption is it well provided for to facilitate genuine adoptions: that protect children from abuse?

How should we treat children cared for within institutions once they attain the age of 18?

With many children taking care of themselves after the loss of both their parents, how can the succession law be useful to their situations? Are the current procedures for administration of estates protective of children? Do the laws provide for participation by children? Should education relating to property rights be included in the information and education of children on HIV and AIDS, as part of the way to deal with the impact of the scourge?

How can we take advantage of the positive aspects of traditional customary laws and systems for the better care of orphaned and vulnerable children? How do we do away with the negative customs that aggravate rather than mitigate the impact of HIV and AIDS on children and young people?

Given that the vulnerability of young people to HIV infection is aggravated by drug, alcohol and substance abuse, what can be done to curb these ills? Are we going to continue being comfortable with the licensing of bars within residential estates? Do children have a right to protection from such circumstances?

How about negative media influence on children and young people through advertising and other literature? Are our laws adequate to the task of providing protection against such negative influences? As a nation, are we able to guide our children and youth to modernize without westernising?

## Summary of Views and Analysis

To achieve any goals on the reduction of the impact of HIV and AIDS on children, a rights-based approach must be adopted by all people planning for children.

Children's rights are interdependent. It is therefore important to adopt a holistic approach when planning for programmes that affect children. The right to education cannot be fully enjoyed in the absence of the right to food, or good health, for instance.

The key principles to a rights-based approach in dealing with matters relating to children and human rights are:

- The "best interest of the child principle"
- The "non-discrimination principle"

The best interest of the child principle requires that those charged with the responsibility of dealing with children should at all times do that which, in the circumstances, is in the best interest or for the good of the child in question. This principle has been domesticated in Kenya by the **Children Act** at Section 4(2) which provides:

"In all matters concerning children, whether undertaken by public or private, social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interest of the child shall be a primary consideration".

The principle of non-discrimination helps to ensure equitable treatment as far as possible. Article 2(2) of the CRC enacts thus:

"States shall respect and ensure the rights of each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his parents' or legal guardians race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability birth or other status".

The **Children Act** states that it is enacted so as to give effect to the principles of the **Convention on the Rights of the Child**, and the **African Charter on the Rights and Welfare of the Child**, and for connected purposes. The

implementation of the Children Act will therefore go along way in reducing the impact of HIV and AIDS on children.

Children are peculiarly vulnerable to the effects of HIV and AIDS; hence the need for specific interventionist measures which are broad in their application. All stakeholders felt that HIV and AIDS interventions targeting children should be given priority.

It was also felt by all that children in more vulnerable positions, including **orphans, street children, disabled children, the girl-child**, should be accorded specific protection from the ravages of HIV and AIDS. Special welfare provisions should also be made with respect to them. Where possible affirmative action should be used to achieve the required goal.

It was further suggested that there was need to empower women and strengthen their capacity both socially and economically, to enable them to cope with the adverse consequences of HIV and AIDS. In particular, the right to information on their reproductive health rights is paramount.

The view was also expressed that there was need to strengthen the provisions of the succession laws to protect children's and women's property and inheritance rights. This will mitigate the socio-economic impact on children in particular.

H.E. the President, Hon. Daniel Toroitich Arap Moi specifically thought that interventions in schools should be expedited. The President expressed his wish to see structures for the care of children and youth set up nationally up to the grassroot communities.

It was felt that mandatory testing of children is generally reprehensible as is the case with the general population. This includes testing in learning institutions.

As regards the criminal law, severe sentences were proposed against those who commit sexual offences against children.

It was felt that the current social set-up is such that extended families are no longer able to cope with the responsibilities of caring for other members. Children orphaned by HIV and AIDS suffer greater jeopardy. After the death of parents, children are often left in destitution and unable to protect themselves.

It was observed that there are different categories of orphans who were affected differently by HIV and AIDS. Some have lost their parents from AIDS. For others, quite apart from losing parents to the epidemic, they are themselves living

with HIV and AIDS. This category will no doubt require much more attention in their needs as compared to orphans not living with HIV and AIDS. The latter category is often neglected by both family and society.

Since Children orphaned by HIV and AIDS suffer more hardship than other orphans, they are in greater need of support. In this regard, it was felt that there is need for care institutions to be strengthened to be able to offer total care for the benefit of children orphaned as result of HIV and AIDS. These institutions include the family care structures (extended family structures, foster care and adoption institutions, children's homes). As far as possible institutionalisation should be a measure of last resort.

The child who is in a family affected by HIV and AIDS is more vulnerable to child abuse. Usually he/she is forced to take up parenting roles, including income generation in order to contribute to the survival of the family unit. HIV and AIDS are thus contributing to the increase in **child labour**.

It was felt that the entry of children into labour set-ups in turn increases their vulnerability to HIV infection, as they become prone to sexual abuse. Some children end up as child prostitutes or commercial sex workers while others are induced into sex for small favours.

There are some categories of children who are especially vulnerable to HIV and AIDS. These include **the girl child, the disabled child, the street child, the disabled girl child and the child who is a refugee**. Any measures to deal with the problem of HIV and AIDS in relation to children, must address these categories in a focused manner.

Children tend to be at the mercy of the adult family members as regards succession and inheritance. This is so despite the fact that the Law of Succession Act does not discriminate against children in distribution of property. It was suggested that there was need to initiate strategies to ensure the protection of property rights of widows and children. It was also thought that the exemption of application of succession laws to Moslems may disadvantage the girl-child who is entitled to receive less than the male children. However Islamic law at least guarantees the girl-child some property; this is hardly the case with customary law.

The Children Act seeks to remedy this situation by providing elaborate safeguards to protect the property rights of children. It provides for the appointment of guardians to administer estates on behalf of children, and these may be appointed even during the lifetime of a parent, in anticipation of the parent's death. The Act

imposes a responsibility on parents to appoint guardians in respect of their children even when death is not contemplated.

It was observed by many stakeholders that HIV and AIDS have had significant consequences on the education of the child. This includes dropping out of school by children who lack fees where resources have been diverted to deal with the consequences of HIV and AIDS, or children who themselves are living with HIV and AIDS and are denied a chance to learn. Where parents are living with HIV and AIDS, children may drop out of school in order to provide for the family. In addition, a child from an HIV and AIDS-affected household, where this is known, is subjected to discrimination and stigmatisation in the school environment, causing them psychological stress.

The education sector is critical in the fight against HIV and AIDS, as it has the potential to influence the behaviour of most Kenyan youth. It was felt by many that the strategy to combat HIV and AIDS must be focused in the education sector, which is the custodian of over 50% of children and the youth. H.E. the President has expressed the view that strategies to control the impact on children and youth must be the first priority.

It was also observed that HIV and AIDS exacerbate the gender-based disparities that already exist in the education sector, which in most cases disadvantage girls in their access to quality education, and disadvantage women in their employment opportunities as educators and administrators. The result of this was expressed to be that, many countries, including Kenya, fail to meet internationally agreed targets for gender equality in education and education for all.

In terms of article 13 of the CRC, a child's right to receive and disseminate information should not be fettered. This right becomes relevant in regard to sex/family education which is critical in the containment and management of the pandemic. Stakeholders recognised the fact that the success of the fight against HIV and AIDS largely depends on access to proper information on facts touching on HIV and AIDS prevention, care, treatment and other related issues. The right to information is, therefore, primary to the strategies to combat HIV and AIDS and it must be responsibly accorded to children and youth.

In terms of **The Children Act, (No. 8 2001)** Section 7, every child is guaranteed basic education. The responsibility is placed on parents and the government. Such education is stated to be "free and compulsory". The section carries hope for the Kenyan child if it is implemented to the letter. It would reduce many evils, including child labour.

Mandatory HIV pre-admission testing in some learning institutions is a reality in Kenya, as evidenced by submissions made to the Task Force. Indeed, some thought that Section 25 of the **Education Act**, (Cap 211) by allowing the minister or the manager of a school to exercise the power to require a medical examination prior to admission, would impliedly authorise such testing, or at least condone it.

Stakeholders gave examples of instances of refusal of admission on the basis of a pupil's HIV status, although **The Children Act** (No. 8, 2001) prohibits discrimination against children on certain grounds, including the ground of disability or other status.

Under the **Education Act**, (Cap 211) the Minister is charged with the responsibility of making regulations on the conduct and management of schools, on matters such as prescribing minimum standards for the health and safety of pupils. It was felt that this provision could be misapplied to unjustifiably discriminate against pupils living with HIV or AIDS.

Stakeholders felt that there may be instances where a **person** living with HIV or AIDS may be suffering from a communicable opportunistic disease or infection. In these circumstances, the person may have to be temporarily excluded either from admission or employment for the purpose only of controlling the infectious disease.

The view was expressed that those responsible for the running of schools are under obligation to respect the privacy and confidentiality of students living with HIV and AIDS or those whose parents are living with HIV and AIDS.

Transmission of the HIV virus from parent to child (PTCT) contributes significantly to the spread of HIV among children. There is consequently a need to control or eliminate parent-to-child transmission through various measures. This requires availing drugs and procedures that serve to reduce the transfer of the virus from the mother's bloodstream to the child during gestation, and in the course of birth. Such drugs include anti-retrovirals (e.g., azidovudine and nevirapine). It also calls for greater investment in research on PTCT.

The reduction of parent-to-child transmission imports the necessity to beef up the reproductive health rights of women, to enable them to have access to the correct information for making choices that are beneficial to themselves and the unborn child. The right of access to reproductive health services for women will translate into a reduction of the cases of PTCT. As these rights are sought for the mother, the right of the child to life, and from being infected, must also be considered.

Sexual abuse of children also contributes to the spread of HIV infection among children. There is need to take more decisive measures against culprits. The Penal Code currently treats defilement as a less serious offence than rape. It was recommended that more severe penalties be imposed against offenders. The Criminal Law Amendment Bill partly addresses this problem but it does not have provision for the punishment of sexual abuse against young boys.

### **Comparative Jurisprudence**

The **United Nations Convention on the Rights of the Child (CRC)** so far represents the global consensus on the need to address matters relating to children.

The CRC categorises children's rights into:

- *Survival rights* (linked to good health and adequate growth)
- *Development rights* which emphasise the need for opportunities and means for access to education, skills, training, information, parental care and social security.
- *Protection rights* (which relate to legal and social structures for protection from exploitation, drug abuse, sexual abuse, cruelty, discrimination and protection from all disasters (natural and man-made))
- *Participatory rights* (which allow children to play a role and be able to express themselves in matters affecting them).

For children, all rights are interdependent hence the need to have a holistic approach in addressing matters affecting children.

### **International Guidelines On HIV/AIDS and Human Rights (United Nations 1998)**

After the Second International Consultations on HIV and AIDS and Human Rights held in Geneva in 1996, the United Nations came up with some guidelines. These were compiled by experts from governments, voluntary bodies, AIDS service organizations, networks of people living with HIV/AIDS, academic and regional bodies and agencies. The guidelines were endorsed by the Executive director of the Joint United Nations Programme on HIV/AIDS, Dr. Peter Piot and the United Nations High Commissioner for Human Rights, Ms. Mary Robinson.

Guideline No. 8 on the promotion of a supportive and enabling environment on Women, children and other Vulnerable Groups States as follows:-

“38 States should, in collaboration with and through the community, promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups”

In this regard governments are encouraged to form community associations to work in the quest for peer education, empowerment, positive behaviour-change and social support.

The guidelines also emphasize the right to access adequate and accurate information on HIV and AIDS and matters relating to reproductive health.

### **South Africa**

- (i) It is acknowledged that HIV and AIDS education in schools is the key to the prevention, care and management of HIV and AIDS within the school set-up.
- (ii) The department of education developed a policy that addresses HIV and AIDS in the educational set-up. It seeks to protect the constitutional rights of all students on an equal basis.
- (iii) It requires the provision of education about HIV and AIDS on an ongoing basis, the aim being to prevent the spread of HIV and AIDS; to allay fears of the epidemic; to reduce the stigma attached to it; and to reduce stigma and discrimination against persons living with HIV and AIDS.
- (iv) It proscribes unfair discrimination on students with HIV and AIDS, or those perceived to be so infected.
- (v) It prohibits denial of admission to, or continuance in attendance at, school on account of HIV status.
- (vi) It prohibits routine testing of students and mandatory pre-admission testing.
- (vii) It calls on educational institutions to ensure the provision of basic education on HIV and AIDS, and to seek to accommodate the needs of students living with HIV and AIDS within the learning institutions,

- (viii) It bans compulsory disclosure of information relating to HIV and AIDS.
- (ix) Schools are required to implement universal precautions to effectively eliminate the risk of transmission of all bloodborne pathogens, including HIV virus, in the school environment.

As regards the regime under international law, although it is recognised that the international legal instruments do not specifically address the issue of HIV and AIDS, many of their provisions have been taken as covering the protection of children. In the context of HIV and AIDS, the non-discrimination clauses have been singled out as being directly relevant. The International Guidelines on HIV and AIDS and Human Rights, though not law in the strict use of the term, provide concrete suggestions for governments that seek to come up with specific laws and policy on HIV and AIDS. Specifically, the Convention on the Rights of the Child proscribes discrimination against children on the basis of their HIV status.

### **Recommendations**

- (i) Enactment of anti-discrimination and protective laws to reduce human rights violations against children in the context of HIV and AIDS so as to reduce vulnerability to infection by HIV and AIDS. The law will specifically proscribe pre-admission HIV testing and denial of admission to school on the basis that a prospective student is HIV positive.
- (ii) Penal laws ought to be amended so as to provide more commensurate penal measures for defilement, at par with the offence of rape.
- (iii) Sexual abuse and defilement of boys should be specifically outlawed and a sentence prescribed, as with rape or defilement of girls.
- (iv) The age of sexual and marital consent should be increased to 18 years.
- (v) Mandatory testing of children is prohibited. Exceptions may be made in accordance with the relevant circumstances, e.g. where it is necessary for the determination of an appropriate treatment regime for the child. In all cases, consideration should be given to the requirement of privacy and confidentiality, and the principle of the best interests of the child together with non-discrimination must be observed.
- (vi) In the case of orphans or children under the control or custody of care institutions, specific officers must be identified who will be held

responsible in the decisions involving the lives of the children under their custody, including decisions on medical and health measures.

- (vii) The Children Act should be used to create a framework for the supervision of child care institutions. The framework must provide for a quality control mechanism to ensure that minimum standards are set for protection of children in these institutions. The case infrastructure for children in institution should include properly trained personnel with further training on the rights of the child.
- (viii) Routine testing of children for HIV and AIDS is reprehensible and hence prohibited.
- (ix) Sections of the Education Act should be amended in tandem with the general flow of the Children Act .
- (x) Section 25 of the Education Act which allows the Minister or the Manager of a school to require medical examination prior to admission should be repealed, as the HIV status of a student is irrelevant in admission decisions. Exclusionary measures may be undertaken but the only on the basis of sound medical data, and only in exceptional circumstances.
- (xi) Children's institutions and school managers and all persons in charge of children are obliged to respect the privacy and confidentiality rights of all their wards, particularly as regards information touching on medical condition or health status.
- (xii) Biomedical research involving children living in care institutions must be completely prohibited, as such children are in the category of vulnerable persons.
- (xiii) Stricter sanctions and tighter control over intermeddlers under the Law of Succession Act (Cap 160) should be provided.
- (xiv) Section 39 of the Law of Succession Act should be amended to make it difficult for a guardian to pass good title of property of an estate held in trust for children to a third party.
- (xv) The Law of Succession Act (Cap 160) should be reviewed with the aim of simplifying the procedure for applying for grant of representation, and generally for protecting the inheritance rights of children.

- (xvi) There is need to review the regulatory framework under which the various adoptive societies and children homes operate, including the age limit at which wards should remain in their care.
- (xvii) Given the age at which young people become independent in Kenya (between 22-25), there is need for some protection to extend to these young people who cannot ordinarily be defined as children. Under the Children Act some of the protections provided under the Convention on the Rights of the Child need to be extended to those aged over 18 and under 25.
- (xviii) Affirmative action for the more vulnerable children should be effected in schools and public health care institutions. This should target the girl child, the street child, the disabled child and the disabled girl child.

### **Policy Recommendations**

All Stakeholders, led by H.E. the President would like to see an institution set up for the care of orphans. In this regard, a national trust fund should be put in place to help set up care institutions within the communities all over the country to address the effects of HIV and AIDS. Many have suggested a specific levy from all citizens for the running of this trust.

The **Ministry of Education** should develop Guidelines on HIV and AIDS in learning institutions, promoting the following principles:

- (i) Prohibition of mandatory pre-admission testing for HIV and AIDS
- (ii) Prohibition of discrimination of students on the basis of their HIV status.
- (iii) Promotion of privacy and confidentiality of students.
- (iv) Promotion of universal precaution to minimise the risk of bloodborne pathogens, including HIV, within the school set up.
- (v) Promotion of education and dissemination of information on HIV and AIDS.
- (vi) Provision of a safe learning environment to the more vulnerable members of society, including the disabled children to avoid exploitation and abuse.

- (vii) Promotion of equality in access to educational opportunities to both gender.
- (viii) Promotion of effective sexual and reproductive health education aimed at changing behaviour.
- (ix) Ensuring that those infected and affected are not excluded from education, and that they are given counselling and support, and that they acquire life skills that will be crucial for their survival.
- (x) Influencing social attitudes and cultural norms acquired by young people.
- (xi) Addressing the separate needs of girls and boys to enable them to adopt beliefs, attitudes and behaviour that will not only safeguard their immediate situation but also contribute to a long-term social re-orientation that ultimately secures gender equality.
- (xii) Encouraging open debate on the issues arising in the wake of HIV and AIDS.
- (xiii) Promotion of the rights and special needs of children orphaned by HIV and AIDS.
- (xiv) Promoting education about the responsibility of persons living with HIV and AIDS towards others in the community.
- (xv) Promoting awareness and education on the basic facts about HIV and AIDS i.e. modes of transmission, economic consequences, containment and prevention measures, relevant treatment and prophylactic measures and living positively with HIV and AIDS, or on how to live with people living with HIV and AIDS.
- (xvi) The National Medium Term Strategy for HIV and AIDS, and other Strategic Policy Development and Implementation Tools on HIV and AIDS in Kenya, should include a comprehensive plan for the protection of Children infected or affected by HIV and AIDS with a well defined plan of action.
- (xvii) All Children's Officers including paid staff and volunteers, should be trained on the situation of HIV and AIDS infected and affected children, including on the range of abuses to which they are most vulnerable to.

Human rights education on matters affecting children must go hand in hand with HIV and AIDS education.

- (xviii) There shall be constant monitoring and inspection of orphanages and other Homes for Children by the Children's Officer in each District, particularly with regard to protecting HIV and AIDS affected children from discrimination, mandatory testing and abuse. This will help to maintain quality control and lessen institution-based modes of abuse of the vulnerable children admitted therein.
- (xix) Every effort should be made to implement free and compulsory primary education for all children.
- (xx) There is need to simplify the Children Act and to disseminate it.

The **Ministry responsible for Culture and Social Services** should come up with a policy on Information Education and Communication for children that may not be reached through the formal education system. A deliberate effort should be made to identify and promote the positive traditional customs that can help in mitigating the impact of HIV and AIDS on children.

The **Ministry concerned with labour issues** should specially address matters relating to child labour. In this regard all the ratified ILO conventions on child labour should be domesticated and implemented.

### **3.9 HIV AND AIDS, AND GENDER ISSUES**

#### **Issues**

The question of HIV and AIDS in gender is a serious and an emotive one. Gender disparities have generally ensured grave imbalances in the socio-economic sphere, with the position of males vastly superior to that of females. In the wake of HIV and AIDS, this tilt has doubly disfavoured the female gender, not only in risk of infection, but also in suffering the consequences of infection.

Issues arise regarding the testing of expectant women and girls. Should they be tested with their consent only? Do their spouses or partners have any say in the matter?

Reproductive health rights become quite relevant in this context. Should the expectant woman or girl, especially one living with the virus, have the exclusive right to determine whether or not to terminate the pregnancy? Should such woman

or girl determine whether or not to have a caesarian delivery? What should be the policy on anti-retroviral therapy, in such cases – should such woman or girl be required to take the therapy or should it be purely voluntary? Who is to meet the costs of such therapy?

The use of condoms also becomes relevant especially the femdoms (female condoms). Should the use be regulated by law, or merely encouraged by policy? Should hotels and other places of lodging be mandatorily required to stock and provide condoms? Including female condoms?

What measures of law and policy can be employed to address the special vulnerability of women? How far does the proposed Gender Bill go in this respect?

### **Summary of Views and Analysis**

The view was expressed that the unique situation of women must be addressed, as their weak position in society places them at greater risk of infection than their male counterparts. As regards the aftermath of HIV and AIDS, it is the women who bear the greater burden, since they have a restricted access to the resources required for the discharge of crucial family responsibilities.

It was suggested that the law ought to protect women's interests in situations of inheritance and succession as they are usually dispossessed of their entitlements by the relatives of deceased husbands.

It was further suggested that pregnant women should be mandatorily tested for HIV, for the purpose of managing the risk of spreading the virus to unborn children. However, it is the view of the Task Force that even under such circumstances there does not seem to be compelling need to subject pregnant women to mandatory testing for HIV, since it would not be compatible with the rights-based approach. As far as possible, testing should be voluntary, and the requirements of Counselling, privacy and confidentiality observed.

It was recognised that there are certain cultural practices that are harmful to women, and the society generally, and which should be outlawed since they also encourage the spread of HIV and AIDS.

The view was expressed that women must be empowered to have control over their reproductive, economic and social lives so as to resist those situations that generally put them at risk of HIV infection. Further, it was thought the law should accord protection to women who are exposed to situations of violence at home.

Gender inequality, poverty and violence converge to give impetus to the HIV and AIDS pandemic and have resulted in profound differences in the underlying causes and consequences of HIV and AIDS in women and men.

It was felt that although there is a growing recognition that women's disempowerment is largely responsible for the rate at which HIV and AIDS has spread in the country, it must be understood that inequality between the sexes is the key factor that has contributed to the pandemic. Inequality distorts and impairs every aspect of women's lives, making them vulnerable to all sorts of abuse and exploitation.

It was further noted that responses to the pandemic need to take into account the multiple ways in which power imbalances between men and women have exacerbated the situation in all spheres of life. Responses that confine themselves to women's right to health by themselves cannot explain the magnitude of women's vulnerability. There is need to articulate all aspects of the denial of women's right to equality and to freedom from discrimination.

It was remarked by stakeholders that women are more vulnerable to HIV infection not only due to biological reasons, but also due to social reasons. For instance, gender power imbalances make it difficult for women to negotiate safer sexual practices with their partners. Economic dependence and fear of violence coerce women to consent to unprotected sex. When afflicted, women receive inadequate care and treatment, and what they get is sometimes unsuited to their health needs.

Concern was expressed that women are not receiving the information they need about HIV and AIDS, to enable them to protect themselves from infection. In most cases women play a passive role in sexual interactions, in the context of social and cultural pressure for women to remain ignorant in matters touching on sex and sexuality. Women and girls are themselves hesitant to seek information, owing to inhibitions that come with their overall socialisation. Society expects girls and women not to be knowledgeable on sexual matters, as otherwise they will be viewed as promiscuous. Therefore, women can neither express nor seek information on matters of sex and sexuality. This lack of knowledge is risky especially when girls are sexually active as they are likely to expose themselves to situations of risky sexual relations.

This lack of knowledge was said to have negative consequences not only on women, but also on men and boys. Society has stereotyped the male gender as the all-knowing type for whom a show of inexperience is deemed as a weakness. This

encourages men and boys to do acts that will put them at risk, in an attempt to prove their masculinity.

Central to the entire gender question is the issue of empowering women to negotiate safe sex. Social and cultural norms have conspired to take away the woman's power and will to express her preference, and confined her to passivity and submissiveness. The power to decide when and how the act of sex is to occur is generally the preserve of men, especially outside the domain of commercial sex. But even in situations of commercial sex, women are more often than not restricted in their bargaining power as having been in many instances driven into it by a pressing economic need.

It was noted that women's physiology makes them more susceptible to infection than men, since they have a large mucosal surface exposed to abrasions during sex, and their organs remain in longer contact with fluids from the male body after the cessation of the act of sex. In addition there is usually a higher concentration of the virus in the semen than in the vaginal fluids.

Stakeholders felt that ethical and social practices centered around the woman's sexual organs exacerbate the weaknesses already caused by biological factors, e.g. female circumcision, child marriage, dry sex.

Domestic violence in the form of spousal abuse, marital rape, incest, have made the home an unsafe place for women. Exposure to violence increases women's exposure to HIV.

The precarious situation of women and girls makes them vulnerable to sexual exploitation, e.g. in situations of conflict, in the workplace, refugee situations, commercial sex work situations, etc.

It was said that pregnant women are usually subjected to coercive testing for HIV, and that health authorities may impose abortion or sterilization on them. In a culture where women's value is tied to their ability to bear children, they may risk unprotected sex, in their anxiety to become pregnant. In addition for fear of disclosing her status an HIV-positive woman may continue to breastfeed her child rather than opt for safer alternatives.

The general tendency is that a household bereft of older male members, passes on the burden of care to women, often grandmothers who have survived their children. Where no grandmother is present, the burden often falls on the elder female siblings. Widows left after the death of their husbands are often in a weak economic position, without the resources to take care of themselves and their

family. Households headed by women are often left vulnerable and prone to abuse and exploitation.

### **Recommendations**

- (i) There is need to enact legislation to domesticate the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), so as to incorporate the progressive standards provided therein into the national legal system.
- (ii) There is need to incorporate the non-discrimination standards in CEDAW in the Kenyan Bill of Rights.
- (iii) Section 82 of the Constitution, which permits the application of personal law, in effect allows the application of discriminatory laws against women and other vulnerable groups of the society. The fact that a matter is personal should not be used as an excuse to discriminate against women and other vulnerable members of the society.
- (iv) Parliament should pass all pending proposed legislation that seek to protect women and promote their rights. This includes the Bill on Domestic Violence, and the one on Affirmative Action for women.
- (v) There is need to streamline other legislation to regulating social relations, e.g., marriages and family relations. Such a legislation should ensure due protection for all members of the family.
- (vi) There is need to implement the provisions of the Industrial Property Act (2001), to make accessibility to essential drugs and services easier for PLWHAS.
- (vii) Mandatory testing of pregnant mothers is reprehensible and is to be outlawed.
- (viii) Every woman should be free to decide on issues of reproductive health.
- (ix) The law of succession should be clear and easily accessible to enable protection of inheritance rights. There is need to make the law less complicated and user friendly.
- (x) The law of succession should be reviewed, with a view to giving equal protection to men and women. There is need to reconsider the rule

requiring the joinder of a male relative of a deceased husband in the process of administration of the deceased's estate by the widow.

### **Policy Recommendations**

- (i) There is need to protect newly born children by making it easy for women to access those medicines that are relevant in reducing transmission from parent to child.
- (ii) The National Policy on Education and Health must be reviewed and reformulated to reflect the minimum requirements in CEDAW. This includes the elimination of prejudices and other practices based on the idea of the inferiority or superiority of either sex, or stereotyped roles for men and women, and the elimination of discrimination against women in the context of marriage and family relations.
- (iii) Health and Education policies must reflect women's special vulnerability.
- (iv) There is need to recognise the importance of letting commercial sex workers organise themselves around issues that affect their rights and livelihoods, and to participate in health promotion activities.
- (v) There is need to adopt and emphasise a gender perspective in all spheres of public and private life, including education, employment, family, health, economy, politics.
- (vi) There is need to allocate sufficient resources to provide for women's social needs.
- (vii) The Ministry of Health should come up with a policy that sets out the manner in which Health Care Workers should deal with pregnant women. Such policy should expressly prohibit coercive testing, and emphasise the need for consent for every decision concerning them.
- (viii) Relevant information on HIV and AIDS should be disseminated to pregnant women, including information on prevention, treatment, parent-to-child transmission, alternatives to breastfeeding and other related matters.
- (ix) Women must be involved in the design and implementation of responses to HIV and AIDS. Gender perspectives and sensitivities may not have been

fully canvassed in responses that have been developed with respect to the HIV and AIDS pandemic.

- (x) There is also need to encourage women to participate in all aspects of public life and political decision-making.

### **3.10 HIV AND AIDS, AND THE LAW OF PATENTS**

#### **Issues**

The right of an inventor to enjoy the profits of his/her invention are well recognized in law. However, there are certain instances where that right may yet be sacrificed for a public good. Owing to the public health consequences of HIV and AIDS, is there a need to make an exception so as to avail important ameliorative medicines for PLWHAS without undue regard to issues of patent rights?

There are certain obligations that bind Kenya in international law relating to patent rights. Does Kenya have an option, as regards these obligations, when it is clear that allegiance to them would jeopardize the public health situation as precipitated by HIV and AIDS. What measures are necessary to ensure that internationally patented medicines can be availed locally to alleviate the HIV and AIDS pandemic?

Is there a duty on the part of the Government to take measures to avail essential drugs to PLWHAS and particularly to pregnant women with HIV and AIDS in order to reduce prevalence levels?

Certain laws have been used to stifle innovativeness so far as medicines are concerned e.g. Witchcraft Act, Pharmacy and Poisons Act, Public Health Act, Narcotics, Drugs and Psychotropic substances Act. Is there a need to revisit these laws so as to strike a balance between harmful and beneficial uses of substances?

#### **Summary of Views and Analysis**

In the wake of HIV and AIDS, patents and other intellectual property rights should be reviewed with the aim of removing restrictions on the use of certain inventions in the wider interest of humanity. Such rights ought to be flexibly enforced, so as to promote affordability and availability of essential medicines in Kenya.

The view has been expressed that the Industrial Property Act No. 3 of 2001 is a progressive piece of legislation in that it incorporates principles/safeguards

enunciated in International Agreements intended to promote accessibility of essential medicines. These principles include:

- (a) *Parallel Importation*: Section 58(2) of the Industrial Property Act No. 3 of 2001 offers Kenyans the opportunity to shop around the world for the most affordable medicines without the fear of legal action by the patent holders or licensees. The section as clarified by Regulation 37 of the IP Regulations, 2002 allows the importation of any medicines put on foreign markets legitimately. Legitimacy of products on the market implies that the medicines comply with the laws of those countries.
- (b) *Compulsory Licensing*: The compulsory licensing regime established under Sections 72 to 78 of the Act provides an avenue for enhancing access to essential medicines. The Act allows compulsory licensing in a wide range of circumstances including situations of high prices and unstable market supply. Section 74(2) provides the possibility of waiving the requirement for prior negotiations in cases of emergency or extreme urgency.
- (c) *Government Use Orders*: This refers to a situation where the Government or its appointed agent exercises the right to ignore the restrictions placed on the supply of products. The Act gives the Minister for Trade wide Government-Use Powers, and allows any person to petition the Minister to issue a Government Use Order in the interest of the public. Compulsory licensing may give authority to a generic manufacturer to manufacture particular medicine, or use a particular process of manufacture without the consent of the patent-holder. In the wake of HIV and AIDS, and having regard to the high prices of many of the inventions, this process is clearly advantageous to Kenya.
- (d) *New Use Pharmaceutical Patents*: Section 21(3)(e) of the Industrial Property Act gives the Minister responsible for health full powers to restrict the patenting of new uses of known molecules. The non-patentability would mean that they would be available without restrictions to patients who need them.
- (e) *Early Working (Bolar) Exception*: Section 54(2) of the Act provides legal protection to generic manufacturers from being sued by patent-holders when they perform otherwise prohibited acts under the Act, for purposes of preparing for and obtaining registration and approval of their products before the expiration of the patent. This safeguard is

important to ensure that generic versions of the product are available on the market immediately after, or within a reasonable time of the expiry of the patent. This is in recognition of the need to avail essential medicines to PLWHAS, to manage the conditions of HIV and AIDS.

Achieving the goals of access to essential medicines does not only depend on intellectual property law, but also on other legislation:

- (a) The Public Health Act (Cap 242) makes provision for the prevention and suppression of infectious diseases, formidable epidemic, endemic or infectious diseases and treatment of venereal diseases. This Act is of particular to the Industrial Property Act No. 3 of 2001, especially with respect to procurement of essential medicines under the powers given to the Minister for Health (Section 21).
- (b) The Pharmacy and Poisons Act (Cap 244) makes provision for the control of the profession of pharmacy and trade in drugs and poisons. The first issue relates to the speed and procedure for the registration of medicines in Kenya. For example, even with the declaration of HIV and AIDS as a National Disaster, the Pharmacy and Poisons Board has not established a fast-track procedure for the registration of generic ARVs. As a result, generic ARVs in respect of off-patent medicines are not yet registered, and therefore not available in Kenya. The provisions under the Pharmacy and Poisons Act are tedious, this denies PLWHAS in Kenya the benefits of use of available ARVs. It becomes necessary that the procedure of drug registration be reviewed, to establish a procedure to enable fast-track registrations for essential medicines such as ARVs.

## CONCLUSION

- (i) The Industrial Property Act No. 3 of 2001 contains reasonable provisions allowing the use of international guidelines to improve access to essential medicines in Kenya. The challenge is to implement these provisions.
- (ii) The public health safeguards present an opportunity for improving access to essential medicines in Kenya. The Government has the power to use fast-track procedure under the Government Use provisions to access ARVs to deal with HIV and AIDS. The same powers can be used to deal with more systemic problems in accessing other treatments for opportunistic infections such as Malaria, TB and Meningitis.

- (iii) The Government also has the opportunity to resort to Compulsory Licensing, to avail generics at an affordable cost.

### **Recommendations**

- (i) There is need to repeal or amend the **Witchcraft Act** (Cap 67) which has been traditionally used against practitioners of traditional medicines/herbalists. This Act has been used to curtail alternative medicines and their use in Kenya.
- (ii) There should be amendments to the **Pharmacy and Poisons Act** (Cap 244), the **Public Health Act** (Cap 242), the **Mental Health Act** (Cap 248), and the **Narcotic and Psychotropic Substances Act** (No. 4 of 1994) especially in the provisions that have hindered access to essential medicines for both practitioners and patients.
- (iii) There is need to revisit the **Narcotics and Psychotropic Substances Act** (No. 4 of 1994) with a view to delinking the medical aspects from the acts proscribed in the legislation

### **Policy Recommendations**

- (i) The Government, through the Minister for Trade, should immediately exercise its sovereign powers under section 80 of the Industrial Property Act 2001 to access anti-retroviral and other essential medicines for opportunistic infections. Government-use must now be resorted as a fast-track mechanism in this regard.
- (ii) Generic manufacturers with the capacity to manufacture anti-retrovirals and other critical medicines currently under patent in Kenya should be encouraged to apply for compulsory licenses under the IP Act 2001. It is also recommended that that the Minister for Trade exercise his powers under section 74(2) of the Act to ensure that anti-retrovirals and treatments for opportunistic infections are made available.
- (iii) Greater use of the opportunity for parallel imports will ensure access to urgently needed medicines at more affordable prices.
- (iv) Under the IP Act 2001, the provisions dealing with new use pharmaceuticals patents (sec. 22) and Early Working (Bolar Exception) are important public health safeguards that will ensure fast-track access to essential medicines when their patents expire or are about to expire.

- (v) Under the Pharmacy and Poisons Act (Cap 244), regulation of the pharmacy and pharmaceutical practice is placed under the control of the Pharmacy & Poisons Board. The Board should expedite the registration of quality generic medicines, to ensure competition and fair pricing. Out of the 12 Anti Retrovirals registered in Kenya, only five are patented locally; so generics of the other seven should be immediately registered for use.
- (vi) As currently constituted the Pharmacy and Poisons Board is not an independent corporate body but is run by Ministry of Health officials. Technically, the board is a department within the Ministry of Health. Most practitioners in this sector would like to see a more independent board, preferably in the form of a parastatal body with independent management. This would ensure speedy drug registration and better post-market surveillance of pharmaceuticals products.
- (vii) There is urgent need for the Minister of Trade to set up the Industrial Property Tribunal as stipulated in the Industrial Property Act 2001. The rules and procedures of this tribunal should also be published.
- (viii) Access to drugs should be ensured while at the same time guaranteeing quality. This should apply especially in the case of generic drugs.
- (ix) There is need to ensure that doctors and other medical personnel are adequately trained in the prescription and dispensation of drugs.
- (x) There is need to establish a trust fund for purposes of ensuring access to drugs by the disadvantaged.

### **3.11 HIV AND AIDS, AND CULTURAL AND RELIGIOUS MATTERS**

#### **Issues**

As a constitutional right, Kenyans are free to express and exercise cultural beliefs and practices that are peculiar to themselves. However some cultural practices are risk factors in the spread of HIV. Should legislation be used to proscribe those cultural practices that increase the chances of HIV infection? How do we strike a balance between rights to a people's cultural identity, and public health concerns?

HIV and AIDS touch on issues of sex and death issues that carry mystique in an African cultural set-up. The silence that surrounds these issues spawns ignorance, as public debate on HIV and AIDS is stifled. How do we ensure that the silence

surrounding issues of sex and death is broken, to encourage publicity on issues regarding HIV and AIDS?

Currently, commercial sex workers and people expressing alternative sexual preferences, i.e. gays and lesbians, are people confronted by rejection and discrimination from mainstream society. However, such discrimination is inimical to efforts aimed at stemming the spread of HIV. Consequently, is there need to recognize and ultimately decriminalise commercial sex work? Is the country ready to accept gays and lesbians as part of its mainstream society, and with such acceptance adopt measures to promote risk-free behaviour among these groups? What is of more importance to Kenya as a nation: are we only concerned with moralistic arguments or should our goal be to arrest the spread of HIV?

In the debate on HIV and AIDS, religious groups have been very vocal particularly as regards the use of certain preventive measures (the condoms). It is said that publicly encouraging people to use condoms is tantamount to endorsing adultery and fornication. But if people do not practice safe sex, then the battle against HIV and AIDS will be difficult if not impossible to win. In this context, what should be the role of religious organizations in the fight against HIV and AIDS. Should they be allowed to protest and campaign against the use of certain preventive mechanisms, and in the process undermine current anti-HIV and AIDS. Should we ignore religious organisations' protest against the introduction of sex education (family life education) in our learning institutions?

### **Summary of Views and Analysis**

There are several cultural practices and beliefs which have been identified as promoting the spread of HIV. These include early marriages, polygamy, wife inheritance, male circumcision, female circumcision, cleansing ceremonies, wife-sharing among peers, prolonged post-partum abstinence, immediate post-partum sex, ceremonies associated with burial rites and sexual intercourse, insertion of vaginal products, dry sex, witchcraft among others. All of these invariably involve sexual relationships and are pertinent in contributing to the spread of HIV and AIDS.

It was noted that most cultural practices in Africa had the welfare of the community at heart and are generally positive in providing social security for the vulnerable, but these have been misinterpreted to benefit selfish individual needs, and it would be prudent for the government to outlaw cultural practices that are not only harmful and detrimental but which also fuel the spread of HIV and AIDS.

It was suggested that an understanding of the role of sex in people's lives will assist Kenya to develop interventions that are culturally acceptance and which address the real problem.

A general overview of African culture indicates a trend where the male are dominant over the female members of society. Consequently, females tend to be in a position that greatly reduces their ability to make certain decisions that may enable them to avoid getting into risky situations. They are therefore more vulnerable than their male counterparts.

It was recognised that the status of the African woman in society was contingent on child-bearing, with a preference for male offspring. This was said to affect decisions on family size, fertility and sexuality. On this account, women will continue bearing children even with a knowledge of the risky situation, as they have no power to bargain for safe sex in the home.

It was said that cultural, biological and personal considerations influence early sexual activity with young girls, and this predisposes them to HIV infection.

The conclusion reached by some stakeholders was that socialisation of girls in many communities dictated submissiveness, thus creating a situation where girls cannot negotiate or reject sexual advances, thereby putting them at risk of sexual abuse and of HIV infection.

More than 80% of Kenyans are believed to belong to some religion. Religious organizations are therefore key to the strategies to combat HIV and AIDS in Kenya.

The fight against HIV and AIDS initially met a cautious and distant welcome from the religious organizations. Some policies, like the condom strategy and sex education in schools, were resisted. The religious organizations tended to give moral judgement to the trends of infection, which contributed to the high stigma relating to the condition, particularly within the various churches and mosques.

It was noted that religious organisations in Kenya have now shown their commitment in the fight against HIV and AIDS and have issued policy statements that recognises the AIDS challenge as a challenge of the church as well, and committed themselves to be actively involved in developing policies that will contribute to prevention, better care and support for infected persons and affected families.

In addition, religious organisations operate and support a number of health-care institutions as well as schools. They also operate counselling services for varied groups, such as the youth and married couples, provide home-based care and support to orphans and to PLWHAS.

Since religious organisations are known to enjoy a high degree of credibility among the communities in which they operate, and have a unique infrastructure that has sustainable human resources and divergent focus groups such as the youth, women, men and children in their formative ages, it was thought they are in a strategic position to influence the fight against HIV and AIDS and to instill positive attitudes in society.

Some religious organisations have been vocal against certain control and preventive devices such as condoms, as well as sex education in Schools. Although abstinence has been faithfully advanced as the only intimate and effective means of infection prevention, infections have greatly increased, indicating the inadequacy of doctrines in the fight against HIV and AIDS.

It was suggested that since the religious setting provides a strong social background with a networking of the various groups, religious organisations can be used to provide social support for groups of PLWHAS.

### **Recommendations**

- (i) Wilful infection should attract penal sanctions so as to encourage PLWHAS to exercise responsibility towards other persons.
- (ii) There is need to provide penal sanctions against those activities that put women and children at risk, e.g. violence in the home. In this regard, support for the Domestic Violence Bill (2002).
- (iii) Cultural practices that are harmful to certain sections of the population, e.g. women and children, should be outlawed. This is the general trend being adopted under new legislative measures, e.g. the Children Act.
- (iv) People who father children without expectation of assumption of responsibility should be made to provide for them by re-introduction in Parliament of the Affiliation Act. This should emphasise the right of the child to parental support, irrespective of whether the parents married or not.

## Policy Recommendations

- (i) There may be a need to remove legal restrictions on transactional sexual liaisons (commercial sex work) if only for the purpose of regulation and control.
- (ii) There is need to enforce rules regulating the operations of leisure places such as bars, theatres, movie halls, video halls and such to reduce the opportunity of bad influences. The distinction between modernizing and westernizing should be made clear with the positive local social and cultural practices being encouraged. The blind adoption of western cultural and social trends without the necessary social infrastructure to handle it contributes to the bad effect on our youth, including through some of the programmes they are exposed to.
- (iii) There is need to develop new and appropriate guiding messages for evaluating approaches to advocacy for impact on behavioral change and AIDS control.
- (iv) Policy should provide informed direction, development and implementation of strategies that would enhance behavior-change and provide care and support for those infected and affected by HIV and AIDS.
- (v) Religious institutions are an essential element of a successful intervention programme in Kenya. Where the population generally accepts the advice of religious leaders; they would assist in creating a conducive atmosphere and environment for the development of appropriate policies.
- (vi) Religious leaders should use their influence to encourage discussions about HIV and AIDS and to promote openness so as to demystify and lessen the stigma associated with the pandemic.
- (vii) Support, design and development of gender and culturally-sensitive media dissemination is essential.
- (viii) Information that highlights the roles of women in society should be developed and widely disseminated.
- (ix) Development and support for gender sensitisation programmes at community level, specifically on HIV and AIDS, and its relation to gender, should be undertaken.

- (x) There is need to pursue policies that seek to promote the economic status of women.
- (xi) Men and Women living with HIV and AIDS should be encouraged to form organisations that promote their specific needs.
- (xii) There is need to promote changes in cultural practices, to keep up-to-date with modern trends, while discouraging those practices that promote the spread of HIV and AIDS.
- (xiii) It is also necessary to discourage the sexual link in burial rites of some Kenyan communities.
- (xiv) Enhancing the capacity of women and children to engage the legal process to protect their rights to property inheritance and succession should be undertaken.
- (xv) There is need to change people's attitudes towards the use of some of the existing preventive measures, such as condoms and femdoms with a view to appreciating their importance in situations where abstinence is not possible.
- (xvi) Learning institutions should implement family life education. Where appropriate, information on sexuality and the HIV and AIDS pandemic should be disseminated, as appropriate to the age levels.

### **3.12 THE RIGHTS AND RESPONSIBILITIES OF PEOPLE LIVING WITH HIV AND AIDS, AND OTHER RELATED MATTERS**

#### **Issues**

The rights of PLWHAS have been variously addressed. Simultaneously, such rights must be accompanied by certain responsibilities. What these responsibilities and what is to be done in the event of failure to live up them?

People living with HIV and AIDS are key players in the role of society in preventing HIV infection, caring for those infected and affected, and controlling the scourge.

One of the key questions is what controls should apply to a person living with HIV and AIDS, who despite knowing his or her status, intentionally or recklessly infects another person, or puts such other person at risk of infection? What

recommendation should be made on the provision and use of condoms? Should every hotel or place of accommodation be required to provide condoms? Should persons living with HIV and AIDS be required to disclose their status to their sexual partners, and to use condoms?

Should there be a policy on the use or abuse of alcohol, drugs and other psychotropic substances, as a factor in the spread of HIV and AIDS? Should there be advertisements that negatively impact on efforts to control HIV and AIDS? How can any measure taken in this regard be rationalized with the freedoms of the press?

### **Summary of Views and Analysis**

Reactions to HIV and AIDS pandemic have typically centred the form of denials which are compounded by ignorance. In order to correct this failure to make proper responses, there is need to give HIV and AIDS "a human face", through the principle of Greater Involvement of People Living with HIV and AIDS (GIPA). This principle, launched at the Paris AIDS Summit on 1<sup>st</sup> December 1994, encourages PLWHAS to bring their personal experience to the planning and implementation of strategies aimed at stemming the epidemic. GIPA means recognising the important contribution that PLWHAS or those affected by HIV and AIDS can make in the response to the epidemic, and creating space within the society for their involvement and participation in all aspects of the response.

Generally the view was expressed that measures that stigmatize and discriminate against PLWHAS are incompatible with efforts aimed at encouraging participation of PLWHAS in the fight against HIV and AIDS. Consequently, an enabling environment should be created to facilitate the provision of care, support.

The principle of involving PLWHAS has been part of the response to HIV and AIDS since the onset of the epidemic. It was first articulated in the Denver Declaration of 1983, and endorsed at the Paris AIDS Summit where it was dubbed the "Greater Involvement of People living with HIV and AIDS (GIPA). After the Denver Declaration PLWHAS sought not only to secure the promotion of their rights, but also to achieve a recognition for the roles and responsibilities they were expected to carry as PLWHAS.

In 1993, 42 states signed the **Paris AIDS Summit Declaration**, which acknowledges the central role of PLWHAS in the prevention of HIV and AIDS. By the declaration, Governments took the responsibility to involve PLWHAS as partners in the fight against HIV and AIDS.

Whereas the rights-based approach against the pandemic entails the protection of the rights of PLWHAS, it correspondingly entails the promotion of respect for the rights of other persons. PLWHAS have a responsibility to respect the autonomy and health-needs of others, and to take reasonable measures to prevent the transmission of HIV to others.

In order for PLWHAS to fulfil their responsibilities to others, there must be an enabling environment that promotes their own interests.

A fair construction of the body of international human rights law, would bear an inherent requirement on the part of PLWHAS to respect the rights of others, and take measures to safeguard the health of others, or at least not expose others to infection through their action.

During all consultations with the public and other stakeholders the view was expressed that where PLWHAS act recklessly and intentionally, and in the process infect other persons with HIV, then they must be made to take responsibility for their action. It was recognised that whereas criminalisation of wilful acts of transmission was not *per se* an appropriate reaction, yet it is necessary to pass the message that wilful or reckless infection of others is wrong and carries some responsibility with it.

The general view as expressed by the respondents was that arbitrary or unlawful interference with one's privacy, family, home or correspondence was reprehensible. Everyone has the right to the protection of the law against unwarranted attacks on their honour and reputation. By the same token, it was felt that PLWHAS should bear the responsibility of informing other persons placed at risk, by themselves, of their status and to take measures necessary to prevent wilful or reckless infection.

International human rights instruments impose an inherent duty on PLWHAS to respect the rights to health and physical integrity, of others and to take appropriate steps to ensure this where necessary.

## **Recommendations**

- (i) Mandatory testing and other non-consensual medical examinations or inquiry are generally reprehensible especially where the test results are to be used in a discriminatory manner.
- (ii) It is necessary to enact laws that protect PLWHAS from discriminatory practices.

- (iii) There is need to explicitly provide for the protection of the human rights of PLWHAS, and to create an atmosphere that is not compromising to their survival.
- (iv) Although it is recognised that punitive measures against PLWHAS is not an appropriate reaction, yet in cases of wilful or reckless infection of others, there may be need to take adverse measures in order to promote responsible behaviour among PLWHAS. Any restriction on the rights of a PLWHAS must follow due process, e.g. the right to be heard, and the right to appeal for review of decisions. Consequently, it is suggested that the penal laws be amended to reflect this need.
- (v) Every Hotel, Hostel, Motel or other places of temporary accommodation shall provide, on request, condoms and/or femdoms of reasonable quality on request, either freely or at a reasonable price.
- (vi) Every such Hotel, Hostel shall ensure proper disposal methods, and observe necessary discretion in condom or femdom handling, placement and disposal.

### **Policy Recommendations**

- (i) A conducive environment should be put in place to encourage all Kenyans to voluntarily go for HIV testing with a view to knowing their status and subsequently making deliberate choices to live responsibly with the virus.
- (ii) Provision of education and dissemination of awareness on HIV and AIDS would be more effective if people living with HIV and AIDS were actively involved. When PLWHAS participate in the initiative, the impact is greater, and it also serves to break the silence over the pandemic and lessen discrimination and stigma towards PLWHAS.
- (iii) The primary aim of such participation would not be to give factual information, but to portray the realities of living with HIV and the challenges faced by PLWHAS. All interventions taken with a view to disseminating information about HIV and AIDS must involve the PLWHAS. This includes schools set-up and workplaces.
- (iv) There is need to include PLWHAS in key decision-making forums both at the grass root and at national levels, as an official recognition of the key role they play in reducing stigma and discrimination.

- (v) There is need to build the capacity of PLWHAS to enable them to influence their own treatment and access to health care. In this regard, PLWHAS must be considered key players, and key determinants in issues regarding access to essential drugs, treatment, care and support.
- (vi) There is need to encourage PLWHAS to form networks so as to collectively promote their interests.
- (vii) PLWHAS ought to be able to form organisations to effectively advocate for their own rights. Specifically, there should be District and Constituency focal points in line with the National Aids Control Council. Also, there is need to build the capacity of PLWHAS to enable them come up with strong organisations through which they can take up their responsibilities and play an effective role in prevention, care and mitigation.
- (viii) There is need to enhance the capacity of PLWHAS networks to strengthen leadership and governance, which are critical elements in changing the course of the epidemic.
- (ix) Financial support will necessarily be required for such networking to be effective. The establishment of micro-grant facilities to promote and support community-based initiatives emanating from groups of PLWHAS would be essential in sustaining relevant projects.
- (x) Organisations and networks of PLWHAS and those interested in the issues should be able to actively participate in, and indeed influence the making and the content of policies aimed at addressing the HIV and AIDS pandemic. PLWHAS must be able to participate at all levels of formulation and implementation of policies and programmes that will create a supportive ethical, legal and social environment for an expanded response to the epidemic. These strategies should provide an appropriate leverage for individuals living with HIV and AIDS to influence policy and programmes in the various relevant institutions, and at the national level. They are also likely to empower individuals living with HIV and AIDS, to strengthen their organisations and networks, and to constitute them into a mechanism for promoting greater involvement of people living with HIV and AIDS.
- (xi) PLWHAS are unlikely to open up to the society and take up their social responsibilities, unless society itself opens up to them and stops vilifying

and viewing them with suspicion and hostility. There is, therefore, a need to invest in programmes aimed at changing the mindset of the general public.

### **3.13 HIV, AIDS AND OTHER HUMAN RIGHTS QUESTIONS**

#### **Issues**

The basic question to be addressed is whether the Constitution as it is protects the rights of People Living with HIV and AIDS. If not, how best can the Constitution be amended to provide for this? Can such provision specifically mention HIV and AIDS or should it be generic?

Quarantine and segregation has been employed in some countries. Are these appropriate and effective measures on checking the spread of the virus? Can these be entertained in special situations like schools and prisons?

How are we to deal with travel restrictions, and requirements of AIDS-Free Certificates by some countries? Recognizing that the question of who to allow into the country is at the sole discretion of each sovereign country, and also that no legislation enacted could regulate foreign nations, what options should one consider? Should we consider reciprocity – that we shall require such certificates for every country which requires such certificate for Kenyans?

How should we address discrimination and stigmatization in admission to Universities, Colleges and Schools, including in private institutions? Can such private institutions be forced not to discriminate? Recognizing the special position and vulnerability of people with disability, what additional measures may be taken to protect them? Should the use of brail and sign language be mandatory in such institutions?

The right to sexual orientation, which has been recognized by some countries, is also relevant. Are we, as a country ready and prepared to accept homosexuality and lesbianism? How do we enforce the rights of the citizens to AIDS information – especially how to ensure those with disability have equal access to such information? Should HIV and AIDS be taught in schools? If so, what sort of information should be included?

Access to Justice by People Living with HIV and AIDS remains an important question. How can we ensure confidentiality of People Living with HIV and AIDS who wish to litigate in the event of abrogation of their rights? Should it be

recommended that in such event, filing fees should always be waived? Would such special concessions contribute to the stigma?

### **Summary of Views and Analysis**

The legal issues arising in the wake of HIV and AIDS are varied and far reaching, even though this is not often fully appreciated. However the HIV and AIDS pandemic has precipitated a legal and human rights crisis of not only national, but also international, proportions. Hence, HIV and AIDS is as much a legal, as it is a medical problem.

As much in panic as in an attempt to come to grips with the spread of HIV and AIDS, many governments instituted measures that amounted to an affront on human rights. The result has been the unwitting stigmatisation of PLWHAS, their isolation and subjection to discrimination. Whereas stigmatisation and isolation may amount to social consequences, discrimination is more of a legal issue, requiring specific legislation to deal with.

It was felt that lack of specific legislation to guarantee the rights of PLWHAS and to regulate the way people interact with them was one of the reasons why the morbidity and mortality resulting from HIV and AIDS could not properly be tackled. Such legislation could be given proper backing if premised upon the Constitution, hence the need to entrench those rights within the Constitution.

Stakeholders were of the view that quarantine and segregation of people living with HIV and AIDS is discriminatory and inimical to measures for the containment and prevention of the spread of HIV and AIDS. However, it was felt that isolation may be justifiable under certain instances, but that this must be based on sound medical criteria, e.g. where it is necessary to stem the spread of infectious opportunistic diseases. Generally, it is important that PLWHAS stay close to their family members for material, social, emotional and psychological support. It was felt that isolation of people from the general community on the basis of sero-status negated the essence of existence in community. An exception was suggested in the case of prisoners: where in the interests of other prisoners it was not medically safe that they be integrated, then isolation would be justified.

The view was expressed that restricting the right to travel for HIV and AIDS patients is a violation of their freedom of movement. Further, it was thought it would limit the options of PLWHAS in seeking treatment and proper medical attention, as well as curtailing their liberty. There was a view expressed that visitors be screened for HIV and AIDS, but since no other view supported this stand, it was felt not to be proper.

It was also felt that discrimination against, and stigmatisation of PLWHAS exacerbates the prevalence levels of HIV and AIDS. They are incompatible with HIV and AIDS prevention strategies. It was shown discrimination against PLWHAS is rampant in health-care, employment and insurance sectors, among others. Respondents believed that the failure or omission by the Constitution to expressly outlaw discrimination based on medical condition, left an exploitable loophole the consequence of which is that at both the formal and informal levels, discrimination is perpetrated against PLWHAS.

It was stated that the plight of the disabled was more serious than that of other PLWHAS with "normal" physical attributes. First, a disabled person living with HIV and AIDS will have been subjected to discrimination on the basis of his or her physical or mental attributes. The incidence of HIV and AIDS finds them already in a disadvantaged position and hence reinforces this discrimination. On the other hand, different categories of disabled persons faced discriminatory treatment differently. For instance disabled women suffer more discrimination, not only on the basis of their physical inadequacies, but also in terms of their sex. With the onset of HIV and AIDS, it becomes clear that their situation is more disadvantaged.

Respondents were of the general view that the citizenry have a legitimate expectation, if not a right, to receive information about HIV and AIDS and in particular, information touching on infection rates, mortality, transmission, treatment and prophylactic measures, care of PLWHAS, new discoveries and other relevant information on curative discoveries. This right or expectation encompasses the entitlement to receive the right and scientific based information. Hence this implies a duty on the government to protect against the exploitation of those infected or affected by unscrupulous individuals making false claims of discoveries.

## **Comparative Analysis**

### **Australia**

- (i) The framework for combating the HIV and AIDS epidemic in Australia has been provided by a comprehensive National HIV and AIDS Strategy in recognition of the value of a single strategic document in providing a cross-cutting framework relevant at all levels for coordinated coherent national responses.

- (ii) Throughout the strategy, it is recognised that an environment that respects and protects the rights of PLWHAS and those affected by HIV and AIDS as well as those at risk of HIV infection, is vital to effective HIV prevention, education and health promotion.
- (iii) The strategy seeks to promote non-discriminative practices in relation to HIV and AIDS.
- (iv) It emphasizes the need for the legal environment to emphasise a rational, humane, non-coercive and responsive approach to the serious problems posed by HIV and AIDS and the promotion of policies designed to eliminate discrimination against marginalisation of and prejudice against PLWHAS.
- (v) The Australian approach is general and non-exclusionist and seeks to address the rights of all people, inclusive of those said to be in vulnerable positions e.g. gay and lesbian peoples, racial minorities, injecting drug users, people in custodial set-ups, sex workers, women and children
- (vi) The Federal Disability Discrimination Act, 1992 makes discrimination on the basis of disability (which is defined to include HIV and AIDS) illegal *per se*. There are certain instances, especially in employment, where a person may be allowed to discriminate but the burden of proving the justifiability of the same vests on that person. An act of discrimination can be exempted if it is reasonably necessary to protect public health or if the disability relied on to support the act of discrimination is an infectious disease.
- (vii) The Federal Court of Australia in *Commonwealth of Australia v. The Human Rights and Equal Opportunity Commission and "X"* (No. Qg 115 of 1995, 1996 Aust. Fed. Ct. (Lexis 859). Found that the exclusion of a recruit with HIV from military service constituted discrimination on the basis of disability because seronegativity was not a *bona fide* job qualification.

## United States

- (i) The Rehabilitation Act provides a measure of protection from discrimination on the basis of disability with specific reference to employment situations. The Act has been interpreted by U.S. Courts as banning discrimination against persons with HIV or AIDS.

- (ii) The Rehabilitation Act has limited application and does not provide a comprehensive national protection against discrimination hence the use of the federal Americans with Disabilities Act (ADA) which provides comprehensive protection against discrimination on the basis of disability. Generally, people living with HIV and AIDS are covered under the ADA and given some measure of protection from discrimination on the basis of their HIV status.
- (iii) No definitive and clear situations exists as yet, in the USA on the various matters relating to HIV and AIDS and human rights. Currently each State operates under its own regime which is emerging from judicial review rather than straight HIV and AIDS related legislations.

## **Canada**

- (i) The Canadian strategy to combat HIV and AIDS incorporates a component of legal, ethical and human rights issues.
- (ii) The Canadian strategy recognises that the epidemic affects two distinct populations differently, that is, those who have access to all the benefits that are available to the society, and those who form the minority and who, because of societal prejudices, have no such access.
- (iii) Hence the goal of legal, ethical and human rights activities should be to ensure just laws, policies and programmes that respect and promote the rights of people with HIV or AIDS, to promote and facilitate rather than hinder prevention efforts; and promote and facilitate rather than hinder efforts to provide care, support and treatment to people with HIV or AIDS.
- (iv) The Ontario Human Rights Code and the Canadian Human Rights Act provide fairly comprehensive legal provisions stressing the right to equal treatment and non-discrimination.
- (v) The Canadian Courts have generally viewed HIV and AIDS as disability and hence extended anti-discrimination protection to them.
- (vi) Whereas HIV and AIDS Specific Legislation has not been the chosen options for Canada, the law organisations have engaged in discussion of the various legal issues through literature and publication.

## **Philippines**

Under the AIDS Prevention and Control Act No. 8504 of 1998, the state commits itself to extend to every person suspected or known to be infected with HIV or AIDS full protection of his/her human rights. The Act bans discrimination in various areas inclusive of employment, learning institutions, travel, public service, credit insurance, health care and burial services.

## **Tasmania**

The HIV and AIDS Preventive Measures Act, 1993 provides measures for the prevention and containment of HIV and AIDS, and for the protection and promotion of public health and for appropriate treatment, counselling and care of persons infected with HIV and AIDS or at risk of HIV and AIDS infection. It seeks to ensure protection of the rights of all persons in relation to HIV and AIDS. It also prescribes penalties for failure to disclose one's status.

## **Framework Under International Law**

The major international human rights instruments do not make specific provisions on HIV or AIDS, although unarguably, their application extends to cover the human rights of PLWHAS. They provide a coherent normative framework for analysis of the HIV and AIDS problem and a legally binding foundation with procedural institutional and other accountability mechanisms to address the societal basis of vulnerability and implementation of change.

They provide certain guarantees which, when applied, are relevant in the context of HIV and AIDS. These include:-

- (i) Non-discrimination and equality before the law; relevant in the areas of discrimination against PLWHAS in the areas of health care, employment, education, immigration, international travel, housing and social security.
- (ii) Health; relevant in the requirement of equal and adequate access to the means of prevention, treatment for vulnerable populations with lower social and legal status (such as women, children, social and sexual minorities).
- (iii) Privacy, both informational and physical; relevant in ensuring confidentiality of HIV test results and prohibiting mandatory/compulsory testing.

- (iv) Education and information; relevant in ensuring equal and adequate access to prevention education and information.
- (v) Freedom from cruel, inhuman or degrading treatment or punishment relevant in prohibiting automatic isolation or segregation of HIV positive prisoners.
- (vi) Autonomy, liberty and security of the person, relevant in the prohibition of HIV testing or research without informed consent, and prohibiting detention or quarantine solely on the basis of HIV status.
- (vii) Freedom of expression assembly and association relevant in ensuring availability of registration for groups of PLWHAS, sex workers etc.
- (viii) The right to marry and found a family, relevant in prohibiting mandatory premarital testing and coerced abortions or sterilisations.

### **Current Trends**

- (i) The international community has expressed commitment towards the creation of obligations on states with implications for HIV and AIDS.
- (ii) The International Consultation on Health and Legislation and Ethics in the Fields of HIV and AIDS convened in 1988 by the World Health Organisation called for the eradication of discrimination against PLWHAS.
- (iii) On 13<sup>th</sup> May 1988, the World Health Assembly passed a Resolution entitled; "Avoidance of Discrimination in Relation to HIV – infected People and People with AIDS" which underscored the need for respect and protection of human rights.
- (iv) In July, 1989, the United Nations Center for Human Rights held an International Consultation on HIV and AIDS and Human Rights which highlighted the human rights issues arising in the context of HIV and AIDS.
- (v) The UNDP facilitated an Inter-country Consultations on Ethics, Law and HIV in the Philippines in May, 1993 and in Senegal in June, 1994, both of which produced consensus documents re-affirming a commitment to voluntarism, ethics and the human rights of those affected.

- (vi) The United Nations General Assembly in Resolutions passed in 1990 and 1991 emphasised the need to counter discrimination and to respect human rights and recognised that discriminatory measures drove HIV and AIDS underground making it more difficult to combat.
- (vii) The United Nations Commission on Human Rights at its Annual Sessions since 1990 has also adopted numerous Resolutions on Human Rights and HIV and AIDS which *inter alia*, confirm that discrimination on the basis of HIV and AIDS – status is prohibited by existing international human rights standards and clarify that the term “or other status” used in the non-discrimination clauses of international human rights documents should be interpreted to include health status such as HIV and AIDS.
- (viii) There are also numerous Charters and Declarations which specifically or generally recognise the human rights of people living with HIV and AIDS adopted at both national and international conferences and meetings.
- (ix) The Joint United Nations Programme on HIV and AIDS (UNAIDS) and the United Nations High Commissioner for Human Rights promulgated 12 guidelines entitled “International Guidelines on HIV and AIDS and Human Rights”

These guidelines present concrete measures which legislation can take to protect human rights and promote public health in responding to the HIV and AIDS epidemic.

They also provide explicit benchmarks to implement and measure performance in developing an effective rights-based response to the HIV and AIDS epidemic. They further clarify obligations under the international human rights instruments already acceded to by states.

## **Conclusion**

- (i) There is need to promulgate legislative policy instruments that recognise and protect the human rights of PLWHAS and those affected thereby. This need is informed by the fact that the effective approach to combating the HIV and AIDS epidemic is one that lays emphasis on the rights of PLWHAS and those affected by HIV and AIDS.

- (ii) We need to recognise that HIV and AIDS affects different populations of the society differently and any intervention must pay specific regard to this need.
- (iii) Since HIV and AIDS thrive alongside poverty, it is time for Kenya and the International Community to start laying emphasis on the importance of implementing Economic social and cultural rights. As at this time, the world has placed a larger portion of its resources and emphasis on Civil and Political rights at the expense of the other rights.

### **Recommendations**

- (i) The Constitution must make reference to a category which upon construction will extend to protect persons with HIV and AIDS e.g. it should outlaw discrimination on the basis of "health status".
- (ii) It may be necessary to amend the Constitution to reflect the need to protect PLWHAS from unauthorised or unethical biomedical research although in the final analysis this may have to remain in the domain of policy considerations. (Elsewhere in the report a Biomedical Research Act is proposed).
- (iii) The Constitution should be more specific on the protection of privacy and confidentiality; not only physical but also in terms of information. Every person must have the right to control the use and dissemination of personal information.
- (iv) No person's freedom of movement should be denied on the basis only of health status.
- (v) All personal laws that are discriminatory either of themselves or of their effect must not be applied under any circumstances. This will prevent the application of discriminatory customary laws in matters of adoption, marriage, divorce, or other matters deemed to be of a personal character. In this regard the exception provision to Section 82 of the Constitution should be repealed.
- (vi) The Constitution should be reviewed so as to expunge those provisions that are themselves discriminatory as against particular sections of the population e.g. the provisions relating to citizenship which unfairly discriminate as against women.

- (vii) No persons' liberty ought to be curtailed on the basis only of their HIV status where it is necessary to do so due to a person's illegal behaviour, there should be a real danger of substantial harm to other persons and due process must be adhered to before restriction is imposed.
- (viii) The Constitution should proscribe discrimination on the grounds of age so as to protect PLWHAS also advanced in age from discrimination on that ground.
- (ix) Just as we have done with the convention on the Rights and Welfare of the Child, and the African Charter of the Rights of the Child, the Government should domestic the key human rights instruments which it has ratified. These include the International Covenant on Civil and Political Rights (ICCPR), The International Covenant on Economic, Social and Cultural Rights (ICESCR), The African Charter on Human and Peoples Rights and the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW) and also the relevant ILO instruments.

### **Policy Recommendations**

- (i) The Government should promulgate policies through its various departments that call for the promotion of non discriminatory practices in the various sectors, both public and private.
- (ii) There may, be need to propagate policy directions that encourage more liberalised views and tolerance of certain minorities hitherto deemed abnormal for the safe, proper and effective containment of the epidemic; there include commercial sex workers, and the community of Gays and Lesbians.
- (iii) There is need to promulgate a policy statement that explicitly recognises the vulnerability of people with disability in the society in the face of HIV and AIDS and seek to promote their basic rights. (The People With Disabilities Bill is a step in the right direction)
- (iv) The Government should come up with Policy Guidelines on the dissemination of information on rights and responsibilities relating to HIV and AIDS. This may involve action through the various Ministries and Departments of the Government.
- (v) There is need for policy directions that regulate the conduct of health care workers towards patients with HIV and AIDS and which should emphasise

the necessity of a non-discriminative approach that upholds the human rights of patients.

- (vi) Policy guidelines should also seek to regulate the field of biomedical research for purposes of upholding the human rights of persons participating in research.
- (vii) Policy guidelines should direct the approach and attitudes of legal and judicial officers towards persons with HIV and AIDS. They should encourage a sympathetic and accommodative outlook and the need to handle matters relating to HIV and AIDS sensitively and with the necessary expedience.
- (viii) Means of access for redress of alleged violations should be simple sensitive and accommodative of the needs of PLWHAS, including the need to protect their privacy and confidentiality.
- (ix) PLWHAS must have their right to access treatment and medicines guaranteed.
- (x) The public institutions concerned with legal issues should include legal advocacy and education of the citizenry on human rights. This role should not be left entirely to the civil society alone.

#### 4.0 SENSITIVE LANGUAGE AND PHRASES RELATING TO HIV AND AIDS

As the Task Force undertook its work, it became apparent that the language and phrases used in matters relating to HIV and AIDS are relevant to the fight against this scourge. Members learnt that language use has heavily contributed to the high stigma relating to HIV and AIDS. Below are some of the phrases that are believed to either misinform society or contribute the high stigma associated with HIV and AIDS. These have been included to help educate and caution people on the language use in the fight against HIV and AIDS. In many fora, people have got upset because of the language used and interpreted the same as a violation of their human rights.

	<b>Language/Phrases that contribute to the high stigma</b>	<b>Correct Language/Phrases</b>
1	HIV and AIDS Victims People with unclean blood (Watu wa damu mbaya) Those People (Wale Watu)	People Living with HIV and or AIDS Patients
2	AIDS Victims/AIDS Sufferers	AIDS Patients
3	HIV/AIDS	HIV and AIDS
4	Mother to Child Transmission of HIV (The phrase 'Mother to Child' is thought to unfairly focus on the women and indirectly blame them for the infection of the child when the infection in the woman is likely to have originated from the father to the child.)	Parent to Child Transmission (This phrase is however not officially adopted).
5	AIDS Orphans	Children Orphaned by AIDS
6	Disabled People	People with Disability  (In some countries disability is defined to include living with HIV and or AIDS; Many stakeholders in Kenya find a problem with this definition as is explained elsewhere in this report).
7	AIDS Widows	Widows
8	Dirty Blood	HIV infected blood

## 5.0 THE WAY FORWARD

### **Enacting the HIV and AIDS Prevention and Control Act**

In view of the various issues raised at public hearings and the presentations on the various legal issues relating to HIV and AIDS, it would be prudent to enact an HIV and AIDS-specific legislation. It is proposed that the said statute be referred to as "**The HIV and AIDS Prevention and Control Act**". The Act is intended to deal with most if not all the legal issues arising in the wake of HIV and AIDS. In enacting an HIV-specific legislation, novel issues raised in the course of the work of the Task Force would be covered. The Act would deal with specific areas and address the concerns raised in relation to, among other things:

- (i) Testing and confidentiality
- (ii) HIV and AIDS in the workplace
- (iii) HIV and AIDS and insurance
- (iv) Human rights
- (v) HIV and AIDS in the education sector
- (vi) HIV and AIDS in prisons
- (vii) HIV and AIDS in criminal law – except where amendments to the exiting penal statutes is necessary
- (viii) HIV and AIDS and the Gender question, except where addressed by bills already presented to parliament.
- (ix) Responsibilities of People Living with HIV and AIDS and
- (x) Cultural Issues, among others issues

These are issues that may not immediately be dealt with by way of piecemeal amendments to the existing legislation. The Act will create duties and obligations of all parties concerned. Where necessary it will create sanctions or penalties for breach and/or violation of human rights.

In addition, there may be need to effect amendments of the various existing legislation to ensure harmony with the HIV and AIDS prevention and control Act.

### **Establishment of the National AIDS Control Council under an Independent Statute**

It is highly recommended that the National AIDS Control Council be established under its own statute, perhaps a National AIDS Control Council Act. The enactment of the specific legislation will clearly define the mandate, structure and role of NACC agencies. The details of the functions of these agencies will be laid down and this will help to give identity to the National AIDS Control Council, and

entrench it as the coordinating body for the national strategy on the fight against HIV and AIDS.

In particular, the following will be achieved:

- (i) The current role of National AIDS Control Council *vis-a-vis* other players will be defined in detail and clarified.
- (ii) The Act will strengthen the community-based National AIDS Control Council structures through legal recognition and provision for their existence with the necessary budgetary allocation. This will strengthen the implementation of the National Policy at the grass-root level.
- (iii) The legal obligation of the National AIDS Control Council as a State Corporation will be more clearly defined; the State Corporations Act does not have detailed provisions on all the duties and obligations of a State Corporation.
- (iv) Under its own Act, details on the role of the National AIDS Control Council as a resource mobilizer will be set out, with clear provisions on accountability for resources mobilised from all sources. It will help the government to better capture such resource envelopes and monitor utilization of such resources.

### **The establishment of an Implementation Committee**

The recommendations of the report of the Task Force include the need for amendments to certain various sectoral legislation. They also include the need to have a deliberate advocacy policy for all sectors, to inculcate respect for human rights, respect for laws of the land, and the use of law and the legal system for the protection of individual rights. Given the urgency of actions in the fight against HIV and AIDS, it is proposed that an **Implementation Committee** be established by the Attorney-General.

- (i) To work with implementers in the various sectors and to give periodic updates of progress in achieving the suggested recommendations on the various thematic issues especially the policy recommendations.
- (ii) To co-ordinate a nationwide advocacy programme on legal issues.
- (iii) To give a periodic review of achievements on implementation of the legal measures necessary for the fight against HIV and AIDS.

The establishment of an **Implementation Committee** is a prerequisite to the attainment of the recommendations made by the Task Force. It is proposed that the Implementation Committee be lean and be clothed with the quality of persons who understand the issues at hand or who would be able to co-ordinate the actualization of the proposed recommendations.

It must be pointed out that the **Implementation Committee** will in its implementation programmes work with all stakeholders in the various sectors with a view to effecting all the necessary amendments to any sectoral legislation, give guidance on legal issues affecting the sectors, and most important, help smoothen the Bill for the proposed HIV and AIDS prevention and control act for presentation to parliament with all reasonable dispatch..

### **The Enactment Of The Bio-Medical Research Act**

Given the unclear situation relating to biomedical research involving human participation in Kenya, and given the fact that the international legal provisions on biomedical research have largely not been domesticated in Kenya, and regarding that development application and monitoring of research protocols has not been well regulated, it is suggested that a **Biomedical Research Act** be enacted.

This Act Would clearly address the following matters:

- (i) Domestication of international principles on biomedical research involving human participation
- (ii) Providing for a National Ethical Review Committee and other committees which would address ethical issues on biomedical research.
- (iii) Providing for the ethical review of externally-sponsored research
- (iv) Incorporating the protection of the rights of those affected and involved in biomedical research and in particular addressing issues such as:
  - (a) Individual informed consent
  - (b) Essential information for prospective research participation
  - (c) Benefits and risks of study participation
  - (d) Justification of risk in research
  - (e) Research in population and communities with limited resources
  - (f) Involvement of vulnerable persons in research
  - (g) Research involving children

- (h) Equitable distribution of burdens and benefits
- (i) Women as research participants
- (j) Pregnant women as research participants
- (k) The right on confidentiality
- (l) The rights of research subjects to compensation etc

Such legislation would need to be preferred with the involvement of all stakeholders; hence the urgent need for these stakeholders to be convened to begin the work. It is proposed that the work begin as soon as possible since HIV and AIDS have elicited a great interest in research for vaccines and therapy drugs, and Kenya is a prime target for interventional researchers and research organizations.

### **Establishment of An Employment Equity Tribunal**

Since the current laws and structures under the Labour and Employment regimes have many loopholes that are commonly abused by some employers to dismiss employees for flimsy or no reasons, and the ordinary Courts lack jurisdiction to grant meaningful remedies, like reinstatement or compensation commensurate to the loss, the establishment of an Employment Equity Tribunal for HIV and AIDS related cases would help to ensure the protection of the rights of PLWHAS who are terminated or discriminated on grounds of their status. In relation to HIV and AIDS, the tribunal would among others:

- (a) Vet any legitimacy of requests for pre-employment HIV-testing policies
- (b) Preside over cases of termination on grounds of HIV and AIDS.
- (c) Determine fitness to work based on the Work Ability Index.

### **Establishment of a National Children's Trust Fund For The Care Of Orphans**

Establishment of a National Trust Fund for the co-ordination of the care of children orphaned by AIDS or otherwise vulnerable will help to mitigate the impact of HIV and AIDS on children. The Trust should be manned by responsible people and financed from the Consolidated Fund, or from a national levy set up for this purpose. The laws already announced for cell phone tariffs could for instance, be directed to this kitty.

The fund should facilitate certain matters, namely:

- Establishment of structures/institutions for the care of children within the community;

- Together with the Children's Council under the Children Act, help in the implementation of the national strategy on HIV and AIDS as it affects children.
- Pay particular attention to the protection, medication and education of children orphaned by AIDS, whether themselves living with the virus or not. Necessary education and access to essential drugs may be considered to be accorded free of charge to these children.

