Beyond the Shadow

Unmasking HIV/AIDS-related stigma and discrimination in Nigeria

EDITED BY OMOLOLU FALOBI

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Foreword

Except for children born with HIV, most people living with HIV get infected several years after birth. These people live their lives like any other people, until the time a diagnosis of the infection is made.

With a rise in public response, many groups got engaged in prevention efforts through dissemination of HIV related information which in the early years were intended to cause fear that would consequently lead to behavior change.

A morbid sense of fear was quickly created in the minds of people about the infection and this is commonly depicted with the "skull and crossbones" image. HIV-positive people were believed to be "dead but living" people. The term "they" as opposed to "us" became the norm when referring to PLWH as no one wants to be associated with HIV, let alone being infected! "No, it cannot happen to me; neither can it occur among us. It is a disease found among them, the promiscuous, the irresponsible, the poor, etc."

Against this background, an HIV-positive diagnosis is received with horror and shock, not only for the infected but also for his/her family, home, community, peers, etc. All the misinformation that has gone out about HIV and AIDS now come reeling through the mind. The result of this is that fear is created both in the mind of infected, the affected and the general community. Fear, ignorance and misconceptions about HIV and its implications are the root causes of stigma, leading to discrimination against, and rejection of PLWH and their associates.

This then, is the plight of persons living with HIV: severe stigma from within and without, dehumanizing discrimination and defeating rejection on all fronts. These, coupled with tokenism from those purporting to show love and understanding, completely seals the hopelessness of the PLWH. Messages that reinforce this hopeless situation of death, imminent death and suffering for children that will soon be left behind echo loudly every time, creating a "critical situation" for the PLWH.

From whatever angle you view it, stigma is a negative force. It is negative for the HIV-positive person, for the person affected, the community, the national HIV response, the economy and the overall survival of the society. It negates and actively undermines all national responses including voluntary counseling and confidential testing (VCCT), which is generally perceived as the entry point to all interventions. Stigma drives the HIV epidemic underground where it continues to spread unhindered. It forces people living with HIV into hiding and consequently deprives him/her of necessary assistance in dealing with the situation. This lack of support and assistance eventually leads to increased morbidity and mortality.

Nigeria is nearing the end of the second decade of the epidemic. This is the time to review the state of stigma in the polity. This publication is therefore coming at a very good time and will go a long way in pointing out the course of future activities and interventions. It will form a veritable reference material which should guide all stakeholders in programming interventions aimed at reducing stigma and discrimination involving persons living with HIV.

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The project aims to harness the capacity of the Nigerian media and communities as a potential force for change to reduce the high level of HIV-related stigma and discrimination in the country. The goal is to reduce HIV/AIDS-related stigma and discrimination in drastic, measurable terms within the media and other identifiable communities in Nigeria by mid-2005.

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Journalists Against AIDS (JAAIDS) Nigeria is a media-based non-governmental, not-for-profit organization, with a mission to contribute to the prevention, care and control of HIV/AIDS in Nigeria by providing innovative communication interventions that will facilitate positive behaviour change to reduce the spread of HIV/AIDS.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral therapy
CiSNHAN	Civil Society Network on HIV/AIDS in Nigeria
HEAP	HIV/AIDS Emergency Action Plan
HIV	Human Immunodeficiency Virus
ICPD	International Conference on Population and Development
JAAIDS	Journalists Against AIDS
LGA	Local Government Area(s)
MOU	Memorandum of Understanding
MTCT	Mother-to-Child Transmission
NACA	National Action Committee on HIV/AIDS
NASCP	National AIDS and STD Control Programme
NGO	Non-Governmental Organization(s)
PLWHA	People Living With HIV
PMTCT	Prevention of Mother - to - Child Transmission
VCCT	Voluntary Counselling and Confidential Testing
MSM	Men who have sex with men
S & D	Stigma and Discrimination
NELA	Metwork on Ethics, Law & HIV/AIDS
UN	United Nations
UNGASS	Un General Assembly Specials Session on HIV/AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS

Introduction

More than two decades into the HIV/AIDS epidemic, stigma and discrimination against people living with HIV (PLWH)[1] or are affected by HIV/AIDS, continue unabated. The HIV challenge has shown itself capable of triggering compassion, solidarity and support, bringing out the best in people, their families and communities. But stigma and ostracism, repression and discrimination continue to be reported in developed and developing countries of the world.

Herek et al[2] reported that AIDS remains a highly stigmatized condition in the United States though the form of expression has changed over the years. Similarly, reports in literature from Thailand[3], India[4], Uganda[5] and Zimbabwe[6] discuss HIV-related stigma in various contexts and forms in these countries.

The international community had long recognized the limiting effect of HIV-related stigma and discrimination on the control of HIV/AIDS. It is known to undermine the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected[78]. Various declarations and resolutions had been made at regional and international conferences for a recognition of the effects of stigma on HIV prevention and control programmes. The making of these various declarations spanned over 15 years including the recent ones such as resolution 49/1999 of the UN Commission on Human Rights which affirms:

> “Discrimination on the basis of HIV or AIDS status, actual or presumed, is prohibited by existing international human rights standards and that the term 'or other status' in non-discrimination provision in international human rights text should be interpreted to cover health status, including HIV and AIDS”.

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[1] We recognise the current debate about the use of acronym 'PLWHA' and the concern about referring to persons living with HIV as acronyms. The use of PLWH here is just to ensure that the text is short and would aid easy reading

[2] Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United State: prevalence and trends, 1991-1999. *Am J public Health*. 2002Mar;92(3):371-7

[3] Songwathana P, Manderson L. Stigma and rejection: living with AIDS in villages in Southern Thailand. *Med Anthropol*. 2001;20(1):1-23

[4] Balasubrahmanyan V. Health care and human rights. *AIDS Asia*. 1995 May-Jun;2(3):17

[5] Williams G, Ray S. AIDS and the workplace: signs of hope from Zimbabwe. *Glob AIDSnews* 1994;(1):3-6

[7] Mann J. Statement on an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly, New York. 20th October 1987.

[8] Merson M. discrimination against HIV infected people or people with AIDS, WHO/GPA. Speech to Commission on Human Rights, Geneva. 18th October, 1993.

The Abuja Declaration on HIV/AIDS, Tuberculosis and other related Infectious Diseases made in April 2001 states in point 12, that:

> "We are aware that stigma, silence, denial and discrimination against people living with HIV/AIDS increase the impact of the epidemic and constitute a major barrier to an effective response to it."

Also, **the Declaration of Commitment on HIV and AIDS** made during the UN Special Session on HIV and AIDS on the 27th of June 2001, noted in paragraph 13 that:

> "Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations and (this) must be addressed".

The session went on to make resolutions (paragraphs 58-61) which should help in the realization of human rights and fundamental freedom for all so as to reduce vulnerability to HIV, in view of stigma and discrimination associated with the infection.

Despite all these declarations of commitment and call for action made over the decade, the full understanding of what drives the epidemic of stigma remains an enigma. Fundamental questions still remain about its causes and persistence despite increasing awareness and knowledge about HIV and how to effectively confront it.

This report describes a study which tries to unravel some of the issues surrounding stigma in Nigeria. It tries to investigate the forms HIV- related stigma takes, the context in which it occurs and its various determinants in Nigeria. It then uses this to analyse existing policies, pronouncements and programmes in the country to identify their successes, gaps and barriers they create in HIV and AIDS control and mitigation efforts . Finally, the study comes up with recommendations for future actions and focus.

Background

HIV-related stigma and discrimination has been identified as a universal phenomenon which occurs in every country and region of the world. It was identified as the 'third epidemic' early in the history of HIV by late Jonathan Mann; the first being the hidden but accelerated spread of HIV, while the second was the visible rise of AIDS cases.

Stigma continues to be potentially the most difficult aspect of the HIV epidemic to address. However, addressing it would likely be the key to overcoming and reducing the impact of HIV/AIDS in its various ramifications and the key to tackling the first two epidemics identified by late Jonathan Mann.

In recognition of the potential importance of combating stigma and discrimination, the Worlds AIDS Day campaign for the year 2002-2003 focused on stigma, discrimination and human rights. The main objective of the campaign was to prevent, reduce and ultimately eliminate HIV-related stigma and discrimination wherever it occurs and in whatever form.

HIV-related stigma and discrimination are triggered by many factors. These include a lack of understanding of the disease. Many do not understand that HIV and AIDS cannot be transmitted through everyday contact. Myths also exist about HIV transmission. Lack of treatment, irresponsible media reporting on the epidemic, the fact that AIDS is incurable, social fears about sexuality and fears relating to illness and death are factors that further fuel the epidemic of HIV-related stigma.

Unfortunately, this has led to shame and secrecy associated with the epidemic all over the world, both at individual and government levels. It has also led to fear and discouraged open discussions about the causes of HIV and AIDS and the appropriate response that needs to be taken at all levels. There is also increased vulnerability of individuals infected and affected by HIV and AIDS. Individuals feel guilty and ashamed, leading to depression, lack of self worth and despair. In extreme cases, premature death through suicide have been reported. Infected persons are unable to declare their serostatus openly and express their views and opinions which could positively contribute to the control of the epidemic. This secrecy, in turn, had led governments, politicians and policymakers into continued denial of the need for urgent action[910]. The various regional and international declarations are often not backed by national legislations and programmes. The picture of the global epidemic therefore continues to appear gloomy, especially in developing countries.

Presently, 70 percent of the 40 million people living with HIV/AIDS in the world live in sub-Saharan Africa. 90 percent of all people infected with HIV and AIDS live in developing countries. AIDS has reduced the life expectancy of Africa by 15 years. Stigma still remains one of the most significant challenges in this region for all HIV/AIDS programmes, from prevention to care[10]. It has continued to increase vulnerability to infection as fear of being identified with HIV keeps people from learning about their status and seeking treatment. It also prevents those at risk of infection and some of those affected from changing their behaviour in the belief that behaving differently would raise suspicion about their HIV serostatus. Access to health care services has also been limited by stigma, as many health workers do not understand that the adoption of simple precautionary measures can prevent transmission of infection.

Unfortunately, the vulnerability of women, young adults and children is most often increased in these same developing countries due to cultural norms and practices and existing social prejudices which had penalised these vulnerable people. Women are erroneously perceived as the main transmitters of STIs, including HIV infection,[11] and are often treated differently from men[12]. Whereas men are excused for their behaviour that resulted in infection, women are not; They are rejected by wider family members and are blamed for the AIDS - related death of their husband[13]. These assumptions, in addition to stigma, further fuels the epidemic.

The resultant consequences of HIV-related stigma and discrimination then become far reaching.. It affects the capacity of societies to respond constructively to the devastating effects of the epidemic; silence continues to prevail and action remains slow. In Nigeria, where HIV-related stigma is strongly felt, the prevalence rate has continued to increase. Life expectancy fell from 53 years in 1990 to 4 5 years in 2002 largely due to AIDS. Resources needed for AIDS care and support programmes would soon exceed 35% of the health budget with mounting effect on hospital bed utilization and there is an increasing number of orphans as a result of the epidemic (about 900,000 orphans were reported in 2001)[14].

This catastrophe calls for more action. Part of the response lies in addressing the widespread stigma and discrimination which still remain poorly understood, particularly in developing countries. Internationally, there has been a resurgence of interest in HIV/AIDS - related stigma and discrimination, triggered at least in part by the growing recognition that negative social responses to the epidemic remain pervasive, even in seriously affected communities.

A review of abstracts from peer review studies, regional and international conferences show that very few studies on HIV-related stigma in developing countries had looked at the forms, consequences, context and determinants of HIV-related stigma. A few studies had focused on the result of stigma interventions with results showing that programmes which foster direct contact with PLWH are more effective[15]. However, very little has been done on analyzing the effects of policies and pronouncements on HIV-related stigma and discrimination. Rarely are there studies which examine notions of stigma and discrimination, interrogating them for their conceptual adequacy and their usefulness in leading to the design of effective programmes and interventions. Similarly, not much appears to have been done about policies and their effects on HIV-related stigma.

This study addresses some of these gaps. It tries to identify successes, gaps and barriers created by national policies and government designed programmes in Nigeria and makes appropriate recommendations for future policy/programme review and design or redesigning.

1. Firstly, the study tries to identify the forms HIV-related stigma takes in Nigeria, the context in which it occurs and its various determinants.
2. Secondly, it links HIV-related stigma in Nigeria to broader issues like inequalities, injustice and denials of individual human rights and freedom.
3. Thirdly, it analyses government policies, pronouncements and programmes in terms of how they have or can efficiently and effectively tackle HIV-related stigma.
4. Finally, opportunities for action across each and every regional and international commitment made by the Nigerian government to tackle HIV-related stigma are identified.

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[9] Nyblade L et al. Disentangling HIV and AIDS stigma I Ethiopia, Tanzania and Zambia. International Center for Research and Women. 2003

[10] UNAIDS. A conceptual framework and basis for action. HIV/AIDS stigma and discrimination. Revised version 2002

[11] de Bruyn M. Women and AIDS in developing countries. *Social Science and Medicine.* 1992;34:249-62

[12] Aggleton P and Warwick I. *Community response to AIDS.* www.unaids.org/publications/documents/children/children/sexandyouth99.html# young. 1999

[13] UNAIDS. HIV and AIDS-related stigmatization, discrimination and denial: forms, context and determinants. Research studies from Uganda and India. 2000

[14] Federal Government of Nigeria. National policy on HIV/AIDS. 2003

[15] Brown L et al. intervention to reduce HIV/AIDS stigma: what have we learnt? *AIDS Education and Prevention*. 2003;15(1):49-69.

CHAPTER ONE

Theoretical framework

Defining stigma and discrimination

Stigma is often described as a significantly discrediting attribute possessed by a person with an undesired difference[16]. It results in the reduction of a person or group from a whole and reduces the person to a tainted and discounted one. It is a quality that 'spoils' an individual/groups' identity, rendering them 'unworthy' in the eyes of others. Those stigmatized are regarded negatively, while stigmatizing individuals or group conforms to their own 'normalcy' and legitimizes their devaluation of the 'other'.

Stigmatization is actually a dynamic process of devaluation and has ancient roots in long existing cultures that branded people or groups as outcasts. It exists within the context of power wherein individuals or groups targeted are identified and labeled 'tainted' from other people by associating negative attributes with the labeling[17]. This results in a separation of 'us' from 'them'. The stigmatizing response that results is that the 'them' are perceived as non-persons with the 'them' eventually losing status[18] and being discriminated against.

Parker and Aggleton[19] suggest that stigma is a product of relationships based on power control in which the dominant group legitimizes and perpetuate, inequalities, thereby limiting the ability of the stigmatized to resist because of their entrenched marginal status. The resulting effect is that of reduction in life chances of the stigmatized through the process of development of negative thoughts which leads individuals to do things or omit to do things that harm or deny the stigmatized services or entitlements. This is called discrimination.

Discrimination occurs when a distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of belonging or being perceived to belong to a particular group. Discrimination is a negative act that results from stigma and serves to devalue the stigmatized. Because of the link between the two concepts - stigma and discrimination - this work does not conceptualize the two terms as separate entities.

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[16] Goffman E. Stigma: notes on the management of spoilt identity. New York, Simon an Schuster inc. 1963.

[17] Link B and Phelan J. Stigma and its public health implications. Stigma and global health: developing research agenda. Washington DC, National Institutes of Health. 2001

[18] Gilmore N and Somerville MA. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming 'them' and 'us'. *Social Science and Medicine.* 1994;39(9):1339-58

[19] Parker R and Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine.* 2003;57(1): 15-24

HIV-related stigma and discrimination. This had arisen out of a response to fear, risk or threat of HIV infection being incurable, highly contagious and deadly. The HIV epidemic spreads rapidly with so much uncertainty about how the disease spreads, threatening community values. This evokes a stigmatizing response as stigma is used to enhance or secure social structuring, safety and solidarity and to reinforce societal or community values by excluding divergent or deviant ones[20].

HIV-related stigma becomes more intense as it builds upon and reinforces earlier negative thoughts. It reinforces dominant ideologies of good and bad with respect to sex and illnesses, proper and improper behaviour,[21] as HIV infection is believed to arise from deviant behaviour and caused by individual's irresponsibility. PLWH are often believed to be deserving of whatever fate befalls them, because they have done something perceived by the community as wrong. Oftentimes, these 'wrongdoings' are linked to sex, especially 'improper or perverse' forms of sex and the infection is therefore a form of punishment. Men who become infected may therefore be seen as having patronised sex workers, while women with HIV infection are viewed as promiscuous or even sex workers.

The family and community often perpetuate stigma and discrimination partly out of fear, partly out of ignorance and partly because it is convenient to blame those who are affected first as it is seen to bring shame on the family and the community[22]. PLWH and those affected by the infection are therefore denied the love and friendship of family and friends. Oftentimes, they are ostracized from homes and communities with little or no care and support.

In the workplace, PLWH lose their jobs because of perceived increased vulnerability of colleagues to HIV infection when working together. The employers also feel that HIV infection translates to increased man-hour loss, increased tendencies for health benefits and compensations. This therefore manifests as discriminatory hiring and promotion practices, establishment of unfair benefit packages, limiting coverage for HIV- positive employees and in a number of cases, outright dismissals.

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[20] Nyblade L et al. Disentangling HIV and AIDS stigma I Ethiopia, Tanzania and Zambia. International Center for Research and Women. 2003: page 9

[21] Warwick I et al. Household and community responses to AIDS in developing countries. *Critical Public Health.* 1998;8(4):291-310

[22] Panos. The third epidemic, repercussions of the fear of AIDS. London, Panos Institute. 1990.

The government also perpetuates stigma and discrimination through enactment of rules, laws and legislations which prohibit PLWH from occupations and types of employment, limits international travels and migration, restricts certain behaviours such as sex work and homosexuality, and compulsory screening and testing of groups and individuals and failure to respond to the care and support needs of PLWH. This in turn leads to a false sense of security and complacency in those not belonging to the stigmatized group.

HIV-related stigma has been further distinguished as *felt* and *enacted* stigma. Felt stigma is more prevalent and this is described as the feelings that individuals habour about their condition and the likely reactions of others. This often makes the individual react negatively to society with a feeling of shame and guilt oftentimes resulting in depression and withdrawal symptoms. The tendency for this increases in the African culture which is predominantly collectivistic; individuals are defined as part of a group such as families, rather than independent entities. HIV-positive status therefore casts a negative reflection on the group and not on oneself. This increases the feeling of guilt, shame and loss of face. On the other hand, there is the enacted stigma which refers to the actual experiences of stigma and discrimination[23].

There are also reported cases of secondary stigma wherein people associated with PLWH become stigmatized. These include children, spouses, friends,relatives and care-givers. They end up also experiencing discrimination as they are erroneously assumed to be infected.

Many who had to face stigma before the HIV epidemic now face reinforced stigma when infected with HIV, thereby compounding pre-existing stigma. HIV/AIDS justify further marginalisation of such people, enhancing deeply rooted prejudices. Unfortunately, people who often experience dual or compound stigma often have fewer resources with which to cope and resist. For men who have sex with men, (MSM), sex workers and intravenous drug users-groups of people with high risk behaviour, HIV infection compounds their already existing institutional stigma problems

However, PLWH may face positive discrimination wherein an infected individual is selected for undue favour because of his or her health status. They are related to as the 'weak ones in the pack' who should enjoy all luxuries and exigencies otherwise not merited.

Although the images associated with HIV/AIDS vary, just like the virus itself, they are patterned to ensure that HIV-related stigma reinforces existing societal inequalities and the solution remains as elusive as a cure for the infection.

Implication for enquiry

The dynamic and ever- evolving nature of HIV-related stigma makes it complicated to tackle. This study tries to understand HIV-related stigma and its effects in the Nigerian context, taking it from the starting point of stigma being a discrediting attribute and moving on to conceptualise stigma and discrimination as intimately linked to the production of social differences; social differences wherein groups of people are identified as 'good' in reference to the 'bad' stigmatized group. It would be discussing how adept policies and programmes on HIV-related stigma can be formulated and redefined based on analysis and understanding of its forms, context and determinants in Nigeria.

Study design and method

The project described here studies the forms, context and determinants of HIV-related stigma in Nigeria in an effort to analyse and provide suggestions and directions to programmes and policies that tackle stigma in the country. This project was conducted over six weeks between September 2003 and October 2003. Data was collected through the use of open-ended questionnaires designed to elicit specific information from persons, personal key informant interviews, telephone interviews of key respondents and the use of e-mail-based discussions.

The key components of the study are:

1. Baseline survey to determine key issues: factors and determinants of HIV-related stigma and discrimination in Nigeria.
2. Analysis of key policies, pronouncements and programmes on HIV/AIDS stigma and discrimination in Nigeria
3. Compilation of case studies of best practices from the African and global context.

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[23] UNAIDS. HIV and AIDS-related stigmatization, discrimination and denial: forms, context and determinants. Research studies from Uganda and India. 2000: page 9

[*] http://archives.healthdev.net/af-aids

HIV activists, PLWH, persons affected by HIV/AIDS, women infected and children of infected parents, home-based care providers, men who have sex with men, religious leaders, health professionals, educators, journalists, lawyers and employers were interviewed. Information was sought on individual's understanding of HIV-related stigma, those who are affected by the stigma, those who stigmatise, where HIV-related stigma occurs, its possible causes and its varied effects. The study also sought suggestions on possible ways of tackling HIV-related stigma.

An analysis of reports in the print media was also included to assess whether or not there was a link between the language used by the media and fueling of HIV-related stigma. The study also tried to assess whether there was a link between the language used by the press and the derogatory language used by people in the community when referring to PLWH.

All relevant key national policies were analysed. These included the 2003 edition of the National Policy on HIV/AIDS, the 2002 HIV/AIDS Workplace Policy, the 1996 National Health policy, the 2001 National Policy on Reproductive Health, the 2001 draft National Policy on Women, The 2001 draft National Policy on Population and Sustainable Development, the 2002 National Policy on the Elimination of Female Genital Mutilation in Nigeria, the 2002 Children and Young People's Bill and the 1995 National Adolescent Health Policy.

All existing regional and international conventions and declarations of commitment and pronouncements which Nigeria ratified were analysed to examine their possible inclusion in the national response activities. These include the UNGASS Declaration of April 2001, the UN Special Session Declaration of Commitment of June 2001; The International Covenant on Economic, Social and Cultural Rights 1966; and the International Covenant on Civil and Political Rights 1966.

A review of the 1999 Constitution of the Federal Republic of Nigeria and the Criminal Law of Nigeria were also undertaken to assess how the laws relating to the bill of rights, grants and pensions, insurance, health, children and criminal law protects the human rights of individuals against HIV-related stigma and discrimination.

The HEAP, which strategically outlines the national plan of action for HIV/AIDS over three years, from 2001-2003, was also analysed for possible HIV-related stigma reduction activities.

The authors subscribed to an e-mail discussion on stigma and HIV (AF-AIDS) so as to learn about practices from other nations in controlling HIV-related stigma. Extensive reviews of reports from other nations were also undertaken. These include a study of the report from the International Centre for Research and Women (ICRW) on HIV-related stigma in Ethiopia, Tanzania and Zambia (2003), a study on Uganda and India reported by UNAIDS (2000), studies on children and youths infected and affected by HIV/AIDS in South Africa by Save the Children Fund, (2002), and studies in the workplace reported by the Global Business Coalition on HIV/AIDS (2003).

Finally, the authors undertook a review of several abstracts on the issue that popped up during an electronic search using the Medline search engine. The key word entered for the search was HIV-related stigma. A review of a compilation of all abstracts and articles published by the data bank of the Nigerian Institute of Medical Research, (NIMR) Lagos, was also reviewed. Published peer review articles downloaded from various referenced websites were also reviewed for this project.

CHAPTER TWO

Stigma as a concept

Stigma is defined in different ways by different people. The various definitions of stigma help to understand its different concepts.

Stigma has been described as a quality that 'significantly discredits' an individual in the eyes of others. Much HIV/AIDS-related stigma builds upon and reinforces earlier negative thoughts. People living with HIV/AIDS are often believed to be deserving of what has happened to them for doing something wrong. Often, these wrong doings are linked to sex or to illegal and socially frowned upon activities, such as drug abuse. Men who become infected may be seen as homosexual, bisexual or as having had sex with sex workers. Women with HIV/AIDS are viewed as having been 'promiscuous' or as having been sex workers. The family and community often perpetuate stigma and discrimination partly through fear, partly through ignorance, and partly because it is convenient to blame those who have been affected first.

Self-stigmatization or the shame that People Living with HIV/AIDS experience when they internalize the negative responses and reaction of others, is also evident. Self-stigmatization often leads to depression, withdrawal and feelings of worthlessness. It silences and saps the strength of already weakened individuals and communities, and causes people to blame themselves for their predicament. It affects an individual's or community's feelings and sense of pride.

Stigma is linked to power and domination throughout society as a whole. It plays a key role in producing and reproducing relations of power. Ultimately, stigma creates and reinforces social inequality. It has its origins deep within the structure of society and in the norms and values that govern much of everyday life. It causes some groups to be devalued and ashamed, and others to feel that they are superior. For example, long-standing ideologies of gender have resulted in women being blamed for the transmission of sexually transmitted infections or HIV. This has influenced the ways in which families and communities react to the sero-positivity of women. Many are blamed for the illnesses from which they and their husband suffer.

Recurrently, stigma has often been used as a language of attribute rather than relationships[23] and subsequently, practice has often transformed stigma into attributes of persons. The stigma or mark is seen as *something in the person* rather than a designation or tag that others affix to the person. It develops from cultural stereotyping which then gives rise to the development of prejudices that lead to an emotional reaction. Discrimination is the behaviourial consequence of prejudice.

Stigma as defined by many experts also varied but reflects a single concept. Examples of some of the definitions are:

> "Attaching bad names, bad feelings or shameful meanings to a situation that may appear not to be agreeable to one's feelings or value."
>
> *Femi Soyinka, NELA, Ibadan*

> "It is a negative social label that casts aspersion on an individual or group of persons. It could be a thought, belief, action or utterance based on preconceived notion."
>
> *Lekan Otufodurin, Media Development Network, Lagos*

> "Stigma is a negative labeling of some sort."
>
> *Bunmi Lawal, Nurse, and Educationist, Ile-Ife*

> "Stigma is a bad label on something you do not know anything about."
>
> *Dare Odumuye, Alliance AIDS Initiative, Ibadan*

> "It is a powerful and debilitating way of treating a particular group due to perceived thought about them. Stigma often breeds negative reaction against some people as such people are shunned, rejected and treated with disdain."
>
> *Ebenezer Durojaiye, Centre for the Right to Health, Lagos*

> "It is an evil and bad happening attached to someone."
>
> *Stephen Kitchener, Nigerian Medical Association*

> "A conscious or subconscious manifestation of negative attitudes towards people on the grounds of an assumed or actual difference."
>
> *Matt Greenall, International AIDS Alliance, UK*

"Society constructs specific norms and values in order for it to function. Anything that disrupts society is stigmatized. HIV/AIDS pose a threat to the security of societal norms and values and this is society's way of protecting itself by blaming a specific group for the problem of infectious diseases. This attitude gives a type of self imposed safety attitude towards itself."

James Hoyt, HIV political activist and researcher, USA

The concept of stigma as defined by these individuals connotes that stigmatization is a negative concept with a corresponding negative action.

It is however important to define HIV-related stigma from the perspective of people living with HIV/AIDS. This is because studies could be conducted from the vantage point of theories that are uninformed by the experiences of the people they study. When little priority is given to the words and perceptions of people studied, misunderstanding of the experience results and there is continued perpetuation of unsubstantiated assumptions. HIV-related stigma as defined and understood by some people living with HIV/AIDS include:

> "Stigma is an act of abandonment or rejection of someone."
>
> *Kenny Akintifonbo, Living Hope Care, Ilesa*
>
> "Stigma is something that puts fear in the heart or makes an individual to isolate his or herself from the community."
>
> *Kehinde Omotoso, Living Hope Care, Ilesa*
>
> "Stigma is a negative branding or labeling which leads to a feeling of unworthiness, devaluation, shame and disgrace. It often results in spoilt identity and discrimination."
>
> *Rolake Nwagwu, Treatment Access Movement, Lagos*

These definitions do not differ significantly from those of the researchers in terms of content. In all, the term stigma tends to be applied in situations where labeling, stereotyping, separation, status loss and discrimination co-occur in a power situation that allows the components of stigma to unfold[25]. It may occur without knowledge. Oftentimes, it is an unreflective action which comes from unconscious inputs from events encouraged by multiple factors such as culture. Thus, in studying and understanding stigma, one needs to focus on both the stigmatized and on those who do the discrimination- the producers of rejection and exclusion.

CHAPTER THREE

Discrimination

Discrimination occurs when a distinction is made against a person that results in his being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong to a particular group. HIV/AIDS-related discrimination is the outright denial of opportunity, unfair and unjust treatment of person(s) presumed to be or actually infected with HIV/AIDS.

Because of the stigma associated with HIV/AIDS and the discrimination that may follow from this, the rights of People Living with HIV/AIDS and their families are frequently violated. This violation of rights increases the negative impact of the epidemic. At the level of the individual, for example, it causes undue anxiety and distress. At the level of the family and community, it causes people to feel ashamed, to conceal their links with the epidemic, and to withdraw from participation in more positive social responses. And at the level of society, discrimination against people with HIV/AIDS reinforces the mistaken beliefs that such action is acceptable and that those infected with HIV/AIDS should be blamed and ostracized.

In Nigeria, there have been numerous instances of such HIV/AIDS-related discrimination. People living with (or believed to be living with) HIV/AIDS have been discriminated against as can be seen in the various accounts of PLWH narrated below.

Martha's experience:

> "I had registered for ante-natal care in a private hospital near my house. I was told to do an HIV test as part of the routine test. I refused and they bluntly told me they cannot take my delivery if I do not take the test. I went to a government health center, they filled out a form for blood test. I read it, but there was nothing indicating HIV test so I went for the test. During my next visit, I was worried when the midwife told me that I have to go to the teaching hospital for special management. She would not explain why, rather she gave me a letter out of curiosity, I read it on my way home and learnt that I had tested HIV positive. My world crashed on my face. I locked myself up and cried for weeks. At the teaching hospital, the nurses kept on passing the letter from one to another and eventually asked me to return in four weeks time because the doctor who will

attend to me is on leave. By this time, I was already seven and half months pregnant. I fell into labour before the appointment date and had to go to a traditional birth attendant who took my delivery. I did not tell her my HIV status because I was scared she would refuse to attend to me too".

Catherine's experience:

"I went to the clinic and the doctor filled out a lab form and asked me to give the lab man my blood and urine. I took the form , read it. I saw urine test and retrovirus test. I did not understand what retrovirus test meant. So I called one of my colleagues and asked her to explain what it means. She shook her head and told me to go and ask the doctor. I was confused; I could not understand her reaction. I asked her, "do I have cancer, why are you behaving like this?" She insisted I must ask my doctor. I went back to the doctor who told me not to worry, that I should just give the lab man my blood and urine and bring my husband next week. I had hypertension till I reached home. I told my husband, he refused to go saying that he was busy. I went back to the doctor and insisted that I am the one that is sick; since my husband has refused to come, won't he just tell me what is wrong with me. He looked at me for a long time and asked if my mind, is strong, if I have lost somebody before. I told him that I have strong mind even more than my husband and that I lost my brother last year. Then he told me to go and see the nurse. I went to see the nurse and asked her, why are you people turning me here and there? What is wrong with me? The nurse seeing that I was very angry, just told me that I have HIV that causes AIDS. I was mad. I held her uniform and asked her if I looked like a prostitute. She just said, "It is only I that can answer that question" and walked away, giving me a withering look. I sat on that spot for over four hours. I cannot remember how I got home."

Maddy's experience was at the dental hospital where he went to pull his teeth. He actually told the dental surgeon that he is HIV positive, and paid dearly for it:

"On hearing I have HIV, the surgeon told me outright that they cannot attend to me because it is risky. I challenged him, threatening to report to the authorities concerned, as I am entitled to treatment. He eventually asked me to come back in two weeks time to enable them prepare well. Again, I was messed up. Even though I came before other patients, I was the last patient they attended to. Still, they found a reason to ask me to come back two days later. Meanwhile, they were busy passing my case note from one person to the other, during which I found out that they wrote HIV positive on top of my case note. Again, I objected strongly to such labeling, threatening to go to the media with the way they are treating me. (Already I had gone public about my HIV status). They went on about wanting to warn other doctors to be careful. I asked them if they knew the sero-status of all the patients they had been attending to? what about universal precaution? Is this the price I pay for being open about my status? My tooth was finally extracted in circumstances that should have being filmed rather than discussed. People were wearing four gloves, masks and goggles, and moving about on tiptoe, as if the virus would jump at them."

Abigail's story:

Rachel Obeten was born normal and healthy weighing 4.2kg. Unaware of her sero-status, her positive mother breastfed her. At two, Rachel tested positive to HIV. Her mother, determined to give a human face to HIV/AIDS and help fight stigma and discrimination, appeared on *Newsline,* a national network television magazine programme. On the programme, she canvassed strongly for the rights of persons living with HIV/AIDS and urged the society to show love and compassion rather than condemnation. This added to little Rachel's problems. The school in which she had hitherto spent one year in day care refused to admit her in the nursery class, claiming that other parents might withdraw their children from the school. They claimed they cannot admit the daughter of an HIV-positive woman. While her mother and other AIDS activists fought this discrimination, she became very ill. She was admitted to the Lagos University Teaching Hospital (LUTH) for three weeks. She lost so much weight and fluid. She was later placed on antiretroviral drug, but it was too late. She died on November 26, 2002.

Forms, context and determinants of HIV-related stigma in Nigeria

CHAPTER FOUR

Stigma and discrimination takes different forms in Nigeria. Felt stigma, which is the feelings that individuals harbor about their condition and the likely reactions of others, appears to be more prevalent. Enacted stigma refers to actual experiences of stigmatization and discrimination. Felt stigma often precedes enacted stigma and may affect the extent to which the latter is experienced.

Varied forms of HIV-related stigmatization were identified during the study. They include employment loss, reduced access to health care, rejections from friends and family. There are also a range of contemporary behavioural responses to HIV-related stigma. This varies from withholding of help to avoidance, including landlords who would not lease houses to or employers who would not hire people living with HIV.

The Family

Neglect and rejection of people living with HIV/AIDS by their family members such as parents, spouses, in-laws and other immediate and extended family members, have been reported in many support groups of PLWHA in the country. Other forms of S&D (stigma and discrimination) commonly seen at the family level in the country are:

- Denial of inheritance, especially for women who lost their husbands to AIDS related illnesses
- Denial of marriages between families.
- Accusation of sexual infidelity
- Denial of access to household utensils and toilets used by other members of the family.
- Non-payment of educational fees of students infected by HIV/AIDS by parents.
- Refusal to care for sick PLWH.

The Community:

- Avoiding contacts or relationship with PLWH and their immediate family members.
- Gossip, bullying, castigating side remarks and isolation of PLWH.
- Denial of PLWH membership of or participation in local community associations and activities.
- Denial of PLWH renting apartment or using common household facilities like bathroom, toilets etc. with other tenants.
- Accusing and passing judgments on PLWH of moral infidelity.
- Children of PLWH are often avoided within communities and denied education at school.
- Dismissal or rejection of PLWH from school facilities.

Health care Institutions:

- Health care providers avoiding treating PLWH
- Refusal of admission to hospital facilities
- Refusal of adequate and comfortable bed space
- Testing without informed consent
- Health care providers keeping HIVs positive patients at arms length
- Refusing to touch, bath or dress wounds of HIV-positive patients
- Addressing HIV/AIDS patients in unfriendly and derogatory manner
- Breach of confidentiality of test results-sharing positive test results among other health care workers (even among those not directly involved in treating the patient) and family members.
- Using double or triple gloves by health care practitioners when attending to HIV-positive patients.
- Admitting HIV-positive patients in separate wards from other patients
- Labeling or using red ink or piece of cloth or papers to denote HIV-positive sero-status on the case notes and bed head of HIV-positive patients.
- Mandatory testing for patients undergoing surgery and ante-natal care. Patients known or suspected to be involved in sex work or drug use and women from polygamous homes.

The Workplace:

- Termination or refusal of employment on grounds of HIV-positive sero-status
- Pre-employment and on-the-job screening for employment, promotion or training or other benefits.
- Breach of confidentiality of medical information including HIV status
- Threatened job security
- Stigmatization and discrimination of HIV infected staff in form of gossip, rumors, segregation, isolation, verbal abuses etc.

Cases of segregation had also been recorded, as well as coercion (mandatory treatment or criminal justice behaviour). There have been nationally reported cases of children of people living with HIV/AIDS expelled from school and a person living with HIV denied access to a court- room because of her status.

> "I have had to face stigma from a sister-in-law. My parents and siblings know of my HIV status and care for me, but my sister-in-law keeps her distance from me along with her children. Her embarrassing acts made me leave the house we were living in. I had to take up a new place of my own."
>
> *Sikirat Lasisi, NELA, Ibadan*

> "There was the case of a sero-discordant couple. The husband was HIV-positive. As soon as he learnt of his status, he informed his wife so that she could also get tested. She however tested negative. Following the test, the wife has been treating her husband shabbily, even when other members of his family show him love and care."
>
> *Kemi Adejumo, Home- based care provider, Ibadan*

> "I was stigmatized when I was receiving medical care in the University College Hospital, Ibadan. I developed ear and eye problems following my diagnosis. Once when I went to the ear clinic, the consultant informed me that I needed to wash my ears and she wondered why that had not been done. On reading my case note, she decided to place me on drugs and never discussed the ear wash again. The same thing happened at the eye clinic. Despite the fact that I kept complaining of deterioration, I was never slated for surgery to remove the cataract, even when others had surgery done for them. I kept using drugs which were not working. I finally stopped attending the clinic".
>
> *Tajudeen Raji, NELA, Ibadan*

> "I worked with Pacific Freightliners Limited, Ojota, Lagos, for 10 months before being laid off on the 12th of October, 2001 after testing positive to HIV. The company got to know about my status because the hospital had to report back to the company on every staff that received medical treatment from the hospital. I presently find it difficult to get any new employment. My only alternative is to resort to farming as a source of livelihood. I find this quite difficult after being gainfully employed for 11 years."
>
> *Femi Ibitayo, Living Hope Care, Ilesa*

> "I have been ejected out of my house twice because of my HIV status. I have gone public about my status and so I am easily recognised in the community. Presently, I live within the hospital where I have a corner to myself. At the end of each day, after counseling new clients diagnosed with HIV in the hospital, I go to sleep in my little corner.
>
> *Titi Adeniyi, Living Hope Care, Ilesa*

Cases of associated secondary stigma also occur. This usually occurs with home based care-givers and relatives of persons living with HIV/AIDS. Although the level of stigma for the care-givers is less than for those infected, nevertheless, they are also stigmatized.

> "I noticed that people started watching and noting houses I go to visit. It was assumed that any house I enter, the occupant must be infected with HIV. One of my clients once asked me to stop visiting her at home because my presence was causing a lot of suspicion in the neighbourhood about her being HIV positive."
>
> *Bola Oke, Home based care-giver, Ile-Ife*

> "People appear to have stigmatized our institution. They do not want to be associated or seen in the building. They feel that people coming to our organization have AIDS or have relatives living with AIDS". *Femi Soyinka* (NELA, Ibadan)

Usually, when people are identified as being infected with HIV, they tend to be sneered at, talked to in a derogatory way or isolated. Cutlery and household utensils are separated, even in homes and in some cases, there is outright neglect and abandonment.

> "There is this 28-year old lady, a member of our support group, who was isolated by her family members because she was HIV-positive. She was put in a room and given all necessary household utensils for her sole use. When the public started getting to know about her status, she was then sent packing from the house."

> *Kehinde Omotoso*

> "There was once a young girl in Ejigbo (Osun State) who was diagnosed HIV-positive. She was ill at the time of diagnosis. Once the parents learnt of the sero-status, she was moved from the main house into the uncompleted building at the back of the compound. She was fed like a dog. It was when the home-base care team started visiting that their attitude gradually changed."
>
> *Ibiyemi Fakande, Home base care-giver, Ilesa*

Although the of forms in which stigma is enacted by the various sectors in the community were enumerated, self stigma was also identified. This self-stigmatization occurs as a result of enacted stigma which affects labeled persons significantly. Many people who are infected with HIV are aware of HIV-related stigma. Some accept the stigma and live with it. The individual then avoids social behaviour and processes that increase the chance of identification as a person living with HIV and thus a potential object for stigmatization. One person living with HIV reiterated:

> "I do not subscribe to the anti-retroviral programme of the organization even though I can afford it because daily intake of the medical pills would make people suspicious of my HIV status. I still want to marry."
>
> *S.F., Living Hope Care, Ilesa*

Apparently, women are worst affected by stigma in the community. The Nigerian culture and value system increase their vulnerability. This is because of the erroneous perception of women as direct and indirect vectors of STIs. This influences the way family and community members react to HIV-positive women. Most times, people living with HIV/AIDS receive care and support from their immediate families, but there are a number of reports of women being ill-treated by their husband's relatives who outrightly accused them of being the source of their son's infection. One of the home care providers interviewed reported:

> "Because women are already culturally disadvantaged in the country, they are easily accused of infecting their husbands with HIV. *Ebenezer Durojaiye*

Other groups of people were also identified to be badly affected by HIV-related

stigma because of their increased vulnerability. These are sex workers, prisoners and men who have sex with men (MSM).

> "Sex work is criminalized under the Nigerian law. The society already has a negative impression about sex work. Sex workers become further stigmatized when they become infected with HIV. The perception of the society is that an HIV-positive sex worker needs no support since she is merely reaping the fruits of her promiscuity. Prisoners are seen as dishonoured members of the society. Therefore, when they become HIV-positive, the society tends to shun them the more."
>
> *Ebenezer Durojaiye*

For many, it is believed that fear arising from poor knowledge and understanding about the possible sources of infection is a main cause of stigma. The belief that HIV infection is as a result of a lifestyle not acceptable or in conformity with the acceptable norms and values of the society further reinforces the process of stigmatization and discrimination of people living with HIV/AIDS. The fear of death arising from a communicable disease that has no cure further heightens the tendency to discriminate against and ostracize people infected with or suspected to be infected with HIV.

> "Many of those who stigmatise people living with HIV/AIDS lack adequate and correct information about HIV/AIDS. Ignorance about the epidemic is not limited to the uneducated. It is also exhibited by the elites. For instance, a High Court judge had ruled that unless expert evidence is provided indicating that the courtroom will not be infected by the plaintiff who is HIV-positive, she could not enter the court."
>
> *Ebenezer Durojaiye*

> "Many usually think it affects only people who are promiscuous. Because of their level of ignorance about the disease, many are not too comfortable relating with PLWH. Even in religious circles, they are sometimes treated as outcast without much care and support."
>
> *Lekan Otufodunrin*

An association between stigma and ignorance has long been demonstrated, though the nature of the relationship is unclear. Educational programmes do create enlightenment but often do not take care of people's deep fears. A further understanding of the possible causes of HIV-related stigma may give insight into how to best tackle this epidemic. Other perspectives on the possible causes of HIV related stigma include:

> "HIV related stigma arises because the disease is incurable."
>
> *Stephen Kitchener*
>
> "The feeling of righteousness or superiority spiritually, socially or financially encourages stigmatization."
>
> *Femi Soyinka*

But then, stigma associated with discrimination and ostracism has had an enduring history in the country long before the HIV epidemic. The Nigerian legal system had long labeled some groups of people as 'bad'.

> "Sections 214 and 215 of the Criminal Code of Nigeria label men who have sex with other men, commercial sex workers and intravenous drug users as 'bad' people by criminalizing their choice of lifestyle. The people in the 'good' group then point fingers."
>
> *Ebenezer Durojaiye*

Also, the Nigerian culture has a long history of labeling. The culture has, in many ways instituted the violation of human rights. In Igboland, South-eastern Nigeria, there is the *Osu* caste system where people from a particular lineage were meant to be sacrificed to the gods and are not fit to marry 'normal' citizens. People with diseases such as leprosy, epilepsy and psychiatric illness had long suffered stigmatization. HIV-related stigma has only built on a system that readily stigmatizes and discriminates as a justifiable means of societal preservation when ignorance and misconceptions prevail. The tendency to stigmatize readily increases in a society like Nigeria that judges and condemns actions with capital punishment.

> "Ignorance is often cited as the main cause of stigma but I think stigma can also be created and aided by culture where there is attack on the dignity of people and where references are made to specific groups and behaviours in judgmental ways, in particular, where there is lot of talk of morality." *Matt Greenall*

Even though societal prejudices had encouraged HIV-related stigma, certain factors further promoted its propagation. One of these factors is media reports of HIV-related issues. In the early stages of the epidemic the print media reported much false information and negative reports on HIV/AIDS. It had done little in correcting misinformation, misconceptions and reducing stigma.

> "To a large extent, negative media reports on HIV/AIDS contributed to stigmatization of people living with HIV/AIDS. The media remains the main source of information for the public. Unfortunately, they hear and read about the largely negative slants on HIV/AIDS projected by the media. Pictures of people dying of AIDS were often projected, creating a hopeless state in the campaign against the virus. Even now that there is improvement in the quality of reporting on the virus, the general public still stigmatizes people living with HIV/AIDS because of past reports and persistent negative reporting in the media."
>
> *Lekan Otufodunrin*

The doomsday metaphors often used by the media in reporting HIV stories create a sense of and need for self preservation. Unfortunately, the people take the fear out on people living with the virus and not the virus itself, resulting in discriminatory actions against people living with HIV. These reports, in an attempt to create a sense of emergency, inadvertently promote stigma and discrimination.

The language of reporting may however be a reflection of the attitude and predisposition of journalists to HIV. A survey carried out as part of a pre-training assessment during a workshop organized by JAAIDS for leaders of the Nigerian Union of Journalists (Southern Zone) in September 2003, revealed that 50 percent of the participants did not believe that HIV/AIDS was real (8 out of 16), while 31percent (5 out of 16) strongly felt that HIV infection was caused by promiscuity.

> "A report on the MSM convention by Nasir Dambatta of the *Weekly Trust* newspaper published on the 24th of October, was highly stigmatizing. The reporter was not at the convention yet he wrote an extensive report on the convention based on personal bias. Unfortunately, Nigerians take the reports of the media as wholesome truths. This kind of biased reporting only aids stigmatization of MSM." *Dare Odumuye*

Nationally designed programmes can also promote stigmatization. Often times, the national HIV prevention and control programmes direct their actions to high risk groups and not people with high risk behaviour. This concept of programme planning and design further reinforces the notion that certain groups of people are the cause of HIV infection, rather than the notion of high risk behaviours which may be applicable to all persons. In addition, awareness raising messages also help to perpetuate negative images of HIV/AIDS and risk re-inforcing stigmatization of persons infected with HIV.

> "The IEC materials are often of poor quality. In particular, they attack the dignity of persons living with HIV. They make reference to specific type of people and behaviours in judgmental ways; they talk about morality and they promote abstinence as the best approach to prevention; abstinence for good people and condom for bad people." *Matt Greenall*

Religion had also helped to fuel the HIV-related stigma epidemic. The reference to HIV infection as sin and punishment from God further alienation of the 'bad people' from the 'good people'.

> "Religion plays an important role in HIV-related stigma. Many religions preach that if you are ill, that is God's way of telling you that you have done something wrong and that you need to get back on the right path."
> *James Hoyt, HIV activist and researcher, USA*

> "People often talk about health care settings as a stigmatizing setup, but I think there is a need to take care not to give the impression that health professionals stigmatize more than other people. Perhaps the results of their stigma have more immediate effects. I think many religious institutions create HIV related stigma, perhaps not so much as against people living with HIV/AIDS, but against people who have sex outside marriage in general, highly affected groups in particular".
> *Matt Greenall*

HIV-related stigma, like other causes of stigma, might actually be an attitudinal problem with a cultural context to the stereotyping process. Various factors may then be responsible for its expression. This attitudinal concept of the origin of all

forms of stigma is further corroborated by the reports of MSM.

> "Even within the organization, members who are HIV-positive are castigated by those who are not." *Dare Odumuye*

It is very important to understand the factors that enable it to thrive in all the settings stated above. These include:

Low levels of HIV/AIDS knowledge: Despite the various prevention, care and support messages relayed through the print and electronic media in Nigeria, a lot of people still do not really understand the meaning of HIV/AIDS and its mode of transmission. While some people know some basic facts about HIV/AIDS, quite a large number lack adequate information. Fear and misconceptions are still the major factors fueling ignorance in Nigeria. A large gap still exists between what people hear in the various HIV/AIDS messages and what people really do. A lot of advocacy campaign and behavioural communications are still needed to enable people really "hear", "understand" and "act" on HIV/AIDS prevention, care and support messages.

Fear and Misconceptions: Fear still underlies and fuels stigma and discrimination in Nigeria. The misconceptions about what HIV is and its transmission mode make a lot of people stigmatize and discriminate. People are basically afraid of contracting HIV and dying therefrom. This is even more pronounced among HIV-positive people as they are usually afraid of:

- Being identified with 'deviant and sinful behaviour', mainly sexual promiscuity and sex workers
- Loss of reputation in the family and society
- Damaging the family's social reputation
- Falling sick repeatedly and not receiving medical attention, or being denied admission to hospital
- Being deserted, loss of significant relationships and loss of trust and confidence
- Losing one's job or source of income

This is further fuelled by certain wrong perceptions about HIV/AIDS by members of the society who believe that HIV/AIDS:

- Is a form of punishment from God or traditional gods for immoral behaviour
- Is a crime (e.g. in relation to innocent and guilty victims)

- Is a war (e.g. in relation to a virus which needs to be fought)
- Is seen as shameful (bringing shame on the reputation and name of families and communities)
- Erroneously believed to be a communicable diseases from casual contacts or association
- Seen as a result of personal irresponsibility.

Traditional and Cultural beliefs: Some traditional and cultural beliefs (1) suggest that HIV/AIDS is consequent upon acts of witchcraft or a curse, (2) "excuse" men who are HIV-positive on the basis of traditional and religious norms to have more than one wife and being able to have sex at will with even concubines and "accuse" women of unfaithfulness to marital vows and "bringing the infection home." These misconceptions predispose PLWH to S & D (stigma and discrimination) in Nigeria.

Poverty: The very low socio-economic status of most PLWH is a major factor fueling S & D in Nigeria. Most PLWH are unable to pay for their drugs, even at the government-subsidized rates. Allied to this is their inability to feed well. These two factors compel most PLWH to approach friends and relatives who, most of the time, do not want to 'waste' their resources on them because of the misconceptions that the PLWH are going to 'die' after all. If most PLWH are economically empowered and able to take care of themselves, then they will be less exposed to S & D.

Ineffective policy and legislation:

CHAPTER FIVE

In Nigeria, there are 20 legislations that protect the rights of PLWH against S & D. However, the policy statements and programmes of government are clearly stated in the National Policy on HIV/AIDS and the HIV/AIDS Emergency Action Plan (HEAP).

Despite the unfolding understanding of stigma and stigma-related behaviour, a lot still needs to be done to further understand this complicated issue. This is particularly in Nigeria where some geographical variation are noted in its context of expression.

> "I noticed that more people are open about their HIV status in the southern part of Nigeria than in the North. This may be because there is more awareness about the disease in the South, unlike in the North, where a lot of myths about HIV/AIDS still prevail."
>
> *Lekan Otufodunrin*

> "There is less stigma attached to HIV infection in the Hausa area (North). This may be because of the attitude of the people which overlooks issues and explains it off as God's wish."
>
> *Stephen Kitchener*

Presently, research on HIV-related stigma in Nigeria is very sparse. The use of a search engine, the *Pubmed*, for the listing of abstracts of peer-reviewed and published articles on HIV-related stigma yielded only 85 articles. None of the articles reported about HIV-related stigma in Nigeria. Also, a review of publications by Nigerians on HIV/AIDS over the last decade compiled by the Nigerian Institute of Medical Research (NIMR) showed that only 31(6.03 percent) of the 514 article enumerated were identified to be on human rights, politics, commitments and action. Of this, 3(9.7percent) were on human rights and ethics. The need for more country-specific HIV-related stigma research cannot be overemphasized in view of the need to identify indicators for stigma which would be used to develop multidimensional measures appropriate for the local context. There is a need to understand the ways stigma is perceived and measured in the various Nigerian cultures. This would enable planning of appropriate strategies and interventions which would mute the self interest that drives HIV-related stigma.

3. Consequences of stigma

Stigma, when applied to health conditions, is a globally pervasive problem threatening psychological and physical health at the individual and group level. The stigmatizing treatment of an individual leads to poor outcomes that perpetuate other adverse health, social and economic consequences for the individual, families and communities, often beyond their prevalence in the population. Such consequences include:

a. Poor access to medical care: There are varying reasons for poor access to medical care but one of them is stigmatization of people living with HIV/AIDS by health care workers. Stigma is not new to public health, neither is it unique to HIV/AIDS. Reports of prejudices and discrimination against persons who are ill or perceived as ill in the health setups have often been linked with infectious diseases that are poorly understood. People apprehensive about health care workers' attitude are less likely to seek treatment for HIV-related opportunistic infections in a timely manner if they have fears that they might experience discounting, discrediting or judgmental attitudes from health care providers [26]. This in turn, limits the effective treatment of HIV/AIDS, predisposes one to late diagnosis and encourages further spread of the infection.

Secondly, stigma leads to poor utilization of health care facilities, even when available. The use of specific health facilities may lead to the labeling of people who access health care services there. Hence, potential clients may opt not to access care as a way to avoid labeling and the resulting discrimination.

> "I know of a lady who developed cardiac failure due to HIV-related complications. We encouraged her to go to the hospital for treatment as she would require specialized care. She continually refused this because of her past negative experience in the hospital because of her HIV status. She could afford the cost of treatment and she had so much will to live but she refused to go to the hospital. She later died at home as a result of cardiac failure."
>
> *Ibiyemi Fakande*

The effect of stigma even limits the success of the antiretroviral (ARV) programme. For many months after the initiation of the Nigerian government's programme on ARV, in which the cost of treatment was heavily subsidized, most of the 25 centres

which administered the drugs could not fill their quota of recruiting and managing 25 HIV-positive clients[27]. Yet the country has an under-estimated 3.5million adults living with HIV. Stigma is recognized as one of the factors limiting access to these services[28].

> "I know of a couple who would not start the ARV treatment in our center because they refer patients down here for treatment. There is also a member of the elite class diagnosed at the center who decided to relocate and access treatment somewhere else outside Lagos. She would not want to be seen accessing HIV treatment."
>
> *Taiwo Adewole, Nigerian Institute of Medical Research, Lagos*

Thirdly, even when health facilities and services are accessed, stigma may result in poor compliance with treatment regimens.

> "There is a high drop out rate for the ARV treatment programme here. Many dropout because they cannot afford the cost of the drug regimen. A number drop out because of stigma. We however do not have the statistics to corroborate this because follow-up of clients at home is a task the center finds really hard to combine with our patient's clinical management programme."
>
> *Taiwo Adewole*

Conversely, the increasing accessibility of persons infected with HIV to treatment and antiretroviral therapy could drive the HIV epidemic further underground. This is because stigma prevents people from openly living with their status and with ARV therapy, individual health is improved and so would be the tendency to live in secrecy about HIV status.

> "I have clients on antiretroviral therapy who are less likely to declare their status because of stigma. They are much healthier and have everything to lose by telling people they are HIV-positive"
>
> *Femi Soyinka*

b. Interference with prevention programmes: Stigma may influence HIV risk behaviour. Lowered self-esteem that results from self stigma may negate motivation for self protection (consistent practice of safer sex), leading to multiple sexual encounters in an attempt to seek self-validation. Also, it may lead to use of alcohol or substances which impair judgment and interfere with a person's ability to negotiate and practice safer sex. These lead to interference with prevention programmes. For many, the fear of receiving a positive result remains a potential disincentive to voluntary counseling and testing.

> "In a research I conducted, more than 70 percent of the 221 women I interviewed were ready to do a VCCT (Voluntary Counselling and Confidential Testing). However, over 90 percent of the other 30 percent who were not willing to do a test said stigma was the reason for not wanting to know their status."
> *Ebun Adejuyigbe, Paediatrician, Ile-Ife*

This result is similar to that of the study by Msobi *et al* done in Dar es Salam[29]. Although stigma may not be the sole reason for many individuals not testing, clients are however more likely to seek out and follow through with HIV testing services they perceive to be non-judgmental[26]. The Center for Disease Control and Prevention unequivocally asserts that stigma hampers prevention[30] and there is need to work towards minimizing these negative consequences. This is even more compelling for stigmatized groups and individuals whose HIV-positive status would worsen their plight in the community.

> "Stigma and discrimination feed the secrecy in which MSM live and socialize. Taking a test and finding out one's HIV status may mean disclosing one's sexual orientation, facing stigma as an MSM and being HIV-positive. Non-friendly services and an unfriendly legal environment increase the tendency for not taking an HIV test." *Dare Odumuye*

For some that know their sero-status, non-disclosure, even to close relations such as spouses, have been a major way of coping with the possibility of HIV-related stigma. This may negate the practice of safer sex and in turn, interfere with prevention efforts.

> "We had a person living with HIV/AIDS in our organization who never disclosed her HIV status to her husband for over three years after diagnosis until she died. She felt the stigma she would face from her husband and the family would be more than she can cope with."
> *Ibiyemi Fakande*

c. **Loss of Status**: With stigma, the stigmatized is reduced in status or hierarchy. This, in turn, can have an effect on the individual's life chances because the lower status itself becomes the basis for discrimination. Low status may make a person less attractive to socialize with, or involve in community activities. In this way, stigma can have a cascade of negative effects on all manners of opportunities for the stigmatized.

d. **Effects on business**: Whether woven into company policies or unintentional, stigma can be pervasive in the workplace and discriminatory HIV practices hamper company operations. Because of stigma, HIV-positive persons do not apply for jobs because they fear discrimination and feel they will not be hired, based on their status. Even with a company policy in place, the attitudes of fellow workers can also have a negative impact and hamper the use of company-organised health care facilities because of concerns of confidentiality and privacy. This results in compromised employee health. Unfortunately, many employees fail to acknowledge the possible effect of HIV on their business now or in the future. Denial was the order of the day.

e. **Effects on HIV mitigation activities**: Stigma also has its negative consequences and effects on activities of oragnisations working towards mitigating the impact of HIV/AIDS in Nigeria.

> "As a journalist, HIV-related stigma adversely affects my job because people are not willing to openly declare their HIV status. The media is therefore forced to continue to use pictures of the same few individuals out of the over 3.5 million infected Nigerians who openly declare their status. In the Nigerian situation, where many do not believe about the existence of the virus until they hear personal testimonies, the job of the media is then made difficult."
> *Lekan Otufodunrin*

> "Stigma affects my work as a home-based care provider. Unfortunately, this often emanates from the people living with HIV/AIDS that we work with and their family members. They often refer to us as vultures who use their plight and situation to make money. This can negatively affect the zeal to work.
>
> *Kemi Adejumo*

> "People living with HIV/AIDS become more difficult to access and work with, making intervention programmes harder to introduce and sustain."
>
> *Bunmi Lawal*

f. Effects on children of people living with HIV/AIDS: Stigma makes disclosure of parent(s)'s status to children difficult. This is worrisome, as parent(s) cannot prepare the children for their death or prepare them to be cared for by others. This only increases the children's vulnerability. Less than 20 percent of the people living with HIV interviewed with during this study disclosed their status to their children.

> "I did not tell my daughter about my HIV status because of her possible reaction. I live with my parents. My siblings and father had shown very little care and support for me. My child might also react negatively if she knows."
>
> *Toyin Idowu, Living Hope Care, Ilesa*

> "My child comes with me to support group meetings but she does not know my status. I have not discussed about my status with any of my children because of what I saw a neighbour go through after informing her children about her status. She was completely abandoned. I do not want to go through that harrowing experience. They would know about my status when I become very ill."
>
> *Florence Adeyeye, Living Hope Care, Ilesa*

> "I only told my children about my HIV status recently following the advice we received during the support group meeting. I had kept the knowledge away from them for so long because I wanted to limit the number of those who know my HIV status and prevent stigmatizing action from people. But I told them not to tell anyone about it."
>
> *Afusat Fakayode, NELA, Ibadan*

4. Coping with stigma

Many persons living with HIV use different strategies for coping with the experience and impact of stigma. Some cope by disclosing their status in order to get the support of family, friends and health care workers

> "I disclosed my status to all members of my family because that way, I can get help and support from them.
>
> *S.O. NELA, Ibadan*

Another coping strategy is denial and non-disclosure of status. The Nigerian culture, which is collectivistic, causes stigmatization of the group and not the individual. This increases the feeling of shame. In this culture, concealment of one's sero-positive status is made even more attractive as this helps to protect against stigma and discrimination.

> "My status is a secret. I have not told any of my family members or my in-laws. If I tell them, I do not feel I would face any stigma from them, but I would rather keep it a secret than find out what anyone may do."
>
> *Afusat Fakayode*

A few cope by joining support groups, while others play active roles in HIV/AIDS education and advocacy efforts.

> "By coming out and educating others, by openly declaring my status, I reduce the tendency of people pointing fingers at me and stigmatizing me. There is nothing new they have to say because I have said it".
>
> *Matthew Babade, Living Hope Care, Ilesa*

Others move away from their community and go to a new place where they are not well known. That way, life starts a new, with the individual making efforts to prevent any stigma.

> "The fiancé of a member of our support group left town when he realized she had gone public about her status and people would soon realize that he must also be infected. He left his clinical practice and moved to an unknown destination."
>
> *Kehinde Omotoso*

CHAPTER SIX

Policy Analysis

Policies and plans are meant to support individual and community health and research efforts to find innovative solutions to health problems. With an enabling policy environment, every segment of the community would be able to confront the impact of HIV/AIDS stigma. It is the duty of countries to develop policies with a view to facilitating the full realization of the right to development as noted in Article 4(1) of the UN Declaration on the Right to Development (1986). The need to formulate policies which would effectively enhance the national HIV/AIDS mitigation and control efforts is therefore highly appropriate. However, for effective implementation of the policies, the enactment of laws which would ensure their enforcement, is the necessary first step.

The Nigerian Constitution and HIV- related stigma: The 1999 constitution of the Federal Republic of Nigeria consists of eight chapters. Chapter II deals with the fundamental objectives and directive principles of state policy. The chapter outlines the fundamental duties of the government as providing for the security and welfare of its citizens. Section 14(2)(b) of the same chapter and Section 24(c) also recognize that it shall be the duty of every citizen to:

> "respect the dignity of other citizens and the rights and legitimate interests of others…"

The government's obligation to provide for the security and welfare of its citizens, including the welfare of people living with HIV/AIDS, includes the need to provide judicial means of enforcing the various conventions and declarations of commitments binding on it. These include the International Covenant of Economic, Social and Cultural Rights (1966), the International Covenant of Civil and Political Rights (1966), the International Guidelines on HIV/AIDS and Human Rights (1996) and the International Labour Convention (1957). There has been the Abuja Declaration of Commitment (2001) and the UNGASS Declaration of Commitment (2001).

The Conventions impose on all states that ratify them the obligation to respect, protect and fulfill a comprehensive set of rights based on the rights set out in the Universal Declaration of Human Rights (1948). Furthermore, some principles in these conventions, guidelines and declarations are so general that they form part of customary international laws which are binding on all countries, including those that had not ratified the specific treaties. These customary international laws are binding on member- countries despite the fact that they are not part of national laws. They are taken automatically as the law of the land.

These customary International Laws and Declarations of Commitment often recognize the need to protect and promote the rights and dignity of all persons irrespective of status. Many specifically address discrimination and the right to health. They include Article 5(e)(iv) of the International Convention on the Elimination of all forms of Racial Discrimination; Articles 11 and 12 of the Convention on the Elimination of all forms of Discrimination Against Women; and Article 24 of the Convention on the Rights of the Child. Articles 2 and 7 of the Universal Declaration of Human Rights also recognize discrimination. A clause reads:

> "Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty."
>
> **Article 2 of the Universal Declaration of Human Rights, 1948**

> "All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.
>
> **Article 7 of the Universal Declaration of Human Rights, 1948**

In recent years, a number of these declarations have been specific on the issues of human rights and HIV/AIDS. The 2001 UNGASS Declaration of Commitment noted that 'respect for the rights of people living with HIV/AIDS drives an effective response, while Point 58 recognises the need for appropriate legislation to give legal protection against all forms of discrimination. It also recognizes the need to combat stigma and social exclusion connected with the HIV epidemic. Also, the International Labour Organisation is actively promoting the universal acceptance of the eight core Conventions which its governing body identified as being fundamental to the rights of human beings at work, irrespective of levels of development of individual member-countries. One of the two equality conventions is the Discrimination (Employment and Occupation) Convention, 1958 No. 111 which deals with freedom from discrimination in the workplace. It reads:

> **"The term *discrimination* includes: (a) any distinction, exclusion or preference made on the basis of race, colour, sex, religion, political opinion, national extraction or social origin, which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation; (b) such other distinction, exclusion or preference which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation as may be determined by the Member concerned after consultation with representative employers' and workers' organisations, where such exist, and with other appropriate bodies. Any distinction, exclusion or preference in respect of a particular job based on the inherent requirements thereof shall not be deemed to be discrimination."**

Through the ratification of conventions, countries recognise these universally accepted goals and rules as legally binding. Once ratified, member- states are expected to formally undertake to make the provisions of the convention effective, both in the national law and practice. The standards promoted in convention become incorporated into national law and legal procedures are used to uphold them. As an expert in International Law explains:

> "Conventions are international treaties. Treaties need to be transformed to laws to be binding. It has to be passed into law by the National Assembly as stated in Section 12 of the 1999 Constitution of the Federal Republic of Nigeria".[31]

Although the resolutions of the UN General Assembly do not have the same legal status as treaties, they are strong statements of international concerns that should guide actions of member- states.

There is however so much unwillingness to modify laws and change constitutions according to the adopted commitments. Without these adoptions, the international treaties and commitments remain inactionable. As at the end of October 2003, there are just about 10 countries of the 189 that ratified the UNGASS Declaration that have enacted specific legislations protecting people infected with HIV[32]. Nigeria is not one of them.

Nigeria's commitment to enacting legislation to protect the rights of people living with HIV/AIDS continues to appear as mere political statements. Although Section 42 and chapter IV of the 1999 Federal Constitution of Nigeria guarantees every Nigerian freedom from discrimination, there is still the need to formulate specific HIV- relevant legislation to take care of HIV- related stigma and discriminatory actions. Stigma and discriminatory actions usually strip individuals of their fundamental rights. Legal machineries help to reinstall them. The need for appropriate legislation to address HIV-related stigma can therefore not be overemphasised.

On Worlds AIDS Day 2002, President Olusegun Obasanjo was quoted thus:

> "(The Federal Government) intends to initiate legislation against all forms of discrimination against people living with HIV/AIDS. Appropriate strategies also need to be developed and implemented to ensure and protect the rights and fundamental freedoms of such persons." *Daily Times. 2nd December 2002, page 1*

Two years before this, the *Post Express* of 4th November 2000 had reported about a proposed bill to be sent to the National Assembly for the formulation of a law to protect persons living with HIV/AIDS from discrimination. The draft was to be passed to the Ministry of Justice for technical interpretation. This legislation has yet to be enacted. In trying to understand the seeming reluctance of the Nigerian legislature to pass a bill for the enactment of such laws, a lawyer with interest in jurisprudence and international law explains:

> "A legislation has to be generally applicable. A specific law on a particular subject is not always allowed. It is called the '*ad hominien*' law, meaning that a law should not be concentrated on a single subject. HIV is a single disease amongst others".
> *Toyin Babatunde, Lecturer, Faculty of Law, Olabisi Onabanjo University, Ogun State*

The conservative nature of the Nigerian judiciary and the *ad hominien* law may explain the slow pace of the Nigerian government in adopting the international declaration. This probably may not be unrelated to a poor understanding of the HIV epidemic and the role of stigma in fuelling it. Also, there is the probability that the control of the epidemic is not viewed as a collective responsibility.

Not only has the Nigerian government been slow to enact new laws, but it has also not taken steps to revise laws that discriminate. Sections 214 and 215 of the Criminal Code criminalise homosexuality and commercial sex work. This contravenes Section 35(1) of the 1999 constitution which provides that:

> "Every person shall be entitled to his personal liberty and no person should be deprived of such liberty"

But then, according to Article 214 of the Penal Code, "any person who has carnal knowledge of any person against the order of nature or permits a male person to have carnal knowledge of him or her against the order of nature is guilty of a felony and liable to imprisonment for 14 years".

Under Section 215, "any person who attempts to commit any of the offences defined in the last preceding section is guilty of a felony and liable to imprisonment for 7 years. Under Section 217, "any male person who, whether in public or private, commits any act of gross indecency with another male person, or procures another male person to commit any act of gross indecency with him or attempts to procure the commission of any such act by any male person, whether in public or private, is guilty of a felony and is liable to imprisonment for three years. Maximum penalties for non-consensual acts are the same as for consensual acts".

Thus, under Section 352 of the Penal Code, assault with intent to have "carnal knowledge with a man (or woman) against the order of nature" also carries a maximum penalty of 14 years' imprisonment, while unlawful and indecent assaults on a male person can be punished with up to three years' imprisonment. (PB and IB 2/92).[33] This negates the principles of personal liberty.

> "The section of the Criminal Code that criminalises homosexuality has become obsolete. The British laws from which the Nigerian law and constitution was derived has since expunged this discriminatory part of its law. Consenting adults should not be criminalised for their

> sexual orientation. A MSM does all things according to the law of the land and so that Criminal Code is illegal and not MSM. For example, how do you reconvict incarcerated men who have sex with other men in prison"?
>
> *Dare Odumuye*

The role of the judiciary in compounding the epidemic of HIV- related stigma is further exemplified by the poor access to justice by people faced with HIV- related stigma. The only case noted in the Nigerian judiciary wherein a person living with HIV sought legal recourse for HIV related discrimination is still stuck at the hearing process two years after filing the suit.

> "The Nigerian legislation has not done anything to correct the discrimination people living with HIV/AIDS face. Inequality has occurred in different forms, including lack of access to justice for marginalised groups, the cost of justice which is very expensive and tortuous, takes a long time and wears people out."
>
> *Ebenezer Durojaiye*

Most times, people faced with HIV-related stigma do nothing about it. Unfortunately, silence about stigma and discriminatory actions further encourages the perpetuation of discrimination.

> "Most people living with HIV and AIDS I know, who faced HIV-related stigma and discrimination, none ever took legal recourse. This is because few people believe in the legal system in the country. Many who are affected do not know their rights. Even when they did, they are too poor to take up legal action." *Femi Soyinka*

CHAPTER SEVEN

The National Policy on HIV/AIDS

The policy document acknowledges that stigma and discrimination worsen the spread and the impact of the epidemic in the country. One of its guiding principles therefore is the principle of human rights, social justice and equity. The goal of the policy document is

> "to control the spread of HIV in Nigeria, to provide equitable care and support for those infected by HIV and to mitigate its impact to the point where it is no longer of public health, social and economic concern, such that all Nigerians will be able to achieve socially and economically productive lives, free of the disease and its effect". *National Policy on HIV/AIDS 2003:pp13*

In order to achieve this goal, 12 focal objectives were defined around which a number of policy statements were drafted. One of these objectives is the need to

> "protect the rights of those infected and affected by HIV/AIDS as guaranteed under the constitution and laws of the republic."
>
> *National Policy on HIV/AIDS 2003, objective vii page 14*

This is a restrictive statement. As noted earlier, the Nigerian law and constitution therefore pose a limitation as to the extent to which the rights of people infected and affected by HIV can be guaranteed.

Nigerian HIV/AIDS Policy: addressing HIV- related stigma determinants

One of the recognised determinants of HIV- related stigma is poor knowledge of the issues about HIV/AIDS. Various studies have shown that public attitude to stigmatised health conditions significantly improve with even relatively brief education programmes[34]. Education programmes will help people identify the inaccurate stereotypes about HIV/AIDS and replace these stereotypes with factual information.

The policy statements on comprehensive information, education and communication system in the country should help remove information barriers that create stigma (see pages 27 and 28 of the Nigerian HIV/AIDS policy document).

This objective is complemented by the target set by the policy document which aims at ensuring that 20percent of Nigerian youths and 10percent of the general population's knowledge, attitude, behaviour and practices improve by the year 2005.

The legislation in its present form, has been highly instrumental to promoting HIV-related stigma. The effects and consequences of stigma are legal matters which the present constitution had failed to adequately address. The HIV/AIDS policy document noted that:

> "the lack of appropriate HIV- related legislation affects the ability of persons living with HIV/AIDS to live positively and persons susceptible or vulnerable to the disease from being able to protect themselves from the disease. In recognition that this lack adversely affects the nation's ability to reduce the spread of HIV/AIDS and mitigate its impact, the government of Nigeria commits itself to reviewing existing legislation and enacting appropriate new laws".
> **National Policy on HIV/AIDS 2003: page 24**

The document then goes on to enumerate the areas in which changes in the legislation are expected. One of them is legislation to improve the protection of the rights of all persons in the workplace, irrespective of HIV status. Access of persons infected and affected by HIV/AIDS to legal services, care and support are to be improved through enactment of appropriate legislations.

Although the first and second policy statements on page 25 of the policy document under the subtitle 'ethics and human rights' recognise the illegality and unethical nature of all forms of discrimination against persons living with HIV, no policy statement specifically states how legislation would address the issue and which legislation needs to be reviewed or which ones need to be enacted to adequately address HIV- related stigma and discrimination. Evaluation of this aspect of the policy document may become difficult.

While there is a need to enact new laws to effectively curb HIV-related discrimination, plan should also be in place to allow speedy access to justice. Justice delayed is justice denied. A cue could be taken from the Kenyan legal system. The Kenyan judiciary set up a tribunal to address HIV- related discrimination cases with appropriate penalties outlined for identified offences.

Also, the amendment of Sections 214 and 215 of the Nigerian Constitution is highly recommended.

> "Due to stigma and undue societal and family pressures, MSM are forced to have wives and children whilst still keeping their network of male sexual partners. This constitutes a major route of HIV transmission with wider implications for the sexual and reproductive health of women, children and the general public."
> *Dare Odumuye*

Case Study
Kenya
The Bill no 22 of the Republic of Kenya to be introduced to its National Assembly addresses HIV/AIDS prevention and control issues in the country. Called 'The HIV and AIDS prevention and control bill, 2003", its section 25 established a tribunal known as the equity tribunal with the sections 25(1)(a-d) defining its composition. Its section 38 defines the contravention of the Discriminatory acts and policies as an offence while the section 28 and 29 defines the punishment for offences and the mechanism for enforcement of orders for damages and costs.
Kenya Gazette Supplement No. 76 (Bill No. 22) 2003

Criminalisation of actions done with consent results in the development of countercultures, such as the creation and fostering of milieu of short term and often anonymous sexual relationships for MSM. This aids the spread of HIV, stalls prevention programmes and inhibits the creation of support programmes that are humane and sensitive to the need of these criminalized groups.

Also, the judiciary should consider the inclusion of the 'suppression of identity' clause in their order of proceedings. This would allow persons living with HIV to file cases under pseudonyms.

Case Study
In India, the Lawyers' Collective in Mumbai had done a lot in terms of defending workers who lost their jobs based on HIV related discrimination. They had also done a lot on mobilizing public opinion against stigma and discrimination. One of its most significant achievements to date has been the upholding of the 'suppression of identity' clause. This allows a person with HIV/AIDS to file his or her case under pseudodnym.
UNAIDS. A conceptual framework and basis of action: HIV/AIDS stigma and discrimination: 2002:16

There is the need for cultural reforms. A culture that readily labels people as bad rather than judge actions and rightfully deal with those actionss is a culture in which stigma and discrimination thrives.

Attitudinal reforms are of paramount importance as the experience of HIV- related stigma and discrimination cannot be limited to attitudes and actions actionable under human rights and law. Though most laws are designed to produce attitudinal and behavioural changes, justice and compassion - the bedrock for change - are not the prerogatives of the state; such values have other springs.

Usually, when attitude - the root cause of stigma - is not addressed and the mechanisms currently in place for producing stigma are blocked through legislation, new mechanisms tend to be created. Without changing the deeply held attitudes that arise from beliefs leading to labeling, devaluation and discrimination; without making fundamental changes in attitudes and beliefs, the effectiveness of interventions would be limited.

Contact has been shown to yield significant improvements in attitude. Researches show that contact increases the tendencies to relate daily with persons living with HIV and AIDS. This increases familiarity and would disconfirm stereotypes about persons living with HIV and AIDS. This results in less prejudice [32]. And when contact is maintained over time, behaviour changes also.

Policies can help create enabling environment to facilitate contacts between persons living with HIV/AIDS and the general public. The newly revised HIV/AIDS policy, in its present form, does very little to facilitate this contact. Contact can be increased through the involvement of persons living with HIV in information dissemination processes. The Bill No.22 of 2003 of the Republic of Kenya is a good example of how policies could help facilitate contact between persons living with HIV and the general public.

Case Study
The Kenyan government realizes the importance of education in bringing about attitudinal and behavioural changes which is the key to reversing the country's HIV epidemic. The section 4 to 8 of the 2003 Bill No 22 extensively enumerated how to facilitate this process. The government recognized that contact with persons living with HIV enhances attitudinal and behavioural changes and makes such changes more enduring. The section 4(3) of the Bill therefore outlined that “in conducting educational and information campaigns referred to in this section (section 4), the government shall ensure the involvement and participation of individuals affected by HIV and AIDS, including persons with HIV and AIDS.
Kenya Gazette Supplement No. 76 (Bill No. 22) 2003

The attitudinal change should, in turn, result in a positive change in language used by the media in addressing persons living with HIV and AIDS.

Nigerian HIV/AIDS Policy: addressing forms of HIV-related stigma

HIV related stigma could occur as enacted stigma or as self stigma. Issues outlined above to address the determinants of HIV/AIDS can also address the various forms of enacted stigma. However, there is a strong need to deal with self stigma.

Oftentimes, when discussing the consequences resulting from enacted stigma in the stigmatised, persons living with HIV and AIDS are portrayed as helpless victims. Ironically, this increases undesirable attributes that form stereotypes about the stigmatised group. Persons living with HIV and AIDS actively use available resources to resist stigmatising tendencies. The most often used form of resistance is secrecy and avoiding people and places that may be stigmatising. This was collaborated by a person living with HIV;

> “I do not face stigma because I keep my status a secret. I do not discuss about it, so no one stigmatises me.”
> *Female person living with HIV, NELA, Ibadan*

Unfortunately in Nigeria, the forms of resistance used have not fully overcome stigma. The need to empower persons living with HIV to act up for their rights becomes highly important for the speedy control of the epidemic. Empowerment produces good self esteem, positive beliefs about self and optimism about the future. It encourages persons living with HIV to advocate for themselves.

> One of the few successful approaches to empowering persons living with HIV is through provision of information. This has been shown to counter self stigma for some people; not all.

Though Objective (ix) of the HIV policy document identifies the need to empower persons infected and affected by HIV to cope through training, counselling and education, nothing in the target or expected output outlined the monitoring and evaluation indices for this objective. There is also no policy statement regarding the support persons living with HIV will receive to get them empowered to cope. The outlined objective therefore has no means for achievement and the document is limited in addressing self stigma.

> The seventh policy statement on Voluntary Counseling and Confidential Testing, (VCCT) of the policy document states that counselling would be used as a tool to:
>
> > "encourage positive individuals to live openly and positively with their condition."

Caution should be exercised when counselling clients about disclosure. Although stigma is a social problem that needs to be addressed by public approaches, this approach involves client having to make decisions to disclose or not. Full disclosure usually fosters a sense of empowerment but the information may also be used to stigmatise. Counsellors should therefore be encouraged to support persons living with HIV in making disclosure decisions by reviewing the costs and benefits of disclosure in various situations.

A pursuit of the VCCT policy should yield positive results in controlling the effects an consequences of self stigma. This should be effectively complimented with policies that support the formations of support groups where persons living with HIV and AIDS can readily access empowering information from peers. As articulated by one of the persons interviewed during this study:

> "People cope with stigma in various ways, including hiding information about their status. However, I have noticed that those that cope by belonging to support groups become better empowered to cope with stigma. They become more open about their status much earlier than others.[35]
>
> *Femi Soyinka*

Best Practice

Combining information-based approach with counseling has been shown to increase disclosure among people living with HIV/AIDS and has triggered improved community attitudes, compared with baseline measures in countries like Uganda and Zimbabwe. In Uganda, the work of TASO, an NGO, and other community-based groups has been central to encouraging greater openness about the epidemic and in improving support and care for individuals, families and communities living with HIV/AIDS

UNAIDS. A conceptual framework and basis of action:
HIV/AIDS stigma and discrimination: 2002:15

Women are worst affected by HIV-related stigma and discrimination. This tendency has roots in the culture that identifies women as vectors of STI. Approaches towards cultural reforms should take note of this during program implementation.

National Policy on HIV/AIDS: Addressing the context of HIV-related stigma

HIV related stigma takes place in the workplace, schools, health institutions, affects housing and access to credit and insurance services. Presently, HIV-positive persons are excluded from the planned National Health Insurance Scheme and are precluded from taking insurance of any kind.

While the policy document explicitly made two policy statements on protecting the rights of persons on the job, it does not address the other context in which HIV-related stigma and discrimination takes place.

i. The first point on page 32 of the document under the subsection titled 'Support for the infected' refers to the need for guaranteeing and enforcing equal access of Nigerians to employment, housing, health, education and social services. However, there is no defined legislation to support enforcement.

ii. On the other hand, legislations are to be enacted and enforced to protect the rights of orphans and vulnerable children (1st, 2nd and 3rd points on page 32 under subsection 'Support for people affected by HIV/AIDS including orphans and vulnerable children'). This proposed legislation does not define support for other groups of persons affected by HIV and AIDS. The policy document in its present form, would be discriminatory on implementation as it excludes legislative protection for some group affected by HIV and AIDS.

iii. The Nigerian government has made efforts to put in place an HIV/AIDS workplace policy and developing the HIV/AIDS workplace policy document. However, very few (less than 30 percent) Nigerians are formally employed. Although the place and importance given to the prevention of workplace discrimination would help enhance the sustainability of income for persons living with HIV and AIDS, the same emphasis should be displayed with the formulation of other policies that would adequately take cognisance of the other context in which HIV-related stigma takes place, such as the health sector.

iv. The Nigerian policy on the National Health Insurance Scheme is discriminatory. The statement in the HIV/AIDS policy document that addresses persons living with HIV/AIDS and access to insurance is also discriminatory as it seeks to protect persons who take insurance cover before their HIV-positive status is detected. The policy therefore provides no support for any person living with HIV who would like to take an insurance cover. Lessons could be learnt from Kenya.

Case study

Many persons living with HIV would want to take out insurance for themselves or their families when they die. However, insurance companies exclude persons living with HIV and AIDS from taking insurance policies and would not pay out any benefits if they find out that the person had HIV or AIDS at the time of death. Currently, insurance companies are allowed to take client's HIV status into account when deciding whether to grant insurance. However for Kenyans, this would no longer hold once the Bill No. 22 of 2003 is passed into law. In the bill, HIV status does not exclude an individual from accessing health insurance.

Section 35(1) of the bill states that no person should be compelled to go for a HIV test for the purpose of credit facilities, accident, life and medical insurances. However, for healthcare services insurance cover, section 35(2) explains that a reasonable limit of cover should be devised for which disclosure of HIV status is not required. Where a proposer seeks a cover exceeding the 'no test' limit, a test could be taken. When the result is positive, section 35(94) explains that the insurer or reinsurer may impose a reasonable additional sum to the premium ordinarily levied for the cover sought. Aggrieved individuals have appeal through provisions made in sections 35(5) and 35 (6).

Kenya Gazette Supplement No. 76 (Bill No. 22) 2003

Table 1: Review of the National HIV/AIDS Policy and its Effects on HIV Related Stigma and Discrimination

Successes	Gaps	Recommendations
The policy is well defined on the need to promote knowledge and education of the general population about HIV and AIDS. This would significantly reduce stigma arising from poor knowledge and understanding of HIV/AIDS	The policy document does not adequately address the need to enact new legislations against HIV related discrimination for the various context in which HIV-related stigma and discriminations occur.	The illegality of all context of HIV related discrimination needs to be adequately addressed by the legislation. Specific laws to be enacted to address these should be identified in the policy document. Appropriate policy statements could be derived from sections 35, 37 of the Bill No. 22, 2003 of the Republic of Kenya.
	There is the need for legal reforms, especially for the discriminatory laws that promote stigmatisation and increase the rate of HIV infection	The policy document should stress the need to review Sections 214 and 215 of the Criminal Code of Nigeria
	The policy document does not make room for persons living with HIV and AIDS to make adequate contact with the general public to help reduce myths and misconceptions about HIV and AIDS.	The Section 4(3) of the Bill No. 22, 2003 of the Federal Republic of Kenya can help with new policy definitions in this aspect.
The policy states that the insurance policies of any kind for persons living with HIV should not be revoked based on HIV status	The policy does not address the issue of persons living with HIV and AIDS who want to take out insurance policies of any kind	The section 35 of the Bill No. 22, 2003 of the Republic of Kenya can help with new policy definitions in this aspect.
The policy identifies the need to empower persons living with HIV and identifies the need for counseling as a tool for empowerment	No target output was identified for this objective of the policy. Monitoring and evaluation of the achievement of this objective would therefore not be possible.	There is a need to set targets to be measured by appropriated monitoring and evaluation indicators. This is most important as this is the only aspect of the policy that could address self stigma.
The policy defines the need to formulate legislations to protect orphans from the effects of HIV-related discrimination	No policy statement was made on the need to enact legislation to protect other persons affected by HIV-related discrimination	The rights of all persons affected by HIV related stigma need to be addressed adequately.
One of the goals of the document is to reduce the prevalence of HIV-related stigma by 25%	There are no reference baseline data on the prevalence of HIV related stigma and discrimination in the country. Also, only overt forms of discrimination would be measured. The subtle forms and expressions of stigma cannot be measured. Measurements and information from such assessments may therefore be inaccurate.	Redefine monitoring and evaluation tools for assessing stigma and discrimination

CHAPTER EIGHT

Analysis of the HIV/AIDS Emergency Action Plan (HEAP):

The Nigerian HIV/AIDS policy document is complimentary to the HEAP; it creates an enabling environment for the implementation of the strategies identified for HIV/AIDS control and mitigation efforts in Nigeria. The HEAP was developed as a response to the HIV epidemic in Nigeria and it is to be pursued between 2001 and 2004. It is a short term plan with expected high impact interventions which implementation will form the base for a medium term strategic plan and act as a bridge for the definition of a longer term vision.

The HEAP adopted a multi-sectorial approach for its implementation. The approach is also multifaceted and multilevel. Its multifaceted nature helps to address the many mechanisms that lead to disadvantaged outcomes, otherwise, the effort to eliminate one bad outcome of the epidemic produces strains that lead to another. The multilevel approach helps to address the problem of HIV control at both individual and structural levels.

The HEAP defined 16 guiding principles. None specifically identified the need to reduce HIV-related stigma. Although the 2nd and 8th principles could help address two of the five identified determinants of HIV-related stigma in Southwestern Nigeria, and the 13th principle could address self stigma, none of the principles addressed the context in which HIV-related stigma occurs. The strategies identified for controlling the Nigerian HIV epidemic are divided into two components: creation of an enabling environment and specific HIV/AIDS interventions for HIV control.

Creation of an enabling environment; effect on reduction of HIV-related stigma

One of the four strategies identified to achieving this is the removal of socio-cultural barriers which lead to abuse of human rights of persons living with HIV and those of women. The need for appropriate legislation to help create an enabling environment for HIV prevention and impact mitigation was also identified. To achieve this, research would be initiated to assess the extent of abuse of the human rights of persons infected and affected by HIV and AIDS (activity 1.3.1), review existing policies to better promote gender equality relating to HIV infection (activity 1.3.2) and review or modify existing legislation which does not pay attention to discrimination of persons infected and affected by HIV and AIDS (activity 1.3.3). However, there are gaps identified in the enumerated activities to remove socio-cultural barriers to HIV control and impact mitigation in Nigeria.

i. One is the fact that the strategy does not identify the need to enact new laws to appropriately address HIV-related discrimination. It also fails to identify activities to enable persons affected by HIV-related stigma access prompt legal services. The only constitutional guarantee of equality is the section 42(1), section 17(2)(a) and section 17(3)(a). These provisions of the constitution do not adequately cover all forms of HIV-related discrimination that persons infected and affected by HIV may face. Also, although activity 1.3.3 identifies the need to review legislations, it did not identify activities to review laws which are in themselves discriminatory and the enforcement of which promotes further HIV infection.

ii. Another strategy identified in the document that could help reduce HIV-related stigma and discrimination are activities to increase awareness about HIV and AIDS in the general population (activities 1.2.1 1.2.5). Education would be through the use of revised IEC materials and the organisation of awareness creation seminars.

> IEC materials are effective in educating and reducing stigma when they present factual information. Unfortunately, many IEC materials produced by NGOs and government agencies in the country are stigmatising in themselves, thereby limiting the success of their use in reducing HIV-related stigma.
>
> Also, the activity 1.2.5 which identifies the need for awareness seminars in all sectors does not promote the inclusion of persons living with HIV/AIDS in those programmes. Various studies have shown the significant impact of involving persons living with HIV in programmes in reducing stigma. The direct involvement of persons living with HIV in delivery services helps to break down discrimination. Vice versa, it empowers infected persons and reduces felt stigma.

The involvement of persons living with HIV should not be limited to seminars and awareness-creation activities. They should be involved in the decision making process, especially on issues that affect infected persons. Stigma is often a problem, even at decision making levels, and the increased involvement of persons living with HIV in official decisions will help to ensure that institutional stigma is tackled.

Specific HIV/AIDS interventions; effect on reduction of HIV-related stigma

One of the four strategies identified is the need for workplace policies and programmes. The substrategy 5.7, which addresses workplace policies and programmes related to HIV/AIDS, is a specific intervention designed to address one of the contexts in which HIV related stigma occurs. The government has since produced a national Workplace HIV/AIDS Ethics, Human Rights Manual and policy document. Efforts are being made to pass a bill for legislation of the workplace policy.

However, activities to ensure the development of policies to address some other context in which HIV-related discrimination occurs, are not being adequately pursued. A review of the various policy documents show that policy statements on HIV/AIDS are included in the National Reproductive Health Policy, Children and Young Person's Bill, the National Population Policy, the National Policy on HIV/AIDS in the Workplace. The National Policy on HIV/AIDS in the Workplace extensively addressed HIV/AIDS discriminatory workplace policies. Unfortunately, although the National Policy on Women identified the effect of HIV/AIDS on women's health in its Section 8.1.3, it identified no strategy to specifically mitigate the impact of HIV related stigma and discrimination which women face. Neither did the 1996 National Health Policy address HIV-related stigma and discrimination in health institutions. A number of these policy documents need to be revised in view of the impact of HIV in all sectors of the Nigerian economy.

The HEAP and the National HIV/AIDS Policy: Are they really complementary?

The National Policy on HIV/AIDS should create an enabling environment for the implementation of the HEAP. However, not only is the policy document coming out very late (two and a half years after the launching of the HEAP) but also, a lot of gaps exist between the two documents. There is a need to review the documents to

ensure they are truly complementary in action and that they adequately address emerging challenges surrounding the HIV epidemic. A review of the documents in relation to their impact in reducing HIV-related stigma and discrimination is presented in Table 3 on page 65.

Table 2: The HEAP: Successes, gaps and recommendations for reduction of HIV-related stigma and discrimination

Successes	Gaps	Recommendations
The HEAP adopts a multisectoral outlook for the design and implementations of its activities. The approach is also multifaceted and multilevel, leading to the possibility of addressing issues at both the individual and structural levels.	The document does not outline enough activities to adequately address all forms, context, determinants and consequences of HIV related stigma a. the need to review discriminatory legislations b. the need to enact new laws and policies that specifically address HIV related stigma. These include issues related to housing, education, health care services, travels and credit and insurance.	Review Sections 214 and 215 of the Criminal Code highly recommended. Strategies for achieving this should also be identified. Strategies and activities to be highlighted to enable the enactment of new laws and development of policies to address the various context and consequences of HIV-related stigma
IEC materials to be developed to educate the general population.	There are no mechanisms to ensure that IEC materials developed are not stigmatising, discriminatory or judgemental in their language and content	National guideline on appropriate development of IEC materials may need to be drawn up.

Table 3: Gaps between the HIV policy document and the HEAP in addressing HIV-related stigma

Policy Document	HEAP	Recommendation
The document identified the need to enact appropriate new laws in the workplace to protect the rights of employees. It also identified the need to enact new laws to protect inheritance and properties of orphan and vulnerable children.	The document only recognises the need to review and modify existing legislations which does not adequately address discrimination of people infected and affected by HIV and AIDS.	1. The policy document need to be reviewed to take cognisance of the need for legislation to protect the rights of other persons affected by HIV in addition to orphans. 2. The HEAP should be modified to include activities which would help with the enactment of new laws and modification of discriminatory criminal laws
The policy does not facilitate contact between persons infected with HIV and the general public .	The HEAP does not have activities that would facilitate contact of persons living with HIV with the public	Both documents should be modified in line with this observation. Targets to be measured for monitoring and evaluation purposes should be defined in the policy document
The document recognises the role of VCCT in encouraging the empowerment of persons living with HIV to enable them live positively and openly with their status.	The HEAP does not identify any activity under the VCCT strategies for empowering persons living with HIV to live positively and openly. However, this could be achieved through activity 7.1.1 under its Activities for care and support of persons living with HIV/AIDS.	1. The documents need to reconcile the policy statements and strategies for implementation. 2. The activity 7.1.1 does not fully take cognisance of the purpose and intent of the policy statement. Activities to complement the policy statement may need to be designed under the VCCT programme in the HEAP.

CHAPTER NINE

Recommendations

Studies show that HIV-related stigma, in both developed and developing countries, can be reduced through a variety of intervention strategies, including providing information and counselling, fostering of coping skills of persons living with HIV to deal with stigmatising attitudes and increasing individual contacts with people living with HIV/AIDS. A multidimensional approach to reducing stigma, which is multifaceted and multilevel, produces significantly measurable impact[36].

Presently in Nigeria, civil society organisations are the main organ involved with HIV control and impact mitigation. They have been the main tool used in decreasing HIV-related stigma in a number of countries, including Uganda[37]. Unfortunately, the programmatic and institutional capacities of most NGOs in the country are weak. Most are involved in awareness creation programmes and fail to address the structural, cultural and societal factors that promote HIV spread, such as stigma. The capacities of NGOs need to be built to effectively address stigma through the various prevention, care and support programmes.

Secondly, efforts to reduce HIV-related stigma must be made an integral part of nationally designed programmes. A comprehensive response is needed for HIV/AIDS, with involvement of the national, state and local governments working collaboratively and interactively, along with all stakeholders. Unfortunately, a comprehensive response to HIV at the community level is still a major challenge in Nigeria. Most programmes address specific HIV issues without adequate community participation, thereby limiting their effectiveness. In addition to this, there is a poor working relationship between the government and the civil society groups leading to poor implementation of government policies and action plans. This produces obstacles to an effective response to HIV/AIDS in Nigeria. HIV related stigma inadvertently continues unabated.

Success story

In Sao Paulo, Brazil, research showed that in order to implement HIV/AIDS prevention programmes among inner-city youths, it was first necessary to confront poverty and economic marginalisation, the stigma and racism associated with being a migrant and the unequal gender-based power relations and norms in Brazilian culture. By focusing, not only on HIV/AIDS, but also on these issues, Brazilian health promotion workers have demonstrated the potential of what a 'community pedagogy' could do for an effective response to HIV/AIDS

UNAIDS. A conceptual framework and basis of action: HIV/AIDS stigma and discrimination: 2002:19

> "There is a wide gap between government policies (where they exist) and the activity plans of organisations working on HIV/AIDS. The gap between policy and action creates an obstacle for the achievement of stigma reduction." *Lekan Otufodunrin*

Linkages and collaboration between all sectors and actors in HIV/AIDS control efforts need to be encouraged actively, alongside ensuring a comprehensive response to HIV/AIDS at the community level for any meaningful impact to be made in reducing HIV-related stigma.

The need to reduce HIV-related stigma as a component strategy for HIV/AIDS control and impact mitigation is poorly defined in the present national working documents. The documents do state that HIV-related stigma is a driving force for the epidemic but programmes are not designed to directly address the issue. For this reason, stigma reduction is not on the agenda of most civil organisations in the country. During the study, we noted that only support groups and those that address human rights abuse had HIV related stigma reduction as a mainstream objective.

The gaps noted between the government and the civil organisations efforts to provide a comprehensive response to the HIV epidemic as a continuum has resulted in the failure to effectively address a number of the forms, contexts and determinants of HIV-related stigma in Nigeria and reduce its consequences.

Success story

In Phayao Province in Thailand, multisectoral work bringing together a wide range of governmental and non-governmental organizations was key to reducing new infection rates in badly affected areas in the late 1990s. A people-oriented approach facilitated greater openness about the epidemic and stimulated greater social cohesion and support.

UNAIDS. A conceptual framework and basis for action: HIV/AIDS Stigma and Discrimination: 2002, 15

Even while emphasising programmes, more efforts should be geared towards the provision of home-based care for persons living with HIV and AIDS. Many. countries reported a reduction in negative attitudes towards persons living with HIV and AIDS through this programme. Zambia is an example of such countries.

Success story

Zambia was one of the first African countries to implement HIV home care services. The Ndola Catholic Diocese home-based care programme has been internationally recognized for the high quality of its work. This is due to strong community participation and the motivation of the programme's volunteers. This way, over 70percent of those in need of HIV-related care are being reached. Consequently, perhaps, negative attitudes towards HIV/AIDS reported lessened and local people have been empowered with the knowledge, skills and self-confidence they need to cope with the impact of the epidemic.

UNAIDS. A conceptual framework and basis for action: HIV/AIDS Stigma and Discrimination, November 2002:15

The National HIV/AIDS Policy notes that 'appropriate mechanisms will be put in place to increase the availability of home-based care', and it aims at ensuring that at least 20 percent of all local government areas will be able to offer home-based care services to people living with HIV/AIDS in their communities by 2010. Unfortunately, it hinges the success of this programme on the government. All over Africa, home based care services had hinged on NGOs. Till date, home-base care services in Nigeria had been provided by NGOs. The government's effort to hinge the success of home-based care service provision on the government would therefore lead to limited success.

Advocacy-related activities aimed at empowering persons infected with HIV to challenge stigmatising social norms and tackling the forms of felt and enacted stigma that makes open disclosure of sero-status difficult, should be supported.

Advocates work with decision-makers and other agents of social change to reduce and possibly eliminate discriminatory perceptions and behaviours. Organisational and technical support should be given to organised support groups of persons living with HIV and AIDS which would help them build skills for advocacy.

Success story

Lack of access to anti retroviral treatment is a key issue that worsens HIV-related stigma and discrimination in many countries. The perceived 'untreatability' of AIDS is a key factor contributing to stigma. HIV continues to be equated to serious illness and death, and the public attitude remained unchanged. For this reason, as well as on grounds of equity and justice, the Treatment Action Campaign (TAC) was formed in South Africa in 1998 with the aim of improving access of persons living with HIV and AIDS in South Africa to drugs. It had also continued to advocate and struggle for human rights, deploying a number of strategies aimed at challenging stigma. Activists have made famous t-shirts with the phrase 'HIV-positive' emblazoned on the front. This re-appropriation of the stigma associated with HIV/AIDS has led wearers and observers to question what the virus does to an individual's personality, leading to greater awareness.

UNAIDS. A conceptual framework and basis for action: HIV/AIDS Stigma and Discrimination, November 2002, 17

While concerted efforts are being employed in controlling HIV related stigma through HIV-related activities, there is need to focus on the deeper structures of inequalities that fuel the negative responses of stigma and discrimination. Broad based alliances therefore need to be formed between HIV activists and activism and others works and workers in other fields to promote gender equality and sexual equality.

The significant role of research in HIV/AIDS control efforts cannot be over-emphasised. Research is needed to help find innovative solutions to problems including that of HIV-related stigma. It helps in understanding and developing various theoretical structures used for designing strategies that reduce stigma. Support for research must continue in the domains of intervention, programmes operations and policy formulation to give greater insight and understanding to the various geographical variations in the forms, context and determinants of HIV-related stigma and how to effectively address it. Research forms the bedrock for defining strategies to minimise stigma. Most of the researches on stigma were carried out in countries with cultures significantly different from that of Nigeria. Therefore defining strategies for HIV stigma reduction in the Nigerian context using those other studies may result in limited success.

Such research studies must involve the participation of researchers from a broad range of biomedical and non biomedical fields. Interdisciplinary studies are needed which use current behavioral, social and biomedical approaches to elucidate the aetiology of HIV-related stigma, as well as develop and test interventions to mitigate its negative consequences. The research findings are then fed into the policy-making process.

Presently, the scientific knowledge on HIV-related stigma in Nigeria is low. The absence of baseline data makes monitoring and evaluation of programmes and policies poor. Efforts must therefore be geared towards encouraging research to elucidate a better understanding of HIV-related stigma and discrimination in the Nigerian context.

Conclusion

The negative consequences of stigma are usually very difficult to eradicate. This is because of the multitude of associated outcomes. The existence of multiple stigma mechanisms and multiple stigma outcomes calls for multifaceted and multilevel approaches to eliminate HIV-related stigma and its outcomes. Action should be taken to prevent stigma, challenge discrimination when it occurs, monitor and redress human rights violations. Most actions are directed at challenging discrimination when it occurs and redressing human right violations. Preventing stigma, which would otherwise eliminate discrimination and human right abuse is a more difficult task. It is an issue of value.

Best practice

In South Africa, the Centre for the Study of AIDS at the University of Pretoria has been active in challenging HIV-related stigma. It has introduced HIV/AIDS-related concerns into elements of the higher education curriculum, in subjects such as law, agriculture and engineering. This has led to greater understanding of the issues within the university context, de-stigmatizing and enhancing discussion of HIV/AIDS-related concerns.
UNAIDS. A conceptual framework and basis for action: HIV/AIDS Stigma and Discrimination November, 2002:17

Therefore, efforts should be geared towards safeguarding the dignity of individuals affected and infected and the respect of human rights. Approaches must be multipronged, with policies put in place to ensure the prevention of stigma, the ability to challenge discrimination when it occurs and ensuring the monitoring and redressing of human right violations. In Peter Piot's words:

> "HIV/AIDS-related stigma comes from a powerful combination of shame and fear…… Responding to AIDS with blame, or abuse towards people living with AIDS simply forces the epidemic underground creating the ideal conditions for HIV spread. The only way of making progress against the epidemic is to replace shame with solidarity and fear with hope."[38]

20 years into the epidemic, with stigma and discrimination still acting as a catalyst, the global prevalence is still increasing. The control of the HIV epidemic needs the personal commitment of each individual. The control of the epidemic needs to be seen and addressed as a collective responsibility, thereby promoting human rights and tolerance.

Human Rights & HIV/AIDS Experiences of PLWHA In Nigeria
Center for the Right to Health, 2001

The Centre for the Right to Health (CRH) is a non-governmental organization based in Lagos. Its mission is 'to advocate for the full realization of the right to health and respect for ethics and human rights in healthcare policies, especially for vulnerable groups, such as people living with HIV/AIDS, women, youths and children. With offices in Lagos and Abuja, the organization has a program staff of eight and six support staff.

The study conducted by the organization focused on getting the testimonies of stakeholders like PLWH, to assess the extent of stigma and discrimination in Nigeria. The methodologies used were focus group discussion (FGD) and in-depth interviews with PLWH, community members, health care workers, community leaders, lawyers, judges, journalists, and employers of labour and family members of PLWH.

The study revealed widespread violation of the human rights of PLWHA. All the participants revealed that they feel stigmatized, and many have actually experienced enacted stigma in a variety of settings. Most of them live in fear of further violation. Because of this, many of them avoid places and situations that may expose them to violations. In essence, they miss out on social, family and institutional support that are vital to their survival. Only two among those interviewed expressed willingness to seek redress. The others were reluctant, citing publicity and undue delay in the judicial system as their main reasons.

Healthcare: The study documented the forms of stigma experienced by some PLWHA in settings like the healthcare facilities, workplace, family and the community. Most of the experiences encountered centered around breach of confidentiality of HIV sero-status, testing without consent, testing without pre & post VCT, rejection, mandatory testing and denial of care, use of verbal and foul language or abuses and refusal to treat HIV-positive patients. Most doctors and even chief medical directors of some big government hospitals did not know about the existence of any National HIV/AIDS Policy or even attempt to have one in their hospital. Universal Precaution is very largely unknown by most health care providers interviewed.

Workplace: The study discovered that PLWHA interviewed live in fear of losing their jobs if their employers or colleagues find out about their HIV-positive status. There is also a synergy between violation in healthcare institutions and that of the workplace, with the first leading to the latter. Pre-employment test on the job and test without consent of the subject have been the major forms of S & D in the workplace

in Nigeria. Fresh applicants are turned down, while the already employed are most of the time sacked.

Family & Community Setting: This takes the form of gossip, ejection from house by landlords, refusal of educational facilities, rejection by family members, etc.

Church setting: Mandatory HIV test before marriage and refusal to wed consenting adults because one or both partners tested HIV-positive, (Some priests still see HIV as a death sentence).

CHAPTER TEN

Experience from other Lands

HIV/AIDS- related Discrimination, Stigmatization and Denial in Uganda
The AIDS Support Organization (TASO), Uganda

Uganda is a country that has witnessed a lot of HIV/AIDS interventions. Its early response to the epidemic has greatly helped in drastically bringing down the level of the epidemic. Stigma and discrimination are also getting reduced in most parts of the country. With the unrelenting efforts of some AIDS service organizations like TASO, research studies were conducted to investigate the problem of HIV/AIDS-related stigma and discrimination in Uganda.

Before the research study was conducted, earlier research had suggested that Uganda faces a number of particular problems in relation to stigma and discrimination. First, because of denial, some young people were felt to be complacent about the risks of HIV transmission and lacked basic information about the epidemic (Nuwagaba, 1994).

Second, particular difficulties were reported in relation to safer sex for married women although the majority of married women were aware of HIV transmission issues; they felt unable to control the risky behaviour of their male partners or to negotiate safer sex. Because Ugandan society regards extramarital sex as socially acceptable, it has been difficult historically to induce safer sex among married couples, many of whom (despite having occasional partners see themselves as "protected" by the marriage bond. A third area of concern centered on the attitude of community members. Two studies found that community members were sometimes unwilling to provide care and social support to people living with HIV/AIDS because of fears of HIV transmission, the stigma associated with AIDS, and judgmental attitudes. A further study has reported that, although close neighbors extended assistance, they usually did so only when asked directly (Nuwagaba, 1994).

Fourth, research has identified concerns relating to the attitudes of family members, particularly towards widows of men who have died of AIDS-related conditions (Asingwire 1992). Ostracization of children and lack of family care (including being denied food) threatened the survival of widows and their children, particularly in rural communities.

Finally, HIV/AIDS was seen to cause insecurity in employment and discrimination in the workplace. It has been reported that some organizations terminated the contracts of people with AIDS when they become ill (Uganda Ministry of Health, 1995). Those who were HIV-positive and unemployed found it difficult to find work; those who did find work were likely to encounter discrimination because of their HIV status. Considering that almost every household in Uganda has been affected by HIV/AIDS in some way, it may appear surprising that 53.5 percent of respondents in one study said that people with HIV/AIDS should not be able work alongside those who were uninfected (Uganda Ministry of Health, 1995)

The research aimed to:
1. Analyze the different forms of HIV/AIDS-related stigma in contrasting sites within Uganda.
2. Establish which factors influence different forms of HIV/AIDS -related stigma
3. Assess the various responses to which HIV-related stigma and discrimination give rise to.

The research was carried out in Kampala District, the largest urban area in Uganda, and Mbarara, a typical rural area in Uganda. The methodologies used are individual interviews, focus group discussions and observations**.** The people interviewed were PLWHAs, medical personnel, families affected by AIDS, Counselors, legal professionals, community leaders, religious leaders, NGO workers, community-based association workers.

The study recorded unsuspected but declining levels of HIV/AIDS-related discrimination and stigmatization, particularly in relation to family and community attitudes towards PLWHA. HIV/AIDS-related stigma and discrimination were also found in health care institutions and workplaces. Despite progress in these areas, the importance of self-stigmatization was highlighted repeatedly throughout the study.

AIDS-related stigma and discrimination were particularly apparent in relation to the inheritance and succession rights of women: suspicion about HIV and AIDS tended to cause husband's parents to react negatively towards the daughter-in-law and her children. The belief that an infected individual might die in a short period of time, along with continuing fears of witchcraft, further compounded the difficulties many women faced.

While there is evidence that information campaigns have improved the situation as regards stigma and discrimination in the community, there is still much work to be done in challenging AIDS-related stigmatization and especially self-stigmatization. This is particularly the case in terms of a legislative framework.

The outcomes identified in the study suggested that counseling services are effective in dealing with people's feelings of isolation, embarrassment and despair following a diagnosis of HIV/AIDS. The research also suggests that denial, stigmatization and discrimination (DSD) have serious consequences for people living with HIV/AIDS, although it was suggested that being open about one's sero-status boosted feelings of self-worth and confidence.

The report revealed significant levels of stigma, yet there are some positive features that must be stressed. First, the Ugandan government has been supportive of a general climate of anti-discrimination in the country. Second, information campaigns have improved people's knowledge. Third, the health care system would appear to be relatively enlightened in its dealings with and attitudes towards people with HIV, at least in contrast to cases reported in other studies. Finally, it seems that services provided by AIDS NGOs and other groups can help people with HIV become more assertive, be more open about their sero-status, and live truly positive lives.

HIV/AIDS-related Discrimination, Stigmatization and Denial in India.
Tata Institute Of Social Sciences, Mumbai, India

The research aimed to examine the forms, determinants and outcomes of HIV/AIDS-related DSD in India, and to explore their possible social demographic, and cultural correlates.

The research was carried out in two Indian metropolitan cities: Greater Mumbai in the state of Maharashtra in the west, and Bangalore in Karnataka state in the south of the country. Key informant interviews, in-depth individual interviews, and focus group discussions were the main methodologies used during the research.

The research studies on stigma and discrimination reveal that social reactions to people with AIDS have been overwhelmingly negative. For example, 36 percent of respondents in one study felt it would be better if infected individuals killed themselves; the same percentage believed that infected people deserved their fate. Furthermore, in this same study, 34 percent of respondents said they would not associate with people with AIDS, while about one-fifth stated that AIDS was a punishment from God. A hostility index developed in this study revealed that almost 90 percent of respondents harboured at least one hostile view, and more than half held three or more such views.

Just as in Nigeria, negative responses and attitudes towards PLWHA are strongly linked to general levels of knowledge about AIDS and HIV, and in particular, to the causes of AIDS and routes of HIV transmission. In most societies, AIDS is associated with groups whose social and sexual behaviour does not meet with public approval. In another study by Ambati and Rao in India (1997), 60 percent of respondents believed that only gay men, prostitutes and drug users could get AIDS.

With these findings in mind, it is perhaps not surprising that virtually every Indian setting in which HIV-positive people interact with other people provides a back-drop for discrimination and stigmatization. Studies have documented HIV/AIDS-related stigma and discrimination in context such as the family, the community, the health care system, and the workplace. Discriminatory restrictions have also been reported in relation to travel, immigration, insurance and health benefits.

In the research sites, significant levels of discrimination, both overt and covert, were identified in the health care setting. In an attempt to avoid having to provide care, health care staff discharged patients from hospital. There was uncertainty among health care staff about basic HIV-transmission information and about the need for, and purpose of, universal precautions. Staff, particularly those with a secondary care role, held exaggerated fears about the infectiousness of HIV, which profoundly affected their ability to provide good care. No matter how minuscule the risk of infection, treatment interventions were often selected, not on the basis of what was best for the patient, but on what would prevent any risk of infection. Staffs' negative views about people with HIV also affected the care provided. In sum, the study revealed a depressing picture of widespread labeling and stereotyping and lack of care throughout the health sector, with the possible exception of a small number of hospitals where good policies and practices have been established.

The study also revealed that HIV/AIDS-related stigma and discrimination in India is, in some respects, a gendered phenomenon. Issues such as inheritance, housing, and care-giving were found to be particularly suffered by women. Moreover, women were often blamed by their parents-in-law for infecting their husbands, or for not “controlling” their partners' urges to have sex with other women. The quality of care provided for women in the family was significantly poorer than the care provided for men. While a small number of cases were cited in which women had abandoned their husbands, more common was the neglect and maltreatment of women by husbands and parents-in-law.

Schools and the insurance business were also found to be places in which HIV/AIDS-related stigmatization and discrimination normally take place. Children of HIV-positive parents, whether positive or negative themselves, were often denied the right to go to school or were segregated from other children. Life insurance companies were not trusted by people with HIV, despite assurances that benefits would be paid if the policyholder had tested positive after taking out a policy. Concern was expressed by people with HIV that they faced harsher treatment from insurers than did people with other health conditions.

Detailed interviews with female sex workers and gay men revealed the extent to which HIV/AIDS-related stigmatization and discrimination can lead to double discrimination. People in these marginalized groups are stigmatized, not only on the grounds of HIV/AIDS status, but also for being members of a socially denigrated group. Stigmatization of members of marginalized groups was also felt to be more severe, because the stigma arose from two sources: fear of HIV and fear or hatred of the group in question.

Based on the study, the following recommendations, which can also be adapted to Nigeria, were made to effectively challenge HIV/AIDS-related stigma and discrimination in India:

People living with HIV:

- People living with HIV/AIDS need to be better educated about their rights as patients and how to get help to change the discrimination and stigmatization they face in health care settings;
- People living with HIV/AIDS need legal education and access to the justice system to address the violation of their rights in the context of employment and education;
- A more enabling environment needs to be created to increase the visibility of people with HIV/AIDS and to facilitate the work of support groups so that discrimination, stigmatization and denial can be challenged collectively.

Members of marginalized groups

- Social marginalization of members of infected minority groups will only intensify the spread of HIV infection. It is therefore imperative to protect the rights of minority group members and address their needs specially, so that they are not overlooked in more generic approaches to reducing HIV/AIDS-related DSD.
- Stigmatization of women who are the wives of HIV-positive men or who are pregnant must be given special attention in relation to testing, pregnancy, abortion, and breastfeeding. Discrimination in the form of early discharge from, or denial of services on grounds of gender must be strongly challenged.
- With the health care system, the concept of universal precautions needs to be promoted and irrational and selective use of inappropriate "safety measures" reduced. The latter not only create a false sense of security among health care workers, but also adversely affect the emotional health of HIV patients.
- Human rights principles of informed consent and confidentiality need to be more widely adhered to in medical practice so that health care staff and professionals do not violate patients' rights to informed choice, privacy and counseling
- Newer concepts and labels such as "barrier nursing or immune-compromised patient" are becoming synonymous with HIV/AIDS and hence serve the same functions as the label "AIDS". These concepts need to be used for all types of infections without revealing the nature of infection to staff involved in providing care.
- There is an urgent need to extend awareness among health care staff concerning their legal duties and responsibilities towards patients in general, and patients with HIV/AIDS in particular.
- Necessary protective gear, including good-quality gloves, must be supplied in adequate quantities to all staff in government hospitals so that the non-availability of such items is not used as an excuse to deny care to HIV-positive patients.
- Mandatory testing must be strongly discouraged for individuals, including pregnant women, regardless of what treatment (invasive or otherwise) they seek, as it often leads to denial of services to those found to be HIV-positive.
- Counseling services must be made available in all health facilities to provide for the psycho-social needs of HIV-positive patients
- To help individuals who wish to learn of their HIV status without the fear of disclosure to others, voluntary testing accompanied by counseling, must be provided in all cities and districts
- Lack of adequate AIDS education can give rise to irrational fears and inappropriate care practices. Hospital staff at all levels need access to appropriate HIV/AIDS education. No medical institution should be allowed to withhold or limit HIV/AIDS education to any group of staff
- HIV testing should not be carried out without the informed consent of the patient and without pre- and post-test counseling. Treatment and care must be provided following positive test results.
- Above all, in order to reduce levels of discrimination within the health care sector, it is important to challenge beliefs about casual modes of HIV transmission and address the diffuse and irrational sense of personal risk among ancillary staff.

Anti-discrimination legislation and other legal measures

- Legislation is needed to reduce discrimination and stigmatization of PLWHA in all areas, but particularly in relation to health care and employment.
- An effective complaints mechanism should be put in place in the health care sector for HIV-positive people to seek protection of their rights as patients.
- Fear-based AIDS messages and biased social attitudes towards infected people urgently need to be tackled, as fear and prejudice lie at the core of S & D

- It is not enough to raise awareness about HIV/AIDS, its transmission routes, or even about legal rights. What is urgently needed is anti-discrimination policy supported by law that will ensure the protection of HIV-positive people's rights.

Other Important measures include:

- The employment sector must develop policy guidelines on AIDS to help and support HIV-positive workers. HIV testing, when beginning a job or as part of routine medical check-ups for existing staff, must be strongly discouraged, as such tests prevent individuals from earning a living and can lead to social isolation and rejection for those found to be HIV-positive.
- Child care institutions must be allowed to transfer responsibility for care and protection of HIV-infected children to other institutions. Existing institutions must add special facilities to provide all necessary care and treatment for infected and sick children.
- Life insurance policies must be expanded in appropriate ways to address the needs of HIV-positive people desiring insurance cover, and efforts must be made to dispel misconceptions and fears about claims to existing insurance policies.
- Research on drug trials or any aspect of HIV patients' lives within the health care sector may be conducted only after the informed consent of the patient is secured.

International instruments on protection from stigma and discrimination

Several policy documents and pronouncements exist at the international level, which can be used to advance protection from discrimination at national levels. Below are some of the international legal and policy instruments that may be applicable in Nigeria by virtue of Nigeria's membership of the bodies.

Name	Place	Statement	Year
The London Declaration on AIDS	World Summit of Ministers of Health on Programmes for HIV prevention.	"Discrimination against, and stigmatization of HIV-infected people and people with AIDS and population groups undermine public health and must be avoided" (paragraph 6)	1988.
Resolution WHA 41.24	41st World Health Assembly	We urge member states to foster a spirit of understanding and compassion for HIV-infected people and those suffering with AIDS. We recommended member states to protect the human rights and dignity of affected individuals and population groups so as to discourage discrimination and stigmatization in the provision of services, employment and travel.	1988
United Nations Center for Human Right	1st international consultation on HIV/AIDS and Human Rights	We reaffirmed the Public Health rationale for the prevention of HIV/AIDS-related discrimination and promotion and protection of human rights in the context of HIV/AIDS.	1989

Name	Place	Statement	Year
Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS.	2nd and 3rd International Consultation on HIV/AIDS and Human Rights.	Guideline No. 5. "states should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sector, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation and provide for speedy and effective administration and civil remedies."	1996, & 2000 respectively.
UN Commission on Human Rights.		Guide 7: "States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise and utilize means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaints units and human rights commissions." "Resolution 49/1999 "Discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing international human rights standards, and that the term, 'or other status' non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS.	
United Nations General Assembly. (UNGASS)	Special Session on HIV/AIDS.	Declaration 58: By 2003, states should enact, strengthen or enforce as appropriate, legislation, regulations and other measures. To eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups in particular to ensure their access to **inter-alia**, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality and develop strategies to combat stigma and social exclusion connected with the epidemic.	June 2001
African Development Forum	Gathering of stakeholders in different development programmes across Africa and African leaders	To fight stigma and discrimination in all the ways they militate against interventions against HIV/AIDS in all parts of Africa	2000
Abuja Declaration on HIV/AIDS	Meeting of African Heads of State and many other stakeholders from across the world	We are aware that stigma, silence, denial and discrimination against PLWHA increase the impact of the epidemic and constitute a major barrier to an effective response to it. We recognize the importance of Greater Involvement of PLWHA. We commit ourselve at ensuring coordination of all sectors at all levels with a gender perspective and respect for human rights for PLWHA	April 2001

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