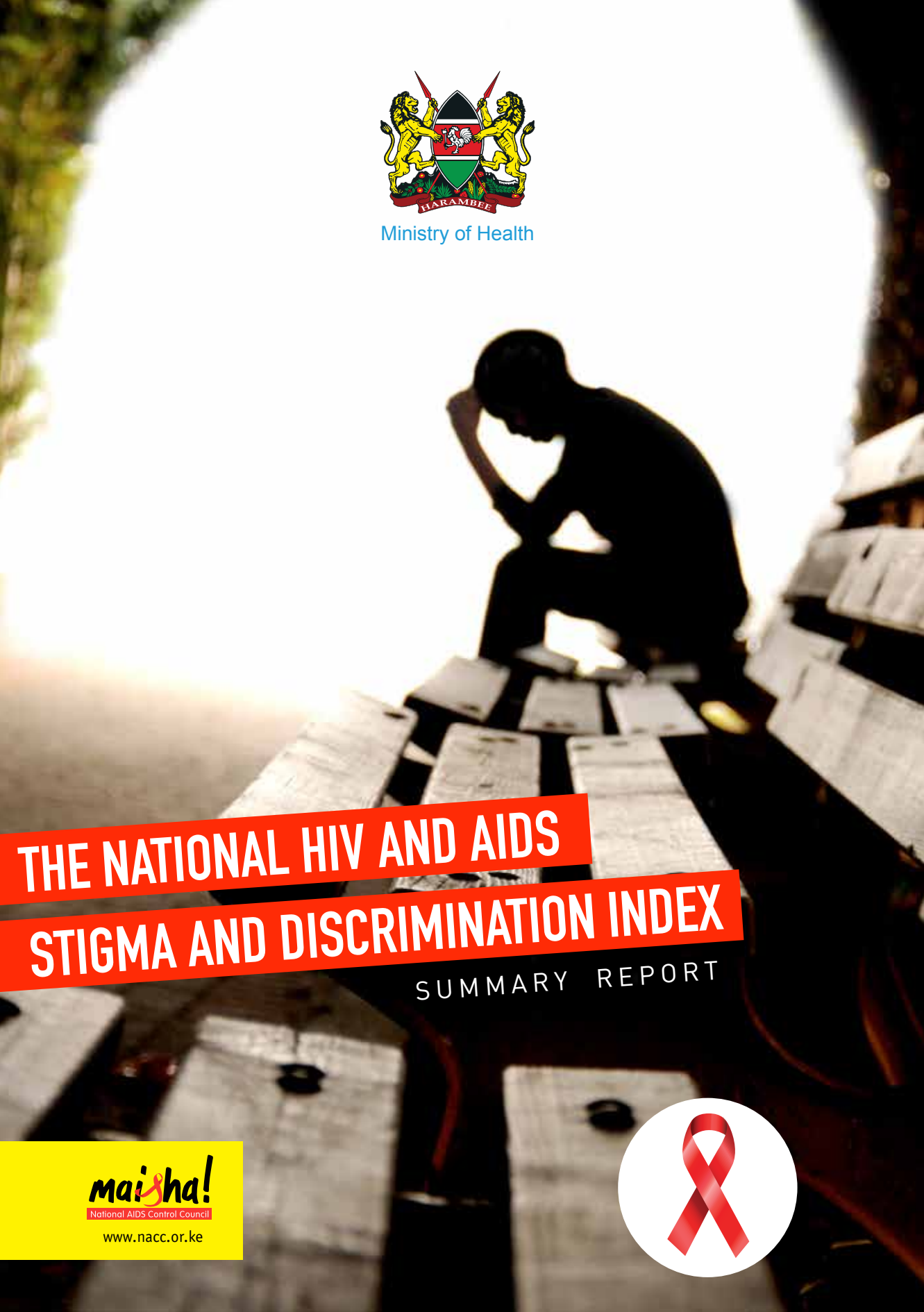

Ministry of Health

THE NATIONAL HIV AND AIDS STIGMA AND DISCRIMINATION INDEX

SUMMARY REPORT

maisha!
National AIDS Control Council
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His Excellency President Uhuru Kenyatta with Elijah and Michel Sidibé, Executive Director UNAIDS during the official launch of Kenya's Fast-track Plan to End Adolescent Aids and HIV situation Room © UNAIDS

"Whereas, we had reached over 80% of adults in need of Anti-Retroviral Therapy, we had only reached less than half of our young people. I made it very clear in February that this was not acceptable anywhere in Africa. Shared prosperity will only be achieved, when we have shared responsibility. I am committed to the future of our young people and I will lead by example."

President Uhuru Kenyatta

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FOREWORD

Three decades since the first AIDS case was reported in Kenya, there has been tremendous progress made in the scale up of prevention and treatment interventions. The number of new HIV infections however remains high with close to 101,560 new infections reported annually making Kenya the third largest HIV epidemic in Sub-Saharan Africa with an estimated 1.6 million People Living with HIV. Evidence has also shown that lack of knowledge of correct HIV status is the leading cause of continued spread of HIV. It also leads to high morbidity and mortality amongst people living with HIV. One of the major barriers identified in access to HIV testing and treatment, care and support services is stigma and discrimination.

The HIV stigma index 2014 a report of the first The National HIV and AIDS Stigma Survey in Kenya. It shows that HIV stigma and discrimination in Kenya is high at 45 with marked regional variations. HIV stigma and discrimination also varies within population groups with some experiencing more stigma and discrimination than others. Key populations for example experience double stigma against HIV and their high risk sexual behaviors.

The Kenya AIDS Strategic Framework (KASF) 2014/2015 - 2018/2019 targets to reduce HIV related stigma and discrimination by 50% by the year 2019. This reduction in HIV related stigma and discrimination will be critical for the achievement of all the other targets in the KASF.

This document forms the baseline against which we will track and measure our performance towards ensuring Kenya is free of HIV stigma. In this regard, therefore, the Ministry of Health through the National AIDS Control Council is committed to leading and facilitating all efforts towards the elimination of HIV stigma and discrimination in Kenya for improved health outcomes.

Hon. James Wainaina Macharia
Cabinet Secretary, Ministry of Health

It is our hope that this report and the Kenya AIDS Strategic Framework provide a basis for direct funding towards HIV stigma reduction interventions in Kenya

Nelson Otwoma - NEPHAK

If we want to achieve SDG3 to ensure healthy lives and promote well-being for all at all ages, we cannot afford to leave people living with HIV and those at risk of HIV behind. We must counter stigma and discrimination, and adopt a people-centred inclusive approach to Fast Track the ending of AIDS in Kenya, Africa and globally.

Jantine Jacobi, UNAIDS, Kenya Country Director

At the beginning of the fourth decade of the HIV epidemic, profound stigma and discrimination is a fact of life for those with the disease- not just socially but within all systems of society. We must fight it with all the resources we have, if we are to achieve sustainable development goals and ensure healthy lives and promote the well-being for all at all ages.

Maria-Threase Keating, UNDP Kenya Country Director

ACKNOWLEDGEMENTS

The National HIV and AIDS Stigma Survey, is a result of efforts by many individuals and organizations in the country led by The Technical Advisory Committee.

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Special thanks to Ruth Laibon Masha, Dr George Githuka and Peter Cheseret for final design of this summary report. This work is inspired by all the People Living with HIV in Kenya.

To all of you, Asante Sana!

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Research Team - Roles-s Management Institute: Dr Stephen Mogere, Dr. Bon Oirere, Vitalis Akora, Dr. Eunice Nyavanga, Dr. Martin Mburu, Rahab Mwaniki, Pauline Kamau.

Nduku Kilonzo, Ph.D
Director, National AIDS Control Council

ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CCC	Comprehensive Care Centre
CDC	Centers for Disease Control and Prevention
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV and AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV and AIDS
IPPF	International Planned Parenthood Federation
KANCO	Kenya AIDS NGO Consortium
KCPE	Kenya Certificate of Primary Education
KEMRI	Kenya Medical Research Institute
KETAM	Kenya Treatment Access Movement
M&E	Monitoring and Evaluation
MSM	Men who have Sex with Men
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Control Programme
NEPHAK	National Empowerment Network of People Living with HIV and AIDS in Kenya
NGO	Non-governmental Organisation
OVC	Orphans and Vulnerable Children
PE	Physical Education
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	United Nations Joint Programme on HIV and AIDS
UNDP	United Nations Development Programme

KEY TERMS

HIV RELATED STIGMA

Stigma is the devaluation of people living with or associated with HIV and AIDS. A person who is stigmatised is seen as having less value or worth than other people. This usually happens when someone's condition is attributed to behaviours that society considers to be improper.

DISCRIMINATION

Discrimination is what happens when someone is treated in an unjust, unfair or prejudicial way, often on the basis of belonging to a particular group. Discrimination is how stigma is manifested or enacted.

STIGMA INDEX

Stigma index is a tool for identifying and measuring trends in stigma and discrimination. Stigma index studies provide evidence of the nature and extent of stigma and discrimination. The tools used in this study were the standard tools used in similar studies globally. The results can therefore be compared with other stigma and discrimination index levels in other regions and countries that have used the standard tools.

Voluntary Counseling and testing during Nairobi ASK 2010 © NACC

EXECUTIVE SUMMARY

Overall composite HIV stigma index for Kenya in 2014 was high at 45

Three decades on from when the first AIDS cases became known to the world, the stigma attached to the syndrome still flourishes despite tremendous in roads made through scaled up prevention and treatment interventions. Kenya has the third largest HIV epidemic in Sub-Saharan Africa with an estimated 1.6 million People Living with HIV (PLHIV) and over 650,000 of them are currently accessing antiretroviral treatment. This situation is, however, compounded by the fact that close to 101,560 new HIV infections occur annual[1]. As the country grapples with how to reduce the number of new infections, stigma and discrimination continue to disrupt and discourage access to HIV education and treatment, care and support services.

The National HIV and AIDS Stigma and Discrimination Study, was a cross-sectional survey which collected data from the 47 counties, grouped into 30 clusters selected based on observed regional variations in HIV prevalence, socio-cultural and economic characteristics.

The stigma study, targeted the general population, key populations as well as PLHIV is a compilation of the thoughts and attitudes regarding HIV, and, far too frequently, painful experiences of people living with HIV.

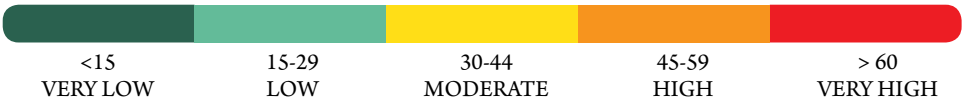
> "My husband told my mother he was dying of AIDS, and she blamed me for it. My children and I were shunned by the rest of the family. Eventually they sent us away from my matrimonial home, accusing me of being a prostitute and a woman of loose morals.
>
> I landed up at my sister's house in Juja. She didn't want us to live in her house because, she said, my children could easily infect her own children while playing together."

The young woman who endured this callous treatment from her own family was lucky. After several suicide attempts, kind neighbours rushed her to hospital where she was counselled and put on antiretroviral treatment. Today she is a volunteer AIDS counsellor at the same hospital and runs a small business from a kiosk. Many others have not fared as well according to *The National HIV and AIDS Stigma and Discrimination Study, carried out in 2014* rated the levels of HIV, related stigma and discrimination in Kenya as 'high' with regional variations.

1 Kenya HIV Estimates Technical Report 2013

Stigma and discrimination Index (SDI) was derived from five (5) key indicators: Fear of non-invasive contact with PLHIV; Values targeting shame, blame and judgment; Enacted stigma; Disclosure and impact. Indicators used for the SDI were each scored on a 100-point scale. Based on their overall scores, individual categories of SDI were then calculated and rated on a scale of 1 to 100.

STIGMA AND DISCRIMINATION RATING



High ratings of indicators such as fear of HIV status disclosure, people fearing to contract HIV from non-invasive contact with PLHIV have direct impact on access to HIV care and treatment

KEY INDICATORS

Indicators	Units	Rating
People fearful of contracting HIV from non-invasive contact with PLHIV	18	LOW
People who judge or blame PLHIV for their illness	47	HIGH
PLHIV who think they have experienced stigma in the last year	17	LOW
PLHIV who are concerned about disclosing their status	70	VERY HIGH
PLHIV who experience stigma's negative effects on themselves, the family, the community	74	VERY HIGH

The findings of the report show that key populations who include sex workers, men who have sex with men (MSM) and drug users experience double stigma associated with their sexual behaviours, practices and HIV status. Children living with HIV were also significantly affected as a result of stigma which could limit access to services.

Despite the availability of legal and support programmes to curb HIV related stigma and discrimination none of the respondents knew of the existence of the HIV tribunal that supports access to justice

KEY HIGHLIGHTS

48% *of respondents fear their children to play with known HIV positive children in schools*

61% *think HIV is a punishment for bad behaviour*

39% *said that HIV-positive men and women should not have children*

44% *believed that people living with HIV are promiscuous*

50% *Consider HIV infection a punishment from God*

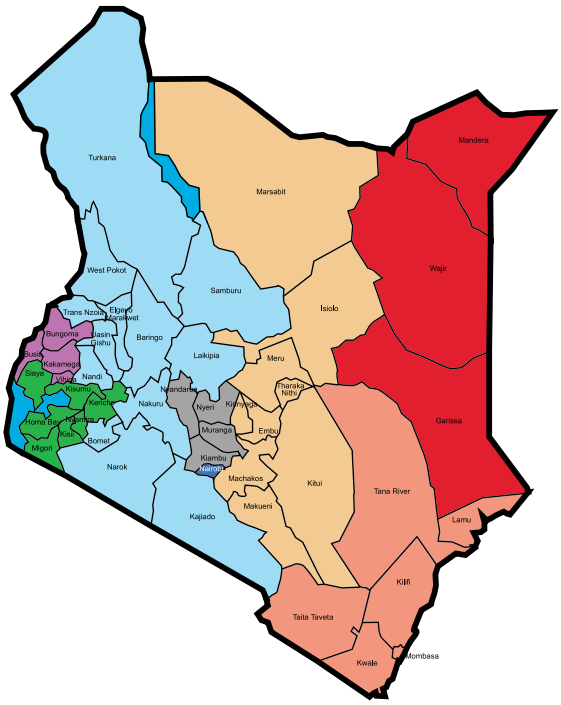
45% *opined that men who have sex with men and injecting drug users deserve to acquire HIV*

55% *believe that HIV is spread by sex workers*

52% *would not buy food in the market from a known person a living with HIV*

COUNTY HIV STIGMA INDEX

County stigma index was derived from data aggregated into regional clusters



60%
Garissa
Mandera
Wajir
49.2%
Embu
Isiolo
Kirinyaga
Kitui
Machakos
Makueni
Marsabit
Meru
Tharaka Nithi
48%
Kilifi
Kwale
Lamu
Mombasa
Taita Taveta
Tana River
47%
Bungoma
Busia
Kakamega
Vihiga

46%
Baringo
Bomet
Elgeyo Marakwet
Kajiado
Laikipia
Nakuru
Nandi
Narok
Samburu
Trans Nzoia
Turkana
Uasin Gishu
West Pokot
40%
Nairobi
38.9%
Kiambu
Muranga
Nyandarua
Nyeri
35%
Homa Bay
Kericho
Kisii
Kisumu
Migori
Nyamira
Siaya

SUMMARY OF KEY RECOMMENDATIONS

1 Create awareness of existence of legal frameworks and institutions such as the existence of the HIV Equity Tribunal's, that promote access to social justice for people living with HIV

2 Intensify programmes for to safeguard against discriminatory employment practices that lock out people living with HIV through strengthening mechanisms of legal redress and speedy justice

3 Create an environment that makes it easier for newly diagnosed people to disclose their HIV status especially to their sexual partners and families to provide support systems needed to encourage early treatment through community and institutions education and sensitization programmes.

4 Provide education programmes for how HIV is not transmitted such as fear of infection from non-invasive contact with PLHIV and the harmful effects of stigma and discrimination in addition to information on comprehensive programs that support physical and psychological wellbeing of individuals such as nutrition and clinical support.

5 Integrate HIV and confidentiality and ethical issues training especially on issues affecting key population, children and adolescents living with HIV health care training programmes for HIV treatment and management

6 Promote and engage political and other public personalities to champion anti-HIV stigma campaigns

7 Design localised, funded county and contextualised specific strategies to eliminate HIV stigma and discrimination led by county governments.

8 Promote anti HIV-stigma campaigns in schools and other learning institutions targeted at administrators, teachers and students. There is need to evaluate existing curricula and eliminate content that perpetuate HIV related stigma and discrimination.

9 Design innovative and cost-effective approaches to improve psychosocial support, and access to care and treatment tailor made for mobile populations such as pastoralist.

10 Conduct regular studies to measure, monitor the levels and underlying causes of HIV related stigma and discrimination and provide localised evidence based interventions to address the situation.

INTRODUCTION

The Kenya HIV and AIDS Prevention and Control Act (2006) safeguards the rights of People Living with HIV (PLHIV), promotes voluntary HIV testing, confidentiality and privacy, non-discrimination in employment and education, and unfettered access to quality healthcare services. It also calls for the integration of HIV programs in all sectors

Stigma and Discrimination Index was conceptualised by the Global Network of People Living with HIV and AIDS (GNP+); the International Community of Women Living with HIV and AIDS (ICW); the International Planned Parenthood Federation (IPPF); and the Joint United Nations Programme on HIV and AIDS (UNAIDS) in response to the phenomenon of widespread stigma and discrimination which was impeding progress in providing access to HIV treatment and care for all.

The National HIV stigma index study was carried out between March and May 2014. The broad objective of the study was to generate strategic information on HIV related stigma and discrimination across Kenya to guide interventions and policies to address HIV related stigma and discrimination to enhance the quality of life of PLHIV.

The specific objectives of the study were to;

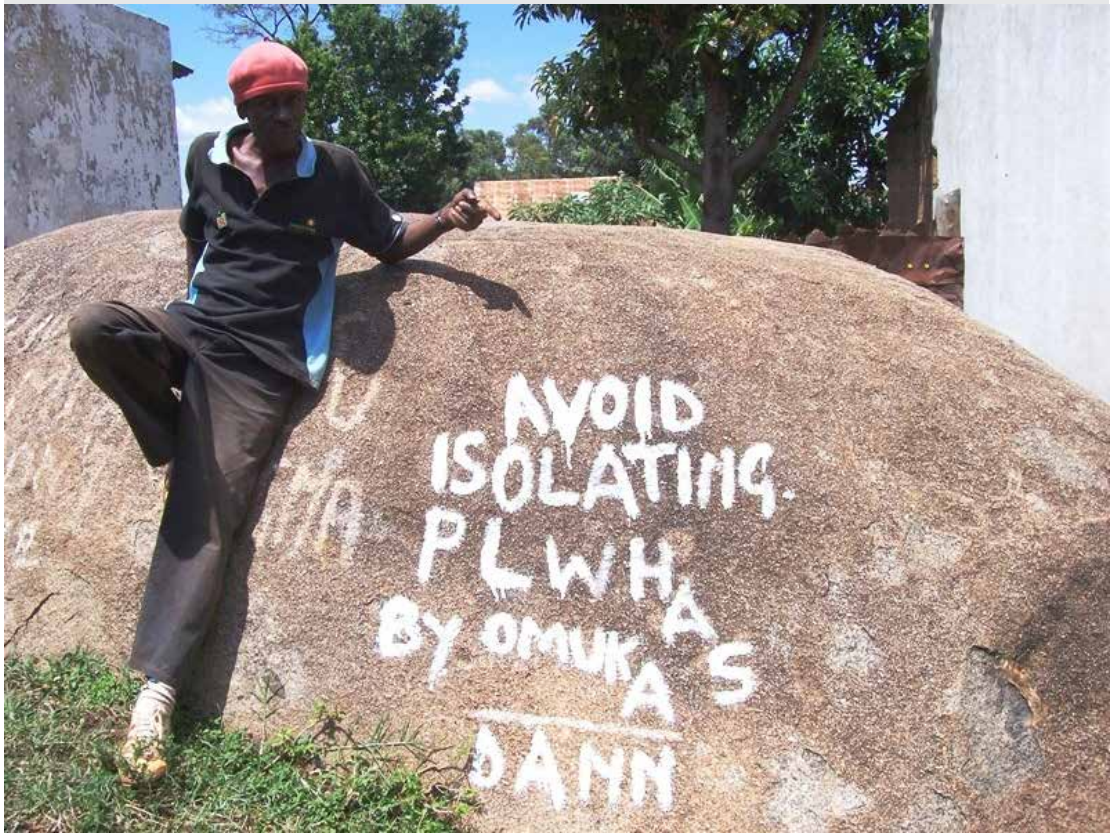
- Document the levels of the various categories of HIV stigma and discrimination
- Identify factors that perpetuate or mitigate against HIV stigma
- Document the effects of stigma and discrimination on the HIV response
- Generate baseline information on HIV stigma and discrimination

CASE STUDY

STIGMA AT THE WORKPLACE

I didn't discover my HIV status of my own volition. In 1997 the company I worked for sent me to hospital for a check-up because I got sick so often. No one gave me any feedback on why I was sick. Eventually, I was laid off so I went back home and took up fishing to earn money. I continued being sickly. My family wanted to know what was wrong with me and if I could be helped as it was becoming too much. They were told that I was HIV positive but they didn't tell me. Instead they took all my wealth including my goats and my shamba.

In 2002, I got advice but didn't act on it. The next year I fell sick again and was advised to visit a CCC. The year after that, in 2004, I decided to start the treatment. In 2005 I began to feel its effects. For the next six years I've been attending workshops on care and support so now I'm well informed. Most people who thought I'd die are shocked that I'm still alive. They come to me for advice. My children are the ones who have been affected the most because they are discriminated against in school and also in the community.



Dan On'gayi writes HIV messages on rocks in Emuhaya village, western Kenya © Kenneth Odiwuor/IRIN

STUDY METHODOLOGY

The sampling methodology considered variations and patterns of HIV prevalence, socio-cultural and socio-economic characteristics of the 47 counties which were then grouped into eight regions

The study was a cross-sectional survey using both quantitative and qualitative methods for data collection. The quantitative survey measured HIV stigma indices for different forms of stigma and discrimination and generated the overall national Stigma Index. The qualitative survey explored the various forms of stigma by population segments and by region.

Nationwide data collection was done from 30 clusters – 21 rural and 9 urban. The sampling was based on variations in HIV prevalence, socio-cultural and socio-economic characteristics in all the 47 counties which were then grouped into eight regions

The quantitative interviews were conducted with PLHIV using standard questionnaires administered by a trained interviewer. A sample of 3,300 was targeted with a 95% (3,127) response rate. The PLHIV respondents were sourced at health facilities providing comprehensive care and treatment for HIV and AIDS services. Qualitative information was collected from 60 focus group discussions conducted with PLHIV, key populations, and the general population. The conversations were recorded and then transcribed.

The following are the demographic characteristics of those interviewed;

- The age was 15 years and above with majority being over 30 years (80%)
- Majority of those interviewed has some form of formal education (84%)
- 42% were self-employed while 31% had no formal employment

COMPUTATION OF HIV STIGMA AND DISCRIMINATION INDEX AND SUMMARY OF FINDINGS

The overall National index was derived from computation of 34 indicators clustered into five key categories. The overall composite stigma rating for Kenya was 45

The Stigma and Discrimination Index used 34 indicators clustered into 5 categories. The index was estimated on a scale of 1-100. Each category was equal to 20 units. The cumulative scores were then averaged to yield an overall stigma score. The extent to which Kenyans demonstrate stigma in each category was rated according to the score of each category.

STIGMA AND DISCRIMINATION RATING

> 60	VERY HIGH
45-59	HIGH
30-44	MODERATE
15-29	LOW
<15	VERY LOW

STIGMA AND DISCRIMINATION INDEX BY CATEGORY

Form of stigma	Score	Unit value	Index
PLHIV who are concerned about disclosing their status	70	20	14.05
People fearful of contracting HIV from non-invasive contact with PLHIV	18	20	3.60
People who judge or blame PLHIV for their illness	47	20	9.36
PLHIV who think they have experienced stigma in the last year	17	20	3.44
PLHIV who experience stigma's negative effects on themselves, the family, the communit	74	20	14.70
Composite stigma rating for Kenya		**100**	**45.16 (High)**

1. FEAR OF CONTRACTING HIV FROM NON-INVASIVE CONTACT WITH PLHIV

Despite the fear of HIV transmission through non-invasive contact being low (18), it is still far from over. Isolation of children in schools if their parents were known to be PLHIV and social exclusion of PLHIV from community functions was reported.

"Since they knew I am positive, they stopped telling me when they are around. My close family and friends leave me out of their activities. I wonder even if I am HIV positive does it mean they discriminate me from family affairs? One day they will come to realize that what they were doing was completely wrong."

PLHIV discussant - Migori

UNAIDS Deputy Executive Director, Luiz Loures, meets the Kenyan President, H.E Uhuru Kenyatta at the launch of the All in campaign to end adolescent AIDS in Nairobi © UNAIDS/T.Karumba

"I have directed the ministries of education and health to initiate programmes that will ensure all HIV-positive children are provided with life-saving medication. The issue of children living with HIV not on antiretroviral therapy must be addressed without further delay."

President Uhuru Kenyatta

CASE STUDY

CHILDREN AND HIV RELATED STIGMA

I lost my parents to HIV and AIDS 15 years ago when I was seven years old. I was taken in by my maternal uncle as my father's brothers and sister did not want to be associated with me.

I was a sickly child, always in and out of hospital. At age 10, I fell sick at school and was taken to hospital where I tested positive for HIV. My uncle refused to believe it was true and immediately took me back to the hospital for a second test which confirmed my status.

My life changed dramatically. My uncle banned me from sharing a room, food and utensils with the rest of the family. He did all he could to separate me from his children, who continued to play with me anyway. But when I reached class seven, my uncle decided to chase me out of his home. I went onto the streets.

I lived on the street for seven months. I had no access to the medication I had been taking and was not interested in looking after myself. I used to seek shelter in a church at night. One evening the priest in charge of the church found me sleeping in a pew. I told him my story, and that is how I got my way back to primary school. He sponsored me in a boarding school.

The first year there were no problems. The priest and I had decided to keep my status a secret between us. I passed my KCPE with good marks and was admitted to a boarding secondary school. The school required a medical examination. Mine showed I was HIV positive, and my admission was immediately cancelled. The father found me another school, but I was expelled a year later because of my HIV status. At the new school only the deputy principal knew my status. Even so, it was not long before fellow students discovered I was taking drugs and started making comments such as, He must have AIDS. They're the ones who take drugs like that.

After high school, inspired by my sponsor, I wanted to join the priesthood. I thought it would be safe as I had no home to go to, and I presumed that priests would not discriminate against me. I was wrong. My sponsor told me that the Church does not admit people who are HIV positive into the priesthood. This was really demoralising. I have suffered from low self-esteem ever since.

Today I'm a volunteer counsellor and live with friends who have no problem with my HIV status. I am working towards furthering my education. I'm also in the process of getting back my parents' property through the help of a local NGO that deals with legal matters.

2. PEOPLE WHO JUDGE OR BLAME PLHIV FOR THEIR ILLNESS

Across the country, a cummulative HIV stigma index score of 47 which is rated as high showed that many respondents judge and blame PLHIV for their status. HIV infection was considered a punishment from God or a punishment for bad behaviour

In all regions respondents significantly stated that HIV was ascociated with promiscuity with scores as moderate as 32 in counties in Central Kenya and as high as 60 in those in North Eastern. Similar findings were reported from community discussions where it was pointed out that places of worship branded PLHIV as promiscuous, and summarily condemned as sinners. In some churches PLHIV were not allowed to marry and wed in the church freely

CASE STUDY

BLAME, SHAME, JUDGEMENT AND ISOLATION WITHIN FAMILIES

I'm a mother of two living with HIV and I attend a comprehensive care centre in Thika. I lost my husband eight years ago. He worked as a policeman in the General Service Unit. He'd been sick for several years, but I didn't know why until finally he told me he had HIV. This shattered me completely. I was advised to go for testing and counselling. It turned out I had HIV too.

My husband told his mother that he was dying of AIDS, and she blamed me for having infected him. My children and I were shunned by the rest of the family. Eventually they sent us away from my matrimonial home, accusing me of being a prostitute and a woman of loose morals.

I went to my sister's house in Juja. She didn't want us to live in her house because, she said, my children could easily infect her own children while playing together. I was really hurt. Even my own sister was shunning me. Eventually my sister allowed me to live in a storeroom. I wasn't allowed to cook or eat with her family. We couldn't share the same bathrooms and toilets. My children dropped out of school because I couldn't afford to buy the uniforms and shoes. My health was deteriorating so I depended on my sister's family to survive. I lost weight and got TB. I was bedridden for several months. I got depressed and tried to commit suicide several times, twice with poison. On two occasions my children found me in the house in a dire condition. They raised the alarm and neighbours rushed me to hospital.

The hospital clinic put me on ARVs. I also joined a support group where I met an old widow who agreed to take in me and my children. Now I help her in her fruit and vegetable business. At the clinic, I helped other people living with HIV, especially on follow up when people defaulted. Eventually I was recruited as a

volunteer and trained to provide counselling services at the clinic. I earn a stipend which has helped me take care of myself and my children. I now live in my own house and have a small kiosk business which I run while I continue to be a peer counsellor at the hospital.

Recently my husband's family invited me to their home and apologised for all they had done. My father in-law gave me back the land that had belonged to my husband along with the legal documents. It's like they got tired of waiting for me to die. God didn't allow death. He wanted me to be able to take care of my children.

3. PLHIV WHO REPORTED TO HAVE EXPERIENCED STIGMA

Counties in Coast, North Eastern and Eastern regions reported high rates for this category with indicators such as gossip, loss of respect and exclusion from a social gatherings being relatively high

The study respondents living with HIV reported having experienced instances of isolation and being disowned by their families in the previous year. Counties in coastal and North Eastern regions had the highest reports of spousal abandonmentrated at 30 and 31 respectively. Respondents from counties in Eastern region reported significantly high rates (30) of being teased, insulted as a result of HIV status.

Married women were blamed for their spouses HIV positive status without any confirmed knowledge of their HIV status especially if they were newly weded. They were branded as 'killers who had brought the disease to their husbands'. More male PLHIVs reported having experienced stigma at the health facility than the female PLHIV respondents.

"…..in my family, once they knew my husband and I were ailing, they took all our property and shared amongst themselves since they thought we were going to die. We moved out of our village home and decided to start life afresh. I thank God for now we are doing better and we have been able to educate our children and I can't complain now, we are happy."

FGD Discussant- Kitale

CASE STUDY

STIGMA IN SCHOOL

I'm 12 years old and I'm in class six at school. I like my social science teacher, Mrs. Rajab. My mother died when I was only three. I now live with a stepmother and my sick father. My father has a disease called bomesa which is making everyone in Isiolo County poor and gradually killing them off. My teacher says that it's not the disease but what people think about it that's killing our people. She says a lot needs to be done.

I stopped the drugs because the other children pulled me down when my body felt weak after taking them. But a health officer from the CCC made a follow up so now I'm taking them again.

Pupils often move away from me unexpectedly. I remember once when five pupils joined our class for interclass PE lessons. They wouldn't sit with me. One girl told me I smelt of drugs. I've lived like this for the last nine years, and I can't take it anymore. I feel rejected.

The other children don't want to play with me. Boys shy away from me. No one wants to talk to me. I live in desperation, and loneliness has engulfed me. I fear that one day I will just die. My dreams will never come true. Nowadays I stay alone. No one comes near me. They say I'm weak and sick. Whenever I move close to them they walk away one by one, even in class. I can't share textbooks with anyone. Its humiliating. So I've decided not to attend school anymore. They all think I'll infect them.

The teachers are helpful. They buy me milk and some food and encourage me to take my drugs. I can't do that at home. There's no food for me. These drugs make me feel sick all the time.

HIV STIGMA AND DISCLOSURE

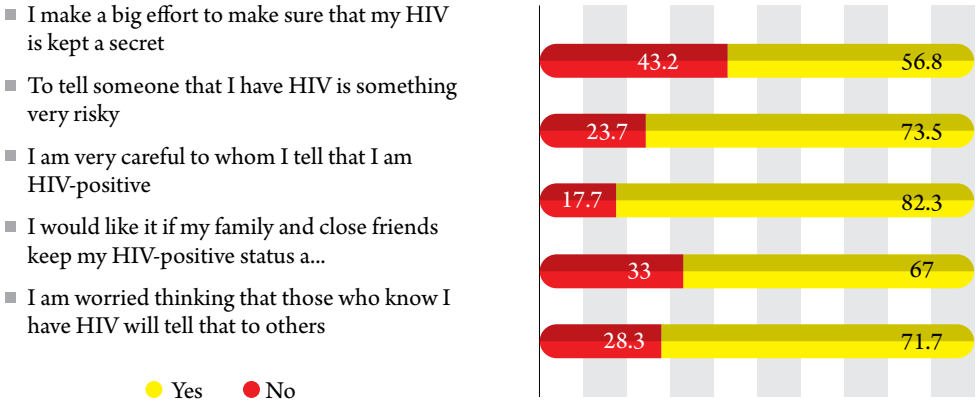
Fear Indicator	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
I am worried that those who know I have HIV will tell others	55.9	54.0	63.8	52.6	77.0	52.3	49.3	56.7
I would like my family and close friends to keep my HIV status a secret	81.6	72.0	81.7	66.4	93.1	78.5	71.9	79.5
I am very careful to whom I tell that I am HIV-positive	85.3	78.6	87.8	70.8	93.1	85.1	85.3	84.0
To tell someone I have HIV is very risky	72.4	63.2	76.8	52.9	87.4	66.6	64.5	66.8
I make a big effort to make sure that my HIV is kept a secret	77.3	63.0	82.1	53.9	87.4	75.8	70.0	78.5
Total	**74.5**	**66.2**	**78.4**	**59.3**	**87.6**	**71.7**	**68.2**	**73.1**

4. PLHIV WHO ARE CONCERNED ABOUT DISCLOSING THEIR STATUS

Disclosure of HIV status which is important for HIV pevention care and treatment programme is largely affected by stigma levels.

The study reported high scores (70) for the number of people who were concerned about disclosing their HIV status across the counties. Indicators such as people who made so much effort to keep their HIV status a secret was higher in counties in North (87) Eastern, Rift Valley (82) and Central (79)

- More female than male PLHIVs disclosed their HIV status soon after diagnosis.
- Many PLHIVs still delayed to disclose their HIV status and struggled to have it kept a secret
- Many PLHIVs preferred to have their HIV status kept secret by their families
- Male PLHIV encountered disclosure of their HIV status without their consent, more than the female population.
- Healthcare providers disclosed HIV status of clients to third parties without their consent (against ethical and professional provisions)



5. PLHIV WHO EXPERIENCE STIGMA'S NEGATIVE EFFECTS ON THEMSELVES, THE FAMILY, AND THE COMMUNITY

Respondents in Counties from North Eastern, Eastern and Central reported higher instances where PLHIV lost family ties because of their HIV status. People living in North Eastern counties reported high (93) cummulative effects of stigma such as being lonely, weakened family bonds and regrets

EFFECTS OF STIGMA WITHIN THE FAMILY

Effect of stigma	Strongly agree	Agree	Disagree	Strongly disagree
PLHIV lose family love and guidance.	34.6	36.4	19.3	9.7
PLHIV are lonely.	37.4	39.1	14.5	9
Family bonds are weakened.	33.2	37.7	19.5	9.6
PLHIV create family barriers.	32.4	39.4	18.6	9.7

HIV STIGMA AND KEY POPULATIONS

Key populations (Sex Workers, Men who have Sex with Men and drug users) living with HIV were reported to experience double stigma from being HIV positive and that of moral judgement imposed by society on their sexual behaviour

*Nearly **55%** of respondents believed that sex workers are responsible for spreading HIV in the community*

Participants in group discussion reported that Sex workers were commonly labelled as "the walking dead" and "HIV carriers" in their communities. The stigma was also extended to children of known sex workers. HIV testing was reported to be significantly affected by the stigma levels for this group.

***44.8%** of respondents believed that MSM and drug users deserve to get HIV*

MSM were reported to encounter stigmatizing incidences such as isolation, being ostracised and lack of support systems other than those led by their peers. Majority of MSM respondents reported fear of being tested for HIV. Partner testing for HIV positive MSM was further reported to draw further judgment and blame. Stigma was blamed for late presentation of MSM living with HIV resulting to disproportionately higher HIV related morbidity and mortality.

> *We get the worst treatment at health facilities. In some cases, health providers break confidentiality by bringing in other colleagues to the room to see a gay person. They lecture us on social and religious values. Sometimes they even include the general public at the hospital when they're doing it. We are subjected to testing and counselling initiated by the provider even though we have a right to refuse to be tested.*
>
> ***MSM Kisumu***

IMPACT OF HIV STIGMA AND DISCRIMINATION

78% of PLHIV concurred that HIV related stigma leads to increased HIV spread

The study's results showed a relationship between levels of education, socio-economic status with stigma and discrimination index. Those with a higher level of education and socio-economic status were more accepting of PLHIV. Counties where access to formal education was higher had a lower Stigma Index.

PLHIV reported incidences of enacted stigma experienced in many aspects of their day to day lives. Stories were recounted on how some respondents had been chased away from their workplace, places of worship, schools and even their own homes through use of direct and indirect verbalised comments. In some places of worship those living with HIV were condemned as sinners destined for hell making PLHIV in attendance uncomfortable.

In other instances, PLHIV respondents reported to be sconned upon when they initiated public education messages on HIV related issues. Some members of the community were claimed to view such voluntary efforts negatively with PLHIV being blamed to use their status for money.

Blatant discrimination against PLHIV was reported to affect self perception with a high proportion (45.9%) of PLHIV respondents reporting that they perceived HIV infection to be a punishment from God and (61%) for bad behaviour .

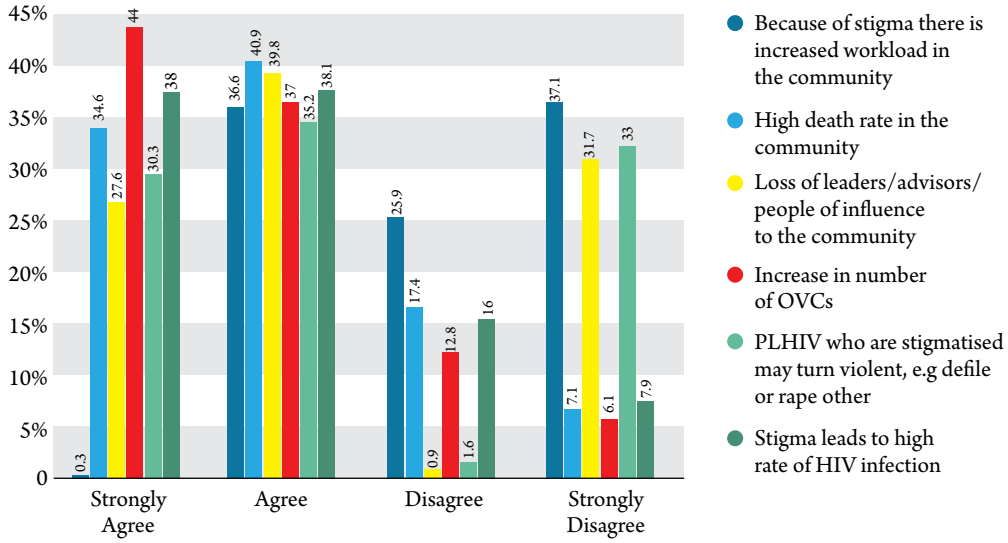
One of the major impact of HIV related stigma and discrimination was abandonment by spouses, family and friends. In all counties, more women living with HIV were reported to have been chased out of their homes with with their children than men. Ironically, men living with HIV were reported to receive support from their families after learning of their HIV status. Their spouses were accused of having infected the men with HIV even when their status remained unknown.

Family and spousal abandonment was reported to cause despair, shame and a sense of hopelessness among the PLHIV respondents. In addition, some PLHIV lost their sources of income, their children often dropped out of school either due to their parents inability to pay school fees or cases of non-acceptance of known PLHIV children in some schools.

HIV stigma lead to low self-esteem and depression among PLHIV with three out of four PLHIV interviewed reporting they had contemplated suicide at some point in their lives. Nearly 90% of PLHIV interviewed indicated that they suffered so much stress as a result of stigma.

Overall, stigma and discrimination undermines the community's ability to control HIV transmission and care for those living with HIV.

PERCEIVED IMPACT OF STIGMA ON THE COMMUNITY



CASE STUDY

ENDING HIV STIGMA THROUGH EMPOWERING OTHERS

I decided to use my experience of living with HIV to give hope to others in the same situation.

I lost my mother and sister at a tender age, and immediately after got married in Makindu.

Three months into my marriage I fell sick and was diagnosed with TB. I was advised to take an HIV test which turned out to be positive, and also discovered that I was pregnant. I was confined to a TB manyatta in the district hospital and given TB drugs and ARVs (antiretrovirals). By the time I was discharged, I had missed out on antenatal care. In my naivety and confusion, I had no clue what awaited me and my unborn baby. Neither did the hospital staff help me much. I gave birth to a sickly baby boy who died a few months later, probably due to complications from HIV. Six months after my diagnosis of HIV and TB, my husband was also diagnosed and put on treatment.

Despite the situation, my husband and mother-in-law continued to care and love me. They both stood by me while I was in and out of hospital. My mother-in-law was exceptional. She treated me like a real daughter. She fed, bathed and clothed me when I was sickly. She even supported us financially.

My relationship with my husband was formalised in 2008 and we were blessed with two HIV-negative children through use of ART and exclusive breastfeeding.

I joined a local support group at the Kajiado District Hospital. My heart went out to the many HIV-positive pregnant women streaming into the hospital and quietly delivering HIV-positive babies and watching them die. Just like me years back, they were left in the dark because of social stigma. Their babies might have survived if they had received the right information and support.

I started a support group for such women, calling it Nannyor, which is Maa for love.

Drawing from my own experience, we educate and guide positive mothers from conception to birth to help them deliver HIV-free babies. We teach them about adherence to treatment, proper breastfeeding techniques and good nutrition. We also do home visits and hold monthly meetings. Our work is done through peer-to-peer referrals. We follow up the women until their babies are 18 months old.

I am very vocal about the harmful consequences of stigmatising HIV-positive mothers as I have seen the effects firsthand on Nannyor members. Not only have they been shunned by the community, their marriages have been annulled or stopped from taking place. And they have been excommunicated from their churches. So it's no wonder that anyone who is diagnosed with HIV tries to keep quiet about it. Denial, because of the fear of stigma, has promoted the spread of HIV within society.

That's why Nannyor also does advocacy against stigma and discrimination on behalf of HIV-positive people. We use barazas, churches, social events and other community forums to galvanise community involvement and support. We are also educating people on the importance of disclosure, family support and good nutrition.

I'm proud to report that 26 HIV-negative babies have been born to our members who are living with HIV. We have also become more socially acceptable. Thirty-five men joined the group this year (2014), and more men are supporting the PMTCT (prevention of mother-to-child transmission) program.

My goal is to reach the unreachable members of society - through mobile clinics, awareness and advocacy - to fight the social stigma and discrimination caused by HIV and AIDS. I have given myself two more years of service to the community before I retire to focus on my family. By that time, the Nannyor group will have prepared the ground for the Beyond Zero Campaign (access to antenatal and postnatal healthcare) should it come to Kajiado County. Whatever happens, it will be enough to know that I have been a role model who shows mothers how to live each day with hope for a better future.

RECOMMENDATIONS

1 Create awareness of existence of legal frameworks and institutions such as the existence of the HIV Equity Tribunal's, that promote access to social justice for people living with HIV

2 Intensify programmes for to safeguard against discriminatory employment practices that lock out people living with HIV through strengthening mechanisms of legal redress and speedy justice

3 Create an environment that makes it easier for newly diagnosed people to disclose their HIV status especially to their sexual partners and families to provide support systems needed to encourage early treatment through community and institutions education and sensitization programmes.

4 Provide education programmes for how HIV is not transmitted such as fear of infection from non-invasive contact with PLHIV and the harmful effects of stigma and discrimination in addition to information on comprehensive programs that support physical and psychological wellbeing of individuals such as nutrition and clinical support.

5 Integrate HIV and confidentiality and ethical issues training especially on issues affecting key population, children and adolescents living with HIV health care training programmes for HIV treatment and management

6 Promote and engage political and other public personalities to champion anti-HIV stigma campaigns

7 Design localised, funded county and contextualised specific strategies to eliminate HIV stigma and discrimination led by county governments.

8 Promote anti HIV-stigma campaigns in schools and other learning institutions targeted at administrators, teachers and students. There is need to evaluate existing curricula and eliminate content that perpetuate HIV related stigma and discrimination.

9 Design innovative and cost-effective approaches to improve psychosocial support, and access to care and treatment tailor made for mobile populations such as pastoralist.

10 Conduct regular studies to measure, monitor the levels and underlying causes of HIV related stigma and discrimination and provide localised evidence based interventions to address the situation.

APPENDIX

APPENDIX 1: SUMMARY OF SCORES FOR THE KEY STIGMA INDEX CATEGORIES AND INDICATORS

Experiences of fear of HIV infection from non-invasive contact

Experiences	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
People unwilling for me to cook at functions	8.6	31.1	19.8	8.8	35.6	28.4	26.7	5.9
People unwilling to share meals at functions	6.1	27.8	18.8	7.7	40.2	24.8	23.5	5.5
People unwilling for me to serve guests meals	6.7	32.0	17.9	8.6	33.3	21.3	23.5	5.5
People unwilling to share bedding	8.0	36.6	18.4	12.2	34.5	24.8	21.2	5.2
People unwilling to share soap	9.8	41.8	18.8	13.9	36.8	26.4	19.4	7.5
People unwilling to shake hands	4.9	27.4	11.3	5.2	34.5	20.0	12.0	2.3
Total	**7.4**	**32.8**	**17.5**	**9.4**	**35.8**	**24.3**	**21.1**	**5.3**

Shame, blame and judgement

Shame, blame and judgement	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
HIV is a punishment from God	43.6	39.5	51.8	51.8	41.5	62.1	55.2	32.9
Some people think HIV is a punishment for bad behaviour	49.1	55.2	66.8	57.3	82.8	70.5	68.2	41.0
Most people with HIV deserve what they get	35.0	37.2	39.3	34.5	51.7	45.3	41.0	19.2
It is sex workers who spread HIV in the community	44.8	56.6	58.5	50.2	72.4	60.9	62.7	38.8
People with HIV are promiscuous.	37.4	37.0	49.5	40.9	59.8	50.1	49.3	31.9
People with HIV should be ashamed of themselves	36.8	29.4	36.6	27.5	42.5	41.3	31.8	21.5
Men who have sex with men deserve to get AIDS.	50.9	52.6	41.2	39.7	52.9	52.1	50.7	33.6
HIV+ women should not have children	39.9	31.7	42.0	35.5	46.0	43.1	40.6	24.8
Total	**42.2**	**42.4**	**48.2**	**42.2**	**56.2**	**53.2**	**49.9**	**30.5**

Perceptions on the cumulative effect of stigma

Cumulative effect	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
PLHIV lose the family's love and guidance	18.4	66.2	70.3	55.2	92.0	80.2	79.7	79.8
PLHIV become lonely	89.6	83.9	76.2	53.3	93.1	82.9	86.6	85.7
Family bonds are weakened	85.9	68.5	70.7	50.5	97.5	78.7	82.5	82.5
Many PLHIV wish they had never married	70.6	61.1	66.9	49.8	90.8	57.6	70.0	63.2
Total	**66.1**	**69.9**	**71.0**	**52.2**	**93.4**	**74.9**	**79.7**	**77.8**

Stigma around disclosure

Type of fear	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
I am worried that those who know I have HIV will tell others	55.9	54.0	63.8	52.6	77.0	52.3	49.3	56.7
I would like my family and close friends to keep my HIV status a secret	81.6	72.0	81.7	66.4	93.1	78.5	71.9	79.5
I am very careful to whom I tell that I am HIV-positive	85.3	78.6	87.8	70.8	93.1	85.1	85.3	84.0
To tell someone I have HIV is very risky	72.4	63.2	76.8	52.9	87.4	66.6	64.5	66.8
I make a big effort to make sure that my HIV is kept a secret	77.3	63.0	82.1	53.9	87.4	75.8	70.0	78.5
Total	**74.5**	**66.2**	**78.4**	**59.3**	**87.6**	**71.7**	**68.2**	**73.1**

Experiences of enacted stigma

Experience of stigma	Nairobi	Coast	Rift Valley	Nyanza	North Eastern	Eastern	Western	Central
Excluded from a social gathering	4.3	21.6	9.8	7.2	28.7	22.4	15.2	4.2
Abandoned by spouse/partner	8.0	29.9	17.4	13.2	31.0	22.0	11.1	9.8
Isolated in the household	5.5	22.5	11.1	7.2	31.0	22.2	10.6	6.2
No longer visited or visited less frequently by family and friends	8.6	29.0	19.8	9.9	32.2	32.1	14.3	10.7
Teased, insulted or sworn at	11.0	37.2	18.5	17.1	39.1	30.1	23.5	16.0
Lost retail/wholesale customers or lost job	6.7	27.4	9.8	6.4	33.3	20.2	16.6	4.6
Lost housing or not able to rent housing	3.1	20.0	5.4	3.3	27.6	12.1	6.5	6.5
Denied religious rites/services	1.8	14.0	3.3	3.3	24.1	8.1	3.2	1.3
Property taken away	8.0	9.7	6.2	4.4	20.7	16.7	11.1	5.9
Subject of gossip	23.3	61.8	36.7	31.1	50.6	51.9	50.7	25.7
Lost respect/standing within the family and/or community	12.3	43.2	18.7	13.2	35.6	33.0	24.0	11.7
Treated violently	5.5	17.5	8.7	6.2	19.5	16.7	11.1	5.9
Quality of health services declines	4.3	18.4	6.4	3.6	13.8	11.4	5.1	3.6
Physically assaulted	4.3	26.2	7.3	5.7	17.2	16.0	9.2	2.9
Denied promotion/ training	2.5	21.9	4.2	4.9	28.7	14.3	8.3	5.2
An increase of visitors “to see how you’re doing”	10.4	37.2	20.4	16.3	27.5	43.3	25.3	13.0
Abandoned by family/expelled from village	6.7	9.9	9.5	4.1	28.7	18.0	12.9	6.5
Delayed or inferior healthcare	4.9	16.3	6.6	4.7	23.0	11.0	7.9	4.2
Partner refuses to touch me after disclosing my positive status	6.7	30.8	15.9	16.8	26.4	22.2	9.2	6.2
Partner departs after disclosing my positive status	8.6	32.4	15.9	12.9	17.2	19.3	12.4	8.1
Total	7.3	26.3	12.6	9.6	27.8	22.2	14.4	7.9

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