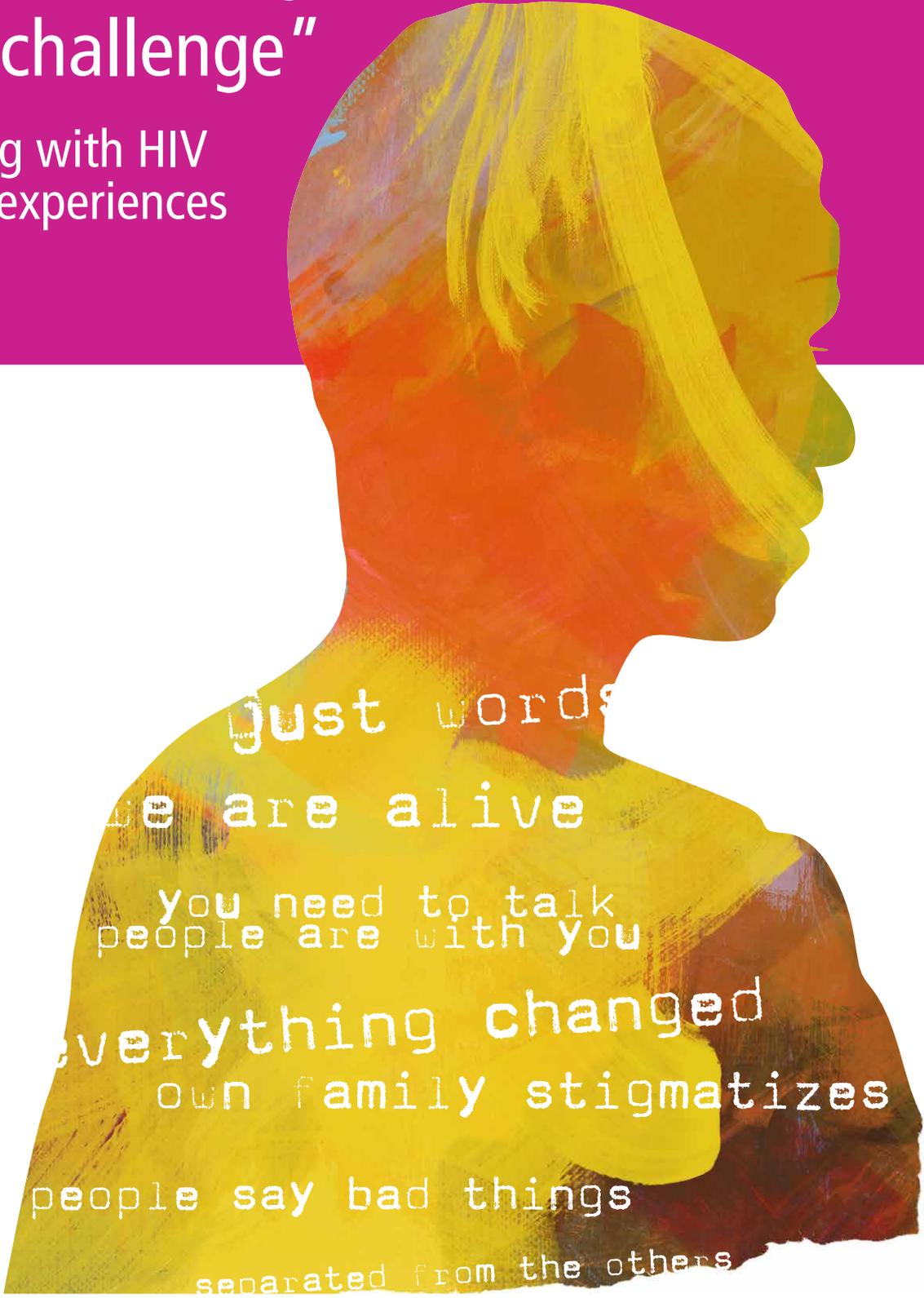


# "Stigma is still my most serious challenge"

People living with HIV share their experiences



Just words  
we are alive  
you need to talk  
people are with you  
everything changed  
own family stigmatizes  
people say bad things  
separated from the others

## About the International Planned Parenthood Federation

The International Planned Parenthood Federation (IPPF) is a global service provider and a leading advocate of sexual and reproductive health and rights for all. We are a worldwide movement of national organizations working with and for communities and individuals.

IPPF works towards a world where women, men and young people everywhere have control over their own bodies, and therefore their destinies. A world where they are free to choose parenthood or not; free to decide how many children they will have and when; free to pursue healthy sexual lives without fear of unwanted pregnancies and sexually transmitted infections, including HIV. A world where gender or sexuality are no longer a source of inequality or stigma. We will not retreat from doing everything we can to safeguard these important choices and rights for current and future generations.

## About Oral Testimony Works

Oral Testimony Works (OTW) supports people to record and communicate their first-hand experience of development issues. The resulting in-depth, personal accounts demonstrate the value of listening to those most affected by development, increase understanding of its complexity, and provide the basis for powerful advocacy work.

## Acknowledgements

Many people have been involved in the recording, translating and preparation of the interviews for this publication. Lindiwe Simelane (Swaziland) and Rondinho Vilegua (Mozambique) deserve special mention given their multiple roles of interviewer, interviewee and coordinator in their respective countries. The following organizations supported the oral testimony activity: Family Life Association of Swaziland (FLAS); the Swaziland National Network for People Living with HIV/AIDS (SWANNEPHA); the Network of Networks of HIV Positives in Ethiopia (NEP+); Rede Nacional de Associações de Pessoas Vivendo com HIV/SIDA (RENSIDA) and Mozambican Association for Family Development (AMODEFA). Panos Eastern Africa and Panos Southern Africa coordinated the related national media work (training and fellowship programmes).

We owe our greatest thanks to the people living with HIV in each country who were involved in the project as interviewers and interviewees. All devoted their time and effort to this initiative and freely shared their stories.

The testimonies were edited by Helen Martins ([www.portfoliopublishing.com](http://www.portfoliopublishing.com)) and Olivia Bennett ([www.oraltestimony.org](http://www.oraltestimony.org)).

\*All names in the oral testimonies have been changed to ensure anonymity and confidentiality.



not alone

stigma within

We are together

you need to talk

without hope

struggling to accept

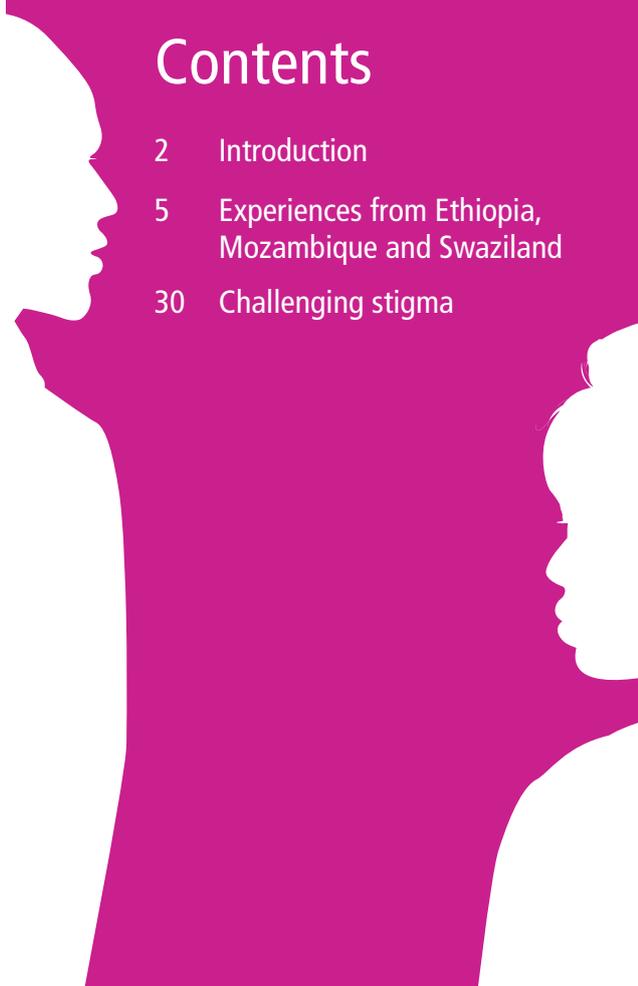
worst time has passed

This publication shares the experiences of people living with HIV. Men and women from Ethiopia, Mozambique and Swaziland talk about HIV-related stigma and describe their courage, inspirations, suffering, resilience and determination to trigger change. Their stories demonstrate how stigma and discrimination can hinder access to vital support and care and the prevention, testing and treatment of HIV.

National and international organizations working on HIV-related issues have an immense responsibility towards people living with HIV, to change the unjust reality revealed by these personal stories into a better one. We must increase our efforts towards ensuring everyone enjoys a dignified, stigma-free life – one where every human being is valued and free of discrimination.

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## Introduction

HIV-related stigma continues to be a major factor hindering HIV prevention, treatment, care and support, and affecting the overall health and wellbeing of people living with HIV.

Stigma can be internal or external. Internal stigma or self-stigma includes negative feelings towards self, such as shame, self-blame, and guilt; self-exclusion such as refraining from social gatherings, not applying for jobs, and refusing to have children; and fear of social judgments, being ostracized, rejected and gossiped about, of being verbally and or physically assaulted, and of being unwanted or undesired. Such emotions can often lead to low self-esteem, depression, and suicidal thoughts.

External stigma or enacted stigma includes experiencing stigma and discrimination by others such as social exclusion, rejection, avoidance, disrespect, social judgments, and verbal, physical and psychological harm. External stigma manifests itself at different levels, such as within the family,



community, institutions or organizations (such as schools and universities, healthcare centres, workplace, churches), and within laws and policies.

In order to tackle stigma, it is necessary to prove that it not only exists but that it also exerts tremendous pressures and negative effects on people living with HIV. Therefore, it was important to come up with a tool to measure stigma. To this end, the International Community of Women Living with HIV (ICW), Global Network of People Living with HIV (GNP+), International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed 'The People Living with HIV Stigma Index'. This global initiative measures and detects changing trends in relation to the stigma and discrimination experienced by people living with HIV, while empowering them in the process.

The Stigma Index has been implemented in more than 70 countries and over 40,000 people living with HIV have engaged in the process and shared their experiences. Its importance lies in providing evidence on HIV-related stigma, which can be used to influence policy change and support the collective goal of governments, non-governmental organizations and advocates to reduce HIV-related stigma and discrimination.

In response to this initiative, Comic Relief funded a three-year project, 'Give Stigma the Index Finger: Understanding and responding to stigma', which was implemented by IPPF and its partners in three countries – Ethiopia, Mozambique and Swaziland.

The project was led by and for people living with HIV and used a combination of community research approaches (the Stigma Index and oral testimony) together with media engagement to increase evidence, understanding and debate on HIV-related stigma, and to advocate for stronger national policies and programmes to challenge such stigma and discrimination.

In each of the three countries, the project enabled people living with HIV to conduct community research and advocacy activities on HIV-related stigma and discrimination; enhancing their skills and knowledge. It increased and enhanced media coverage related to this issue and improved



Participants in Ethiopia and Swaziland train to be oral testimony interviewers.

“ [This is a chance for] people to open up and tell you what was in the bottom of their heart.”

availability of information for policymakers, programmers and researchers on the impact of HIV-related stigma.

### About oral testimony

An oral testimony interview is an open-ended and in-depth interview that is carried out and recorded on an one-to-one basis. The purpose of the interview is not to collect facts and figures but to gather individual life stories – personal knowledge, memory and experiences. Oral testimony does not rely on consensus; rather it celebrates the diversity and – at times – the contradictions between individuals' experiences and perspectives.

By training community members (or people who work closely with them) in oral testimony, interviews can be carried out in people's own languages, in relaxed settings and between people who share aspects of each other's backgrounds. For the narrator, having your story listened to, and your knowledge and experience acknowledged, can be an empowering and supportive experience. Participation does not rely on having the confidence to speak up at a public event. The focus on the individual and the opportunity for interviews to be recorded in people's mother tongue ensures that even the quieter members of the community can participate.



Participants in Mozambique train to be oral testimony interviewers.

sharing ideas

how to disclose

living well

accept the reality

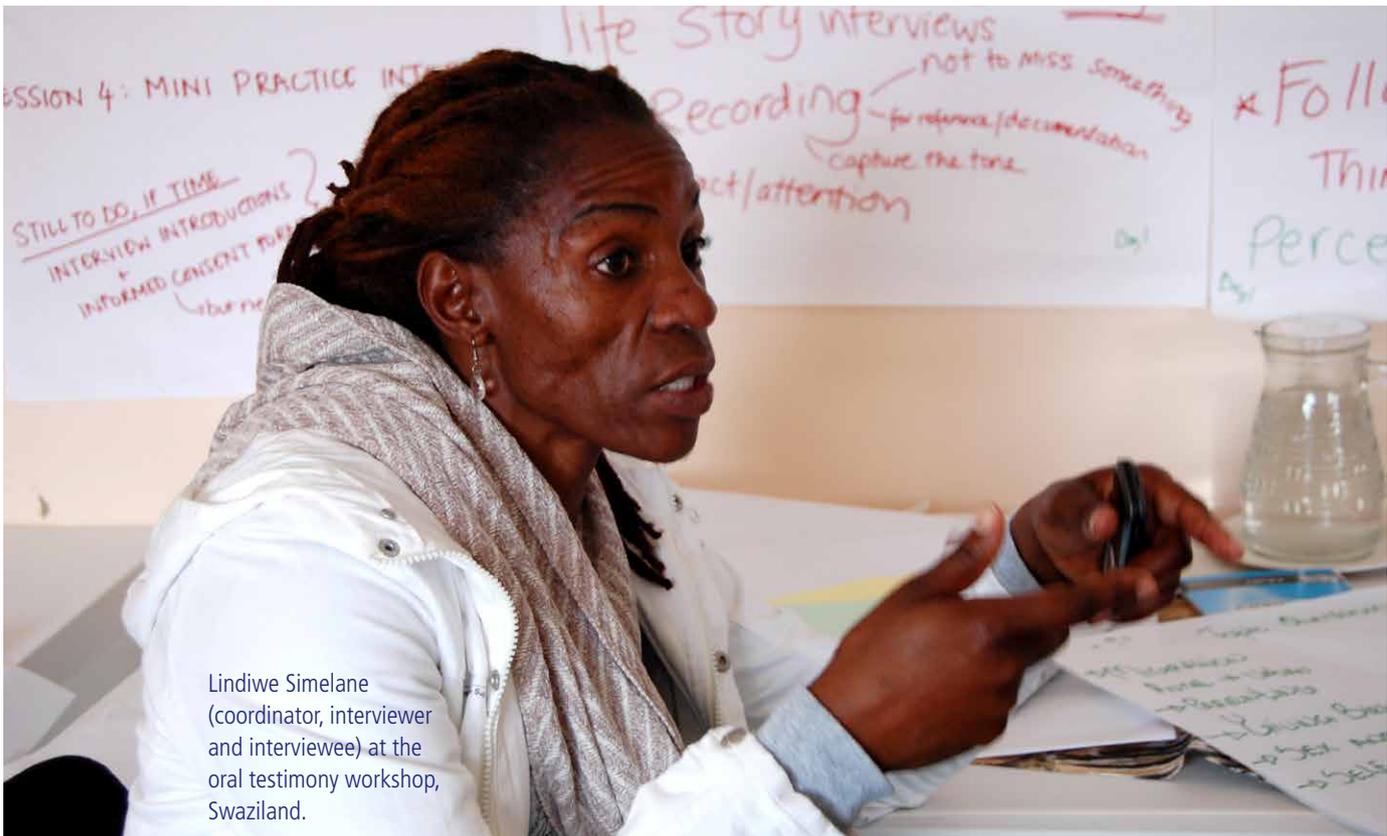
discrimination has decreased

cool greetings

people say bad things

“ [oral testimony training] will have a big impact in getting to know the lives of the people I am working with in support groups”





Lindiwe Simelane  
(coordinator, interviewer  
and interviewee) at the  
oral testimony workshop,  
Swaziland.

### Developing research and communication skills

In each country, at least 10 men and women living with HIV participated in a five-day oral testimony training workshop. Most of those participating had also worked as community researchers on the Stigma Index, and many were adherence counsellors. The workshops involved discussion, role play, practice and reflection, and covered questioning skills, topics for interview, recording equipment, interview relationships, informed consent and transcription.

Following each workshop the interviewers recorded and transcribed a further four interviews with people living with HIV. They generally interviewed people with whom they had an existing relationship with through their support associations. Project coordinators supported the interviewers during this process and organized a review meeting halfway through the interview collection. Interviewers also came together at the end of the process to share their analysis of the testimonies and ideas for communication.

The result is a set of powerful first-hand accounts, which show the reality of HIV-related stigma from people who generally don't get heard and who can contribute new learning and insights to inspire change.

### Process and outputs

In total, 140 people living with HIV in Swaziland, Ethiopia and Mozambique shared their experiences in an open-ended interview, recorded in their own

language by a counsellor or activist living with HIV, with the assurance of maintaining anonymity. Thirty-one of these testimonies were translated into English and from these 12 were edited for publication. OTW and IPPF have supported partners to communicate these testimonies to national audiences through radio and community dialogues.

One of the interviewers from Mozambique described oral testimony as an opportunity for "people to open up and tell you what was in the bottom of their heart", while another added, "people need this type of dialogue so they feel that they are not abandoned". An interviewer from Swaziland stated that the communication techniques learnt "will have a big impact in getting to know the lives of the people I am working with in support groups". At the end of her interview, an interviewee from Ethiopia stated: "We all have a story. To be able to sit here and tell my story is so good for me. It feels good."

### Editorial note

The interviews presented in this publication are only a selection from those recorded and have been edited down from full transcripts, to remove questions, repetition and to reduce length. Square brackets indicate text inserted for clarification; round brackets are translations/interpretations; and dots indicate breaks within and between sentences. All interviews have been translated into English from the language of recording and transcription. Interviews and extracts have been chosen to represent the range of concerns, views and experiences found within the overall collection.

# Experiences from Ethiopia, Mozambique and Swaziland

“ We all have a story. To be able to sit here and tell my story is so good for me. It feels good.”

anyone can have HIV

get the word out

I am not afraid

gossiping was terrible

living normally

gossip and back biting

stigma within me

## Etetu

### ETHIOPIA

Etetu is 22. Aged 13, she was sexually assaulted by her stepfather, which was deeply traumatizing for her. She loved her mother, who later died of AIDS-related illnesses, but her mother's financial dependence on her second husband left her powerless to deal with the abuse. The way her mother was treated by the community left a deep impression on Etetu, who felt her mother "died not of AIDS but as a result of stigma..." Convinced that the greatest barrier to living well with HIV is discrimination, she devotes her life to raising awareness and understanding of the disease.



### Rape brought HIV

My joyful childhood turned to suffering because of my father's death when I was 10 and my mother's lack of income. My mother was forced to marry again... However, my most miserable time began when I was raped by my stepfather.

After I was raped I started to hear about the HIV and AIDS.

After a stressful time, I decided to get tested because the gossiping was terrible and the rape had become apparent to our neighbours. This situation led me to get a blood test in 2003...and I found out that I was HIV-positive.

It was a bitter fact: my life is spoiled and my childhood dreams were lost.

I still feel deep sorrow and regret that my stepfather was not held legally responsible for his crime. He lived freely as an innocent person until he died of AIDS... My mother also passed away from AIDS around 2004.

Another issue which still disturbs me was the stigma against my lovely mother, her suffering and her death. It was a sad time for us all when her right to use the piped water – which all the neighbours use in common – was declined.

Do you know what I believe? My mother died not of AIDS but as a result of stigma and discrimination. I remember how she suffered from worry and

depression. The hearsay and murmuring about her killed my mother. When people looked at her, they automatically started talking about her HIV-positive status. There was no one with whom to eat food and drink a cup of coffee.

In my view stigma and discrimination was the major factor in the death of my mother. If she had got proper care, support and love she might have been alive for many more years.

### Sisterly love

[My sister] felt like I did: both of us had lost our mother and faced almost similar challenges. Besides this, having an elder sister living with HIV was an additional worry for her. Some people still stigmatize her...even though she is HIV-negative.

### Gossip and slander

Psychologically I suffered because I missed out on what I wanted to be. My relationship with others was not good. They stigmatized me. They made slanderous comments about me, gossiping in ways that were overwhelming and scary.

I did try to attend to my education again. But fear of stigma and trauma was not conducive to it. After school, no kids would play with me.

And the neighbours believed that like my mother I had the virus in my blood. They never approached me... Another ugly side of the virus is that it makes you suspicious of everyone...

### **"Stigma pushed me to lose hope"**

I was so frightened then...that my fate was to be the next one to die as a result of stigma and discrimination, like my mother. My thoughts were about death as I was as skinny as those I watched on the TV screen. The way HIV was portrayed negatively made it especially scary in the community and aggravated discrimination. Stigma pushed me to lose hope. I thought of my life as sunset and darkness.

Nowadays people have a good understanding about HIV and AIDS. Of course, there are also people who have limited understanding. When you hear the latter saying: "She has HIV. Oh my God, did you see how many people she has contact with?" you are shocked. It makes you hesitate to communicate with people.

### **"A best and beloved friend"**

I have a best and beloved friend who lives with me. He helped me to change my attitude of despising all men.

It may surprise you that my lover is free of HIV. He has faced stigma and discrimination for being my friend. Moreover, some people do not believe he is HIV-negative. They assumed that he couldn't be my lover unless he is positive. We've been together almost four years.

### **Fear of leaving a motherless child**

I have learned from my life experiences and from society as well. My partner is also a very informed man...about HIV and AIDS. Hence we discuss about giving birth and being parents. I have the knowledge to give birth to an HIV-free child without infecting him.

At the moment I don't wish to give birth because if I die who is going to take the responsibility [for my child]? I don't want the story of my mother to occur again...

### **Taking information wherever it is needed**

I have an immense amount of information since I am a counsellor and have contact with many people. They might call me secretly or ask for an appointment in a cafeteria, due to a fear of coming to the office. Some individuals might ask you to bring them their antiretroviral drugs as well, because of their fear of stigma.

It is my duty to go to any hiding place, even if it is a graveyard, and counsel them – to save their lives.

### **"Stigma is still my serious challenge"**

In my experience, stigma is still my most serious challenge. At this time ART is working a miracle to improve our health. But there is no ART to stop discrimination.

Disclosure is when you find out who your friends really are. Common reactions are shock, pity, disbelief, feeling helpless – or endless questions. Some people may decide they don't want to know or don't want to see you anymore.

### **"I promise to do my best to get the word out"**

Counselling is a challenging profession. When people get tested and find out that they are free of the virus, they instinctively embrace and kiss you. On the other hand, when they find out they are HIV-positive, they blame you fiercely as if you transmitted it to them.

I live in a traditional society and I am not seeing enough about HIV in town. That scares me. For my part, I promise to do my best to get the word out.

“

I live in a traditional society and I am not seeing enough about HIV in town. That scares me. For my part, I promise to do my best to get the word out.



## Abdissa

### ETHIOPIA

Abdissa is 50 and for much of his working life was a soldier. Later, working as a driver with a commercial firm, his health deteriorated seriously. His colleagues shunned him – illness and isolation forced him to return home. Family reaction was mixed but was mostly negative, and he also experienced discrimination in the wider community. He is now happily married, but with no work or income, life is hard. Stigma, however, is in his view less common: "Whatever problems face me, the worst time has passed..."

### Family reaction

When I was diagnosed, I was so distraught that I came close to killing myself because I assumed all people living with HIV were worthless so they [deserved] to die.

I was inseparable from my family...we were like hands and gloves. We fed together, slept together and shared our clothes... But after I fell sick and was diagnosed, their attitudes completely changed... They stopped all contact and left me alone. They refused to touch me or share dinner plates, and they separated out all items that I had touched.

My mother was raising my nephews as their grandmother but my sisters took their children away, due to misunderstandings about the mechanisms and risks of HIV transmission. [My sister said] "You found out that you were HIV-positive – it is a result of your misconduct and wrongdoing."

No one...looked after me when I was chronically sick except my mother.

### Marriage

My first wife died and I married again four years after her death. My new wife is HIV-positive. We take care of and look after each other.

My sexual relationship is with my wife only and the same for her. We use condoms carefully. We live good-naturedly and keep ourselves from harm.

### Working relationships

Before I was sick and told colleagues of my HIV status, our relationship was very close, we cooperated with each other [as we faced] challenges and hard work.

Despite this, their behaviour and actions totally changed following my diagnosis... They froze our relationship, excluding me from the kind of discussions we had had before and isolating me from social engagements.

Now I don't have a salary. I have nothing...

### Changing attitudes

Nobody talked badly to me face-to-face. I heard about indirect forms of gossip and back biting.

Previously the community considered people living with HIV to be inhuman, or like wild animals. Over time, as the community has seen people living with HIV increasing in number and living for five or six years, people understood that HIV is like other chronic diseases. Because of this, people who used to discriminate against me have changed.

### Health professionals: some good, some bad

Some [health professionals] treated me like they were my father and mother. They counselled me and encouraged me not to be demoralized.

On the other hand I have seen some misconduct by professionals, who don't consider you as human and who cursed their patients... I have witnessed them being reluctant to treat you or they might tell you "your card is lost."

### Children

I have a boy. He was born from another woman, before I married my current wife. Now he is supported by his grandparents. I don't have any source of income which would enable me to support him.

From my side I don't want to have a child again, but my wife is always worrying about it and pressurizing me; she is younger than me and wants to give birth. So we have almost agreed to have a child within one or two years.

### A soldier's life

The military fortifications where soldiers serve are mostly in desert areas. You might get a chance to see your family once in two or three years.

On the other hand, we might get permission for time off, to enjoy ourselves in town sometimes – and we had sex with bar ladies and sex workers. We might sleep with many of them on different days and in different places. [As soldiers] we didn't care about the future. We didn't think about what would happen tomorrow. Our concern was when we might die.

### "Stigma still exists"

In my view, there is inequality between people living with HIV and those who are not. Stigma still exists.

Some people who consider themselves as free of HIV still point their fingers at you. They don't regard you as a healthy person, even though a lot of efforts are made through the media to avoid stigma and discrimination.

### A story of changed attitudes

There was an elderly woman who was my neighbour, whose daughter attended school with my wife. One day, this woman saw my young wife around our residence and she asked somebody why she had gone there. She was told that her

daughter's friend was married to me. She was so shocked she shouted out: "How could it be? He is sick as a result of this epidemic. How could they live together under one roof?"

I told the old woman that HIV is not transmitted through living together under one roof. [She replied]: "I don't believe that. If I heard my relative was HIV-positive, I would choose death rather than live with him."

After a while her own son fell sick and she tried to hide the fact that his illness was a result of HIV. After his death, she started to approach me more positively. She even started to enter my home and share things with me.

### "Everything changed after my diagnosis"

To be frank, no one told me in words that they were discriminating against me. However, you can feel how someone is stigmatizing you in their actions – such as cool greetings, facial expressions and other body language. I have witnessed most people turning away their faces – and their attitudes, views and approaches toward me were not as previously... everything changed after my diagnosis.

### The coffee ceremony spoiled

[Before] when we invited each other for the coffee ceremony, we picked up cups of coffee randomly. No one was given a [special] cup for coffee.

But following my HIV-positive status everything changed. No one touches a cup I touched... They look down on you and won't share a cup of coffee with you. Some even think that an HIV-positive person could put blood in the coffee.

### "The worst time has passed"

However, it is true that there are more improvements than before...because of the rising numbers of people living with HIV. How could they stigmatize all of them? Therefore everything becomes a little easier and we start to share everything... We also started to invite and visit each other. You know, it is six years since I started taking antiretroviral drugs...

Yet whatever problems face me, the worst time has passed...



In my view, there is inequality between people living with HIV and those who are not. Stigma still exists.

# Almaz

## ETHIOPIA

Almaz is 24, and explains that her worst experience of stigma was within her own family: "I was ostracized by everyone except my father." While she recognizes that some of her mother's attitude stems from ignorance and isolation within the home, the way she was dealt with has left a permanent "emotional injury". She educates people about HIV, and believes she has had some success, but otherwise she keeps quiet about her HIV status, fearing the loss of her job. Above all, she believes the "ugly effect of HIV is that it makes you lose friends and relatives."



### "I felt nothing"

It was 2008. I was working in a hotel and had been seriously sick and bedridden for two months... Primarily, I wanted to get checked for TB. I discovered I had it, and my friends advised me to get tested for HIV as well – and the result was positive. When they told me, I felt nothing.

### Family hostility

I started ART within a week [of my HIV diagnosis], because there was no other option except suicide.

I was working in a hotel and I asked my friends to send me back to my family.

But my family treated me adversely. They refused to let me live with them. They didn't welcome me, rather they stigmatized me terribly. The ugly words from their mouths made me feel worthless.

### "They regarded me as worthless"

To be honest my father tried to be encouraging. He also advised me to start medication, saying if I did so, I could live a long life. My mother heard my father advising me. From that day on, my mother and my brothers clearly stigmatized me. They stopped touching anything I touched, especially plates and other household stuff. They regarded me as worthless, hopeless...

They excluded me from family events, and separated my sleeping quarters and seating area in the home. They refused to allow me to use the toilet or to fetch water to drink – even to swallow my tablets.

When I was evicted from the family home by my mother, my father rented a small room for me. But my mother and brothers believed that having HIV was my own fault – and that I deserved to be punished...

I also considered myself unworthy and without hope... But I have a child and eventually I convinced myself to live for my child's sake.

### Lack of understanding leads to stigma

My mother knew nothing [about HIV]. She didn't understand anything. Do you know why? She didn't have [the chance] to go out of house and communicate with society. However, my father does interact with the community. I know his friends are mature and dignified people. So he has a better understanding than her.

People who listened to my mother's insults and taunts, to her casting blame on me, those who heard the gossip and rumours – they stigmatized and hated me. Moreover, they refused to allow me to enter their homes. They pointed their fingers at me on the street.

They couldn't grasp or perceive anything about HIV and AIDS. In fact there are meetings and discussions in the community so I don't understand why they don't understand properly.

### Workplace discrimination: "they consider you dead"

I have witnessed first-hand that if employers hear about your HIV-positive status, or you tell them, they automatically fire you.

“ I still wonder why people do not understand.  
There are several ways to access information.

Nobody understands. They don't believe that people living with HIV can be fit for work. If you are sick today, they don't realize you can recover [and] get stronger for tomorrow.

I believe they consider you dead already – or as hopeless as someone who is waiting to die.

### Bad memories

I remember one incident when I was living in the rental house. I went to my workplace to educate people gathered there [about HIV], as I did frequently. Afterwards I was given a water container with a package of medicines to prevent opportunistic infections, and I took it back home.

Anybody [familiar with] health facilities would know that those water containers are donated to people living with HIV by various NGOs. The woman who rented me the house had been looking at me when I took it in; she knew to whom these were given. Some days later she asked me to leave. I was not that surprised: if your own family stigmatizes and evicts you, what can you expect from a woman who isn't a relative?

### Forced into adoption

My biggest wish is to see my boy's success. I had him adopted because I couldn't look after him myself.

You know, I was separated from him since he was 18 months old. He had been living with my parents until I came home... However, they didn't want to look after him then. Due to [the HIV] they hated him. I had to take him to be tested. Thanks to God he was HIV-negative.

### Keeping quiet at work

Of course I had friends before I found out that I was HIV-positive but after my diagnosis they were not as close as before. I believe the other ugly effect of HIV is it makes you lose friends and relatives.

But I don't feel fear as before. Over time I came to believe disclosure is better than hiding. But...I don't want to talk as openly as before. However, I am still willing to help educate my close friends and interested people who need to get information about HIV and AIDS.

I don't meet up with people... I also don't want to be involved in any group work or organizational activity because if I do, it means contact with others and there would be [risk of] exposure, especially [with taking my] ART... Most people do not keep your secrets.

What I have never ever discontinued is my work. Neither my employer nor my organization knows [my status]. I didn't tell anybody – not the manager nor my colleagues.

### “Choosing death was not the right way”

One time I defaulted on taking my medicine... deliberately...because I felt so hopeless. I thought that if everybody isolated me from social interaction, my life would be meaningless, so I might as well die. I saw death as my revenge on those who stigmatized me. Nonetheless, it was wrong to think like that I realized later... [choosing] death was not the right way to show them that living with HIV doesn't automatically mean death.

### Lost opportunities

In my view it doesn't matter that I am HIV-positive because I am not the only person on the earth who contracted the virus. I didn't deliberately buy HIV with my own money...

[Yet] I missed many things and lost opportunities. For instance I [might have] had a chance to go overseas if I was not HIV-positive. I wouldn't be someone's worker or daily labourer if I was not HIV-positive. I would be able to go to any country and work for a better life.

I don't believe that I would get good results later [if I started to study again], with my diagnosis. Beside this, I fear stigma in school if students knew my status. If that happened, I would get very upset. This is why I don't want to go back to education. My aspiration is to change my low standard of living with hard work.

### “Why won't people learn from my experience?”

I still wonder why people do not understand. There are several ways to access information.

If you tell people you are HIV-positive, they think it is some kind of funny story. They respond: “There is no AIDS after sunset.” You can see people, even older and married people, going here and there for sexual relationships, hiding their marriage rings. I don't know what is to be done...

I don't mind being stigmatized if my honesty would teach others. [For that] I feel contentment rather than discontent. So I believe that I have done a good deed because I have saved many people by convincing them to get tested and to know their status.



## Selamawit

ETHIOPIA

Selamawit, 36 and a mother of four, lives in Somali National Regional State. She describes how one aspect of discrimination has been an assumption among many Somalis that only Amharic people like her are affected by HIV. Her second husband has been supportive but lacks her courage to go public and educate others. With treatment for HIV having turned Selamawit's health around, she passionately believes that "the greatest barrier to living a healthier life with HIV is not necessarily the virus. It's the stigma."

### "Fear is more powerful than reality"

I underwent treatment for womb cancer and was forced to give blood for testing.

I hadn't even a little understanding about HIV and AIDS – it was wrongly called pneumonia or 'cold wind-draught' by the community.

At the time, my choice was to die rather than be told that I was HIV-positive, because I had seen terrible stigma and discrimination.

I believed I was infected with HIV through my own mistake... I had remarried. As I heard it, his first wife had died as a result of pneumonia... We were not tested for HIV before our marriage. Nobody knew the real cause of his previous wife's death. A year later I found out that I was HIV-positive.

I decided to get counselling on how to disclose to him and how to overcome the problem if he [did] want to leave me. [My husband's] response was unexpected: "Why should you worry alone? I suspected my late wife was living with HIV. But we didn't get tested. We must accept the reality." I've gradually learned that the fear that I hold onto inside me is actually more powerful than the reality of the situation.

### "There was not a single female"

At that time there was no support group, but I heard that a few people living with HIV had secretly organized themselves under the umbrella of the Red Cross. They were all males. There was not a single

female. On the other hand, I was delighted to find friends living with HIV [in the same situation] as me.

Over time...we went on to found an association.

### Discrimination: emotional and economic costs

As regards stigma, in this region it was scary.

I am engaged in small trade in my home, such as selling *areke* (alcoholic spirit) and *tella* (local beer) and several other businesses. Supplying water at an affordable price through my pipe to those who don't have piped water was one of them. But all the customers stopped buying my water.

One day, I went to church to disclose my status to a crowd of worshippers and to ask them to look after my children if I die. Most of the crowd looked at me with great sympathy.

Others told me that my words would be harmful for me and for my children. Some stigmatized me even more. Some pointed their fingers at me. Others splashed full basins of water on the ground and returned home with empty basins and told others not to buy my water.

I understand why they did it. It was because of their fear of HIV and AIDS, because of what they understood then... I knew my own misunderstandings before my diagnosis.

However, after six months I myself disclosed my HIV status publicly and started to stand on platforms to teach the public.

## Stigma and support within local residents group

The heads of *Idir* (traditional burial society) especially try to support me since I disclosed my status in the church. Before disclosure, they asked me to work as others work in the *Idir*. Afterwards, they said: "Don't work hard because you will be tired." But it was not clear to me whether they genuinely felt sympathetic towards me or if this was implicit stigma...

After a while I decided to reduce my involvement and asked them not to assign me to any activity, pretending I was sick and too tired to fulfil my task. The real reason was that I was worried when they told me not to work and not to touch things.

Now I have come back to my *Idir* and am actively involved again. I asked the *Idir* to allow me to participate actively like the others, because my health is improved and I am energetic enough to do my tasks.

## Ethnicity and misunderstanding: stigma remains

The general public in this region thought that HIV is a disease of Amhara people. The main reason for this was that not a single Somali disclosed their HIV status at that time. So they were pointing their fingers at us [Amhara], who are not indigenous to the region.

There were some Somalis who believed "HIV is the disease of Amhara." Presently this belief has changed into "Somali do not take antiretroviral drugs, only Amhara do."

## Secrecy and denial driven by shame

I have witnessed some [indigenous residents] using antiretroviral drugs secretly. They cover their faces with the *hijab* (Islamic headscarf) to hide their identity and take their antiretroviral drugs from health facilities – because they can be extremely stigmatized by their families and clans if they were identified.

Family and clan shame stems from the belief that people living with HIV behave immorally. In the collective culture of Somali people, the community holds the clan responsible for the behaviour of its individual members. Consequently, fear of bringing shame to a clan becomes a heavy psychological burden. There are a few people living with HIV who have dropped out of ART due to this fear.

## Reaching people in government

After antiretroviral drugs became freely available, we have been trying to tour offices as a group, comprised of five members of our association. I remember that an official warned us against this, when we tried to educate public servants in the

different government offices. He was an indigenous Somali. He was upset when we entered his office. "What are you doing here? This is not a bar, we are not bar employees, you should go to a bar and teach bar ladies."

## A lonely death

I don't want to see women die because they are disadvantaged and powerless in society. If I hear about the sickness of any woman, I go to her home directly and try to counsel her to take medication and join our association for further care and support.

There was a woman who was critically ill and bedridden. She was a commercial sex worker. I frequently went to her home and shared my experience of how I walked through adversity. She was crying while I was counselling her. However, she dropped out of her ART regime, locked her door and hid under the bed covers...

After a short time, her neighbours alerted the Red Cross, as there was a bad smell. The Red Cross called us as well. When we entered the house, she had not passed away but her soul was clearly in turmoil. What met our eyes was a shock. It was difficult to differentiate her from the bed she slept on. All the household items she used were smeared with dirt. There was urine, faeces and vomit everywhere. We washed and cleaned everything but we couldn't find anywhere to empty the dirty water because of her neighbours' refusal to let us do that.

So we were obliged to dig a hole and bury the dirt. In addition, her neighbours refused to let us hang her clothes up to dry. We were forced to buy a separate line to hang up the washing. Meanwhile we sent her to the health centre. Sadly she was too weak and sick to take medicine and she passed away after a week. Her resistance to the disease was over.

We realized later that she wanted to die secretly, without anyone knowing. All these terrible incidents showed us that stigma continues to have an impact on people living with HIV.

## Financial support alone is not enough

We [have been] offered financial support for income-generating activities but...behavioural change must be brought about so we can sell our services or products. If the community doesn't want to purchase from people living with HIV, our efforts are without value.

You know, we all start laughing when we remember the first time we met and how [secretively] we talked about HIV! The greatest pleasure I have experienced is becoming an example of 'living long' with my children.

# Mateus

## MOZAMBIQUE

Mateus is 57 and was in his early 40s with 13 children when he learned that his HIV status was positive. He lost his job as a driver, but later found some part-time work, and also publicly acknowledged his circumstances. Much has changed since then: his health improved dramatically since starting ART, and he founded an association to help other people living with HIV. Trained as an educator and armed with knowledge of the law, today he would challenge the discrimination he originally received from employers and some medical staff. His driving force remains "to break the silence" around HIV.



### "I had no hope"

[After hospitalization for three months to treat ophthalmic herpes] a Nigerian doctor suspected the cause to be HIV. He advised me to do the test and the answer came back that I was HIV-positive. At that time [the information] they were giving about HIV and AIDS is that if someone gets this disease he would only live for a maximum of five years. I had no hope... I thought that there was nothing except dying ahead...

### Discrimination begins

But I had the courage to continue taking some medicine and the doctor told me to go home to Mocuba. At that time (the late 1990s)...the only centre that was doing treatment for HIV was Hospital Padre Osená where the Sisters dispensed medicines using garlic, onion, lemon and other things.

I also felt discriminated against in that hospital. One of the Sisters used to tell the doctor: "Listen...that patient there has to be separated from the others. Be careful with him because he has AIDS", and she would say that in a crowded place and in a loud voice.

### Employment and health problems

I wanted to work to sustain my family. But when I went back to the bank they already knew I was

HIV-positive so they dismissed me. I worked in Beira until 2003 doing a part-time job, but then I got TB.

I ended up giving up work and then I decided to break my silence on Mozambican radio. I appeared on TV too. In Mocuba I saw that I had no way to live. I went to look for a job but they also dismissed me when they found out that I am HIV-positive.

### Fighting back

Just because I am living with HIV that does not mean that I cannot work. I am useful for society, I am equal to someone who is not infected, but they were the bosses and they have the power.

Now that I have attended some courses, I would do something like go to the companies and tell them that there is a law about people living with HIV.

### Family

Thank God none of my children behaved badly, nobody thought bad things about his father. Thank God all of them did the test and none of them got a positive result. My wife and I are both living with HIV but the kids are all negative.

### "People dying for lack of information"

In 2007 I had the idea of creating an association. I could see people dying for lack of information, knowledge and explanation. We started explaining

to people how to stop themselves from getting HIV and to prevent its spread.

### **"You mustn't stigmatize yourself"**

I feel good because even people in the community who know that I am HIV-positive cannot believe it because of the activities that I do, because of my health and power to work.

I cope well and when I talk about HIV and AIDS, some people really hear me and go off to hospital [for testing], something that did not happen before.

You mustn't stigmatize yourself because sometimes you might find people talking about HIV, then you'll think "they are talking about me." You have to feel as free as if you don't have this disease. And if you find them talking and you are afraid of approaching them, then you are the one who is stigmatizing yourself and not those people.

### **Helping others**

In the beginning [when people come to the association] they don't manage to say what is on their mind. People sometimes call me if someone is sick, they talk to one another, and say maybe this is something related to HIV and AIDS; maybe we should go and hear about what we should do.

Then I advise him saying that this is something that cannot be seen by the naked eye – you had better go and do the test. Those who are living with HIV come back to me to ask about treatment procedures. Now they are good in their houses, with their spouses.

### **An association: "people with the same objective"**

We had 30 members, most of them people living with HIV. But people do not understand what an association is. So we used to explain to them that an association is a gathering of people with the same objective, which is to do something in a certain area which is not being done.

We can do something to sustain ourselves and not just lie down. We walk 25 kilometres to give lectures about HIV and AIDS, and teach ways of preventing the spread of this disease, about birth control, the use of mosquito nets, because it is our duty to explain and break the silence for people living with HIV.

### **"There is still stigma, discrimination"**

There is still stigma, discrimination... [Sometimes] other family members get to know about this, and start calling them names. They say: "Look at that guy – he has got big cheeks like he is taking antiretrovirals." If somebody tells you that, then it is stigma, and stigma kills...

[After my own diagnosis] I found it strange because at first, when my colleagues knew about it they did not say anything – but they did not want me to be close to them. In the bank, they said that you should only come in on Mondays to sign the attendance book and go back home. I couldn't even use the desks there, because in their minds they thought that if I sit at one of the desks and someone else sits there he would also be infected.

Disclosure was very difficult for people: first, because of the illiteracy, and second, because they are not used to going to hospital. If a woman tried to explain to her husband about this there would be a big quarrel. But now things have changed. Some people break the silence to their spouses saying: "I am in this situation and on that date I will start with the treatment." And when that date comes the husband says go and get the medicine for both of us, and it is good for people.

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You have to feel as free as if you don't have this disease. And if you find them talking and you are afraid of approaching them, then you are the one who is stigmatizing yourself and not those people.



## Henriques

### MOZAMBIQUE

Henriques is 34. His childhood was poor and blighted by the loss of his parents. He had no one to support his education or ambition to become a football player. A five-year relationship with a widow, who helped him financially and emotionally, came to an end when she died of AIDS-related illnesses. He cared for his partner until her death, at which point poverty threatened his own health and survival. His family ostracized him, but with the help of activists and others living with the virus, he found a new 'family' and the conviction that being diagnosed with HIV "is not the end of life."

### Relationships

I was born into a happy large family.

I always dreamed of becoming a football player. But things do not happen the way we want. I lost both my parents so there was no one to help me with school expenses... My adolescence started to get complicated by financial problems; I couldn't move forward either in football or school.

I kept on getting involved with older women, as a way of gaining more things... I could overcome my financial problems, lack of food, and so on.

The woman with whom I was involved [at that time] was a widow. I did not want to know the source [of her money] or even how she lost her husband...all I cared about was the things she gave me.

We tried to have our [own baby] but we did not succeed...but we lived together happily – the age difference meant nothing... We were very close... I lived with her for five years...

Then she started to get sick and went to hospital. At first it was hard for the doctor to believe that I was her husband; he thought I was her son. Because I was her partner, he thought she had already told me [about her status], but she had never told me anything. It was thanks to the doctor, who made me aware of that situation, that I did the test. It was then that I found out that I had been infected by HIV.

### "There was no way back"

It was hard, very hard. On television it said "*Cuidado Malume AIDS mata*" (Take care sir, AIDS kills), so I considered myself a dead man.

I tried to talk with her [and eventually] she decided to be open...there was no way back.

I did not have any help [from others], because... my family had disagreed with me staying with my partner. I supported her all the time she was sick. And none of the family came to visit her until she died.

### "I lived like a beggar"

Then I also started to get symptoms: I started to cough, got some wounds, some spots. One month later her family came to take the house back because it was theirs and I had nothing but my clothes. So then I had to go my uncles, but they did not welcome me.

I lived there like a beggar. They separated the cutlery and plates – even the food they ate was different...

### Helping hands

I know what it is to be HIV-positive; I know what it is to feel discrimination. When I used to go to the health centre I had to stand in a long queue and people would look at me. We fear being recognized by people who know us and so we end up giving away our place in the queue.

I ended up [abandoning] treatment until I came across an old friend. He took me to a health centre where he introduced me to a health worker who gave me some advice. I saw other people there who had gone through the same feelings but had already overcome them. Then I started taking the medicines.

It was difficult at the beginning. I did not have any help where I was living. The disease started to get worse and I had to leave because they stopped giving me food. I had to go onto the streets. I ended up begging... I felt hopeless and getting so little food drove me to alcohol and things got even worse. I got sick and had no shelter, no food, until a man came and told me about God. He took me to church.

### **Finding a new family**

The church advisors told me that I should go back to hospital, to continue treatment. That is how going to church rescued me. Because when I arrived at the hospital I met a group of people who had the virus – and then I felt that I had found a family.

They told me that they had been in the same situation for years, living normally with other people.

They had passed the stage of prejudice. They showed me how I could get help.

They would give lectures in small meetings. It was through those people that I started living normally, doing community work, small jobs that could give me some money.

### **An important message for others**

I feel that I came back to the world, despite people still pointing at me. Today I am an example of how, when we get HIV, it is not the end of life – but just one more disease like others. Today I am living normally. I pass this message to everyone who lives with the dilemma of HIV and is scared to go to a health centre.

People who live with this disease, I advise them to look ahead. Nothing is finished. Yet in my family the discrimination still exists...they do not accept me. I feel better when I am there in this community, in meetings, with the activists. I feel that I have a family and life is continuing.

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I feel that I came back to the world, despite people still pointing at me. Today I am an example of how, when we get HIV, it is not the end of life – but just one more disease like others.

## Liloca

### MOZAMBIQUE

Liloca is a mother of four. Now 44, she was brought up by her grandmother, who, as she expressed it, taught her "how to survive". Her husband would not acknowledge his HIV status and when he died, his sisters threw Liloca out of their home. It was when she was pregnant that she discovered she had HIV. Gradually her health recovered with ART, and she has been able to do odd jobs and support her children. Being a member of a church and an organization that supports people living with HIV has helped her. Her ambition is to get a job caring for people with HIV.



#### No disclosure from husband

I lost my husband when my son was six months old. My husband was HIV-positive, but only his sisters knew that. He was having treatment but he quit. After that he died... He had infected me and his son.

His sisters accused me of killing their brother. I had to leave my home.

Now I live at my friend's home and I am happy... I take antiretroviral drugs and I can help other people who have not yet started the treatment and those whose parents do not help them.

I got the diagnosis when I became pregnant. The hospital could not find out what was going on. I was only prescribed headache pills: paracetamol. At the fourth month of pregnancy I started coughing. It was a symptom of tuberculosis but I did not know. I was weak and I did not feel like doing anything.

My husband knew what was happening. [Apparently] he wanted to tell me but always wondered how to do it, and so he did not tell me...

#### Grandmother "taught me all about life"

I grew up with [my grandmother], she taught me all about life and I helped her. That is the reason why I am not suffering like others. She taught me how to survive.

I have got four children altogether and I have got three grandchildren.

I am well. Since I started doing ART I have never fallen sick. I do odd jobs...

I have also taken care of my granddaughter since her first month. I would like to see my granddaughter growing up, studying. She has been well since she was born; she is HIV-negative... When she grows up I will tell her that I am living with HIV. She has to protect herself using condoms when she has a sexual relationship. If she does not listen to me that is her problem.

#### "I have helped many people"

I am a member of Hixikanwe (We are together) Association. We have meetings every Wednesday.

There we learn about adhering to the treatments and give moral support to those who quit or do not adhere. I am only doing voluntary work there. I assist seriously sick people. I wash them. When I have something at home to cook, I take it for them to eat. I take the patients to hospital when necessary. Since 2010 I have helped many people.

#### "You have to be their friend"

To find out if someone is living with HIV, you have to conquer [their fears] first because they can tell you that they have malaria or TB whereas it is not. If they do not accept [what you say], you have to be their friend. Then, they will start sharing their health conditions with you and then you can help them. They can join you [later] to help others.

### "Responsibility lies with the woman"

Women suffer too much and they are sensitive. Men are not sensitive, they may know that you are not well or may die – but they do not care. But a woman always wants to help everyone. The man is only the head at home but responsibility lies with the woman.

Being a mother means having responsibility. Being a father is just having a child.

### Discrimination can cost lives

I know many people who suffered from discrimination, some of them even died. A mother went to hospital to get the tablets but she did not give them to her child, alleging that it was a lie and that her child was not HIV-positive. The child had never taken antiretroviral drugs and died. There are many people dying because of discrimination.

To get rid of the discrimination we should talk. Priests and pastors should talk, or allow the activists to talk, about HIV and the use of condoms because someone may be living with HIV without knowing it. We know that men do not accept [their status] but we have to insist.

### "I am not afraid"

Church is very important because it is a place where many people meet. Even for the ones who are not there, those who are present will take the message to share with them.

Sometimes, the family abandons the patient because they think that he will not get better. We need to talk to the family about taking care of the patient.

I have to fight until I die. Now I do not work full time, I depend on odd jobs. But if I find a job I will help those who cannot do anything, who cannot stand nor sit [by themselves]. I will also help my family...

It is not easy and other people do not accept us. But I am not afraid. I can appear on television. I do not care. Whoever talks about me – it is their problem, not mine.

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It is not easy and other people do not accept us. But I am not afraid. I can appear on television. I do not care. Whoever talks about me – it is their problem, not mine.



## Lucilia

### MOZAMBIQUE

Lucilia is 53 and a mother of five. Her marriage was unhappy and she left Mozambique to work in South Africa. After a decade, her health began to decline and she returned home, where she was diagnosed with HIV. After some initial misunderstandings, her children have been supportive. She trained as a teacher, and is working again, but she struggles economically – her youngest child is still in school. She feels strongly that people living with HIV must resist stigma and the temptation to hide away. She gained a lot from meeting others like herself and being able to share experiences. She now has a loving partner, and is grateful for their honest and supportive relationship: "Maybe I am regaining my lost happiness."

#### "At that time AIDS was said to kill"

I lost my mother very early, when I was still a child, and was brought up by my godmother. Later, I trained for two years [and became] a primary school teacher.

I worked for 10 years at a primary school, and as time went by I got married. I had problems in the marriage, we separated, and I ventured to South Africa, where I lived and worked for another 10 years. That is where I began to get sick...

When I arrived back here, [a friend] took me to a hospital.

An advisor chatted with me and advised me to do the HIV test: the result was positive. I felt terrible, because at that time AIDS was said to kill, so I considered myself a corpse. But the advisor told me that if I managed to take the medicines, I would get better.

I seemed to be recovering. Then I went back to South Africa...but when I got there the climate [seemed to make me] relapse. I went back to the hospital. The doctor said: "You could die any time, but I advise you to have hope. You have to learn how to take the antiretrovirals that can save your life."

[Another] doctor said I had tuberculosis and needed two weeks of TB treatment first... I accepted it but was a bit desperate.

#### "I had no food"

It was August 2004 that I was to start with the TB treatment and taking antiretrovirals at the same time. I was facing a lot of problems. Because I had been living in South Africa, here in Mozambique I no longer had any work. I had nothing, so I was taking medicines without eating; I had no food. I had a neighbour, who has since died – she used to come and give me little bit of mush which was useful.

[At first] I had a reaction to the medicines, with spots on my body. My neighbours forbade their children to come and play in my house, you see? My children could not even enter their homes, so we lived closed off [from everyone].

#### Meeting others

The time came when I realized that I could live normally in the world. At the hospital I met one of the church mothers who offer soup [to others]. It helped me a lot to recover, because I could see other people in the same situation. While I was [isolated] at home, it was different.

One day I met another mother, who invited me to join an association, a place "where you will meet people like you", she explained, "and you can talk about everything you go through outside." I became a member, I would share all my problems there and the colleagues used to advise me to continue living with hope.

### **"Only my children help me"**

In my house, my children were discriminating against me. One day I fetched water from the drum using a cup and I drank, then my son said: "Mum, why are you using that cup to drink water while you know that you are coughing?" I answered my son: "...how can you [believe that] I as your mother would do anything to infect you?"

Then my son realized that he was wrong. He did not buy different cups and they continued using the same objects that I used.

I have five children, three daughters and two sons... I am not very close to [the rest of] my family now... they don't come often, only my children help me.

### **Independence and life today**

Today I have my own house; it is not a good house, but it is mine. I put in a lot of effort and have water and electricity. The house is not finished yet. My financial conditions are not good... I can only buy a small sack of rice, pay the water and electricity; the rest is just survival.

I do not have a husband but I have a friend who is also infected. I think that he is better for me, you know! It was not hard for us to reveal our situation to each other, and we are coping well together.

Maybe I am regaining my lost happiness...we are not living together, so we just meet sometimes.

### **Dreams**

I am studying and am now at grade 10. I am doing sciences now, but my dream was of becoming a PhD, even if it was to live just a single day as a doctor.

The other dream is to marry...if I had the chance...

I would also like to have employment that satisfies me. I have participated in leadership training, positive prevention, stigma and discrimination, finance management, home care, activism.

### **Resist stigma and socialize**

The example I can give to others is that when I come across someone infected by HIV...I mean someone who does not know yet how to live positively...they should not be closed but should socialize with other people, because that will help them to live.

If they close themselves off, death will come fast. It is a fact that outside they can face discrimination, but they should resist that and they will see that life goes on.

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I would also like to have employment that satisfies me. I have participated in leadership training, positive prevention, stigma and discrimination, finance management, home care, activism.

## Zodwa

### SWAZILAND

Zodwa, aged 29, got pregnant while still at school, for which her mother never forgave her. Shuttling between the father and her family, she eventually finished school and trained as a secretary. Later, Zodwa lost her job and the relationship faltered but they continued to see each other as she needed financial support for the children. She got pregnant again and tested positive for HIV. Zodwa feels that much stigma stems from ignorance, and she has drawn on her own experience to talk to others and break down prejudice. Stigma is potentially life-threatening, she points out, since fear of exposure also contributes to people not continuing with their treatment for HIV.



#### **Educating herself**

While I was in Form five...I met a boy...it was my first time to have sex. I got pregnant...

I gave birth, he gave me money to support the child.

I went back to school, but things were not well with my mother. She would shout at me: "You are no longer counted as one of us."

I completed Form five and took a secretarial course...

While at the college the fees were paid by the father of my child. I completed the course and the following year I had another child and I also got a job as a secretary.

#### **Life gets difficult**

In 2006 I lost my job. At home they were putting me under pressure, saying he has to marry me.

The children were with me at home and I would sometimes visit their father because I needed money for the children. I went there and got pregnant again, it was the third one.

#### **"I had not disclosed to anyone"**

I had had no thoughts of testing for HIV. I had no interest in that but because I was pregnant I had to and I tested positive. That was so stressful because I did not know anything about HIV. All I knew was

that once you are HIV-positive you were going to die. I had a problem as to how to disclose my status to my boyfriend...because I thought he was not going to talk to me or even support his child; he was going to say you got HIV from other men, not from me.

I had not disclosed [my status] to anyone. I said to myself it won't help telling other people because they would say...she is going to die, she has HIV... I thought I would infect the child. I took the child for an HIV test several times and found that the baby was HIV-negative.

#### **Discrimination within the family**

The person I told about my HIV status [and starting the ART] was my father...he said he understood. Life was not comfortable at home because they were discriminating against me. They said I must not touch their belongings because I would infect them with HIV.

They knew my status because they saw my tablets. My mother was the first person to discriminate against me... She didn't want me to go to the toilet because she said I would infect them...she said I had to go to the forests...

The other family members would not associate with me. Even if they were making plans they would not involve me and I would be so surprised: Am I already dead?

My children were not happy about the way I was being treated...they recognized what was happening. They would hear their grandmother shouting at me, so I took them to their father's place.

### Now people are informed

The discrimination was caused by lack of information about HIV issues...they believed that you get HIV by having several sexual partners and such a person was a prostitute... That was why my mother felt she had to treat me as she did.

[Nowadays] people are informed about HIV and they know that you are the same as they are. It is just that the virus is in the blood. They know this...even at home...even my mother did not think of going for an HIV test [before] but one day I heard her saying she had gone for a test. Because they know now that anyone can have HIV, if you see a person walking out there you cannot say this one is an HIV-positive person or not...they know that it might happen that you suspect someone has the virus (HIV), yet you have it. Discrimination has decreased compared to 2005 or 2006.

### Support groups: "these people are with you"

After starting the ART, I heard about an organization called Swaziland AIDS Support Organization, for people living with HIV.

What I really liked about these people is that when you said something they would listen to you and support you. You would see that these people are with you – these are not just people, but a support group...

### The role of the church

There are many people living with HIV who attend church and take antiretroviral drugs, so it is important to talk about HIV issues in church. People must

stop discriminating and these issues must start from [discussions with] the young people... People must be taught what HIV is and what it does in the body.

### Disclosure and defaulting

There are many reasons why people default [taking their antiretroviral drugs]. One reason is that the person is not well informed enough... As the person continues taking the antiretroviral drugs, you will find that they start feeling better and gaining weight. That person would not see the importance of continuing with the ART.

Most cases of defaulting happen to people who have partners, because people fall in love and have difficulty disclosing their HIV status. You find that it is time to take the antiretroviral drugs and the partner is next to them, how is that person going to do that? What are they going to say they are taking?

Partner counselling is very important because when you are a couple...you find that one test is positive and the other one is negative. The life of these people becomes difficult...

### Keeping dreams alive

I have supported many people, even in my own family. I have helped most of them with their health because they were in denial; they were not [convinced] about the results. Others feel anger. They even discriminate against themselves. They have internal stigma. They were able to come to me because they knew that I was HIV-positive. Some of them are now working, they were able to accept their HIV status and they continue with life.

It is important for a person to have their dreams and to encourage them.



Partner counselling is very important because when you are a couple...you find that one test is positive and the other one is negative. The life of these people becomes difficult...

# Futhi

## SWAZILAND

Futhi, 43, is a single mother of four. She had a sad childhood. Her stepmother's hostility almost drove her to suicide, but when she got pregnant at 18 to a much older man, her child gave her a reason to live. By then she had also found solace in the church. When a series of illnesses led to an HIV test, which proved positive, her faith again provided much support. Futhi's experiences have led her to be very self-reliant, but she acknowledges the importance of friendship and support organizations for people living with HIV: sharing experiences has proved helpful. Her children accepted her status and "remain the same loving children." Her main concern is their future.



### Thoughts of suicide

[As a child] I felt like I was not loved at home...[and when] I was a teenager, I began to understand that my stepmother...hated me.

I then became a believer...I was hoping God would change this woman and make her love me, but nothing happened.

I thought it was better to die... So I went to talk to the preacher in church. I told him my life at home was miserable and I thought death was preferable. He said: "No sister, that would be wrong, let's talk and see how you can live [with this]."

### A child changes things

I started having children when I was 18. I then realized that killing myself would not help. Unfortunately I did not marry.

I have four children now. No one is helping me with them and my stepmother is still her old self, not caring.

### A positive test: "I told myself I was dead"

Before I went to the hospital, I was like: I don't understand my sickness... I was feeling so tired... I returned home and got worse.

Then they told me what they suspected.

So they told me that my HIV test is positive and that I needed to start taking the pills (antiretroviral drugs). I agreed and went to be educated on how to live. I learned what it means, how I needed to have a balanced diet. But at that time I told myself I was dead. I did not think it was realistic that one could take pills for the rest of their life.

### Family disappointments

[The challenge] is my family – they did not take care of me, they were not accepting.

Life at home is not alright. It is 'life' because we are alive. You know you cannot change people's minds... You think maybe tomorrow will bring solutions... They have no respect for me, for my children.

### Different reactions

I told my brother, and he said it was good that I went early to test. Other people do not want to go to hospital to test. They are afraid of the pills. Others die having collected them but being afraid to take them...

Stigma and discrimination is there... I don't know if people think the virus lives on our hands, they do not know that it is in the blood. It happened to me one time we had gone to assist in a funeral and one lady said: "I don't want to work with xxx", saying my name, "because she has this thing."

### Support from the church

In churches I am treated like other people. I think we are regarded as the same, equal from the beginning to the end, there is no difference. They love us...

The preacher at church encourages me. He says even if people say bad things about me living with HIV it does not stick to me, it's just words. But for me walking around with people saying things it's painful, it's insulting...

### Fears for her children

Sister, what I usually pray about in my heart is that God would help me build a home for my children.

Because if I think about life here at this homestead, I don't think they would be able to live here when I am not around. It is difficult enough now while I am with them. What about when I am gone?

I think it helped that I disclosed to my children. They remained the same loving children who love their mother.

People help me; I do people's laundry when they ask me and they pay me. I even weed people's fields and I receive maize for food. I am able to buy soap, sugar and we live.

I pray that I could see my children at least grow up and be able to help themselves, and help each other.

### Telling people your status

It is difficult to disclose [your status]... You really have to think about who you will tell and think why, and how close to your heart they are. You think I would tell this one and then find that you have broadcast your story on the radio. You then

have regrets...it is difficult because people then talk about you and then start discriminating against you.

Some women have lovers and when information gets out [that you have HIV] it is a problem.

Men even find it difficult to test. They go there reluctantly...they find it difficult. I heard about another man who would not go for the HIV test even though he was sick. He did not go and the sickness progressed...

### "Sometimes you need to talk"

Some people do not want anyone to know and do not join support groups because they are worried that many people will find out. We have support groups where people join, but they are so reluctant to share their stories. My view is that such a situation hurts the individual, because really sometimes you need to talk to someone.

People hide this thing for 20 years, not wanting anyone to know how they are living.

For young people I think the problem is that they do not conduct themselves properly. Even when they realize they have this disease they do not want to adapt to live like people who know their status; they want to live like everything is fine. So even when they see they have this disease, they keep on spreading it.

### "I am alive because I went to test"

Some died without testing, but many are alive. I am alive because I went to test. People think because I am HIV-positive, that is the problem – but really the problem is not knowing your HIV status.

“

Stigma and discrimination is there...  
I don't know if people think the  
virus lives on our hands, they do not  
know that it is in the blood.



## Sabelo

### SWAZILAND

Sabelo is 25 and confesses that as a younger man he competed with friends to have as many girlfriends as possible: "I was not selective." He also refused to test for HIV. Sometime later, he could no longer ignore his failing health. His family was supportive when he tested HIV-positive, but he was suicidal: "the stigma was within me." Sabelo was helped by learning that his older sister had been living with HIV for years, and by meeting his compassionate and understanding partner. Now, he works for the Family Life Association of Swaziland (FLAS), encouraging people to test and disclose their status. He's seen too many people bedridden because they avoided testing until it was too late. Now, he says, "my talent is to save people's lives."

### Taking the test

After completing school... I [got a job] here where I was baking bread. Life started to change because I had money. I started drinking alcohol and smoking, having a good time with my friends. We were sleeping around with girls, enjoying life. We were competing among ourselves about the number and the beauty of the girls we had.

Then it was December 2009 – we were having a party. We were drunk... From that party [onwards] I had diarrhoea...it was severe...I lost some weight and felt weak.

My mother said I must go and test. I had gone back home because I had lost my job due to the illness. I refused to go. I asked myself why should I? Because everyone gets sick and has diarrhoea so what is different about me? One day I visited hospital feeling very weak. I saw a woman, our neighbour, being pushed past on a wheelchair...and I heard them saying she was living with HIV, she had refused to test for HIV or even to go to hospital for any treatment [before]. I was upset by seeing this...

I went and I tested positive.

### "The stigma was within me"

I had difficulty in disclosing my status at home because I thought they would discriminate against me. But luckily my mother was able to make me feel comfortable enough to tell her, because she was very close to me.

The stigma was within me and I was trying to fight it, but at home there was no stigma or discrimination.

The thing that becomes a problem is fear.

That is what we fear, we think: "What about my friends? What will my parents say? How will they look at me?"

Another thing that helped was that my mother then told me about my older sister, who had been married for a long time. She tested positive in 1998. Knowing that gave me strength.

The [girlfriends] just disappeared, that is what happens when you are visibly sick; they go to sleep with others.

## A good partner

Yes, I got help [through counselling]. One good thing that happened is I met a woman who was working as a counsellor. We got into a relationship and she disclosed to me that she is living with HIV. That helped me a lot because I realized I was not alone in this situation. Now we have an eight-month-old child who is HIV-negative...

I have been enrolled on ART for two years.

When I have problems that are confusing me the one person I think about, who is my best friend, is the mother of my child. She understands me, she has compassion. We sit down and she advises me how to solve the problem. It helped me a lot and I then decided to stop drinking alcohol and smoking so that I can live longer.

## Acceptance

There was a support group. We used to meet at Nhlanguano Health Centre. It is a good support group because in all we do or talk about, we help each other. We give each other tips about medication such that we all have each other's phone numbers and when it is time to take our medication we 'buzz' each other...

There are many [I have helped], especially my clients. At the moment I am working at FLAS in Manzini as an 'expert client' (people living with HIV who help reduce stigma and increase HIV awareness by sharing their personal stories and openly disclosing their status).

...As time went by...and after testing positive, I told myself that my talent was to save people's lives.

At first when you test positive you are so afraid, struggling to accept it, but it is easy to accept and afterwards you feel free. You see, like me, I am proud of myself and no one can look down on me. I enjoy my life... I have accepted [my status] and I am living well.

I would ask those who are living with HIV not to look down upon themselves, to understand that you are a human being and you are alive.

## Telling our child

When the child is grown up and is able to understand [then I will tell them about HIV]; maybe when the child is 14 or 15. I will start by educating the child... I will then disclose my status...

## Encouraging disclosure

I love the work I do because other people have difficulty disclosing their HIV status.

I would say: "Men – it is quite difficult [but] let us stand up and go to test for HIV and know our status so that we would be able to help other people, for example our girlfriends and our wives." Because it is painful when the wife goes to the clinic to test for HIV and finds that she is positive; when she tries to talk to you as a man, you end up fighting.

## "Let us come together and respond to HIV"

To those who have not disclosed their HIV status I would urge them to come out. It is so painful when you see people who are bedridden and not able to feed themselves, all because they didn't want to test for HIV while they were still strong and healthy.

If you are not HIV-positive I urge that if you are not able to abstain, always use a condom... If you have a girlfriend or boyfriend and are ready for marriage, please visit your nearest clinic for an HIV test to make sure that everything is good. It is not an easy thing for a man to have one partner but if you have children all over the country, who is going to take care of the orphans? Let us come together and fight this disease.

“

At first when you test positive you are so afraid, struggling to accept it, but it is easy to accept and afterwards you feel free. You see, like me, I am proud of myself and no one can look down on me.

## Cebolakhe

### SWAZILAND

Cebolakhe, 42, tells a story of abuse by a teacher that haunts him to this day. He was diagnosed with HIV by chance and has experienced some painful episodes of rejection. He is realistic about men's reluctance to discover or disclose their status and women's vulnerability to male economic power: "Women do not have money." He'd like to help by sharing his own experiences, perhaps using sport as a way to reach people.



### Recalling abuse

I can thank my father very much because he was the one who supported the family. I was able to complete school...he was paying the fees properly.

[But] I was staying at the teachers' houses [while at school] and this particular person drank too much alcohol. I did not tell them at home, I just kept this a secret until today...

He would come home at night and grab us. I can say he wanted to sexually abuse us...besides that he was beating us...this thing has remained a wound in me.

I am sick... I am not saying it is because of the person but that person contributed.

### Taxes for healthcare

It is important to pay taxes. I was not courteous about it, but in my situation now of not feeling well – when you go to a hospital and find that there is no medication, my question is that where can this medication come from, [it must be] from the tax which I pay you see?

So, government tax has to be met – it can be painful...but we were not taught about paying taxes. I thought if [the money] was mine [I could spend it all]... Let us start [learning about] it from schools...so that we grow up with this culture of paying taxes.

### Regrets

My mother did not have a big family... I have many children, I did not think about it... I do not blame anyone but I am not able to educate them all...that has contributed to the collapsing of my life..

My father told me to take a wife but I would come late at night from discos [and had lots of girlfriends]... The question still rings in my mind – where did I get the HIV? This question never stops, though they counselled me that it is not going to help, but it won't stop, you see...

### Getting tested by accident

They say knowledge is power.

I have an aunt who worked at Standard Bank. She noticed that I was losing weight. I was going to deposit some money at the bank. When I entered they were testing [for HIV], someone had come to test the staff. My aunt said: go there and test. Seeing that all my children are healthy [I thought] that means I don't have HIV. Ha!

I could have died. When I tested, the lady counselled me. I was happy the way she counselled me, I saw that she was trained...

Fortunately for me...the first people I saw [after the test results] were my elder brother and my father because we used the same bank. I told them and I found that my father was able to accept this; up to today he is supporting me.

### "Sickness is not programmed"

There is a clinic [near here]... Yes, it is functioning... but sickness is not programmed. We have a doctor who comes once a week and you'll find that you were sick [just after] he was last here – so you will have to wait for another week.

I don't think we would be alive [without the clinic], we really appreciate it, but the problem is that we don't have doctors. I would ask that it is improved so that we have a doctor every day.

### Working in the community: "people lack knowledge"

Our community is small...in the [last] 10 to 15 years, those with whom I grew up, most of them are no more. It is difficult to know what people have died of, but they were sick most of them. Those who are left behind are few...

I have requested the community leaders – though I have not said officially that I am living with HIV – that in every meeting they should give me 10 to 15 minutes to teach [about HIV] because I see that people lack knowledge.

I remember one day my father gave me a car to drive. They were surprised to see me driving...[they were] walking, some using crutches – they were so afraid [of the virus] that they even feared riding in

the car...you understand? They preferred walking on foot. I saw that they thought that I am no longer a person like them...

### "Money is power; women do not have money"

I don't know when we are going to understand because in our clinic they teach [about HIV] but men don't come forward. They are the head of the family, but the decision makers don't come, you see. I am saying this because I am a man.

I don't know how we can teach people... Condoms are placed about but do the men use them? No. What I am sure about is that women do not have money – and money is power. [For example] if the wife does not have money I will be the one making the rules. If she asks for [money] and I give her that, the chances are that when we have sex, I will decide whether to use a condom or not.

### "What is important is sharing ideas"

There is a lot to be done and it is painful. I had asked at the clinic how we can work together... How can they use me to explain things to people?

If we start something today and we work together, really our generations will benefit... What is important is sharing ideas...

“

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## Challenging stigma

The oral testimonies provided by people living with HIV demonstrate both the complexity and changing nature of HIV-related stigma. The testimonies suggest that HIV-related stigma has a negative impact on people's lives, such as rejection by the family; loss of love and support; poor living conditions; loss of employment or source of income; hindered access to treatment and healthcare; limited chances of having family and children; and exposure to physical and verbal assault.

The testimonies reveal that the fear and denial generated by stigma can augment HIV transmission. Fear to be tested results in a lack of awareness of one's status and even when status is known fear can prevent disclosure to sex partners.

Though considerable efforts have been made to measure and address HIV-related stigma, a lot of work still needs to be done in order to reduce it. Our understanding of the determinants of stigma and discrimination suggest the need for a comprehensive approach to address stigma at different levels: the individual, community, organizational, coalitions and networks, national and policy levels. Involvement of people living with HIV is vital in conquering stigma at all levels, and in accordance with the greater involvement of people living with HIV and AIDS (GIPA) principle\*.

### Individual level

Stigma manifests itself in different ways, one of which is internal, which includes negative feelings towards self, self-exclusion and fears. These negative feelings of guilt, shame, self-blame, self-isolation, and fear of being verbally and or physically assaulted often lead to poor emotional and psychological health, such as low self-esteem, depression, and suicidal thoughts.

Addressing HIV-related stigma at the individual level is therefore essential to enhance self-confidence, resilience and overall wellbeing. To help people face the challenges of HIV-related stigma with increased courage and determination, there needs to be more effort on education and on raising awareness about the virus and the rights of people living with HIV. This can be achieved through counselling sessions; linkages to peer support groups; strengthening coping skills and resilience; and involving people living with HIV in advocacy activities. Employment opportunities within safe environments are also necessary for those who seek to generate income.

### Community level

People living with HIV might experience stigma from their closest social networks such as their partners, families, friends, neighbours, healthcare providers and colleagues at work. Most of this external stigma is not only related to cultural and social values

“ HIV-positive people can still do many things such as getting married, building, having children and working. But, to do all this depends on your own attitudes. So, do not listen to what people say, do what you want, because being HIV-positive does not mean that this is the end of life, many things can still happen.

Arajuo, male, 35 years, Mozambique

\*The Greater Involvement of People Living with HIV and AIDS (GIPA) is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response and is critical to progress and sustainability. Reference: UNAIDS: <http://www.unaids.org/en/Resources/PressCentre/Featurestories/2007/March/20070330GIPAPolicyBrief/>



If I see a person who seems to have a problem, I am not afraid to advise that there is life here and that if you are afraid to test you are afraid of yourself.

Dudu, female, 42 years, Swaziland

and morals, but most importantly to myths and misunderstandings about the virus and its means of transmission. This results in social judgments against people living with HIV (which sometimes includes their families), social rejection, verbal and or physical assault and psychological harm, and loss of rights.

Addressing the networks of social support for people living with HIV is crucial. Enabling a supportive and accepting environment at the community level can be achieved by raising awareness and disseminating knowledge about HIV through, for example, music, dance and drama; involving community members in social activities with people living with HIV; organizing health are days; collaborating with community leaders to promote positive non-stigmatizing messages around HIV; training key community members to become advocates and peer educators; and establishing support groups.

**Institutional or organizational level**

Organizations and institutions play an important role in enforcing or reducing external stigma. People living with HIV have the right to be part of any institution while being treated equally and justly. HIV status should not deny the rights of people living with HIV, nor should it be used to discriminate. Healthcare centres, schools, universities, workplace and religious institutions can all play a positive role

in promoting a supportive environment for people living with HIV.

This can be achieved through developing and implementing non-discriminative institutional policies; acknowledging and protecting the rights of people living with HIV; raising awareness about HIV through training and educating staff (such as healthcare providers and teachers); and improving the overall organizational environment by, for example, ensuring privacy and confidentiality for people living with HIV – at the work place, healthcare centres, and educational institutions. Media institutions can also play a significant role in influencing the public attitudes by promoting positive messages around living with HIV and responsible reporting.

**Coalitions and networks level**

Addressing external and internal stigma requires the involvement of non-governmental and civil society organizations, and coalitions and networks for people living with HIV. These networks are vital for involving, supporting and empowering people living with HIV to play an active role, and to take leadership in the response to HIV-related stigma. They also help in creating job opportunities and advocating for the rights of people living with HIV. Their importance lies in their ability to mobilize the public and push to have HIV-related issues on the list of national priorities; to create strong partnerships



The support group is in town. I love it a lot and I love the meetings since I get ideas from others... I learnt that I can have a baby. I can even get married to an HIV-negative person even though I am positive... It has helped me a lot... especially knowing that there are other people in the same condition I am in.

Ncamsile, female, 38 years, Swaziland



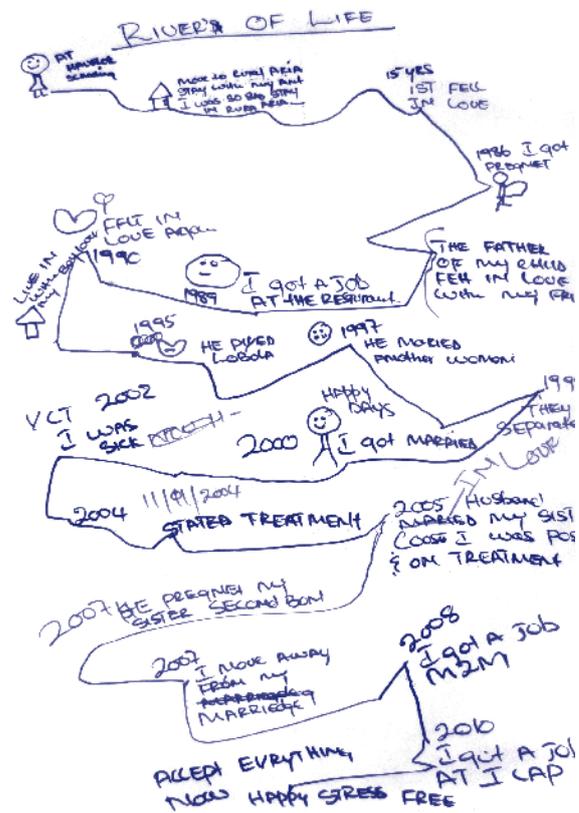
with other national and international organizations; to mobilize funding; and most importantly to advocate for improved policies and legislation.

### National and policy level

Government policies and legislation play a critical role in enhancing or reducing HIV-related stigma. For example, punitive laws towards people living with HIV, such as the criminalization of HIV transmission and prohibiting people living with HIV from travel or residency, violate their human rights and increase HIV-related stigma and discrimination. Governments must be encouraged to put in place laws and policies to protect people living with HIV. This can be achieved in different ways, such as involving policymakers in HIV-related advocacy activities and assigning members of the parliament as national champions for the cause; providing evidence to support policy change; using rights-based approaches and peaceful protests to catalyze change; and urging the government to increase support for national programmes and activities to reduce HIV-related stigma and discrimination.

HIV-related stigma and discrimination remains a major challenge in the response to the HIV epidemic. It can hinder access to prevention, treatment, support and care and augment HIV transmission. In this publication, people living with HIV from Ethiopia, Mozambique and Swaziland shared their personal experiences of HIV-related stigma and their determination to defeat stigma and live a dignified life.

Tackling HIV-related stigma requires a holistic approach at multiple levels. The range and scale of measures outlined above can complement each other and lead to positive change. All are vital, all are possible.



Participant's 'River of Life' drawing, made during the oral testimony training.

“

I was not terrified because I was not going to run away from this, it is part of life... sickness is found in all human beings. I was grateful that it had been detected so that we knew what was wrong... other than going up and down, saying there were people who were bewitching me, going to all the traditional healers... my traditional healer had become the hospital. I was so glad to find the truth about my health, and if I respect the instructions, I will live.

Sipho, male, 38 years, Swaziland

“

I feared more for life than death until I went to my first women's association where I saw women who were much sicker than me, yet looked great! I got educated and, through trial and tribulation, I rebuilt myself. The association, which I joined as a member, has kept me alive with all their support.

Tsehai, female, 30 years, Ethiopia



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