

To Act without Prejudice

UNDERSTANDING HIV-RELATED STIGMA AND DISCRIMINATION

By Kevin Osborne

ADDRESSING AND PROACTIVELY dealing with HIV requires an unprecedented level of honesty. Honesty about the lack of real political and institutional commitment to address the driving forces of this most human of epidemics. Honesty about the way in which we ensure that young people have access to comprehensive sexuality education programs. Honesty about how we have allowed an ‘us’ and ‘them’ approach to form a large part of our global response. Honesty about how our individual and collective actions or inaction have allowed the fertile breeding ground for HIV to grow unchecked. And honesty about the fact that we have all in some way stigmatized people living with HIV (PLHIV). Stigma and discrimination against people associated with or living with HIV is often cited as one of the primary hurdles in addressing prevention and care issues, and is a stumbling block in ensuring access to essential services. Despite all we have learned over the past 28 years about HIV-related stigma, it continues to thrive—fuelling the continued expansion of the epidemic. It is imperative that we find innovative and personal ways to translate the seemingly ever-growing rhetoric on stigma and discrimination into real action that makes a tangible difference in the lives of people most affected by the epidemic.

Our brief HIV history indicates that two of the most important concepts are those

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Educational sign posted in the Simonga village in Zambia.

of justice and compassion. The vast majority of this epidemic is largely based on ignorance, prejudice and shame. People on their deathbeds have been told—and still are—that they deserve their condition; that it is God’s punishment for their behavior. Children have been barred from schools and perhaps, more painfully, from playing with other children. HIV-positive women have been denied the opportunity of fully realizing their sexual and reproductive health and rights. Men who have sex with other men, sex workers and people who use drugs are prosecuted and systematically denied access to life-saving information and services. Public policy and private practice have both been forged from pure ignorance and ugly prejudice.

In the face of this history, we need to be brave, strong and courageous and begin modeling compassion. If we are compassionate, we will not let children pass through our lives too ignorant to protect their own. If we are compassionate we will not teach others—by our own behaviors—to practice discrimination and false ignorance. If we are compassionate, we will not go quietly into the night while others die by the score. If we are compassionate we will raise not only our consciousness, but our voices and our hearts. We will learn to act without prejudice.

All too frequently stigma and discrimination are grouped together as one concept. While they are related and interlinked, the actions to understand and

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address each of the individual elements are as different and multifaceted as the epidemic itself.

Stigma is often seen as a sign of disgrace or shame and is described as a process of devaluation. A person who is stigmatized is seen as having less value or worth than other people. This devaluation is an attitude about how people are viewed or even view themselves. HIV-related stigma is not the sole domain of people who are not HIV positive. Because of years of systematic prejudice about HIV, people living with HIV often internalize or assume that stigma should be an inevitable part of their journey. This 'felt' or 'self-stigmatization' has an impact on how many people living with HIV view themselves, on the kinds of relationships they form and about their own sense of worth. This feeling of being less worthy is often deep-rooted and may take many years (if at all) to be acknowledged.

Discrimination involves treating someone in a different and unjust, unfair or prejudicial way—often on the basis of their actual or perceived belonging to a particular group. It consists of actions or omissions that are a result of stigma and directed towards those individuals who are stigmatized. In other words, discrimination is enacted stigma. However, a person may feel stigma towards another but may decide not to act in a way that is unfair or discriminatory. Discrimination can occur at different levels: individual, family, community or national. HIV-related discrimination is frequently addressed through the creation of policies to safeguard and protect the rights of PLHIV. However, a policy is only as strong as its accessibility to those at the forefront of the epidemic.

Stigma often builds upon and reinforces other existing prejudices, such as those related to gender, sexual orientation, behavior and race. The devaluing power of stigma results in acts of overt discrimination and hampers access to vital services. It is often assumed that stigma is directly related only to the HIV-positive status of an individual, but key vulnerable populations such as sex workers, men who have sex with men and people who use drugs often face a

double stigma. This double stigma is exacerbated by the absence of policies that protect their rights, making access to services a greater challenge. This kind of intolerance is a mobile force. It attaches new fears to old forms. And that is precisely what makes it so hard to pin down and to resist with rational argument—the grounds of racism and intolerance keep shifting. HIV discrimination attaches itself to pre-existing stigmas—to racial stereotypes or to stigma

embraced this reality. For HIV is not only about the perception of personal risk and vulnerability, but also about how to express love and sexuality in the midst of this epidemic. As prevalence levels rise, the chances of meeting and falling in love with someone who is HIV positive will increase. Discordant relationships are increasingly becoming part of the rich fabric of our global society and the challenge of expressing love in this age of AIDS will



In Armenia, stickers that say, "This is what an HIV-positive person looks like" are being posted on public mirrors during major events.

against sexual minorities. A key priority in addressing the stigma felt by people living with HIV is listening to, acknowledging and responding meaningfully to our voices and invaluable experiences.

Stigma and discrimination are associated with lower uptake of preventive services, testing and counseling, reduced and delayed disclosure of HIV status, and postponing or rejecting care or seeking healthcare services outside one's community for fear of breach of confidentiality. Stigma and discrimination affect more severely women and girls, and vulnerable populations including sex workers, widows, prisoners and TB patients.

At the individual level one of the most critical challenges is to individualize and internalize the realities of a world with HIV. For too long we have feared rather than

provide the opportunity to confront the subtle nuances of personal stigma and learnt prejudices. The social discourse has to move away from a single focus on disease avoidance to one which challenges us all—irrespective of HIV status—to find ways of expressing our sexuality in the presence of HIV. Communities of faith, the media, policy makers, healthcare professionals and in- and out-of-school educational facilities are key avenues for building, shaping and empowering individuals to redefine a new way for us to view this epidemic.

Communities too will have to move away from complacency towards transformation—especially as it relates to gender. No longer should culture, religion and tradition be used as convenient vehicles to explain away HIV lethargy. Largely patriarchal societies will need

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to shift to those in which women are truly empowered and men are viewed as equal partners in the solution. Many current interventions have sought to empower young women and girls, further placing the onus for action on them. This is despite the fact that the social structures and cultural norms continue to reinforce the superiority and dominance of men. However empowered women may be, they are still often unable to make decisions about how, when and with whom to have sex. Gender transformation begins in communities where social and cultural factors that define masculinity and shape men's role in HIV and the implications of these factors for their sexual partners (male and/or female) need to be addressed. Faith leaders in every community have a vital role to play in these conversations if we hope to shape a new world order for tomorrow's generation.

It had always been assumed that knowledge alone will ensure that instances of HIV stigma and discrimination will be reduced. However, in many countries where levels of HIV awareness are high, there is no clear pattern that this necessarily translates into acceptance. Since its debut in 1981, the face of HIV-related stigma and discrimination has undergone a subtle shift. In many countries it is no longer the visible signs of Kaposi's sarcoma or wasted bodies that spur discrimination. Many people will now more readily say that they will buy fruit from a fruit vendor who is HIV positive or perhaps even share an embrace with someone who is openly HIV positive. But in many communities we are still not ready to have our food cooked by a chef who is living with HIV or have our children taught by someone who is openly living with HIV—or have them become intimately involved with someone who is HIV positive. Or perhaps it's the tell-tale signs of lipodystrophy that many people can more easily recognize. Whatever the reason, HIV stigma has not decreased.

All too often, the experiences of stigma and discrimination felt by PLHIV are deemed anecdotal. The International Planned Parenthood Federation—in

collaboration with UNAIDS, the Global Network of People living with HIV/AIDS (GNP+) and the International Community of Women with HIV/AIDS (ICW)—have developed *The People Living with HIV Stigma Index* which aims to complement our global understanding of stigma by ensuring that responses deal with the most pressing issues facing the HIV-positive community. Roll-out of this index, which has as its core the involvement of people



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An event organized by Médecins Sans Frontières in Rostock, Germany, demonstrated the high price of anti-retroviral drugs by showing people jumping to catch a pill and then falling into the sea.

living with HIV, has commenced in a number of countries and gives us an important tool to gauge how successful our collective advocacy efforts to reduce stigma have been. *The People Living with HIV Stigma Index* will build an evidence base to inform policy and practice. Guided by a trained facilitator, people living with HIV will complete a questionnaire about their perceptions of stigma. One researcher from the pilot work on the PLHIV Stigma Index stated: "Being interviewed by another person living with HIV does make a difference—as you feel they really would understand more about how you feel about things related to being HIV positive." In ways like this, we will sharpen both our understanding of and response

to HIV-related stigma and discrimination.

Ten things to do to address HIV-related stigma and discrimination:

1. Remain updated on the latest developments around HIV. All spiritual communities and leaders are perfectly placed to deal with both the preventative and care components of HIV and need to remain aware of the salient developments in the epidemic. The treatment as prevention paradigm has the ability to transform the way we not only manage HIV but how we view those who are living with HIV. Building on their role to educate, inform and advise, leaders of faith need to be familiar with the latest trends and developments in HIV. Listening and acting without prejudice is a science we must perfect.
2. Practice what we preach. A few years ago I attended an Easter service conducted by Dean Rowan Smith at the cathedral in Cape Town, South Africa. Amongst all the Easter paraphernalia I found a simple message with a universal ring: a message not of years gone by or one relegated to the dusty verses of a Bible or Torah or Koran. It was a message of our modern times that forms the basis for addressing HIV stigma. Neatly and expertly interwoven into the age-old Easter ritual was the connection of all of our spiritual teachings to HIV—a message of life and love, of care and compassion. The dean of the cathedral challenged all his parishioners to accept the challenges that HIV has placed in front of us. And he challenged his very cathedral to assume a more visible role in the epidemic. For HIV is sitting in the pews of every church, in the halls of every synagogue and mosque. The dean came up with a rather wonderful idea that a board should be put up prominently in the cathedral as there was in the days of apartheid. But the message on this

board would be a little different.

It should simply and unequivocally state: “This Cathedral has AIDS.”

3. Acknowledge and address the stigmatizing attitudes we may harbor about some behaviors or people that are particularly vulnerable to HIV. Spiritual communities will have to face up to their own prejudices on a variety of issues that are so intimately wrapped up in dealing with HIV: issues around homosexuality, sex before marriage, fidelity and faithfulness, disclosure, poverty, sex work, gender inequality, ethnicity, drug use and race. Because the roots of HIV-related stigma and discrimination

services or sympathy. HIV-positive people can and do play a pivotal role in shaping the attitudes of every workplace and place of worship. But for many, they can only fulfill this role when a supportive and nurturing environment has been created. Simple steps make a difference. Workplaces and institutions should ensure that all prospective job vacancies in the organization indicate that HIV-positive people with the requisite skills and experience are encouraged to apply. Implementing the GIPA (Greater Involvement of People Living with HIV) principle recognizes that the personal

acceptance without reservation or judgment. Every parent should have the fortitude to have an open conversation with their children about their attitudes towards HIV. Lethargic inaction is fatal.

6. Work in partnership. Finding your niche in addressing HIV-related stigma should include the creation of core partnerships—for these will help sustain momentum. Working with the media to ensure that sensationalist stories about so-called innocent victims have no place in helping document cases of discrimination will pave the way for increased societal understanding of the impact of stigma on the lives of people living with and affected by HIV.
7. Sensitize all health and social services to discrimination and act against it. In India, the Lawyers Collective in Mumbai has not only been raising awareness among people with HIV about their legal rights, including those as patients, they have also been sensitizing doctors and other healthcare workers to HIV-related legal and ethical issues. For protective laws and policies to have an impact people living with HIV must have ready access to mechanisms to redress discrimination.
8. Become an active citizen through involvement in a campaign to protect and safeguard the rights of PLHIV. There are a number of active campaigns that aim to address various aspects related to stigma and discrimination. From national campaigns to address the criminalization of HIV transmission or exposure to those that aim to remove travel restrictions for PLHIV, one of the most important ways to understand our own feelings about a number of sensitive issues is to become actively engaged.
9. Ensure that a supportive legislative environment exists so that discrimination can be tackled. Protection from discrimination should be everyone’s task. The International



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Stop signs against stigma.

run deep, we need to create spaces to confront and talk openly about our feelings and attitudes about issues and behaviors that are all too often silenced or taboo. Move beyond awareness to unlock those deeprooted prejudices that may silently lurk within each one of us.

4. Meaningfully engage with people living with HIV to better understand and change attitudes. People living with HIV should no longer be viewed merely as recipients of either

experiences of people living with HIV can, and should, be used to shape our response to and attitudes about the epidemic.

5. Challenge personal complacency and fight like hell for the living. No longer should we hide behind ignorance and silence—because that alone is reason enough for condemnation. It is the responsibility of every individual, of every spiritual leader to help shape compassion and care; to foster support and

Labour Organization has developed a code of practice on HIV and the world of work. Workplace and institutional HIV discrimination has been a focus in many countries. In South Africa the Employment Equity Act has made it illegal for the majority of government departments to carry out pre-employment HIV testing.

10. Develop and implement a robust and innovative workplace policy and program. A workplace policy, by bringing HIV out into the open, reduces stigma and discrimination as it lays down a standard of behavior for all employees (whether infected or not). It gives guidance to supervisors and managers and

helps employees living with HIV to understand the support and care available to them. Simple, practical steps, such as the implementation of policies to protect rights help ensure that respect and support are formalized in contexts where, previously, many people faced discrimination or chose to remain silent.

Stigma begins and ends with each one of us. As the triple combination of ignorance, prejudice and fear creates a nurturing avenue for HIV's continued spread, so openness, acceptance and accessible services are the key to its containment. Shame and fear can be defeated, the

chains that link HIV to racism and inequality can be broken and the HIV epidemic can be turned back. The fight against HIV will be won by a unique combination of increased political commitment, adequate resources, sound policies and robust health systems. This much we know. But fundamentally, however, the fight must be won at the personal level. The real battle must be fought by ensuring individuals—be they policymakers or the poor; presidents or patients—have the ability and skills to live, love and find the light that glows in the very shadows of this epidemic. That is where the real battle is. For in truly embracing HIV we can begin the journey of honest reflection and concerted action. ■

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