Stigma and Discrimination

Fr Michael Kelly

Preamble

Allow me to begin by thanking the Irish Government and the Department of Foreign Affairs for establishing this annual lecture. I am humbled and honoured that they should have recognized so generously my limited endeavours to address the scourge of HIV and AIDS, through the education sector and in other ways. But this very recognition is a challenge to redouble efforts to understand this epidemic and find how to get ahead of it.

And equally I am encouraged and heartened by the inspirational, visionary White Paper on Irish Aid launched by the Taoiseach in September this year. The White Paper signals a massive increase in Irish spending for the benefit of those in greatest need in some of the world's poorest countries. But it is more that that. In the words of the Taoiseach, the aid programme it embodies is a practical expression of the values that help define what it means to be Irish at the beginning of the 21st century, the way ordinary Irish people abhor injustice and their determination to help those who are in need.

AIDS and People

Coming closer to the reason for our gathering this evening, the White Paper leaves no doubt about Ireland's commitment to respond to HIV and AIDS. It prioritises the fight against HIV as fundamental to poverty and vulnerability reduction. It commits itself to a broad-based approach in tackling this and other communicable diseases. It undertakes that Irish Aid will continue to work towards achieving universal access to HIV/AIDS prevention, treatment and care. And, in a commitment that is almost unique, it earmarks up to 20% of the additional resources for HIV and other communicable diseases to support vulnerable children.

But above all the White Paper is about people. It is about the inherent and inalienable dignity of every individual and giving ordinary people a fair chance in life. It is about children living happily and looking forward to a future full of possibility and hope. It is about the humanity that all peoples share in common. The words of the White Paper speak for themselves:

> As in Ireland, people everywhere wish to provide for their families and children and to have access to education and health services. They want to live with dignity and to contribute to shaping their own futures.

HIV and AIDS are also about people, but in a very different way. They take away the inherent and inalienable dignity of people. They deny ordinary people a fair chance in life. They cut happiness and hope out of the lives of children. They deny our common humanity.

The real unspeakable tragedy of the epidemic is this destruction of people through the infection, illness or death of individuals. Let us never overlook all that is going on at this individual, personal level. Behind all the mind-boggling AIDS statistics are men, women and children, experiencing a heartbreaking mixture of fear and anxiety, bodily pain and physical disability, isolation and rejection, loneliness and depression, anger and guilt. No matter how much we see on television or read in newspapers about HIV/AIDS, let us never forget the individual human beings who are affected. It is their personal situation that we want to remedy. It is their tragic situation that impels us to do what we can to understand the epidemic, reduce its transmission, and lessen its numerous impacts.

Stigma and Discrimination

We know that about 40 million people worldwide are living with HIV or AIDS. It is probably no exaggeration to say that almost every one of these, together with the further millions in their families, experience some form of AIDS-related stigma and discrimination. Even worse, it is probably just as true that hundreds of millions harbour stigmatising attitudes towards those with HIV or AIDS. Indeed, if we are honest, we may not have to look further than ourselves for evidence of this. Subconsciously and irrationally, we judge them. We put them in a box all by themselves. We separate ourselves from them. Deep within our hearts — so deep that we may not be aware of what is happening — the worm keeps turning, suggesting that they would not be as they are if they had been more circumspect about their behaviour, if they had not been sleeping round or had not been injecting drugs.

In 1987, in an address to the United Nations General Assembly, Jonathan Mann, founder of the Global Programme on AIDS, predecessor to today's UNAIDS, noted that in HIV/AIDS we are confronted with three epidemics, not one.

First there is HIV. This strikes silently and can go undetected for ten years or more. But throughout the course of those years it does two things: it steadily undermines and destroys the body's defence mechanisms; and it makes the person in whom it resides infectious, capable of passing the virus on to others.

The second epidemic is visible AIDS or AIDS-related illnesses, with all their debilitating and life-threatening manifestations.

And the third is the one we are concerned about this evening, the social epidemic of stigma and discrimination that grinds people down in shame, isolation and rejection.

From time immemorial, the history of contagious diseases has been a history of mistrust of the sick, avoidance measures, and exclusion, intertwined with a history of compassion and solidarity. Think of the lepers in the Gospel accounts, the stories of the Black Death in Europe, the leper colonies of Molokai and elsewhere, the way we and the rest of the world treated those with tuberculosis in the 1930s and 1940s, the preparedness today for draconian travel and other restrictions if the bird flu crosses into the human community.

But with HIV and AIDS, the stigma seems to be different, more universal, more comprehensive, more bitter and soul-destroying, more stubborn to root out. It leaves no area of life untouched. Reaching deep into the lives and hearts of those affected it cuts them off from the human family and in doing so destroys their spirit more effectively than the HIV virus destroys their bodies.

What is Stigma?

What do we mean by stigma? Perhaps it's best to think of it as a judgemental approach to another person that arises from our values, prejudices and taboos. The person differs from us in some way that conflicts with our deep-felt values and prejudices. This makes us uneasy. We find the situation undesirable and disturbing. It offends our norms, principles and standards. We react by attaching a negative social label of disgrace, shame, prejudice or rejection to the person. The person becomes significantly discredited in our eyes because of the characteristic that offends us.

If we were alone in this, it would be bad enough. But almost always we share with others the values, prejudices and taboos that the stigmatised person seems to call in question. These are the principles that set the standards for our lives as individuals and within our community. Individually and collectively we will not allow this. Regardless of the cost, we feel that we must protect the personal and community values that the person seems to threaten. Thus, stigma becomes an individual and community occurrence. Individually and communally we brand the person, rejecting and isolating him or her. The stigma then becomes a powerful social label that radically changes the way we and our community view people.

But stigma also changes the way people view themselves. The stigmatised individual becomes laden with intense disabling feelings of anguish, shame, dejection, self-doubt, guilt, self-blame and inferiority. We refer to this as self-stigma. Pre-empting the reactions of society, the person constructs an image of self so low in self-esteem that it positively cowers before the expected comments and behaviours of others. These feelings of shame, self-doubt, guilt, and self-blame can be so powerful in a person living with HIV that they lead to the never-warranted self-judgement, "I'm getting what I deserve." That is totally wrong. Nobody deserves HIV or AIDS. Just nobody. But the self-stigmatising person does not see this.

Features of Stigma

Some things we should note about this act of stigmatising. First, HIV and AIDS do not stigmatise. People do. It is we who do the stigmatising, not the disease. It is we who react in a hostile, antagonistic way. The person being stigmatised may be different in some way, but we are the ones who stigmatise. There is nothing rational or reasonable about our reaction. It springs from a prejudice within us, and a prejudice is what it says — a pre-judging, a judging in advance before we have evaluated any of the evidence for our hostile judgement.

Second, the prejudice we experience is not something isolated inside us. Instead, it finds a place within a family of pre-existing social mind-sets that flourish within us. Most of us are already home to chauvinistic attitudes based on class, race, religion, sexual orientation, gender, and economic status. AIDS-related stigma is layered upon these and supported by them. At the same time it nourishes them and sustains their deeper entrenchment. So it is that when we hear of HIV or AIDS we think very easily of gay men, commercial sex workers, those who lead a liberal sex life, drug users, Africans, immigrants, the poor, women.

Third, stigma almost always means separating "them" from "us". A strong feature of AIDS-related stigma and discrimination is the tendency to regard HIV or AIDS as a problem that belongs to someone else. We see it as a problem “out there”, belonging to others but not to ourselves. Many African countries have interpreted it as an American disease of gays and homosexuals, while much of the world tends to see it as an African disease of promiscuous people. We all share in this unhappy tendency to “otherise” the problem, to look for the scapegoat elsewhere.

If we are being quite honest this evening, we should ask about our own approach to HIV and AIDS. Do we see it as a problem affecting Irish society, or do we see it as something that belongs on the margins of society, to immigrant groups, largely from Eastern Europe and West Africa? How do we look on people, countries and even regions where the disease is very prevalent? Do we subtly blame them for bringing the disease on themselves? Do we stereotype them for what we believe are their liberal sexual or drug-injecting life-styles? Do we place the onus for changing behaviour on them, without ever pausing to think that many millions do not have the freedoms that are needed for any other form of behaviour?

This whole process of “otherisation” troubles me deeply. We keep asking for whom the bell tolls, overlooking that “it tolls for thee”. Until we can identify more closely with all that HIV and AIDS imply, and with those infected and affected, we will never succeed in dismantling stigma and discrimination. And dismantling stigma and discrimination is essential for success against the epidemic. We will never overcome the medical epidemic unless we also overcome the social epidemic.

One other feature is very important. We said already that a person who is stigmatised is discredited, branded as less worthy of respect, or reduced in value in our eyes. However, what we do not always recognize is that the reality of the irrational act of stigmatising is that it makes us, the stigmatisers, lose value and become less worthy and less human — we respond to others as if they were of lesser value and in doing so we become of lesser value ourselves. We pull them down in externals, whereas we pull ourselves down at the very heart of our being and humanity.

Discrimination and its Manifestations

The result of the stigma associated with HIV and AIDS is discrimination. You are treated differently, in an unfair and unjust way, because you are seen as belonging to a different group. Discrimination manifests itself in a wide range of contexts — in the home and immediate community, in a workplace situation, in health care and education settings, in social and religious gatherings, and in the media.

There is no end to the way discrimination shows itself: isolation, being shunned, taunting remarks, children being jeered at school, being spoken to in excessively kind tones, mocking, gossiping, offensive curiosity, not letting children play together, unfriendly and uneasy attitudes, your partner dropping you, not being served in shops or banks, being made to wait until all the others have been attended to in the health centre, customers no longer buying from your stall, people refusing to share cutlery or cups, not being allowed kiss your nieces or nephews, not being promoted, losing your job, being thrown out of your house. The list goes on and on. But let me put some flesh on it.

About three months ago I was working with Christian Brothers from half a dozen African countries who had gathered in Nairobi for a week of reflection and prayer on how they might best respond to the AIDS epidemic in their various districts. On one of the days, six women from different parts of Nairobi came along to talk to us about the AIDS problem as they experienced it. Each was living with HIV and some were on antiretroviral therapy. One woman was a widow, but the husbands of all the others were alive.

Speaking sometimes in English and sometimes through a translator each woman told us how their husbands or their families had thrown them out of their homes as soon as they heard that they had HIV. It was really scary. Here were six young women whose only crime was that they remained faithful to their husbands and thereby became HIV-infected. And what did they get for this? They were disowned, rejected, shouted at, beaten, chased away with their children and without any belongings. And each of these six women affirmed that they were not alone, that the same thing was happening in household after household, wherever there was HIV or AIDS.

Apart from the blatant injustice of it, you can see what this inevitably leads to. Who would want to come out into the open and acknowledge their HIV status if that is the kind of reception they can expect? How can anybody take effective action against HIV and AIDS when stigma and discrimination almost force people into silence and denial?

People who may be HIV infected are afraid to come forward for testing, or to look for information on how to protect themselves and others. People living with HIV are reluctant to access health, prevention and education services for fear of being stigmatised by service providers. And so, the pernicious, ubiquitous and totally unjust stigma and discrimination reduce the effectiveness of efforts to control the epidemic. Fewer people are tested. Fewer people are treated. Fewer people receive the care and support they need. Instead, stigma and discrimination create an ideal climate for the further development of HIV and AIDS.

Stigma Kills

Nelson Mandela once said, “many people suffering from AIDS are not killed by the disease itself; they are killed by the stigma and discrimination surrounding everybody who has HIV and AIDS”. Stigma and discrimination kill because they stop people from coming forward for testing and life-preserving therapy.

Nowhere is this so evident as in the small number of HIV infected mothers who receive treatment for the prevention of HIV transmission from mother to child. It is a damning indictment of global policy and practice that, more than 25 years after the explosion of HIV and AIDS on the world, less than 10 per cent of pregnant women in developing countries are accessing services to prevent the transmission of HIV to their infants.

The reason is not the non-availability of services, although admittedly these need to be expanded greatly. The reason is stigma. Mothers do not want to be tested. They do not want to know their own HIV status, because they fear the stigma they will face in their communities if they do not breast feed their child, or if they have to take antiretroviral drugs — and within a tight-knit community everybody knows, sooner or later, who is taking these drugs. In a macabre way, stigma is killing mothers, leading to the premature and horrendous deaths of their infants, and making orphans of their older children.

Could anything be worse? This is not trainloads of innocent women being brought to gas chambers. This is not masses of children starving to death in refugee camps. This is mothers with their babies, in upright communities, living in their valleys of squinting windows, not able to face up to what they know the neighbours are saying or thinking, not able to take the health-preserving measures they and their infants need, because they are afraid that the finger will be pointed at them.

But stigma kills in other ways also. Eight years ago this very day, Gugu Dlamini, a volunteer worker for the National Association of People Living with AIDS in South Africa, spoke in Zulu on South African radio and television about her HIV infection. At once, her neighbours began to accuse and threaten her for bringing shame on their community. Three weeks later, a mob attacked her house, stoned her, kicked her and beat her with sticks. Within a short time she died from her injuries.

And Gugu's murder has been repeated elsewhere. Just listen to this catalogue of very recent incidents issued by the highly respected Human Rights Watch organisation:

- A Mexican AIDS activist is stabbed to death in his condom shop.
- In China, 23 people infected with the AIDS virus are put under house arrest.
- A Ugandan woman is murdered by her lover after she tells him she has the disease.
- An HIV-positive 15-year-old Kenyan boy is killed by a pitchfork wielded by his uncle as villagers, fearing infection, stand idly by.

To this we can add what happened in Taiwan in mid-October this year when, in response to complaints by local residents, a court ordered the closure of a home caring for HIV-positive children and adults. Clearly, HIV stigma is universal and equally clearly, it is very much alive.

Stigma Denies what it Means to be Human

African philosophy has a wonderful understanding of what it means to be human: a person is a person through other persons — *umuntu ng'umuntu ng'abantu*. More than fourteen years ago, Jonathan Mann expressed the same idea: "To be connected is to choose life. Everyone knows this: …. we need the other; …. we are in some basic and clear way incomplete without the other." And from Africa again, Archbishop Desmond Tutu shared the same thought when he said that the solitary isolated human being is really a contradiction in terms.

A person is a person through other persons. We need the links with other people. We cannot endure isolation from others. Our humanity is defined through our relationships with others. We develop our personality through our interactions with others. Stigma and discrimination put an end to all that. They deny the humanity and individuality of the person with HIV or AIDS. They attack the bonds that join people together. They isolate. They cut off. They don't let a person be a person through other persons.

This undercutting of our common humanity gives a deeply destructive quality to AIDS-related stigma. It puts it in the category of the oppression meted out to those who differ from us on grounds of race, caste, or sexual orientation. But it goes even further. In very many cases the external stigma and the self-stigma feed off each other to such an extent that the infected person can no longer identify any human link without or any form of dignity or self-worth within. The stigma has severed every root that links them with humanity — and for some the outcome is suicide.

What Medicine Can You Give Us against Stigma?

At a conference in late 2005, Vicky Bam, a young Namibian woman, told us that she had been very happily married to a husband whom she greatly loved and that they had two beautiful children. One of the children fell sick, was diagnosed as having AIDS, and eventually died when still very young. This prompted Vicky and her husband to go for an HIV test. Both were found to be HIV-positive.

Because of the death of their child, the HIV-status of the Bam family became common knowledge in the community, where they experienced much hostility and stigma. This became so intense that Vicky's husband, unable to stand it any longer, took his life. Stigma drove him to suicide. Having lost one of her children and the husband she loved, Vicky (who is now taking life-supporting antiretrovirals) challenged those who were present: "With ARVs we can cope with AIDS, but what medicine can you give us so that we can cope with stigma and discrimination?"

We were not able to give any answer. Year after year, meeting after meeting, this same question comes up. What can we do about stigma? We have our toolkits for dealing with the problem. We have our learned articles. We have our conferences devoted to understanding and responding to stigma. But it continues to elude us. It continues to flourish. And as it does so, it mounts an obscene assault on the human dignity and worth of infected individuals and their families and becomes an ever more perfectly fashioned instrument for keeping HIV and AIDS thriving but hidden.

Stigma and Moralising

A major reason for the universality and depth of AIDS-related stigma is undoubtedly the way, from the start of the AIDS epidemic, we equated HIV infection with behaviour of which society did not approve — putting it bluntly, we associated HIV with sin. We identified HIV with sexual promiscuity or with a gay life style or with drug-injecting use. We built up a whole series of mistaken identities: that HIV meant there had been sexual activity, almost certainly of the wrong kind; that illicit sexual activity meant sin; that sin deserved punishment. Wrong statements, every one of them, but that did not stop us from understanding HIV infection in narrowly moralising terms and thereby building up powerful justifications for a stigmatising approach.

The paralysing anguish and shame of all forms of stigma owe much to this basic human inability to deal with sexual transmission and its wrongful association with moral failure. Seemingly in some radical way we are not able to cope with the notion that sexual activity, which should be the channel of ecstatic joy and the possibility of new life, should instead be the route to destructive and dehumanising illnesses and possible death.

Unfortunately, religious perceptions played a sorry role in equating HIV with moral failure. In the early days of the epidemic, many religious leaders were divided within themselves on what their response to HIV and AIDS should be. They combined boundless compassion and magnificent care for the sick with an uneasy false identification between HIV infection and immoral activity. However, they were also people from their communities, speaking to their communities. Much of the way they reacted was a reflection of the way their communities thought about the issue. But as religious leaders they should have gone beyond being mirror images of community reactions. They should have extended their theologies of care, forgiveness and understanding to everybody who had HIV, and not just to those who were already experiencing severe illnesses. They should have reflected more deeply on what was occurring and worked to remove morality and sin from the discourse about HIV and AIDS. Later, almost all of them began to do so. But by then it was almost too late. Stigma, always lurking round, continued and still continues to be enormously reinforced by this latent or express association between HIV infection and alleged moral wrongdoing.

Religious leaders have much lost ground to make up. They must be fearless and tireless in persuading people to accept the message: HIV is not a sin. AIDS is not a sin. The real sin, if we want to use that term, is stigma and individuals and communities must spare no efforts in rooting this out.

Because HIV transmission occurs principally through sexual activity, religious leaders have the further responsibility of helping people develop a more positive attitude to sex. Most of us carry very cumbersome baggage from the time when the mention of sex made us embarrassed and fearful. We were caught up in a culture where the very first thought about anything good and decent was “thou shalt not”. Even today, we still find relatively few religious authorities who dare proclaim the greatness, goodness, wonder, marvel, beauty and godliness of sex and sexuality. This is not a limitation exclusive to the Catholic Church or to the Christian tradition. It is something that appears strongly in Islam and other world religions, including African Traditional Religions. Indeed, this fear of our sexuality seems to be so deeply rooted in our human psyche that we make use of a religious framework to keep it under control and set the parameters within which it can surface.

Religious leaders, thinkers, youth educators, parents – all have a responsibility to change this situation, to proclaim the inherent goodness of the human body and all those feelings, moods and emotions that bring two people together in a creative intimacy of closeness and love. Every advance in this direction will help in dismantling the association between HIV and conduct that is labelled as immoral. By the same token, it will help in neutralising the way moralising attitudes buttress stigma and discrimination.

Stigma and Women

It was no accident that the illustrations I gave referred mostly to women. The AIDS epidemic is savage in its onslaught on women. Almost certainly, HIV and AIDS found their way into the human community through men. It was men that spread the disease initially. It is men who continue to spread it. But it is women who suffer, women who carry the brunt. Men may have opened the ghastly Pandora’s box of the disease. But they have been singularly successful in passing on its contents to women.

Men certainly suffer because of HIV and AIDS. There can be no doubt about that. But women suffer even more. They are blamed for bringing HIV into the family. This is so ingrained in the culture that in Malawi a sexually transmitted infection is designated in local languages as “the women’s sickness”. Very few men will admit to transmitting HIV to their wives. They presume that their wives first contracted the infection and then proceeded to spread it to their husbands. And this, even though the wife may have been exemplary in her faithfulness to her husband.

The stigma and rejection of AIDS affect women very deeply in every sphere. It is not just a matter of their reputation. There is also the question of their economic dependence on men. In many cultures, they lack property rights, ownership of assets and access to credit. They are defined in relation to men and have no independent legal existence. In such circumstances, rejection on the grounds of AIDS is total rejection.

On top of all this and a veritable host of diverse unequal gender relations, a woman is even more deeply affected by AIDS stigma, discrimination and rejection if she is a mother. If she is pregnant and is HIV positive herself, she would die rather than admit it — even though she got the virus from her husband, even though her silence may literally bring about her own death and the eventual death of her infant. If there are other children, she will slave and sell herself so that they can eat — and her husband may acquiesce in what she does because she is bringing food into the family. Yes, men brought the disease, but it is women who carry the burden.

We will never be successful in responding to the AIDS epidemic until we take robust, sustained and specific action to reduce and ultimately eliminate the prejudice, discrimination and unjust treatment that women experience. Without a frontal attack on the injustice of gender inequality, the dominance of the epidemic will continue and the spectre of stigma will remain. Every step that is taken to raise the status of women and to recognise their equal status with men is a step against the epidemic and a step against stigma.

That is a whole developmental agenda in itself. It is an agenda that is needed at all levels, in the United Nations and in sovereign states, in civil society and in the churches, in developed and underdeveloped countries. This will never be a world fit for humanity until it confronts male dominance and acknowledges at every hand’s turn the full equality of the women who constitute more than half the human race. Do you want to see an end to stigma and discrimination? Involve the participation of women. Cut out the exploitation of women. Reject attitudes and practices that offend against the dignity of women. Above all, listen courageously and carefully to the experience of women and hear what they are saying about this epidemic and the stigma that goes with it.

Stigma and International Approaches to HIV

HIV and AIDS run into so many areas of life and activity that we should always be alert to the possibility that features of our policies or practices might be offering them unwitting support. For instance, an education ministry that requires teachers to travel to some central location at the end of every month to collect their salaries is a powerful ally of the disease, since it sets up the situation of men regularly away from family and home and with some money at their disposal — ideal circumstances for behaviour that could lead to HIV transmission. A mining company that establishes single-sex hostels for men recruited from rural areas, as is currently happening in a copper mine development in Zambia, is offering *céad míle fáilte* to HIV infection.

Could global policies and approaches be doing something similar with stigma and discrimination? Almost from the outset, we have exceptionalised the disease to an extraordinary extent. Inspired initially by pressures from the gay community in the United States and other developed countries, we have hedged it round with human rights and legal concerns that we do not apply to other diseases. If I need a medical examination, the doctor will automatically prescribe a number of tests, for my cholesterol, sugar, uric acid and other things, without asking me. But there can be no test for HIV without my prior and informed consent.

Maybe this was all right at a time when no treatment could be given for AIDS. But surely it is unacceptable today that a medical practitioner needs the express consent of a pregnant woman before testing her for HIV and possibly placing her on treatment that will protect her life and that of her unborn infant. Surely it is time that we moved towards normalising HIV and AIDS, making testing part of routine medical procedures, and breaking away from the situation where this is a disease that even the medical profession cannot openly confront. Certainly, there would have to be a reassessment of human rights principles and assurances that these would respected in more liberal testing and confidentiality situations. But normalising HIV and AIDS would do much to take them down off their pedestal, to make them more like conditions such as tuberculosis or cancer (with which they often go together), and to make them more routine, as it were, within human experience.

Doing this would bring several great benefits. It would increase the numbers who know their HIV status. Thereby it would increase the numbers both of those who wish to remain HIV negative and of those who want to avoid transmitting their positive condition to others. It would increase the numbers who would present themselves in good time, before it is too late, for antiretroviral treatment. And it would demystify the whole area of HIV and AIDS and thereby would make a signal contribution to reducing stigma and discrimination.

There is need also to question the global AIDS prevention policy. Despite some successes, the bottom line is that this policy has not succeeded in preventing HIV transmission. The fact of more than four million new infections in 2006 — almost 12,000 each day or 8 every minute — is testimony to that. The fact that in every region of the world there were significantly more people living with HIV or AIDS in 2006 than there had been in 2004 bears witness to the failure of global HIV prevention policy.

A major reason for this failure is that the policy focuses narrowly on the virus and does not pay sufficient attention to the broader environment of poverty, hunger, poor sanitation, inadequate health care services, and gender imbalances, in which transmission occurs. Its vision is limited, its concern mostly with producing immediate results. It fails to take into account that HIV transmission is possible only if, as with every other infectious disease, the environmental conditions are supportive. Louis Pasteur once said, “the microbe is nothing, the terrain is everything”. But global policy is so caught up with the microbe, with the virus, that it pays only scant attention to the terrain, to the circumstances in which people live and behave.

A major concern of this virus-centred global policy is to make people more responsible in their sexual and drug-using behaviour. This seems to be an unassailable approach. But the trouble with it is its unspoken assumption that different patterns of behaviour are real possibilities for an individual. The behaviour change approach simply fails to address the social and economic factors that shape behaviour. Instead it removes sexual encounters from the domain of the passionate and impulsive, and treats the entire process as if it ran in a straight-line direction, guided always by reason and what George Bernard Shaw called “brute sanity”.

In doing so, it places responsibility for HIV transmission squarely on the shoulders of individuals and overlooks the fact that individuals are not always in full control of their choices. In terms of what finally gets to people, the message is straightforward: behave in way X and you will not contract HIV; behave in way Y and you run the risk of becoming infected — but if you do become infected, it is because of your own behaviour, your own choice. You will have only yourself to blame. And so we are back to where we started, people made to feel small, blameworthy, unworthy, because they have HIV or AIDS.

In this way, the global approach has institutionalised stigma at the heart of international policy. It has also very effectively turned HIV and AIDS into a problem belonging to others, those out there, remote from the hallowed halls of policy-formulation. It has stereotyped regions as sexually promiscuous or seriously prone to needle sharing. And it has concentrated attention on the narrow dimensions of individual behaviour change, diverting resources from the all-encompassing supportive environmental factors of poverty, hunger, poor sanitation, inadequate health care services, and gender imbalances.

We have got our act about HIV prevention wrong. And we have got our act about stigma wrong. If we cannot do better, we will never overcome this HIV and AIDS epidemic.

The Road Ahead

We cannot stand by while stigma and discrimination create a fertile terrain that allows the AIDS epidemic to thrive. We must bend every effort to ensure their reduction and eventual elimination. And we must be fired by the assurance that we can succeed. Stigma reduction is an achievable goal.

In our more pluralistic society, stigma on the basis of race or colour is on the ebb. Within the past twelve years, South Africa has shown how quickly a discriminatory situation can change, given the necessary leadership and popular commitment. All may not yet be well, but there have been staggering advances. We have also seen change for the better in other fields. For instance, the stigmatisation of unmarried mothers is much less than in the past. Likewise, wider interactions, persistent highlighting of the issues, some excellent work on the part of the media and our greater human rights awareness have all contributed to a sea change in attitudes towards people of different sexual orientations. Stigma can be reduced. It has been reduced.

But let us also remember that though we can legislate against overt manifestations of discrimination, no legislation can reach into our hearts, into those depths within us where prejudice and stigma originate. It is there, above all, that we must work to bring about change. The Year Against Stigma Campaign that was launched this morning should help to move all of us in that direction. So also should the media through unflagging attention to keeping stigma and discrimination high among public concerns.

Pointers to a way forward come from what we have discussed already. First, there is an urgent need to demystify HIV and AIDS, turning it, as far as medical and social interventions are concerned, into a condition analogous to any other health condition. In practical terms, this implies incorporating HIV testing into routine medical investigations, so that there is no more mystery about one's HIV status.

Integral to this is the need to ensure the availability, now and throughout the decades that lie ahead, of antiretroviral treatment for every person in need. Guaranteed access on the part of every HIV infected person to life-preserving treatment is a powerful antidote against stigma. This is the human right of those who are infected. Equally it is the obligation of those who are not infected to ensure this right, regardless of trade regulations, World Trade Organization conventions, the might of the pharmaceutical industry, or the capacity to deliver. Universal access means life for millions of people who are infected. It also means less stigma.

Second, in practice and in theory, the emphasis in responding to HIV and AIDS needs to be placed squarely on development. Like poverty, the epidemic is one of under-development, though (again like poverty) it can occur in well-developed societies. A developmental approach takes the spotlight off the individual and puts it on the joblessness, poor education and health provision, food insecurity, unsanitary conditions, and other circumstances in which the disease thrives. These may cause horror and outrage, but they do not breed stigma in the way the emphasis on the individual does.

Third, we need massive stress on human rights and justice, in all areas, but very especially in relation to women and to persons living with the disease in any of its stages. We must work strenuously to affirm and ensure the human rights of every person affected by this disease. Governments must take steps to respect, protect and fulfil the rights of every individual, but particularly those of the women, children and infected persons which the stigma associated with the disease puts under such threat. For many, this will entail revisiting their legal systems and domesticating international human rights conventions to which they have already acceded. For all, it will require full and absolute adherence to the first principle of the Universal Declaration of Human Rights: All human beings are born free and equal in dignity and rights. A practical expression of this is that free legal support services should be available to those who experience stigma, discrimination or gender-based inequality.

This is needed for women and children. It is also needed for persons living with HIV or AIDS and for those affected by these conditions. Because of their condition, people living with the disease have privileged access to what it is like. They have inside information. They know what infection means. They know what it is like to have to take drugs at a set time morning and evening every day of their lives. They also know what it is like to be stigmatised and discriminated against. The greater involvement of people living with the disease, the GIPA principle, is a cardinal principle in the global response. Those living with HIV should be our first allies in the struggle with the epidemic and in efforts to deal with stigma and discrimination. But only too often they are the last ones we think of, or we include them in a token way, because it is the politically correct thing to do. Let us change this by listening courageously and carefully to what they want to tell us. Then let us do something about it.

Conclusion

Let the last words be those of a child, Nkosi Johnson, the little South African boy with the big eyes. Nkosi's mother was HIV positive and passed the virus on to her unborn baby in 1989. He should have been a statistic, one of the 70,000 South African children born every year with HIV. But Nkosi was a fighter. For an extraordinary twelve years he lived with HIV and then AIDS. He never knew the support of antiretroviral treatment, because at that time only the wealthy could access this. Six years ago he electrified the world by his address at the opening of the International AIDS Conference in Durban, where he took President Thabo Mbeki to task. He was eleven years old when he spoke so movingly and fearlessly at that world gathering. Less than a year later he died. Listen to his appeal:

> I want people to understand about AIDS — to be careful and respect AIDS — you can't get AIDS if you touch, hug, kiss, hold hands with someone who is infected. Care for us and accept us — we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else — don't be afraid of us— we are all the same!

Nkosi was absolutely right. We are all the same. There is no need to be afraid of anybody. This whole stigma and discrimination scene is utterly nonsensical. Let's make an end of it!

M. J. Kelly,
Lusaka,
November 2006