



On the Record: Against AIDS in Africa

Issue 4: AIDS in South Africa, December 10, 2001

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Announcement: Youth Leaders Invited to Attend Conference on Youth, HIV/AIDS, and Human Rights in South Africa, February 2002

The UN Educational, Scientific, and Cultural Organization (UNESCO) and the International Federation of Medical Students' Associations (IFMSA) will be hosting a workshop for about 50 young African AIDS activists in Cape Town, South Africa, February 9-15, 2002. The aim of the workshop will be to train participants in how to use a new action kit entitled 'HIV/AIDS and Human Rights: Young People in Action.' The workshop will also seek to 'equip participants with the necessary skills to ensure that they, as future community leaders, will advocate the care of people living with HIV/AIDS in an ethical, judicious and most appropriate manner.'

Participants will be young, dynamic youth leaders from about ten African countries. The workshop will last seven days, during which time participants will receive intensive training on capacity building and problem-solving skills with regards to the psychosocial and cultural aspect of the connection between HIV/AIDS and human rights.

It is still not too late to apply...

Applications will be considered up to December 15, 2001. For more information about the workshop, send an email to [this address](#).

From the AP Editorial Desk: Denial and Resistance

The context for this issue of 'On the Record' is a society at war with itself over AIDS.

This society is South Africa. According to some estimates, South Africa has more HIV-infected inhabitants - 4.6 million - than any other country on the planet. According to Charlotte Mjele, the representative of Youth Against AIDS (YAA) in South Africa, over 900 young South Africans are infected every day. The majority are women, raising the possibility that they will pass the virus on to their children.

The worst may be yet to come. According to a recent report from the South African Medical Council, between five and seven million South Africans could die from AIDS by the year 2010. That could devastate this country of 44 million people.

It is an awful prospect. Yet it is made much worse by the government of South Africa, led by its President, declining to make the eradication of HIV/AIDS a national priority.

It is hard to exaggerate the importance of government in a successful AIDS strategy. Uganda is perhaps the best example. Uganda's President Yoweri Museveni took the bold step of acknowledging that AIDS was ravaging his country in the 1980s and appealed for international help. He then reorganized his government to meet the threat head on and created a National AIDS Control Programme in 1986. Ugandans took their cue from their president, and the rate of infection began to fall. It peaked at 30 percent of the entire population in 1993 and stands at 12 percent today.

South Africa's President Tabo Mbeki, is moving in the opposite direction. Instead of listening to his own doctors, he seeks the advice of so-called 'dissidents' who deny that the HIV virus causes AIDS. Mbeki has also used data that are clearly out of date to deny the gravity of the disease in South Africa. The outward ravages of AIDS, he suggests, are likely caused by other diseases like tuberculosis and by poverty.

President Mbeki refuses to distribute and subsidize antiretroviral drugs like AZT, which are known to slow the AIDS virus and even stop its transmission from pregnant women to their infants. These drugs may be toxic, he suggests. He downplays alarming reports, such as that from the South African Medical Council, and questions the motives of the reports' authors. Instead of developing a national plan and allocating the necessary resources, he cuts budgets for AIDS.

This is a bewildering performance from the leader of one of Africa's most populous and respected countries. Instead of rising to the challenge and throwing his government into the battle against AIDS, President Mbeki is - like many South Africans - still in denial.

Social Condition

South Africa underlines the link between human rights and the fight against AIDS by young people in Africa. This is one of the themes of this issue.

It has long been an article of faith that AIDS is a social disease as much as a medical condition. The first to make this connection at the international level was the late Dr. Jonathan Mann, who headed the AIDS program at the World Health Organization (WHO) in the 1980s.

Dr. Mann used to make the point, with passion and eloquence, that discrimination spreads the disease because it discourages those infected from seeking treatment and because AIDS is often spread by sexual violence. In one paper, published posthumously, he wrote about his term as the first director of WHO's AIDS program:

'At that time we learned that married monogamous women were increasingly becoming infected with HIV in Uganda. At first we thought that the women did not know enough about AIDS. This was not the case. Then we thought that perhaps condoms were not adequately available; yet although there were recognizable deficiencies, condoms were often on sale in the marketplaces.

'Then by speaking to the women we discovered the underlying cause of their vulnerability to HIV. Wives could not refuse unwanted or unprotected intercourse with their husbands, even if they knew they were HIV-infected, for two reasons. First, the woman could be beaten with no social or criminal protection or recourse. Second, she could be divorced, leading to a situation equivalent to civil and economic death for the woman. Under these circumstances, the availability of condoms, or the content of AIDS information brochures, was not the key issue. Rather, it was the status and rights of women which created vulnerability to becoming HIV-infected.'

Dr. Mann's point has been echoed by YAA's own representatives in Africa.

People with AIDS Speak Out

South Africa brings Dr. Mann's argument alive and gives it a human face. Four years ago today, on International AIDS Day 1998, a 36-year-old health worker named Gugu Dlamini was beaten to death at her home near Johannesburg after she publicly announced she was HIV-positive.

Ms. Dlamini was a volunteer fieldworker for the National Association of People Living with HIV and AIDS (PLWA), and her death sent a chilling message to people who carried the virus. But in the last four years, a series of courageous South Africans have come forward to announce their seropositivity and make the case for respecting the rights of those who carry the disease. They include a high court judge and Charlotte Mjele, who is profiled in this issue by Adam Frankel from YAA.

Ms. Mjele attended the of the UN General Assembly Special Session on AIDS (UNGASS) in June 2001 and lifted the spirits of everyone she met. She has agreed to represent YAA in South Africa. In his profile, Adam makes the point that Charlotte is a fantastic resource in the fight

against AIDS not just because she is a brilliant communicator but because she bears no outward symptoms of the disease. Many young South Africans still think that people who look healthy cannot be infected. Charlotte can set them straight - but only if she is encouraged to speak out. She will only do this if she is free from the fear of discrimination.

Nkosi Johnson's Appeal from the Heart

The 13th International AIDS Conference, which took place in Durban, South Africa, in June 2000, introduced the world to another remarkable young South African AIDS activist.

Xolani Nkosi Johnson was born with the HIV infection, and doctors gave him nine months to live. He outlasted their predictions by eleven years and became an inspiring international symbol. When he finally surrendered to AIDS in January 2001, heads of state paid homage.

Nkosi Johnson electrified the Durban conference when he asked that people with AIDS be treated like anyone else. 'Take care of us and accept us,' he said. 'We are all human beings. We are all normal. We have hands. We have feet. We can walk. We can talk. We have needs exactly like everyone. Don't be afraid of us. We are all the same.'

This appeal from the heart, delivered by an 11 year-old boy who was facing certain death, made two things blindingly clear.

First, it gave great plausibility to the fundamental idea that discriminating against people living with AIDS is to violate their rights, because so many of these people are unwitting victims. This is often the case with young people. It is undeniably true of young children like Nkosi Johnson who receive the virus from their mothers.

Second, Nkosi Johnson demonstrated - like Charlotte Mjele - that children and young people can be powerful and effective advocates. It is in everyone's interest that they be given the chance to make their case on their own terms.

In legal terms, it is worth noting that children have the right to be free from discrimination and to be free from violence under the Convention on the Rights of the Child. Under Article 12 of the convention, they also enjoy the right to participate. Many governments and right-wing lobby groups fear that this will 'undermine the authority' of parents and of the family.

Nkosi Johnson showed just how wrong this is. The argument will resurface next May when the UN General Assembly meets in a Special Session on Children. YAA will use the meeting as an opportunity to lobby hard for the rights of young people living with AIDS.

AIDS and Racism

Thanks to South Africa, the world knows much more about the link between human rights and AIDS. The World Conference on Racism, which took place in Durban on August 31 this year, underlined the link between AIDS and social exclusion. Precisely because AIDS thrives on discrimination, it preys on refugees, migrant workers, indigenous groups, and social outcasts.

Once again the argument is clear: respect and protect the rights of these vulnerable people, and the spread of the disease will slow.

Notwithstanding their president's skepticism, South Africans have also helped to force the international community to question the fairness of a trading system that prevents poor countries from purchasing cheap versions of antiretroviral drugs. These drugs seem to hold out the best hope of weakening the hold that the HIV virus has on a person's immune system. But a single course can cost up to \$20,000 a year, which is clearly beyond the means of all but the richest. Companies respond that they need the huge profits to reinvest in the development of new drugs - and that this is protected by patent rights and the world trading system.

This year, campaigners have succeeded in translating this issue into the language of rights and fairness. They start by asking why people should be denied treatment simply because they are poor. The argument was first made last year in a South African court by a highly effective lobbying campaign, the Treatment Action Campaign (TAC), which threatened legal action against the South African government for not implementing an HIV/AIDS mother-to-child transmission prevention program using antiretroviral medicines. The threat produced immediate results as the government opened 18 pilot sites around the country. These sites cover 10 percent of the pregnant mothers who visit public antenatal clinics.

Earlier this year the UN's Human Rights Commission, meeting in Geneva, took up the cry and passed a resolution calling for a more equitable distribution of the crucial antiretroviral drugs at the international level. Late in November, at its meeting in Doha, Qatar, the World Trade Organization yielded to critics and agreed that patent rights could be suspended if a government is facing a public health emergency. This opens the way for the countries of Africa to buy cheaper, generic versions of antiretroviral drugs (which are produced in countries such as India and Brazil).

It is not clear how this will happen in practice, and much hard work clearly lies ahead for campaigners. But they have certainly achieved a dramatic breakthrough in forcing the world's trading powers to accept that the threat from AIDS, and other medical emergencies, should take precedence over economic growth.

Legal Support, National, and International

It is entirely appropriate that so many of these revolutionary developments have originated in South Africa.

Apartheid epitomized the sort of institutionalized racism that nurtures AIDS and was highlighted at this year's World Conference on Racism in Durban. Apartheid destroyed the fabric of African society, by splitting families, creating artificial townships, and turning a generation of young workers into impoverished migrants in their own country. In its place, there emerged a society of despair, violence, isolation, and poverty. The townships were infamous for violence and casual sex.

But South Africa has also emerged from apartheid with one of the world's most progressive constitutions and one of Africa's strongest legal systems. The constitution goes further than any other in protecting social and economic rights, and the judges on South Africa's constitutional court have used this legal foundation to pass some remarkably far-sighted judgments on housing and discrimination. South Africa's legal system is a profoundly important ally for AIDS activists.

These activists are receiving growing support from international institutions, particularly those that work on human rights. In 1997 the UN Human Rights Commission adopted a series of 12 guidelines on AIDS and human rights. These set out a series of broad principles for use by policy makers, particularly governments. But in the last four years they have also proved increasingly useful to campaigners from civil society as they seek to pressure their governments and make protections more precise and practical.

The Committee on the Rights of the Child has made extensive use of the guidelines in developing standards to protect children with AIDS. The guidelines are also monitored annually by the UN Human Rights Commission.

Guideline 8 is of particular interest to young people. It reads: 'States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children, and other vulnerable groups by addressing underlying prejudices and inequalities explicitly designed to change attitudes of discrimination of and stigmatization associated with HIV/AIDS to understanding and acceptance.'

Discrimination in the Family

In spite of these exciting advances, there is still a long way to go in deriving practical benefits from the link between AIDS and human rights. The best proof of this can be found in a recent study on Uganda that was released in August 2001 by the Joint UN Program on HIV/AIDS (UNAIDS) on the occasion of the Durban conference.

The study looked at discrimination against people with AIDS in communities, families, and the work place. It was conducted by the AIDS Support Organization (TASO), one of the world's foremost AIDS advocacy groups. (TASO is profiled in Issue 9 of this series.) The study's conclusion, based on research done in the 1990s, was that although huge strides have been made in Uganda, 'discrimination, stigmatization, and denial are still very serious problems in the country.' It concluded that the problems range from complacency among young people to difficulties in promoting safe sex within marriages.

The report makes sobering reading because it confirms that the real battle against AIDS in Africa is being played out in the families and villages of Africa, where the authority of government rarely extends. This sort of discrimination is intensely personal, and it takes many forms: schoolchildren ostracizing other children on the playground, or in-laws boycotting the widow of a son who has died from the disease. In such situations, it might be counterproductive to claim that rights have been violated and demand legal redress. Indeed, the fit between human rights and family behavior has always been awkward.

Governments have also created doubts about their commitment to eliminating discrimination, domestically and at the international level. South Africa's government has made no secret of its skepticism, so it was perhaps hardly surprising that the parents of Gugu Dlamini (the South African health worker who was beaten to death in 1998 when she disclosed her seropositivity) declined to attend an inquiry into her death in January 2001. They had received death threats.

At the international level, the United States, the Vatican, and several Arab governments joined forces at this year's UNGASS to block any specific reference to gays and sex workers in the final declaration. This does not detract from the very real achievements of this meeting, but it may well make it harder for campaigners to work on behalf of these highly vulnerable groups, which are often the first victims of prejudice.

Many feel that the dilution of the UNGASS declaration could also undermine efforts to build on the 1997 UN guidelines on human rights and AIDS referred to earlier. Among other things, the guidelines call for respect for confidentiality and prior notification in testing and even between sex partners.

This is an extraordinarily important advance on the notion of the 'right to information,' but it would probably be even stronger if delegates at UNGASS had grasped the nettle and made a specific reference to those who most need to benefit.

Youth or Children?

Above all else, there are questions about the rights of young people. In all of this discussion, nationally and internationally, the rights of young people are hinted at but not defined with any degree of precision.

Part of this confusion is understandable. Are young people to be considered children - and so covered by the growing body of national and international law that protects the rights of children? In some respects, the answer is clearly yes. Youth is generally defined as being between the ages of 15 and 24, and anyone under the age of 18 qualifies as a child in most legal systems.

But even teenage children are likely to find themselves subjected to a tougher standard than younger children by society. They are more likely to be held responsible for their actions, whether it be choosing a sex partner, leaving school, or failing to earn a living. Physically, they are nearer adults than children, particularly in poor societies where people age quickly. This is why so many teenagers are drafted into work, armies, or prostitution. In parts of the United States, people can even be put to death for crimes they committed under the age of 18.

Policy makers are finding it hard to deal with this awkward period in a person's life, particularly in African countries like South Africa that are under increasing social and economic pressure. More and more, young people are expected to compensate for the failings of government and the prejudices of their elders. This is especially true when it comes to AIDS. It is for this reason that young people are increasingly in need of special protection and support.

YAA's role

Young advocates like Charlotte Mjele, profiled in this issue, are rising to the challenge and showing the world how it can be done. This starts with communication. Charlotte is better placed than adults to explain the deadly threat posed by AIDS because she talks from experience. This puts her on the front line of prevention.

Young campaigners like Charlotte can also identify the special problems that young people face in purchasing condoms or volunteering for an HIV-test. Charlotte Mjele has written a country profile of South Africa for Youth Against AIDS in which she estimates that three out of five young South Africans are using condoms, but that many young people in rural areas cannot afford condoms. In addition, they have to travel long distances to health clinics.

Charlotte also notes that HIV testing is not entirely free - which is another major disincentive to AIDS prevention. And she notes that most youth-led initiatives on AIDS in South Africa 'do not have enough support. some have no support at all.'

Some combination of policy making and presentation, led by young people and directed at youth, is critical to the success of an AIDS policy. Advocates like Charlotte are critically important for developing a youth-based policy on AIDS - and this applies particularly to countries like South Africa, where the government is hiding its head in the sand.

This helps to answer one of the questions posed at the beginning of this series: What exactly is the outline of a 'youth-based approach' to AIDS?

It also suggests an important role for YAA's growing African network. By developing a network of young activists around Africa, YAA can provide people like Charlotte with support, advice, and information. Charlotte Mjele, in turn, has much to teach people like Moses Imai in Nigeria and Inviolata Mmbwavi in Kenya - and vice versa.

They can also work together as a network at international meetings, to make sure that their voice is taken more seriously than it was at this year's UNGASS on AIDS. One of their targets will likely be the General Assembly's meeting on Children next May.

One thing is clear: YAA's exciting initiative cannot allow itself to be held back by the prejudice and ignorance of adults.

- This editorial was written by The Advocacy Project.

Scent of a Plague

How does it feel to treat young people whose lives have been devastated by AIDS? Health professionals are sometimes portrayed as cold and indifferent. But the following extract from the diary of a South African doctor gives a very different impression. The diary was published by a leading Johannesburg paper, the 'Mail and Guardian', on June 29, 2001. Its author asked to remain anonymous.

This week, as in most weeks in my or my colleagues' working lives, I was consulted by a family whose child was probably going to turn out to have HIV infection. The baby girl was three months old and had a mild heart condition. She was sicker and weaker than one would have expected. She had a cough. Was it simply pneumonia?

Oh, one's hands are used to it now: the rubbery feel of the enlarged lymph glands in the armpit, in the neck, and at the base of the skull; the firm enlarged liver and spleen felt in the abdomen.

One's eyes have seen it too often: the rash, the white plaques in the mouth indicating thrush. The baby did not move very much. Was this the deadly brain disease of childhood AIDS, the encephalopathy?

Her mother (a teenager, unmarried) had been trying so hard. She gave intelligent detail to the problems she had noticed with her little daughter. The baby's father sat silently in a corner. This relationship had led to his girlfriend being rejected by her mother.

I began my explanation. Underneath there was a mixture of anguish and despair. Out of my mouth came the professional sound of controlled and concerned care. I gradually opened the door on the monster. (I was lucky. The family spoke English.) 'Virus infection,' 'testing,' 'possible HIV.' One watches the eyes for the recognition or understanding.

This time there wasn't much to see. The implications for themselves were not recognized by the parents. Or had I not put it clearly enough? Sometimes one is so gentle that the import of the message is not communicated. Was I trying to protect myself from witnessing what I know must come into these young people's lives sooner or later if I am right? I am not yet numb to the pain I have to inflict so often. I fear that in time I may lose such feeling. I fear that my young colleagues who have more direct dealings with patients than I do may become inured to this cavalcade of suffering to protect themselves, to protect their minds. The proportion of their time spent giving bad news to parents is so high now. We were not trained for this.

The little family is now moving through the system. The blood test will be done followed by post-test counseling. In the next couple of days they may come to know a future unlike anything people so young would ever have contemplated.

- This family did not have the HIV infection.

Power of Positive Thinking: Charlotte Mjele Defies the Stereotypes

Charlotte Mjele, 24, says HIV has made her a stronger person. She radiates a bright attitude toward life and provides inspiration to people infected and affected by AIDS throughout South Africa. Adam Frankel reports.

Even though he has known Charlotte since she contracted HIV over two years ago, Roger did not know that his friend Charlotte was HIV-positive until I mentioned it.

That is one indication of Charlotte's personality. It's not that Charlotte was trying to hide that fact that she is HIV-positive - indeed she is an AIDS activist. Nor does she deny that she has the disease, as so many people do.

Charlotte simply has a vibrancy, joyfulness, and strength that people do not usually associate with someone living with a life-threatening disease. She does not look like the stereotypical HIV patient who is too frail and too weak to live. And defying that stereotype is exactly the thing Charlotte is determined to do.

Charlotte works as an AIDS educator for HOPE Worldwide-a faith-based international nongovernmental organization (NGO). She is part of a growing community of seropositive educators in South Africa (known as PLWAs, people living with AIDS).

Activists see PLWAs as among of the most precious resources in the fight against AIDS, because they often come from the communities to which they speak. Their lessons stick.

Even so, Charlotte often has trouble convincing students that she is HIV-positive. 'They think someone is paying me to come here and talk about AIDS,' she says. They feel that no one who looks as healthy as Charlotte could possibly have the infection.

If everyone with the virus was thin and gaunt and covered with sores, potential sexual partners would find them easy to identify, she says. The problem is that seemingly healthy people - and increasingly, young people - are the most common carriers of the disease and often do not exhibit the warning signs for which sexual partners look.

A person can carry the disease for years without showing symptoms. And even those who know they are HIV-positive often do not disclose their disease for fear of the shame it will bring to them and their families. South African culture frequently stigmatizes people with HIV/AIDS and muffles talk about sex.

This helps to explain why the disease is spreading so quickly among young people - who generally look healthy, even if they carry HIV. It is one reason half of all 15-year-olds currently alive in South Africa are expected to die of AIDS by the time they turn 35.

Charlotte Mjele was born in Soweto. She tested positive two weeks after her 21st birthday in 1999.

Charlotte had gone to the doctor to get medication for shingles, a painful recurrence of chicken pox in adults. Charlotte did not think it had anything to do with HIV. When the doctor told her shingles was a symptom of HIV and suggested a blood test, she responded with a cool, 'whatever.'

But during the next two weeks, while she waited to learn her test results, the possibility of testing positive became real for her. 'I thought a lot about life,' she says. She thought about friends, family, past experiences, and past decisions. 'I knew I was sexually active and that one time I had not been careful and that that is one mode of transmission.'

'I hated myself,' she says. 'My self-esteem went from zero to negative one. I never thought it could happen to me - anyone but me.'

But Charlotte is not in search of pity. 'I don't live as a victim of anything - cause I'm not,' she says. 'I don't live as a sufferer of anything - cause I'm not.'

In fact, she will tell you that 'more good than bad' has come from her disease. 'I used to think of myself as a coward. But now, no. I'm more assertive and more courageous than I was when I didn't have HIV.'

She did not tell her family that she was HIV-positive until a year after she learned the results of her blood test. She was worried that they would lose trust and respect for her.

What would her three younger siblings-for whom she was supposed to be a role model-think about her after learning she had a disease that people say you get by 'sleeping around'? Would her parents-the heads of a Christian household-ever be able to trust their supposedly devout daughter, who had committed the gross sin of sexual promiscuity?

These were some of the thoughts that went through Charlotte's mind in the months before she disclosed her disease to her parents. But now, she says proudly, her parents respect her more than ever.

It started with knowledge. Three months after she learned she was HIV-positive, HOPE Worldwide contacted her to be an activist. Her job at HOPE helped her understand the virus and how it affects her. Once she helped herself accept the virus, she felt she could start helping other people.

'Knowledge is power, and I cannot be just one of the numbers or one of the statistics,' she says defiantly. 'I need to help dispel the stigma around HIV/AIDS and increase the self-esteem of people living with it.'

Activism helps Charlotte cope. 'I can tell people I'm HIV+ without blushing, and that's a real achievement for me.'

Charlotte partly credits her family and friends for her confidence and what she calls her 'positiveness.' Before she told her parents, Charlotte turned to seropositive friends she knew from church. They became role models, inspiring Charlotte with their positiveness. Charlotte is reluctant to say the same about the institution of the Catholic Church, which has consistently opposed condom use - even though condoms are one of the most effective ways to prevent transmission of HIV.

HIV's greatest weapon is its ability to exist in a body without presenting symptoms for a long time. But this is also a source of reassurance for Charlotte. Because she looks healthy, she feels more confident.

'I'm more privileged than if I had been diagnosed with leukemia [leukemia patients are visibly sick, while the same is not true for all HIV/AIDS patients]. People don't see me getting sick,' she says.

Ultimately, Charlotte will tell you, 'Confidence comes from within.' In a place where pharmaceutical drugs are too expensive for most people, where there is little hope for a cure, and where people with HIV are often shunned by their families and society, Charlotte believes discovering one's inner confidence is the best available treatment for the disease.

Activists repeatedly hear from people with HIV that 'what kills you is not the disease but knowing you have it.' And that is exactly the attitude Charlotte is trying to fight. She is stoical in her advice to help people overcome their depression. The best way to do that, she believes, is to accept the fact that they have the disease.

'I'm happiest when I help someone accept it-their emotions and feelings-and learn that they can live more meaningful, more fulfilling lives now.'

Although she believes it is more painful for people to deny that they have the disease, Charlotte cannot force anyone to accept anything. Nor does she want to. 'Some people cope better by denying it-and I respect that,' she says. But while denial may help someone cope, it may also help that person decide to continue having unprotected sex.

And Charlotte does not mind being an example for people who do not have the disease.

'If that's how I can help, let it be. I don't want people to make the same mistakes I did. It's just not fair,' she says. It's just not fair.

'Declaring one's status gives you a sense of self-worth. It removes a spirit of isolation and self-condemnation and increases love and care from other people.'

- From '[Uganda: HIV and AIDS-related Discrimination, Stigmatization, and Denial](#),' a 2001 study by the AIDS Support organization (TASO).