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## **Taking Action on Stigma and Discrimination**

**Presentations Made on the Occasion of  
the Canadian HIV/AIDS Legal Network  
Annual General Meeting and Skills Building Workshops**

**Montréal (Québec)  
12-14 September 2003**

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## EXECUTIVE SUMMARY

"Taking Action on Stigma and Discrimination" was the theme of the Canadian HIV/AIDS Legal Network's 2003 Annual General Meeting, held in Montréal from Friday, September 12<sup>th</sup> to Sunday, September 14<sup>th</sup>. A skills building workshop on strategies for fighting HIV-related stigma and discrimination was held on September 12<sup>th</sup>. The opening session of the AGM, which was held on the evening of September 12<sup>th</sup>, featured welcoming remarks, a keynote speech, and the presentation of second annual Canadian and International Awards for Action on HIV/AIDS and Human Rights. The formal business of the AGM was conducted on September 13<sup>th</sup>. On September 14<sup>th</sup>, several skills building workshops were presented. The workshops were followed by a closing session which featured a panel that focused on the need to take action against HIV-related stigma and discrimination. This Executive Summary contains a synopsis of the presentations made at the opening and closing sessions. The remainder of the document contains edited verbatim transcripts of the presentations.

### Opening Session

Welcoming remarks were provided by Steven Sternthal, Acting Director of the HIV/AIDS Policy, Coordination and Programs Division of Health Canada.

The keynote speaker, Stephen Lewis, was introduced by Joanne Csete, Director of the HIV/AIDS Program at Human Rights Watch. Joanne said that as special envoy of the Secretary General for AIDS in Africa, Stephen has made it impossible for the world to see the crisis of AIDS without seeing the human rights abuses that underlie and fuel the epidemic. She said that Stephen has brought an enormous number of policy-makers, journalists, diplomats and aid professionals to the realization that HIV/AIDS in Africa maintains itself off the backs of women and girls. As much as any AIDS activist, Joanne said, Stephen has been able to get people to think about how it is that so many million Africans – including so many women and children – could die such terrible deaths without the world being galvanized by outrage and stunned into urgent action.

Stephen Lewis talked about the critical role human rights play in the response to HIV/AIDS. He said that there was nothing in the pandemic that does not speak to human rights. Stephen devoted his address to a discussion of three broad areas of human rights: (a) the right to treatment; (b) the rights of women; and (c) the rights of orphans.

Stephen said that in Southern Africa, where the death spiral caused by AIDS is taking off, treatment has become the over-riding issue because everybody understands that with treatment lives can be prolonged and saved, hope can be given and prevention efforts can have more credibility. He said that treatment has not been provided up to now because some governments in the region have been obdurate; because the donor world has failed to provide the necessary resources; because the pharmaceutical companies argue that the infrastructures are inadequate (whereas it has been shown that it is possible even with frail infrastructures to save all kinds of lives); and because the pharmaceutical industry, in combination with certain governments, have resisted the possibility of using inexpensive generic drugs.

Stephen welcomed the agreement in August 2003 to allow countries to import generic drugs if they do not have the capacity to manufacture them domestically. He said that this represents an astonishing opportunity for Canada. Now that the Canadian Generic Drugs Association has formally asked for the right to provide generic drugs to African countries, Stephen said, the Government of Canada should amend its Patent Act to authorize a "limited exception" to allow this to happen. Alternatively, he said, the Government of Canada could issue a compulsory licence to accomplish the same thing.

With respect to the rights of women, Stephen said that gender is the toughest issue of all, tougher than race. He said that nowhere have we begun to approach gender equality, and that the AIDS pandemic makes it clear that gender inequality is fatal. Stephen said that international agencies, multilateral organizations and NGOs have failed to address gender issues effectively. He said that although we know how to do prevention, how to interrupt the transmission from mother to child, how to do home-based care, how to employ the political and religious leadership, and how to do treatment, what we have not done is to confront the reality of gender, and to confront the reality of the way in which the pandemic zeroes in on the vulnerability of one sex .

Stephen said that in Africa, the human rights of orphan children are in tatters. He said that one manifestation of this is that these children are denied access to schools and school feeding programs. Stephen described the enormity of the problem: 10 percent of the Ugandan population, and 13 percent of the Zambian population are orphaned children; by the year 2010, a third of the youngsters under the age of 18 in South Africa will be orphans; in Swaziland, there are 200 child-headed households where the age of the child who heads the household is six.

The 2003 Awards for Action on HIV/AIDS and Human Rights were sponsored by the Canadian HIV/AIDS Legal Network, Human Rights Watch, the International Harm Reduction Development Program, the Hilda Mullen Foundation and Mark Gallop. The International Award was presented to the AIDS Law Project, South Africa. Presenting the award was Joanne Csete, Director of the HIV/AIDS Program at Human Rights Watch.

Joanne said that the AIDS Law Project (ALP) has been at the forefront of tearing down the barriers to treatment in South Africa. She cited the ALP's leadership role in getting a powerful coalition of over 30 multinational pharmaceutical companies to withdraw a court action that was meant to curtail South Africa's capacity to import cheap generic drugs; and in taking the South African government to court and winning an order requiring the government to provide the drugs and the services that reduce the risk that newborns will be HIV-positive.

Joanne also highlighted the work that the ALP does day in and day out, work such as helping people living with HIV/AIDS fight discrimination; helping women who face domestic violence and sexual abuse bring complaints against the perpetrators of these acts; helping women and children who survive sexual violence obtain drugs to prevent HIV transmission; helping dying patients ensure that their children will be able to inherit property; and dealing with the discrimination and persecution of gay and bisexual men and lesbians.

In accepting the award, Liesl Gerntholz, Head of the Legal Unit of the AIDS Law Project, paid tribute to the staff and volunteers of the Project. She said that the announcement last August by

the Government of South Africa that it would begin the process of rolling out antiretroviral therapy in the public sector has given treatment activists hope for the first time in a long time. However, she said that with these new developments will come new challenges, and that the ALP has to start examining more closely issues around stigma and discrimination and how the impact they will have on people's ability to access treatments. For example, Liesl said, the increasing numbers of orphans raises issues of legal guardianship and who can give consent for the children to be tested for HIV and to receive treatment. As well, she said, if an antiretroviral registry is established to assist in the monitoring of treatment, this will raise issues around privacy and confidentiality.

The 2003 Canadian Award for Action on HIV/AIDS and Human Rights was presented posthumously to Laurence Stocking, a prison activist. Presenting the award was Mary Pearson, a physician and advocate who has provided medical care in prisons and who knew Laurence.

Laurence Stocking was a federal inmate who was incarcerated for 15 years at Millhaven and Joyceville Institutions in Ontario. He died at the age of 39 while in prison. Mary Pearson described Laurence as a man who advocated extensively for programs to prevent the transmission of HIV and hepatitis C in prisons, and to ensure that his inmates who were living with these diseases could access care and treatment. Mary said that Laurence's accomplishments ranged from peer counselling and organizing health care seminars with outside agencies for prisoners, to playing a significant role in the production of two prisoner-produced videos on hepatitis, tattooing and harm reduction. She said that Laurence was also instrumental in helping researchers organize studies on the sero-prevalence of HIV and hepatitis, and the risks associated with the contraction of these diseases, within prison. Mary said that Laurence worked selflessly to help others, despite his own health problems. She said that for an inmate to speak out in the prison system was both exceptional and dangerous, and that Laurence demonstrated incredible courage and perseverance.

Accepting the award on Laurence's behalf were his mother, Eva Stocking, and his daughter, Chantelle Stocking. Eva said that Laurence felt a great deal of remorse for the crime he had committed and that he hoped that if he could help other people, this might atone for his crime in some small way. Chantelle said that because of her father's humble nature, she wasn't fully aware of the work that he was doing while he was alive, but that she feels very, very privileged to be the daughter of such a wonderful and unselfish man.

### **Closing Session**

The closing session featured a panel discussion on Taking Action on HIV-Related Stigma and Discrimination. Theodore de Bruyn, Senior Policy Analyst with the Canadian HIV/AIDS Legal Network, chaired the session and was one of the presenters. The other presenters were Janice Dayle, a person living with HIV/AIDS and an activist; Miriam Maluwa, Law and Human Rights Adviser at the Joint United Nations Programme on HIV/AIDS (UNAIDS); AND Wan Yanhai, Director of the Beijing AIZHIXING Institute of Health Education.

Several panellists spoke about the need to analyze existing stigma and discrimination in order to understand it properly and break it down into its various elements; and the need to develop

concrete strategies to address each of the elements. Panellists pointed out that the stigma and discrimination experienced by people infected and affected by HIV/AIDS is related not only to attitudes towards the disease itself but also to issues of gender, race, culture, sexual orientation and lifestyle. Therefore, the panellists said, in responding to this stigma and discrimination, we need to challenge the very foundations of society.

All of the panellists spoke about the need for concerted action to address HIV-related stigma and discrimination. The following are some of the major actions that were proposed:

- To combat intolerance and ignorance, we need a massive investment in education, including ensuring that HIV/AIDS is incorporated in school curricula as a distinct topic, and educating journalists who perpetuate stigma.
- To address the reproach and shame that characterizes HIV/AIDS, we need sustained, long-term programs that fund organizations to mentor persons living with HIV/AIDS, to engage leaders, to open up the discussion and to challenge myths.
- To respond to systemic inequalities that affect particular populations, we must fund sustained, long-term programs that will allow individual organizations and coalitions of organizations to develop and implement strategies for change.
- To provide support for individuals who experience discrimination related to HIV/AIDS, we need sustained, long-term programs that will fund advocacy and support services; capacity building for local lawyers to enable them to provide legal assistance; advocacy with bar associations and governments to increase rates for, and access to, legal aid; and litigation strategies.
- In societies that repress civil liberties, we need to fight for basic human rights, including freedom of speech and freedom of association.

# **OPENING SESSION**

## **Friday, 12 September 2003**

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### **Welcoming Remarks**

**Steven Sternthal**  
**A/Director**  
**HIV/AIDS Policy, Coordination and Programs Division**  
**Health Canada**

The Minister of Health, Ann McLellan, has asked me to extend her very best wishes to the Canadian HIV/AIDS Legal Network on the occasion of its Annual General Meeting, and to communicate her deep appreciation of the Network's leadership in the field of HIV/AIDS awareness and advocacy.

We are here today to recognize the contributions of some very special people, to pay tribute to their courage and to the lasting influence they have had on HIV/AIDS and human rights both in Canada and on the international stage. There is a common thread that runs through the recipients of the awards for Action on HIV/AIDS and Human Rights both this year and last. It is the determination and vision that has characterized the work of these amazing individuals. Tonight, we are celebrating the success of this year's international recipient, South Africa's AIDS Law Project. Its pursuit of precedent-setting litigation in South Africa has challenged discrimination in employment, health care and education, bringing much-needed hope to a country where one-in-five of its citizens is infected with HIV. The remarkable story of Laurence Stocking, this year's Canadian recipient, is about the struggle of being an activist behind the walls of a prison. What he achieved and the courage he demonstrated were impressive by any measure.

For over a decade, the Legal Network has been a tireless advocate for public education, policy development and examination of the legal and ethical issues that this disease presents. The efforts of the Legal Network are rooted in partnerships, forged with the Government of Canada and with other key organizations. From the perspective of the federal government, this partnership has been indispensable and is highly valued.

The Canadian Strategy on HIV/AIDS (CSHA) has achieved significant progress over the past five years. It has established a strong, community-based approach. It has created a climate in which shared leadership can flourish. It has helped raise public awareness about HIV/AIDS in terms of human rights and harm reduction, and has supported a multi-sectoral infrastructure of community-based organizations. And it has helped Canadian researchers make significant contributions in the fight to eradicate this disease.

I am pleased to report that Health Canada has completed a five-year review of the federal role in the CSHA. The review considered the lessons learned over the past five years, identified current challenges, and set new directions to guide the federal role for the next five years. This was a

major undertaking. Health Canada owes much to the hard work, leadership and contributions of Ralf Jürgens of the Legal Network for helping to ensure the success, not just of this review, but of the CSHA as well. Ralf's work is proof of the special kind of leadership and support that we have been able to count on from the Legal Network as our partner.

In recent public remarks, Minister McLellan noted that the Government of Canada has been listening carefully to those who are on the front lines of the fight against this epidemic. I want to assure you that those of us working day-to-day on HIV issues at Health Canada are just as committed as the Minister is to listening to and supporting our partners.

Health Canada is also supporting the development of a stakeholder-led strategic plan for the CSHA. This will be a plan that all levels of government and community-based organizations can turn to in order to guide their response. To address the gaps and challenges outlined in the Five-Year Review, we want to put in place a plan that will implement activities with measurable outcomes to help stop the spread of HIV in Canada. Not only will this help amplify the voices of advocates and elevate the efforts of people living with, or vulnerable to, HIV, but it will also re-ignite prevention efforts and increase Canada's capacity to monitor and track the disease.

On behalf of the Government of Canada and of Minister McLellan, please accept my best wishes on your deliberations over the next two days. I am looking forward to hearing more about the ongoing work of the Legal Network and about opportunities to work together in partnership with the Government of Canada.



## **Keynote Address**

### **Introduction of the Keynote Speaker**

**Joanne Csete  
Director, HIV/AIDS Program  
Human Rights Watch**

When I worked at the United Nations, I thought that a job with the title of “special envoy” was something that was given to people who had retired, or who were near retirement, and who wanted to give the occasional speech or attend a conference to ensure that they were not forgotten. I would never have associated the notion of a special envoy with someone who wants to mobilize a global movement, and who is committed to changing some of the basic concepts of a tired and stubborn world. If United Nations (UN) Secretary General Kofi Annan thought he was getting the “special envoy light” version when he nominated Stephen Lewis to this position, he was gravely mistaken.

I want to say a few words about Stephen Lewis as a global citizen and international civil servant, in which role I was lucky enough to know him as a colleague. I first heard Stephen speak publicly in the period after he was Canada’s ambassador to the UN, in the late 1980s or early 1990s. He was serving as Special Advisor on Africa to the then Secretary General Perez de Cuellar. The occasion was a panel discussion and the subject was the global environment. Al Gore, then a U.S. senator from the state of Tennessee, spoke in platitudes. He said things that no one could disagree with, and he talked about individuals over-consuming the wrong kinds of fuel. Stephen spoke in accusations and exhortations. He talked about environmental degradation of the planet as an inevitable result of entrenched poverty, global income disparity and racism. He thus permitted environmental degradation to be understood as an issue of injustice as much as an issue of individual behaviour. Anyone who has followed his words and actions as Special Envoy for HIV/AIDS in Africa knows that he is pulling off a similar transformation of the UN discourse on the issue of HIV/AIDS.

As ambassador of Canada to the United Nations, Stephen was noticed instantly for three things – his interest in Africa, his advocacy for human rights issues, and his eloquence as a speaker and a spokesperson for the best values of the United Nations.

I was in the rank and file of the staff of the United Nations Children’s Fund (UNICEF) in 1994 when Stephen became the Deputy Executive Director of that agency. That period in UNICEF, maybe in the whole UN, seemed to many of us to be a time when agencies were losing their way as advocates for the most marginalized and abused people of the world. My friends and I had attended meeting after meeting where our agency was challenged as the global advocate for children to take on repressive governments and greedy corporations, and to take on the United States, which resisted the idea of human rights of children, especially economic and social rights. Too often the strategy had been not to fight, but rather to find some position at the lower common denominator that everyone could live with – in the worst cases, to form “partnerships” with these adversaries. But with Stephen it was different. He brought the sense that armed with

the facts of the situation of children, and with a sense of outrage and a sharp wit, one could, indeed, one *must*, prevail in such battles and with him, we often did. When he left UNICEF, it was hard to absorb the loss.

As special envoy of the Secretary General for AIDS in Africa, Stephen, by his example, has not only redefined the notion of "special envoy," but he has accomplished in his way what many of us strive for day to day – to make it impossible for the world to see the crisis of AIDS without seeing the human rights abuses that underlie and fuel the epidemic. For example, Stephen has brought an enormous number of policy-makers, journalists, diplomats and aid professionals to the realization that HIV/AIDS in Africa maintains itself off the backs of women and girls. As much as any AIDS activist, he has been able to get people to think about how it is that so many million Africans – including so many women and children – could die such terrible deaths without the world being galvanized by outrage and stunned into urgent action.

One of the things that I love about Stephen Lewis is his explicit honing of the lost art and science of oratory and his classic – not to say old-fashioned – conviction that oratory can be a tool for global change. Stephen is able to convey atrocities in compelling ways to many audiences – he has referred to HIV/AIDS as "mass murder by complacency" – but he also truly believes that this epidemic can and must be turned around. A foundation that bears his name, and for which he spends considerable energy seeking resources, also carries that message of possibility by assisting grassroots organizations that meet the needs of African women and girls and others affected by AIDS.

Stephen gives a lot of speeches, but I do not think that he will come closer than he will on this night to having an audience of real peers. The people in the organizations that make up the Canadian HIV/AIDS Legal Network spend every day on the frontlines of AIDS and human rights issues across this vast country. Like Stephen, we are regularly moved to anger and tears by the outrageous injustices associated with this disease. Like Stephen, we have known victories when we have helped get people in power to see the AIDS problem in a new way and to respond accordingly. Like Stephen, we are establishing AIDS and human rights as a graphically real idea, not a theory. We are very pleased to have Stephen Lewis with us here tonight.

## **Keynote Speaker**

**Stephen Lewis**  
**United Nations Special Envoy**  
**for HIV/AIDS in Africa**

Thank you so much, Joanne, for that splendid introduction. I am enormously tickled to be here with you this evening. I spend a lot of my life peripatetically wandering the landscape of Canada speaking, and I rarely get an opportunity to speak to an audience with whom I feel such obvious solidarity. I want to tell you that I appreciate it enormously.

There are three other reasons why I feel so good to be in this room. First, I have known of the Canadian HIV/AIDS Legal Network for some time. Joanne Csete has filled me in on a regular and tenacious basis. Every time I speak to Joanne, she talks about the Legal Network and the extraordinary work that is done and I am genuinely filled with admiration. I know of its connections internationally. I know of the influence that it has. I have read the material which I have often found trenchant, profound and rewarding. I can't get over the quality of thought and analysis that the Legal Network brings to its arguments for human rights.

Second, I want to say that I am truly honoured to be here when the Legal Network is bestowing an award on the AIDS Law Project of South Africa. It is very rare that one has the opportunity to honour an organization that has so effectively represented the uprooted and disinherited in their society. The people in the AIDS Law Project are a principled group of advocates. They forced the Government of South Africa to reverse itself and to champion policies that it might never have championed otherwise.

When I think about the AIDS Law Project, I am inclined to remember a stop I recently made in Durban this past August, on the eve of the South African conference on AIDS. I was there to speak to a group of researchers prior to the conference, and I took a small detour. I went off to speak at the convention of the Treatment Action Campaign, which was meeting in an adjacent and somewhat lower class hotel. I was transformed by the experience. There were six or seven hundred people in that room with enormous energy, ebullience, vigour, excitement and principle. Running through my mind, as I looked out at the audience, was the anti-Vietnam war protest, the civil rights movement in the United States, the campaign for nuclear disarmament, the campaign to ban land mines, the anti-globalization campaign and, above all, the campaign against Apartheid. I thought of all these social movements, which had effected such massive social change internationally, and I equated them with the AIDS Law Project in my mind, as I do now. I thought to myself: "These are people who are creating a social movement. These are people whose genetic molecular structure is exactly the same as all of these historic groups of people who have effected social change. These are people who brought sanity – finally – to the Government of South Africa and, in the process, look as though they may bring the pandemic to heel." I cannot tell you what a pleasure it will be to present them with an award later this evening.

The third reason I am happy to be here is that I am gratified by the subject matter. I am gratified that I can say a few words about AIDS and human rights because from my own, however

narrow, point of view, I consider AIDS to be nothing but a human rights issue. There is nothing about the pandemic that does not speak to human rights – everything is part and parcel of the human rights narrative. In this room, there are all skilled experts and knowledgeable professionals who have used the law, jurisprudence and interventions in the courts; who have altered life for people around employment, health, housing, the criminal law and the prison system; who have engaged, as very few people engage, in the practical application of social change, using litigation as a vehicle for improving the human condition. I can't pretend to speak to those specifics, and I don't want to. What I want to do is lay out, in three broad areas, what it is about the human rights compendium that galvanizes me at this moment in time.

### **The Right to Treatment**

The first human rights issue that I want to raise is the right to treatment. I spent a little time in New York earlier this week meeting with a number of physicians who specialize in infectious diseases. One woman physician, who has been involved in this struggle for virtually the entire 25 years which it has encompassed, said to me, with real feeling, that she remembers vividly how much time in the early years she spent holding the hands of magnificent gay men who were dying, and the hands of their mothers. And then she said to me: "You know, Mr. Lewis, I have a very large case load and I cannot remember the last time that someone died. All my patients are productive, active, working, engaged in families, excited about life."

**There is nothing about the HIV/AIDS pandemic that does not speak to human rights.**

I thought to myself, as I listened to her: "Isn't this the embodiment of the obscenity which exists in this world?" In North America, people have access to treatment and life is, in most instances, prolonged. In Africa, one is surrounded by death. I remember sitting in a little classroom of grade 5 students in Harare. The teacher was doing a life-skills course. She asked the kids to write down on a piece of paper what it is that they were most worried about. On eight out of every 10 pieces of paper was the word "death." Death of a mother, father, friend or relative.

What is happening now, so pronouncedly, in so much of Southern Africa, is that the death spiral is taking off. The infections that occurred in the late 1980s and the early 1990s have moved to full blown AIDS, and an explosion of death is occurring. Last July, I was sitting in a hotel room with Zackie Achmat and Mark Heywood of the AIDS Law Project and the Treatment Action Campaign, and they said to me that they believed they had lost 40 members of the Treatment Action Campaign over the prior two or three months. But then they canvassed their local chapters and learned that they had actually lost 200. In Africa, there is currently no right to treatment. Treatment has become the over-riding issue right across the continent because everybody understands that lives can be prolonged and saved, that hope can be given, and that prevention can have more credibility. With treatment, people will be willing to be tested for HIV infection because if they find out that they are HIV positive, then they know that down the road there will be treatment and life can go on. There is a sense that treatment is now the centrepiece of the response to the pandemic.

Why was there no treatment to speak of before? First, because you had obdurate governments, like the one of South Africa, whose position was, in absolutely every sense, indefensible. Second, because there was a failure of resources being provided by the donor world. I will never

understand why the donor community has been so resistant to providing the dollars necessary to fund the interventions that would save millions of lives. I do not understand, and I will not accept, that millions of people have to die needlessly day after day, month after month, year after year, while the President of the United States goes before his people and asks for 87 billion dollars more to fight a war against terrorism in two countries, a war that has now cost 166 billion dollars. And yet, in the U.S. Senate the other night, when there was a motion to provide three billion dollars to combat AIDS as part of the commitment made by President Bush in his State of the Union speech, the Senate reduced it by a billion dollars, down to two billion. I will never understand why there is so much money for conflict and there is never sufficient money for the human condition.

Why weren't the drugs provided? Because all of the arguments of the pharmaceutical companies about infrastructure were made ad infinitum, whereas we know that in resource constrained societies, it is possible, even with frail and inadequate infrastructures, to save all kinds of lives.

**We know that in resource constrained societies, it is possible, even with frail and inadequate infrastructures, to save all kinds of lives.**

Why weren't the drugs available? Because there was all kinds of gratuitous nonsense about Africans not being able to follow the drug regimens, whereas we now know, by virtue of recent studies, that people in Africa follow the regimens better than people in North America.

Why don't we have the drugs? Because the pharmaceutical industry, in combination with certain governments, resisted the possibility of generic drugs, which was the only level of cost which African governments, whose people live mostly on less than \$1 a day, could possibly afford. Because the World Trade Organization dishonoured the agreement it came to in Doha in the Fall of 2001, when everybody thought that the world had agreed that health trumps trade.

Then suddenly, thanks to an agreement reached on the 31<sup>st</sup> of August this year, the situation seemed to change. Suddenly, it looks as though the world is coming together on the possibility of providing generic drugs to developing countries, particularly to those countries that have such high prevalence rates and are obviously in crisis. By virtue of this agreement, a country is now in a position to import generic drugs if it feels it requires those drugs and does not have the manufacturing capacity to develop them indigenously. Other countries that can produce the drugs have the right to export generic drugs to countries that need them. Some people think that there was a lot of sleight of hand involved in this latest agreement. They are concerned about the many conditions attached to the provision of the drugs. They fear that these conditions may force governments in Africa and elsewhere to buy from big pharmaceutical companies. But I think that this situation really presents an astonishing opportunity for Canada. Let me explain.

Last year, in July, in Kananaskis, Alberta, the G8 got together for what was seen by Canada as the African summit. The new plan for African development was brought to the summit by President Mbeki of South Africa, President Obasanjo of Nigeria, President Bouteflika of Algeria, President Wade of Senegal, and Kofi Annan, the Secretary General of the United Nations. The Prime Minister of Canada made it clear to the world that this was the African summit – this was the breakthrough for Africa, this is what Canada would do to demonstrate solidarity and support

for Africa in all of its public requirements. So, it seems to me that we are now at an extraordinary moment in time where we can test the sincerity of that commitment.

The Canadian Generic Drugs Association has written to the Canadian Government and has asked for the right to provide generic drugs to African countries. As I understand it, what would be required is an amendment to the Patent Act, something called a "limited exception." The drugs would be produced only for export, with no loss whatsoever to the balance sheet of the brand name drug companies. And the drugs would be sold at generic prices to African countries. Alternatively, the Government of Canada could do quite easily what other governments have done, that is, issue a compulsory licence that would allow for the manufacture and export of generic drugs.

What an opportunity this is. There is no question that it would pass the House of Commons. It would signify that a major developed country is taking this pandemic seriously. And since the World Trade Organization has made it absolutely legal now to import and export generics, it would signify that Canada is going to take advantage of the agreement and demonstrate to the world that it is possible. Yes, generic drugs can come from India, they can come from Thailand, and they can come from Brazil, but why not come from a developed country as well?

In order to import generics, a country in Africa will have to make a case before the World Trade Organization Secretariat and its Intellectual Property Rights Council. If Canada moves on this issue, that case could be made in conjunction with the Government of Canada. If the government of a G8 nation went to the WTO in conjunction with an African country, there is no question that the approval would automatically follow.

So why shouldn't it happen? There would be no loss to the drug companies whatsoever. And there should be no concerns about the erosion of patents because this would be done for an exclusive purpose, under a particularized piece of legislation or exception. That is the test for Jean Chrétien, the Prime Minister of Canada. I know that the Prime Minister wants to leave a legacy to this country. There is no greater honour he could bring to the solemnity of the Prime Ministerial position, no greater honour he could bring to his work, than to introduce the legislation that is required to make those drugs available at generic cost.

**What a joy it would be if the Government of Canada were to decide to do something that would honour the call to provide the highest attainable standard of health.**

To be honest, I fear that it will not happen, because my experience is that the brand name drug companies tend to exert an extraordinary influence over the Government of Canada. But what a joy it would be if there were a departure from past practice, and if the Government of Canada were to decide to do something that would honour the call to provide the highest attainable standard of health, a call that is included in one international human rights convention after another. Canadian generic drug companies have asked for permission to provide the drugs and are awaiting the government's response.

## The Human Rights of Women

The second area of human rights, that is absolutely indispensable to this struggle, is the human rights of women. Gender is the toughest issue of all. It is tougher than race. Nowhere in developed countries and in developing societies have we begun to approximate gender equality, although it is perhaps closer here than elsewhere. But the AIDS pandemic makes clear that gender inequality is fatal. Look at the extraordinarily disproportionate number of women who are infected and dying in Africa; the depopulation of parts of the continent of its women; the intense range of vulnerability women face; the extraordinary burden of care that women carry while being ill themselves and under siege; the need for women to be the food producer in the family, to look after the ailing members of the family, and to look after the orphans. Women assume the multiple burdens of care and remain the most vulnerable. We have all failed to protect women in the face of this pandemic. Finally, in 2003, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has launched a campaign on gender equality, which may cumulatively have some impact, but it is very late in starting. Finally, in 2003, the United Nations Children's Fund (UNICEF) is establishing a task force to look at the relationships between gender and food security and vulnerability in a number of Southern African countries where famine stalked the land in the early part of this year.

But this pandemic has been around for a long time, and women have been horrifically vulnerable, and the international bilateral agencies, the multilateral organizations and the non-governmental organizations have watched it happen.

All over the African continent, at the grass roots, there are magnificent groups of women, women at community level whose sophistication, knowledge, commitment, solidarity, intelligence, compassion and decency are simply overwhelming. I first visited the African continent 44 years ago when I taught in Ghana in 1959. I love that continent. It is a continent of enormous human decency even though it has incendiary episodes of fratricide. But we have lost so many of the women of Africa unnecessarily, the women who approach me in their 20s, fighting for their lives, their children in tow, asking: "What's going to happen to my children when I die?" They say to me: "You've got drugs in your country, Mr. White Man, why can't we have drugs to keep us alive in my country?"

**"You've got drugs in your country, Mr. White Man, why can't we have drugs to keep us alive in my country?"**

The struggle for gender equality is at the heart of human rights for women in Africa. The pandemic has resulted in the most palpable violation of human rights one could imagine. If you read through the Convention on the Elimination of All Forms of Discrimination Against Women, you will see that every single clause is violated by the pandemic – whether we are talking about laws on property rights, laws on inheritance rights, laws dealing with sexual violence and rape, laws dealing with the distribution of the female condom, laws trying to protect young children from sexual violence. This panoply of rights has to emerge somehow as we struggle against the pandemic on the African continent. The struggle for gender equality is at the heart of defeating the pandemic in Africa.

What about the men? The truth is that predatory sexual male behaviour is what is driving a great deal of the pandemic, as is the way in which older men violate younger women, and the inability of women to exercise sexual autonomy or to insist that the man wear a condom or to say no. Changing male sexual behaviour will take generations. That is why it is so desperately important to achieve a greater level of gender equality, and to empower women to the extent that they can resist the predatory overtures.

We know how to do prevention, we know how to interrupt the transmission from mother to child, we know how to do home-based care, we know how to employ the political and religious leadership – we have seen the decline and prevalence rate when those leaders are engaged as they are in Uganda and Senegal – and we know how to do treatment. What we have not done is to confront the reality of gender, to confront the reality of the way in which the pandemic zeroes in on the vulnerability of one sex.

### **The Human Rights of Orphans**

Just a couple of months ago, I went on a trip with Graça Machel, the Former Minister of Education in Mozambique, the Former First Lady of Mozambique, now married to Nelson Mandela. She is an astonishingly powerful, charismatic and lovely person in every respect, known everywhere, as I learned while we travelled, as Mama Africa. We were staggered by what we saw in four days in Uganda and four days in Zambia. Everywhere we went, the rights of orphan children were in tatters. These rights are allegedly upheld by the Convention on the Rights of the Child. They include the right to education, the right to be in school. Many African countries maintain school fees, even though the Convention says that primary education shall be free and universal. The countries that pretend to have removed the fees are still charging for books and for uniforms. As a result, many kids who are orphaned by AIDS simply can't get to school, can't get a meal at a school feeding program during the course of the day, and can't have the solidarity and relationships which they would wish.

There is a repugnant irony in all of this. These countries never used to have school fees. Then along came structural adjustment programs from the World Bank and the International Monetary Fund. Inherent in these structural adjustment programs are what they call "user fees" and "cost sharing." Suddenly countries, as a condition of receiving the grants and the loans which the Bank was prepared to make, had to impose school fees. Now, many years later, the Bank admits that it made a mistake. And the countries want to remove the school fees but they are locked into them because they don't have the money to compensate for the withdrawal of the fees. So, the children orphaned by AIDS are denied access to school.

Whether it's the right to education or the right to school feeding programs, or protection from sexual violence, or keeping parents alive by providing treatment in mother-to-child clinics, all of this must focus on the orphans. Ten percent of the Ugandan population are orphan children. Thirteen percent of the Zambian population are orphaned children. It is estimated that by the year 2010, a third of the youngsters under the age of 18 in South Africa will be orphans. In Swaziland, there are 200 child-headed households where the age of the child who heads the household is six. Many, many children, as you know, are living with grandparents and there's no one coming up behind when the grandparents die.



I want to end with an anecdote: I was in a little community outside Lusaka with Graça and we went in to visit an orphan child-headed household. There were three girls, 14, 12 and 10, and two little boys, 11 and 8. We sat on the floor of the hut, the two little boys on my right, the three little girls on Graça's left, and something happened that I will never forget. Graça shooed everyone out of the hut, all the media, all the hangers on, all the UN people -- there was just one interpreter and one NGO staff member. And Graça said to the little girls, "Have you started to menstruate?" And very shyly and very anxiously they whispered, the 14 year old and the 12 year old, that they had and Graça said, "Do you know what it means? Do you have anybody to talk to? Do you discuss it at school? Do you discuss it with your teacher? Has anyone ever given you any pads?"

As I sat and listened to this conversation, I realized that I was observing the first act of parenting around one of the most crucial moments in a young girl's life. It was tremendously moving and yet equally evocative of what it means to have millions of kids who are rootless and unloved and unparented. At the end of it, I said to the 14 year old, "Does anybody put you to bed at night? Does anyone tuck you in?" And she looked at me curiously and said, "Of course not." And I thought of those dark African skies and those little kids going to bed alone at night, and I thought what madness envelops the world. Why is it not possible to engage international society in a way that responds to the human predicament with caring and compassion and decency? And I want to tell you collectively that what you are doing, the way you're living your lives, the work you do, the commitment you have, the intelligence you bring -- you make a profound difference in the human condition and there is no greater reason to be placed on this earth than to make that contribution. I truly salute you for it.

Thank you for having me.

## **Presentation of the International Award for Action on HIV/AIDS and Human Rights**

### **to the AIDS Law Project, South Africa**

*The second annual International Award for Action on HIV/AIDS and Human Rights was presented by the Canadian HIV/AIDS Legal Network and Human Rights Watch.<sup>1</sup> Helping to present the award was Joanne Csete. Accepting the award on behalf of the AIDS Law Project was Liesl Gerntholz.*

**Joanne Csete**  
**Director, HIV/AIDS Program**  
**Human Rights Watch**

We all remember a time when South Africa was in the global spotlight because its repressive government was based on a horrific system of injustice. Civil society and ordinary South Africans won a revolution that deposed that system. It is a terrible and heart-breaking reality that today some of the heroes of that revolution, now in power, have failed to stand up against the injustices that underpin a new enemy, HIV/AIDS – and, indeed, have at times perpetuated those injustices in irrational and cruelly arbitrary ways.

I am referring to the injustices faced by people with AIDS who live lives of discrimination and who die because they cannot afford the drugs that would save them – this in a country with vast resources and one of the few countries on earth with a constitutional commitment to the right to health for all its people. I am referring to the injustice that comes from babies being born HIV-positive because someone in power thinks that antiretroviral drugs are harmful or ineffective in reducing HIV transmission to newborns, in spite of the fact that virtually every other country on earth uses them for this purpose. I am referring to the simple injustice of official silence around an enemy that is ravaging the population and bringing a great country and a great continent to its knees.

That millions have died, are dying and will die for lack of treatment in Africa, including in South Africa, is unspeakably heinous. The AIDS Law Project (ALP), in its close relationship with the Treatment Action Campaign of South Africa, has been at the forefront of tearing down the barriers to treatment in that country. The ALP has been the legal arm and the legal brain trust of the Treatment Action Campaign. The work of the ALP and the Treatment Action Campaign together has galvanized and inspired the global treatment access movement.

In 2001, the ALP spearheaded actions that led a powerful coalition of over 30 multinational pharmaceutical companies to withdraw a court action that was meant to curtail South Africa's capacity to import cheap generic drugs. Also, the ALP was a leader in taking the South African

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<sup>1</sup> Other sponsors of the award are the International Harm Reduction Development Program, the Hilda Mullen Foundation and Mark Gallop. Further information on the awards is available on the website of the Legal Network at [www.aidslaw.ca/Maincontent/awards.htm](http://www.aidslaw.ca/Maincontent/awards.htm).

government to court and winning an order requiring the government to provide the drugs and the services that reduce the risk that newborns will be HIV-positive. For these victories alone, the ALP merits a place of honour in the global fight against AIDS.

But we should not forget the quieter issues, the ones that the AIDS Law Project works on every day, issues such as the following:

- helping people living with AIDS who are fired from their jobs, discriminated against in access to services, unable to get health insurance, and abandoned by their families, to find a measure of redress in the law;
- helping women who face domestic violence, sexual abuse and rape in marriage to bring complaints against the perpetrators of those acts, against all odds;
- helping children and women who survive sexual violence to get drugs that prevent HIV transmission, and pushing the government to provide more basic protections against sexual violence and abuse;
- helping dying parents ensure that their children, who face a life of stigma as AIDS orphans, will be able to inherit property; and
- even dealing with the part of the AIDS epidemic in South Africa that really no one talks about, the deep discrimination and persecution of gay and bisexual men and lesbians.

In the process, the ALP has not just provided services but, in the greatest of South African traditions, has helped to build a movement.

Affiliated with the University of Witwatersrand, the ALP has done ground-breaking academic research. Not content to let its contribution be only academic, the ALP has translated research and legal analysis into what people affected by AIDS need to know. It has used every medium possible to put that knowledge into the hands of all South Africans.

**The AIDS Law Project has not just provided services but, in the greatest of South African traditions, has helped to build a movement.**

The Canadian HIV/AIDS Legal Network was pleased to have at its AGM two years ago the Director of the ALP, Mark Heywood, whose vision and courage have made him a global leader in the fight against AIDS. If one is with Mark even for a short time, one can sense his intelligence, his constructive anger, and his devotion to bringing justice to people affected by AIDS.

We are deeply honoured to have with us tonight Liesl Gerntholtz, the director of the Legal Unit at the ALP. Liesl's pioneering work on women's rights and sexual violence issues is internationally recognized and internationally relied upon. Under her leadership, the ALP has pressured the government consistently on issues of sexual abuse related to HIV/AIDS, including the provision of HIV prevention services to rape survivors. Liesl has helped the AIDS Law Project help the world to understand that HIV/AIDS feeds off human rights abuses of women and girls, and that these abuses must be addressed for AIDS to be vanquished.

When the victory against AIDS is won in South Africa, as the victory was won over apartheid, and it surely will be won, it will be in large part because of the work of the ALP and its

courageous partners in this struggle. We are proud tonight to honour the AIDS Law Project as the recipient of the 2003 International Award for Action on HIV/AIDS and Human Rights.

**Liesl Gerntholtz**  
**Advocate and Head of the Legal Unit**  
**AIDS Law Project, South Africa**

When I was asked to come to Canada to accept this award, and to make this speech, I wondered what I could possibly say about the HIV/AIDS epidemic, and its catastrophic effect on my country, that hasn't already been said by people far more eloquent than I am. I was then lucky enough to read some words that inspired me, not only to write this, but also to think about the work of the AIDS Law Project and my own work.

Stephen Lewis made a speech recently in South Africa, just before the first South African AIDS Conference in August, and the paragraph that I would like to read to you now resonated with me for a long time. It forced me to confront again the terrible knowledge that behind each statistic is a person with a life, with family and friends, with dreams and hopes. It is important that we do not forget that very simple fact.

In his speech, Stephen said:

What is wrong with the world? People are dying in numbers that are the stuff of science fiction. Millions of human beings are at risk. Communities, families, mothers, fathers, children are like shards of humanity caught in a maelstrom of destruction. They're flesh and blood human beings, for God's sake; is that not enough to ignite the conscience of the world? Why should we have to produce all these tortured rationales to drive home such an obvious point? This pandemic has done something dreadful to the instinct for compassion. I don't really understand what's happening; I don't really understand why the simple act of saving or prolonging a human life isn't sufficient anymore.

In so many ways, the vastness of this epidemic and the unspeakable tragedy that it has caused and will continue to cause in the lives of individual people has truly done dreadful things to our collective instinct for compassion. Even those of us who work in the area now remain unmoved by the statistics on orphans, by the anecdotes about the deaths of the young and productive, and by the failure of our governments to act decisively to stem this great tide of suffering. At the AIDS Law Project, we regularly see clients who have been evicted from their homes, whose partners assault them, whose friends desert them, whose families neglect them. Too often, we take down their stories, impatient that they should give us just the facts, and not the emotions, and then we debate the legal merits of the case.

In so many ways, the epidemic has brought out the worst in all of us. But, in many, many other ways, it has also brought out the best. It has challenged some of the most unlikely people – lawyers, nurses, doctors, scientists, economists and actuaries – to become activists for human rights. It has mobilized diverse sectors around the common causes of justice and equality. It has finely honed this instinct for compassion of which Stephen speaks, and, if I may use a hackneyed phrase, it has made ordinary people do quite extra-ordinary things.

I have been privileged to work with and for some of these people at the AIDS Law Project and it is to them that this award truly belongs. I would like to pay tribute to some of them and thank them for their work.

Recently the Project has worked closely with a number of paediatric HIV specialists who are trying to provide treatment to children at the Chris Hani Baragwanath Hospital in Gauteng, one of the nine provinces in South Africa. Until last August, antiretroviral treatment was not available in the public sector, and the vast, vast majority of their patients cannot afford treatment. I am told that many people choose to specialize in paediatrics because it is a “happy” speciality – your patients get better and you have the pleasure of watching them go home to their families. This is no longer the case in South Africa for those doctors who work in the public sector. They watch their young patients return to hospitals and clinics time and time again, getting sicker and sicker, until eventually they die. There is no pleasure in this.

Dr Tammy Meyers, the chief paediatrician at Baragwanath Hospital, has worked indefatigably to raise funds from private donors to provide treatment for these children. When she says that her dream is to treat all children in Gauteng, she really means it. And I have no doubt that she will

**The epidemic has challenged some of the most unlikely people to become activists for human rights. It has made ordinary people do quite extra-ordinary things.**

achieve that, by hook or by crook. What amazes and inspires me about her work and that of her colleague, Dr Harry Moultrie, is that in face of the preventable and unnecessary deaths of so many of their patients, and the pain of watching parents and care-givers grieve for dead children, they are still willing to genuinely care for each child they treat. They most certainly haven't lost their instinct for compassion.

The Project has also worked with doctors who are providing medical care to orphaned and abandoned children. One of the consequences of the epidemic is an increase in the number of children, especially newborn babies, who are being abandoned, and who eventually find their way into children's homes. Dr Gayle Sherman started a project called CHOMP – the Children's Homes Medical Outreach Project. Gayle is a paediatric haematologist, so she could quite legitimately have stayed safely behind her microscope in her lab. Instead, she is working to provide proper medical care for children with HIV in these homes, many of which are over-stretched and do not have the capacity to care for sick children. I am also astounded by Gayle's capacity to remain angry at the inadequate care offered to these children and her commitment to changing that. She too has not lost her instinct for compassion.

Recently the landscape around HIV in South Africa changed dramatically. In August, our government announced that they will begin the process of rolling out antiretroviral treatment in the public sector. For the first time in a long while, we have hope again. We know, however, that these new developments will offer us many new challenges. As lawyers and activists, we must begin to examine more closely issues around stigma and discrimination, and how they will impact on people's ability to access treatment. The new situation has already begun to present the human rights issues in different ways. The increasing numbers of children orphaned by HIV/AIDS has meant that many of these most vulnerable children live without legal guardians. This has serious implications for who may give consent to these children receiving access to HIV

testing and antiretroviral treatment. Issues concerning privacy and confidentiality will also be affected. It has been suggested that once treatment becomes available in the public sector, an antiretroviral registry be established to assist in the monitoring of treatment. This will have an impact on how information about HIV status is collected and how confidentiality is maintained.

At the AIDS Law Project, we have already begun to discuss what new areas of work we need to engage in. I hope that as part of this discussion, we will also discuss the need not to misplace our instincts for compassion.

I am here on behalf of the AIDS Law Project to gratefully accept this award. The Project is unique – started by Judge Edwin Cameron in 1993, run by Zackie Achmat after that, and currently led by Mark Heywood, it has a proud tradition of successfully using the law to defend the rights of people infected and affected by HIV/AIDS. The project brings together an unusual group of people with different views about the law and legal activism, but united in their common desire to pursue justice for its clients.

I accept the award on behalf of the project, but in many ways, it really belongs to Mark Heywood. Mark has been a courageous, unflinching and inspiring leader, not only of the project, but of civil society and its response to an irrational government policy. Although he is not a lawyer, he has taught the lawyers of the project, including me, how effectively we can use the law as a tool to advance the human rights of those who are most vulnerable and marginalized. He has remained acutely aware of the need not to forget the names and the faces of those who are poor, sick and dying. His instinct for compassion has guided and immeasurably strengthened the work of the project.

Finally I would like to thank the Canadian HIV/AIDS Legal Network. We have had links with them for the past eight years and although we work in very different environments, the high quality of their work has enriched our work and their quiet support has meant much to us.

# **Presentation of the Canadian Award for Action on HIV/AIDS and Human Rights**

to  
**Laurence Stocking**

*The second annual Canadian Award for Action on HIV/AIDS and Human Rights was presented by the Canadian HIV/AIDS Legal Network and Human Rights Watch.<sup>2</sup> Helping to present the award was Mary Pearson. Accepting the award on Laurence's behalf was his mother, Ena Stocking, and his daughter, Chantelle Stocking.*

## **Mary Pearson Physician and advocate**

It is a great honour to speak a few words about the recipient of the 2003 Award for Action on HIV/AIDS and Human Rights, Laurence Stocking. Laurence was a federal inmate who was incarcerated at Millhaven and Joyceville Institutions for 15 years. He died at the age of 39 while still incarcerated. I was the institutional physician at Joyceville Institution when I met Laurence. I met him through his extensive advocacy work there. His accomplishments ranged from peer counselling and organizing health care seminars with outside agencies for prisoners, to playing a significant role in the production of two prisoner-produced videos on hepatitis, tattooing and harm reduction. He was also instrumental in helping us organize two of the three published studies on the sero-prevalence of HIV and hepatitis, and the risks associated with the contraction of these diseases, within prison. Without Laurence, we would have had no cooperation from the inmates.

He also worked with Maureen Brosnahan of the Canadian Broadcasting Corporation in a series of award winning stories on HIV and drug use. He did this even though he recognized that by breaking the silence, the major code of silence as it still existed in prisons, he was likely to create trouble for himself, if not outright endanger his life. Throughout all this time, he obtained a B.A. in Psychology from Queen's University.

This is only a partial list of Laurence's accomplishments during his brief life. It does not speak to the person behind these accomplishments. Federal inmates are members of a particularly marginalized group living in communities with high HIV rates, high hepatitis C rates and a huge intravenous drug use problem. It is estimated that the rate of HIV infection in prisons is 10 to 70 times the rate in the Canadian population, and that at least 25 percent of prisoners are infected with hepatitis C. Although there are no studies that specifically support this, I believe that in some institutions the rate of intravenous drug use is over 75 percent. Drugs are very easy to come by in prisons. Sometimes they are cheap, sometimes they are expensive, but they are always available. Heroin is usually the drug of choice if it's available.

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<sup>2</sup> See supra, note 1, for a list of the other award sponsors.

For an inmate to speak out in a system such as this is both exceptional and dangerous. To me, it speaks to Laurence's terrific and unbelievable courage and perseverance, and his ability to act despite the fact that he knew his actions were likely to result directly in danger to himself. I am shocked that he was able to accomplish anything. I know what it's like to work in the prison system. For myself, it was hard to get through my clinic some days. And Laurence, even though he seems very accomplished, did not find his work easy. He had his own personal battles throughout the time of his incarceration. He had left a small daughter at home, Chantelle, whom he loved dearly, and he tried to parent as much as he could while he was in jail. He also he left his mother behind, whom he also loved very dearly. Laurence spoke of his family almost every time I saw him and he visited with them every chance he could. He had his own battle with intravenous drug addiction (to heroin), which he managed to get into remission while he was incarcerated. As well, he had other sorts of medical and health problems.

**For an inmate to speak out in a system such as this is both exceptional and dangerous.**

I first met Laurence when he came to my clinic about two days after an appendectomy. He came in, doubled over in pain. I was used to seeing this in prisons because the general philosophy there is that when inmates ask for pain control, they are seeking drugs. In my opinion, when you have pain, you should seek drugs! That's the reason we have pain control. Seeing him in distress, I said to him that he obviously needed some pain control. But he said, "Oh, that's not really why I came. There's this guy down the range who's hearing voices and he really needs drugs. Can you come and see him? He won't come up here." I was totally shocked. But that's the kind of man he Laurence was. That was the beginning of my at least weekly visits with Laurence. I would book him an appointment at every clinic I did. The nurses never knew why I did that, but it was really just so that Laurence could come up and tell me who was in trouble and who needed help, and so that he could speak for those who had no ability to speak for themselves.

Laurence was able to deal particularly well with very challenging people within the system – people with psychiatric illnesses; people with advanced AIDS; people who could not speak, could not ask for their treatment, and were unable to care for themselves. He came every week to help me try to look after these people. Despite all of this, he always had so much joy in his soul. He was always laughing. Laurence was repeatedly silenced and disempowered by Correctional Service Canada (CSC), and the system that it is has created, but no matter what happened his kindness and determination kept him doing the work he was doing to advocate for his fellow prisoners.

I want to describe what it is like to live in a prison. Life in prison is more desperate than I ever imagined it could be. When I first went to work in prisons, I thought that all prisoners told lies, because that's what I had been told. But all that I have learned about health care in prison, I've learned from prisoners. All the horror stories that they told me have turned out to be true. It is an unbelievable oppressive life to live. The rampant use of drugs is associated with the almost total lack of preventive measures, or even diagnostic and treatment measures, to deal with the drug problem. On top of this, we have inadequate resources, and we don't have enough non-judgemental ways to deal with patients that come to us with risks, or with HIV positive tests, or with any other types of tests, around which there is significant stigma. In the prisons, people didn't want to be tested for HIV for many years because they didn't want to be identified as drug



users. It is a crime to be a drug user in prison. It is a crime to have a needle. There are no needle exchanges in Canadian prisons. As a result, 40 or 50 people on a single range may share one needle.

Laurence was instrumental in bringing all of these important issues to the forefront. He wanted a tattoo parlour set up, he wanted open access to methadone treatment, he wanted clean needles, he wanted adequate counselling, and he wanted adequate health care for the many, many inmates that he knew who required health care and were unable to get it. The community standard of health care is not present in prisons. The nurses are overworked, under-trained, overburdened and under-resourced. They have a total lack of access to the kind of compassion renewal program that we all need so much when we work with people like that, a program that would provide care for the caregivers, compassion for the compassionate and comfort for those who comfort.

Essential medications are often missed or not given at all, not because of malevolence on the part of the nursing or medical staff, but because they can't figure out how to do it. I couldn't just write a prescription for a drug. It had to be approved by the administration of CSC. This raises a massive ethical issue, and is one of the reasons why I stopped working in the prisons (temporarily, I hope). You have to decide whether or not you want to practice ethical medicine or do what you're told. If you don't do what you're told, you don't work there very long, or you work there under great duress. They used to cancel my clinics because they thought I was going to treat someone with methadone. I used to write orders for methadone and they would never fill them. I would write orders for hepatitis treatment and they would never give the inmates the medication they required.

They did not really like having people there who were interested in the problems of the inmates, which brings me to one of the very important things that Laurence did – his assistance with the seroprevalence studies for HIV and hepatitis. Dr. Peter Ford and I worked with Laurence to do

**Laurence was a champion at obtaining medications that no one could seem to get any other way, not for him, but for his inmate friends.**

these studies in Joyceville Institution. After we completed the studies, we went to the officials in the CSC Regional Administration office and we said that we wanted to do more studies. We knew that we had a problem, and we wanted to identify the problem, to do clinical research so that we can figure out how to better look after our patients. We had ethics clearance from ethics committee at Queen's University, which is quite hard to get. The officials said that is sounded like a great idea, but that they wanted to run it by their own ethics

committee, which was meeting the next week. So next week came and went; I called and was told that the meeting was delayed. I called the next month; the meeting was delayed again. As far as I know, there is no ethics committee – certainly none that I could find or that has ever tried to find me. So, this is where we still stand with clinical research in the prisons.

Laurence was a champion at obtaining medications that no one could seem to get any other way, not for him, but for his inmate friends. If a patient missed getting his HIV medications, Laurence would personally find the patient and take him the medications. He would rattle the bars and ask the nurses to give the medications out. He would rat out anyone he had to in order to make sure that it didn't happen again. There is one incident that I remember well: One of Laurence's friends, who was very ill, was admitted to our institutional hospital. He was living with AIDS and was on multiple medications, but he wasn't getting the medications. I went in and visited him, and I wrote a note in the chart about the importance of giving medications on time and at the right dose. The next day, I received a letter by courier from the Chief of Health Care saying that what I had written was inappropriate and that they had deleted the file. Of course, I spoke to Administration and they said, "That's nice." And that was the only action I had.

So if this is the kind of barriers that I was faced with, can you imagine what problems an inmate would run into? Another inmate friend of Laurence was HIV positive. He spent about 30 years in prison. He was a very vocal advocate. He was sent to a special handling unit, and he came back without any medical file, and never spoke another word. I have no idea what happened to him. These stories are true. They are from my own experience, not things that I heard.

I would like to tell you about the end of Laurence's life. After Laurence and some of his fellow inmates spoke with Maureen Brosnahan and brought to light some of the terrible problems in Canadian prisons, there was a sudden move of some of these inmates from Joyceville, which is a medium institution, to Millhaven, which is a maximum institution. Some charges were laid, but they were never followed up. Nevertheless, these people spent four months in a closed unit in Millhaven, without any trial or any kind of hearing being given to them. Unfortunately, Laurence was one of these people. He had been an intravenous heroin user when he was at Millhaven previously. He had spent 15 years in prison, so he was coming up to his 15-year review and he was likely to get out of jail. So, this move to Millhaven pretty well devastated him. He went back to a place where all the triggers to his intravenous drug use were, where his past lay waiting for him. While he was there, he began to use intravenous heroin again. One night when he was using, a friend of his down the range knew he was using and couldn't get Laurence to answer, so he called the guards. The guards came and opened his cell. Laurence was there, unconscious and breathing, with a needle present. I don't know why this happened, or how it happened, but he was observed until he died. No intervention was made to save his life. The very health care system that he worked so hard to improve had let him down in the end.

I try not to get too upset. Despite the fact that Laurence himself is gone, his work does live on. There have been many changes. Maybe they were hard for him to see. But change does happen through the energy and actions of people like Laurence. Laurence will inspire us to continue with his work. It was a real privilege to see the humble man that he was, with his fine sense of humour, doing his work tirelessly throughout the time he was incarcerated.

I would like to read you a poem that I wrote. Two days after Laurence's death, I had my youngest child. Laurence liked to write poetry. He would have written this poem, but he didn't have the chance. This poem is what Laurence might have said to my youngest child.

*Oh you with privilege, don't fail to see  
That saints and angels fly all around thee  
Often unlikely, broken or torn  
Open your doors let them be warmed  
Give voice to those silent, care for the sick  
Comfort the lonely, no judgement be quick  
For only compassion, courage and joy  
Will make the world safer, for you my dear boy*

It is a great privilege to present this award for Action on HIV/AIDS and Human Rights to Laurence Stocking. On behalf of Laurence, I'd like to ask his mother, Ena Stocking, the woman who helped create Laurence, to come up; and Chantelle Stocking, the woman Laurence helped create, and who looks just like him, to come up to accept this award.

### **Ena Stocking**

I am very proud to accept this award on behalf of my son. Laurence spoke to me once of the crime he committed. He spoke of the remorse that he felt, and about the fact that he could never undo this crime. He said, "If I spend the rest of my life helping other people, maybe I can atone for this in some small way." This is exactly what he did. I thank you all for the honour that you have given him on this day.

### **Chantelle Stocking**

I am very, very proud to be accepting this award on behalf of my father. It's great to see that his work is finally being recognized, aside from the person that he used to be and the past choices that he made in his life. Unfortunately, I wasn't fully aware of the work that he was doing while he was alive, and I wasn't able to praise him as much as I would like to now. Due to his humble nature, I wasn't aware of it. I feel very, very privileged to be the daughter of such a wonderful and unselfish man. Thank you very much.

## CLOSING SESSION

### Sunday, 14 September 2003

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### Panel on Taking Action on HIV-Related Stigma and Discrimination

*Speaking at the closing panel were Janice Dayle, Miriam Maluwa, Wan Yanhai and Theodore de Bruyn. In introducing the panel, Theodore said that there is now global recognition that we must reduce or eliminate the many forms of stigma and discrimination associated with HIV and AIDS, so that people with HIV and people vulnerable to HIV can benefit from the information, support, care or treatment that they need and have a right to. Theodore said that taking action on HIV-related stigma and discrimination is the focus of the current two-year World AIDS Campaign sponsored by UNAIDS; that it is the focus of a current three-year campaign of Global Network of People Living with HIV/AIDS and the International Federation of the Red Cross and Red Crescent; and that is also the focus of a three-year project sponsored by the Canadian HIV/AIDS Legal Network with funding from the Canadian Strategy on HIV/AIDS.*

*Theodore said that we all know how difficult it can be to change stigmatizing attitudes and discriminatory behaviours. So much is influenced, he said, by the laws, customs, social structures, power dynamics, resources, advocates and grass-roots support in a country or community. But, Theodore said, we also know stories of bravery and breakthrough, of solidarity and support, of justice and equity. He added that this panel session will remind us of what is common to, and what can be achieved by, efforts to break down HIV-related stigma and discrimination here and the world over. The following are edited verbatim transcripts of the remarks of the panellists.*

#### **Janice Dayle** **Activist**

*Janice Dayle is a 48-year-old HIV-positive grandmother of eight and mother of six. She is a Jamaican national residing in Canada since 1968. In 1999, Janice decided to come forward and use herself as an example to affect change in responses and policies surrounding HIV/AIDS. She has served as a board member to an AIDS service organization for women, Centre d'Action Sida Montréal, and is currently a director on the board of the Global Network for People Living With HIV/AIDS – North America and the board of AIDS Community Care Montréal. She is also a Key Correspondent for the Health and Development Network, which is running a global electronic discussion on HIV-related stigma and discrimination.*

I would like to start with some definitions, so that we have a clear sense of what the problem is that needs resolving, so that we can be certain of the factors that distinguish stigma from discrimination, and so that not only are we more aware of the mammoth task at hand, but we also have a comprehensive outline of what the ultimate aim is.

Stigma connotes a mark of disgrace, a spot or scar on the skin. Being synonymous to words like “shame,” “dishonour,” “infamy,” “blemish,” “blot,” “taint” and, most indelibly, “stain” – as well

as to words like “discredit,” “brand,” “defame,” and “humiliate” – stigma, in the HIV/AIDS context, sprang out of the common outlook of a society that identified anything other than heterosexual relationships as immoral, disgraceful and wrong. The same perceptions were made about other groups who were thought of in the beginning as being the most vulnerable to HIV/AIDS, like intravenous drug users and sex workers, and who have emerged, reportedly, as being the groups most affected in terms of new infections. (I say “thought of,” because in reality HIV/AIDS does not discriminate, so everyone is vulnerable and this fact should be recognized and promoted widely.) Therefore, HIV/AIDS, as a communicable sexually transmitted disease, was immediately equated with everything society had been taught was negative.

Discrimination goes with the words “prejudice,” “inequity,” “intolerance,” “unfairness,” “bigotry” and “bias.” To discriminate is to make distinction, to differentiate. In the HIV/AIDS context, this differentiation takes the form of exclusion and ill-treatment, and springs from intensely ingrained stigma around the issue.

In 2002, I heard the great Nelson Mandela addressing the closing plenary of the XIV International Conference on HIV/AIDS. He said that it is a difficult task to attempt the transformation of a society that has engrained values and belief systems that would require the uprooting of entire traditions and customs in order to enact change. But, he said, it must be done. He called on world leaders to see to it that change comes about.

My colleagues say to me that we can’t change the world. I say that we have to. I also say that it has been done before, so we must draw on the experiences of all the world’s advocacies against all other forms of discrimination, and we must mimic those actions. With its aims firmly placed in the forefront, and with a clear understanding of the barriers, society must make concrete plans to eradicate HIV/AIDS-related stigma and discrimination. We have to plan actions around eliminating the derogatory connotations automatically associated with HIV/AIDS. Since HIV/AIDS does not stand alone, we are forced to attend also to eliminating intolerance for vulnerable groups.

The ultimate goal should be to realize a world where all persons living with HIV/AIDS feel unthreatened, and are able to openly announce, in any arena, under any circumstance, “I am HIV positive,” and expect to be treated with utmost respect and equity following that disclosure. I asked an HIV positive woman why she found it difficult to disclose her status generally, and she said, “I don’t want to be further scorned and rejected.” I asked her why she thought that she would be scorned or rejected. Her response was that she too was scornful of persons living with HIV/AIDS prior to becoming infected herself. She had internalized the damning stigma and it had manifested itself as self-hatred. This fear is the driving force of the wild, seemingly unstoppable spread of HIV/AIDS, and it doubles as the most painful, burdensome and crippling element of being a person living with HIV/AIDS.

**The ultimate goal should be to realize a world where all persons living with HIV/AIDS are able to disclose their status and can expect to be treated with utmost respect and equity.**

So this is what we are up against – that indelible shame and stain; the way society has been taught to respond as a result of the branding; how difficult it is to alter customs; the effects on persons living with HIV/AIDS; and the ultimate results of continuous oblivion to the situation. In

response, we must make strategic plans to wipe out HIV/AIDS related stigma and the resulting discrimination. Having identified many of the problem words, we now need to form questions around these words – like how do we unearth entrenched ideals that associate the words “shame” and “dishonour” with some sexual preferences; “infamy” and “irreparably blemished” with drug addiction; and, most importantly, “inequity,” “unfairness,” “disgrace,” “stain” and “humiliation” with HIV/AIDS?

My instinctive answer is education. It has been over 20 years since this disease of mine has been around. I cannot begin to tell you how much I have learned as an individual in 20 years. I am referring to learning outside of HIV/AIDS. Just think about how much education one can get in 20 years. I am saying this to draw attention to the vast amount of education that could have been initiated through concerted global efforts all these years, education that would have prevented the massive destructive force HIV/AIDS is today. We must learn from our mistakes. We must consider the future. We must the plan to painstakingly educate each corner, each crevice, each area of our society in an effort to avert the perpetuation of an intolerant world, a world that is bent on clinging to destructive notions, and even traditions that, in turn, cause the exacerbation of stigma and discrimination around HIV/AIDS and, subsequently, increased infections. Since the world is on the whole a migrant society, emphasis must be placed on culturally sensitive education.

Another vital area for consideration ought to be the Greater Involvement of People Living With HIV/AIDS, called the GIPA Principle, which would have invaluable ramifications both for the empowerment of HIV positive people (it would help to purge internalized stigma) and for the eradication of stigma and discrimination. First we have to educate our leaders. To make sure that the myths are diffused, we need intensified education and awareness from the cradle up. Our leaders must also be held accountable for the lack of awareness, and must seek ways of integrating sustained educational efforts amongst their constituents.

There is little evidence of serious efforts to stop the spread of HIV/AIDS related stigma and discrimination. There are many dinners, many trips, many conferences that seem to rotate

**We must plan to painstakingly educate each corner, each crevice, each area of our society in an effort to avert the perpetuation of an intolerant world.**

constantly around the converted, but very little change in government policies concerning the inclusion of HIV/AIDS education as a subject in itself, not affiliated with any other subject. We make sure that our children can read and add. We also have to make sure that HIV/AIDS education, this new necessary life skill, is also implemented in educational curricula. This education has to become accessible not only in school systems at every level, but also to the masses. At the top of the prospectus should be education around being tolerant of differences. In a sense, we could say that

HIV/AIDS has brought mankind to the point where we must deal seriously with our ridiculous tendencies to be incessantly damning.

While children and youth have shorter attention spans, and need a classroom setting to fully absorb things, our adult population takes much of its teaching from the media. The media has played a key role in forming conceptions. I am an advocate of monitoring the media's coverage

of HIV/AIDS, and I was happy to see the emergence of a journalist scholarship offered at the last International AIDS Conference. Journalists with scholarships were invited to a seminar linking journalists globally, and sensitizing journalists to the facts and key issues around HIV/AIDS reporting. This is another type of educational process that shows progressiveness in the fight against HIV/AIDS-related stigma and discrimination. Educating journalists who have been guilty of perpetuating stigma, and who have even been blatantly discriminatory themselves, is essential in this struggle. Journalists' access to millions of attention spans daily places them in a highly important position.

Efforts to educate journalists have proven beneficial. There was evidence of that recently within the Global Network of People Living with HIV/AIDS (North America), when our media watch section of the communications committee engaged in enlightening dialogue with a writer about a questionable comment made at the end of an otherwise delightful piece on HIV/AIDS prevention and women.

Then there is the arts. Known to transcend differences, music, in particular, is popular for its therapeutic properties. Unfortunately, this is not the case for those lyricists, singers and producers of mainly reggae songs laced with hatred and terrorist lyrics about annihilating gays and lesbians. Traditionally held in high acclaim by a growing culture of homophobic thinkers, these songs drive home the idea that murder is right when perpetrated against gays and lesbians. These popular lyrical trends perpetuate HIV/AIDS-related stigma and the inhibitions of gay men. As well, it not only inhibits, but totally cripples, the overall wellness of black gays and lesbians. I believe that recognizing and eliminating the gravity of this should also be in the hands of legislators.

Workers in AIDS service organizations (ASOs) have been known to often lament that they do not know what issue is triggering discrimination against persons living with HIV/AIDS, whether it is one of the multiple vulnerabilities, like poverty or addiction, or just HIV. As a result, ASOs need to be equipped to take action against all forms of intolerance. Unfortunately, some of the worst discrimination against persons living with HIV/AIDS comes from some ASO workers and volunteers (they are in the minority, but they exist). What makes this so terrible is that we enter these arenas for support, not to be hurt. If they don't already have one, all ASOs should adopt a complaints process and policy in order to weed out and correct this ever-present phenomenon.

Promoting the advancement of persons living with HIV/AIDS, with an emphasis on encouraging them to achieve normalcy in their lives, would be excellent action to pursue. Taking action means fighting against stigma and discrimination until there is evidence that we are emerging victorious. This evidence will be in the form of reduced HIV infection rates and reduced death rates globally. It will also take the form of the global realization of a greater quality of life for persons living with HIV/AIDS, who could then take off the armour of defeatist words that we subconsciously dress ourselves in daily, shed the fear, and eventually really realize that that we can live with a chronic manageable disease in a manner similar to our diabetic "colleagues in illness," or to others who are chronically ill and yet free from stigmatization and discrimination.

**Miriam Maluwa**  
**Law and Human Rights Advisor**  
**Joint United Nations Programme on HIV/AIDS (UNAIDS)**

*Miriam Maluwa has been UNAIDS' Law and Human Rights Adviser for the past five and a half years. Miriam has 17 years experience in legal and human rights work. Some of her major activities have included: serving as Legal Adviser and Chief Parliamentary Draftsperson to the Malawi Government; serving as representative to the UN Commission on Human Rights (Geneva, Switzerland); serving as the Chairperson of the Malawi National AIDS Board; serving as Secretary for UNAIDS Ethical Review Committee; providing pro-bono legal services to abused women and children; and serving as a Consultant on Legal and Human Rights issues for the European Union, United Nations Development Programme, the British Council, the International Labour Organization and the United Nations Children's Fund (UNICEF).*

My presentation will focus on how UNAIDS understands stigma and discrimination, and on the strategies that we employ to combat stigma and discrimination.

Taking action on stigma and discrimination is not really a choice, it is an absolute necessity to effectively respond to the HIV/AIDS pandemic. It is the greatest barrier to addressing HIV/AIDS. Our experience shows that even though we now have HIV-related treatment, we are failing to treat people because stigma and discrimination is rampant, and because people are unwilling to participate in treatment program. Further, stigma and discrimination continue to hinder prevention in a number of ways. Some people are unable to access prevention because they belong to stigmatised groups. Due to fear of stigma and discrimination, people who are infected continue to pretend that they are not infected, and this creates vulnerability for the rest of the community. Stigma and discrimination also continue to exacerbate the impact of the epidemic. People not only have to worry about being HIV positive, they also have to worry that they are going to lose their human rights because of it, that they are going to suffer injustices, and that they are going to be made to feel very worthless. The sheer magnitude of the problem explains why we need to take action.

Stigma and discrimination are universal. They manifest themselves differently in different contexts and to different people, but they are universal. This makes stigma and discrimination a uniting factor. Normally, issues are marginalized because they don't ring true for all, but stigma and discrimination affect everybody. They do affect some people more than others, of course, particularly when the stigma and discrimination is compounded. For example, if a person is a woman, is black and is HIV positive, she may face stigma and discrimination based on all three of these attributes. Stigma and discrimination are a problem both in countries with high HIV prevalence rates and in countries with low prevalence. Stigma and discrimination are thus entry points for mobilizing everybody – individuals, communities and institutions all over the world.

But we cannot really talk about taking action unless we understand what we are taking action against. I am convinced that one of the reasons we have not been as effective as we could be in addressing stigma and discrimination is because we have never really taken the time to understand it. Many times stigma and discrimination is so subtle that we do not notice it and we do not act against it. Because we do not act against it, we condone it. Because we condone it, we perpetuate it. So, we need to pause and ask ourselves, "What do we understand stigma and



discrimination to be?" We need to identify the elements of HIV/AIDS-related stigma and discrimination and then start addressing them concretely.

Let me make several points about stigma. First, stigma is not a new phenomenon; it has always existed. Second, stigma is not an act; it is a process of devaluation. This means that our strategies to address stigma have to evolve because the process is a moving target. Finally, stigma does not exist naturally; it is created. Because stigma is man-made, it can be unmade.

HIV/AIDS-related stigma reinforces existing prejudices, such as those related to homosexuality, gender and race. People tend to blame HIV/AIDS on women, or gay men or black people. Our strategies need to reflect this reality. To take action against stigma and discrimination means that we need to challenge the very foundations of society. We need to challenge the existing power relations and inequalities.

UNAIDS has tried to better understand stigma and discrimination so that we can better address them. We have undertaken studies in Uganda and in India to examine how stigma and

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discrimination manifest themselves – what form they take, what the context is, and what the determinants of stigma and discrimination are. Other studies that we have done in countries such as Ghana, Burkina Faso and Cameroon have taught us that stigma and discrimination are not one and the same. Stigma relates to the thoughts that people have at an individual or community level. When these thoughts are acted on, this leads to acts of discrimination. So, we need to look at strategies that address stigma in terms of preventing

it from starting, and in terms of overcoming people's prejudices. But we also need to address the discriminatory actions that ensue from these prejudices.

Discrimination can also result from an omission, in situations where action should have been taken but was unfairly not taken. When the human rights awards were presented at the beginning of this meeting, we learned that Laurence Stocking was left to die in his prison cell, and that no action was taken to try to save his life. This is an example of discrimination through unfair omission.

Studies undertaken by UNAIDS confirm that stigma and discrimination are very much linked to human rights violations. Everybody has the human right not to be discriminated against, so when discrimination happens it is a direct violation of that right. More importantly, stigma and discrimination can lead to the loss of other human rights. For example, people who are HIV positive may be refused their right to health because of their HIV status; then, when they start falling ill, they may not be able to go to school to be educated, they may not be able to work, they may not be able to obtain adequate housing, and so on.

Stigma, discrimination and human rights violations are a vicious cycle. Our strategies must aim to break the cycle. The UNAIDS approach has been to view stigma, discrimination and human rights violations as three entry points for action. Each one needs to be addressed separately, as well as together with the other two. We need to develop strategies that address stigma as thought.

We need to develop strategies that deal with discrimination once it has occurred. And we also need to ensure that human rights violations are addressed and that there are policies and legal structures in place that protect the rights of people living with HIV/AIDS.

We need to think of this phenomenon as a cycle. We must find a way to take action at all the three levels, and we must break the chain. This means that we need to take a multi-pronged approach towards dealing with stigma and discrimination. The various elements of the strategy must complement each other, and they must have one common objective – to prevent stigma, to challenge discrimination and to redress any human rights violations that ensue.

As part of the strategy to address stigma, UNAIDS supports advocacy work with religious institutions and political leaders to get them to show compassion towards people living with HIV/AIDS – by eating with them, by talking with them, and by telling their constituencies that compassion and respect is the right approach. Simultaneously, we are also addressing discrimination through supporting litigation where the human rights of people living with HIV/AIDS have been violated. We have supported taking these cases to court. Many of you will recall a case not too long ago in India, where a person living with HIV/AIDS was deemed to have no right to marry. We were able to support an NGO, the Lawyers Collective, to challenge that particular ruling. The Canadian HIV/AIDS Legal Network was involved in the research for this case. We also worked in South Africa to support litigation relating to an airline cabin attendant who was refused employment because of his HIV/AIDS status. We also did some media work in Namibia relating to the dismissal from the military of a person who was HIV positive. We are challenging discrimination as one strategy towards breaking the cycle. Complementary to the above, we have also started rights awareness programs in Burkina Faso, Ghana and Tanzania that look at ways to bring the law to the people. We have hired indigenous lawyers and set them up within community-based organizations. They receive complaints from people living with HIV/AIDS and take up those complaints within administrative and judicial systems.

We all need to take action. Our ultimate objective in addressing stigma, discrimination and human rights violations should be to transform societal thinking – to change behaviours and to change people's conceptual thinking – but also to examine the structural environments and the deep rooted nature of injustices, and to address inequalities that already exist within the society in order to ensure that violations of human rights are no longer sustained. If we challenge violations, if we redress them, then these violations cannot be sustained because people will be held accountable. People will know that they will be accountable for the actions that they take, and that is enough already to start the train moving.

**Wan Yanhai**  
**Director**  
**Beijing AIZHIXING Institute of Health Education**

*Dr. Wan Yanhai is coordinator of the AIZHIXING Institute, a non-governmental organization he founded in 1994. Dr. Wan's work on HIV/AIDS, which began in the late 1980's, has been characterized by strong advocacy for the rights of people infected and affected by HIV/AIDS in China, most of whom have experienced severe discrimination. This began with his advocacy for gay men, sex workers, and people who use drugs, and has continued with the work of the Institute on behalf of orphans whose parents have died of AIDS and rural villagers in Henan Province who contracted HIV through unsanitary blood-collection practices. Last year, Dr. Wan was awarded the first International Award for Action on HIV/AIDS and Human Rights for his action and advocacy.*

I am honoured and excited to be here to share with you our experiences in China. My presentation will be about HIV/AIDS as a human rights issues in China. On the opening day of this meeting, Stephen Lewis said that HIV/AIDS was all about human rights. I think that the example of China illustrates very well the point that Mr. Lewis made. And I think that, in China, human rights violations are not just related to stigma, they are also related to selfish political agendas.

First, I want to talk about the right to information in China as it relates to AIDS. From the beginning of the epidemic in China in the early 1990s, and even up to the present day, people who were found to be HIV positive through testing have not been told that they are infected. In Anhui Province, people were taught about the symptoms of AIDS, about how to prevent the disease, and about how to find a doctor if they got sick, but they were not told that the name of the disease was AIDS. So people couldn't link the messages from the mass media about AIDS to their own illness.

The government covered up information about AIDS, particularly in Henan Province but also in China generally. That is illegal. Our Infectious Disease Law requires that information on infectious diseases be publicized immediately, but our government has been breaking this law since the beginning. Last year, I was detained for leaking state secrets, but there is nothing about health information in the State Secrecy Law, and there was no reason to classify the document I made public as secret.

In China, the government owns the media. There is no independent media. The media in some provinces were not allowed to talk about blood issues. The Party Central Propaganda Department prohibited any reporting about AIDS in Henan. As well, our government wants to control information sent via the Internet and via cell phone messaging.

In Henan Province, people living with HIV/AIDS who got infected by selling blood or through blood transfusion were not allowed to take legal action. The Provincial Government ordered the courts not to accept any legal lawsuit for compensation. If people went to the government to ask for drugs, for support, for education or for assistance for orphans, they could be detained. This is exactly what happened last June. Five activists from one village were detained in the capital city of Henan Province. Some of them are still in the detention centre.

Our government strictly controls NGO development. There are some emerging NGOs in China, but the regulations are very strict. As a result, some environmental organizations, women's organizations and AIDS organizations (like our Institute) try to obtain official registration as an enterprise instead of as an NGO. Our Institute is registered as an enterprise and, as a result, we have to spend a lot of our time reporting on taxes. The Chinese government has no money for NGOs in China. NGOs that obtain funding from overseas, or that have contact with foreigners, risk being accused of spying for other countries. There are still no independent human rights institutions working on these issues in China.

The impact of the AIDS epidemic on children in China is huge. The government has admitted that blood selling caused an AIDS epidemic in 23 provinces. Millions of people could be infected in China, many of them in Henan Province. In some villages, almost half of the adults have been infected. Many have already died, leaving behind large numbers of orphans. Many children cannot go to school because of discrimination and lack of funding. Some children get some support for education, but they still don't have enough money to live. In some villages, people try to organize to help provide education and support for the children, but the people are often harassed by the government. This harassment sometimes takes the form of the Secrecy Department knocking at the doors of these people and issuing them a warning.

**NGOs that obtain funding from overseas, or that have contact with foreigners, risk being accused of spying for other countries.**

In China, there is still a lack of voluntary testing, especially for former blood donors, most of whom have not been tested. As for people who used blood or blood products, the government is not willing to provide free testing to enable them to find out how many of them got infected and how many of them transmitted the virus on to a wife, husband or child. On the other hand, China now imposes compulsory testing for sexual workers, prisoners, drug user, blood donors and patients of STD clinics.

In some provinces, especially in Henan Province, the government tries to stop people from asking for compensation or even talking to each other. Government officials tell people that having AIDS is shameful and that if they told others about it, their sons will not be able to go to school and their products will not be sold. Also, they use political measures to prevent people from advocating and organizing themselves. People who communicate with foreign international journalists, embassies or the United Nations can be labelled a traitor. A New York Times journalist, Elizabeth Rosenthal, who reported on the Henan AIDS epidemic in October 2000, was called a U.S. spy by a government official. Some doctors are challenged for having relationships with foreigners. Last year, our project was labelled an illegal social organization because we had contact with people in Taiwan and the United States.

In China, sex work and drug use is illegal, and people who engage in these activities can be detained. Many researchers, educators, journalists, activists and families of persons living with HIV/AIDS have been persecuted in the past ten years. I lost my job because of my AIDS activities. Local authorities monitor doctors 24 hours a day. Some doctors have lost their jobs, and their institutes have been closed. Journalists and activists have been detained. I was detained for four weeks. Last June, in Henan, hundreds of armed police and government officials attacked

a village of less than 600 people. More than 10 people were beaten; 13 people were detained. Many of these people are HIV positive, and some of them are still being held after three months.

In conclusion, let me tell you a little bit about what our Institute is trying to do. The AIZHIXING Institute has been working on AIDS-related human rights advocacy for the past 10 years. We also do some research on policy and legal issues. In the 1990s, we translated documents from UNAIDS. We have done research on how children have been affected by the AIDS epidemic. We recently published a report and translated documents from the United States Agency for International Development (USAID) and the United Nations Children's Fund (UNICEF) on the subject of how other nations are working to help children orphaned by AIDS. We support people to get organized and get involved in AIDS campaigns. We support students to set up student organizations and to get others involved in AIDS issues. We support farmers to become organized. We also do some informational and educational activities. We plan to continue all of these activities, but our goal for the next few years is to systematically organize our AIDS legal education and investigation work.

Thank you for providing me with this opportunity to speak to you.

**Theodore de Bruyn**  
**Senior Policy Analyst**  
**Canadian HIV/AIDS Legal Network**

*Theodore de Bruyn has been a member of the Canadian HIV/AIDS Legal Network since 1996. He has written many reports and articles for the Network and joined the staff of the Network on a part-time basis in April 2003. Theodore served for three years as Senior Policy Analyst on HIV/AIDS with Health Canada. He has worked as an independent researcher and consultant, in which capacity he has contributed to strategic planning in HIV/AIDS, policy development in complementary and alternative therapies, and work on health promotion. From 1997 to 2002, Theodore chaired the National Ethics Review Committee of the Canadian HIV Trials Network.*

My presentation will focus on the need to take action in Canada against HIV/AIDS-related stigma and discrimination.

It has been almost 25 years since the first AIDS case was diagnosed in Canada,<sup>3</sup> 13 years since the federal government announced its first national AIDS strategy, and five years since the Canadian AIDS Society and the Canadian HIV/AIDS Legal Network published its discussion paper on HIV/AIDS and discrimination.<sup>4</sup> Where are we now in our fight against HIV-related stigma and discrimination? Not as far as we should be.

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<sup>3</sup> As reported to Health Canada; see Health Canada. *HIV/AIDS in Canada: Surveillance Report to June 30, 2002*. Ottawa: Minister of Public Works and Government Services, 2002, at 23.

<sup>4</sup> T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network and Canadian AIDS Society, 1998  
([www.aidslaw.ca/Maincontent/issues/discrimination/discussionpapers/DISCtoc.html](http://www.aidslaw.ca/Maincontent/issues/discrimination/discussionpapers/DISCtoc.html)).

For the past year the Network has been preparing an update on HIV/AIDS-related stigma and discrimination, with the help of an advisory committee and organizations serving specific populations. I have interviewed support workers across the country and held focus groups with people with HIV. I won't say that we haven't made any progress since 1998, when the discussion paper was published. We have. There has been a sea change in the recognition and protection of the rights of gays and lesbians, thanks to the work of EGALE, individual lawyers, and gays, lesbians, bisexuals and transgendered people across Canada. There is widespread acknowledgement of the ways in which social and economic inequality, historical and ongoing, contribute to the HIV epidemics in so many populations. There has been some success in ensuring that prisoners have access to supplies and programs that will prevent HIV transmission and access to medical care and treatment for HIV.

But too much is still the same or even worse for people affected by the HIV epidemic, particularly poorer or more marginalized people. There are still many systemic barriers that make it difficult, if not impossible, for marginalized people to obtain the social services, health care, and drug treatment they should be getting. There are still violations of the rights of women, drug users, street-involved people, prisoners and others with regard to testing with informed consent, access to information and services, and so on. There is still professional behaviour that demeans and discriminates against people on social assistance; women; youth; people who use drugs; prisoners; Aboriginal people; gays, lesbians, bisexuals, and transgendered people; and people of colour. There is still a lack of comprehension of what it means to live physically, emotionally, spiritually and sexually as a person with HIV. We have failed to adapt health care, the workplace and social life to enable people to live as well as possible with HIV. And, on an individual level, I continue to hear stories of people living with HIV/AIDS who feel like they are marked as they walk down the street, who have been let go from their jobs, who have been evicted from their apartments or harassed by their landlord or other tenants, who have been beaten up, who won't enter the door of an AIDS service organization because they fear the consequences of this becoming known, who have been refused to be taken on as a patient by a doctor, who cannot afford to let anyone in their community know they are HIV-positive because it will mean social isolation, and who have been stigmatized by other people in the cultural community with which they identify.

**There are still many systemic barriers that make it difficult, if not impossible, for marginalized people to obtain social services, health care, and drug treatment.**

The Canadian Strategy on HIV/AIDS has developed a draft five-year strategic plan for the Canadian response to HIV/AIDS, based on priorities identified by participants at a meeting in St Adèle (Québec) in late 2002. One of the priorities identified at that meeting was reducing HIV-related stigma and discrimination against people with HIV. As far as I know, this is the most explicit statement in the history of Canada's national HIV/AIDS strategies that reducing HIV-related stigma and discrimination has to be a priority. This is not to say that HIV programs, past and present, haven't tried, and tried hard, to create a more supportive environment for people living with, or affected by, HIV/AIDS. But it is a frank acknowledgement that we haven't changed some of the fundamental realities for HIV positive people or people vulnerable to HIV.

So what should we do now, 25 years into the epidemic in Canada? First, in communities where there is public reproach or unspoken shame around HIV – the reproach and shame that makes it unsafe to disclose that you have HIV – we must fund community activists and organizations to work over many years with members of the community, to mentor people with HIV, to engage leaders, to open up discussion and to challenge myths. This is not the work of a report or even a project. It is the work of a sustained program that gets more and more people in the community thinking and talking and acting about HIV in a non-judgmental way.

Second, to respond to specific systemic issues of inequality and discrimination that affect particular populations – issues such as the lack of relevant, honest, and non-judgmental education about HIV, or gay/lesbian/bisexual/transgendered sexuality, or drugs in high school curricula; or the failure to provide uninterrupted antiretroviral medications to prisoners and people who use drugs at a standard equal to that available to others; or the poor treatment in emergency rooms of people who use drugs; or the failure to respect the rights of women and prisoners and others to consent, with information, to any medical procedure (including HIV testing); or the lack of flexibility in social assistance programs for people with a lifelong disability and fluctuating health; or the lack of safe and affordable housing for people with no or low income; or the failure to accommodate people with HIV in the workplace; or the lack of comprehensive harm reduction programs (including needle exchanges) in prisons; or the need to educate social assistance workers or health care workers about non-discriminatory responses to diverse people with HIV; or the lack of research on prevention technologies and treatment modalities specific to women – to respond to these system issues, we must fund organizations and coalitions to develop and implement strategies for change. Again, this is not the work of a report or even a project. It is the work of a

**We must fund organizations and coalitions to develop and implement strategies for change. This is the work of a sustained program.**

sustained program that follows developments in policy and services, puts accurate information before the public, makes the case with politicians and public servants and other parties, mobilizes groups to demand change and, if necessary, takes legal action.

Third, to provide support to individuals who experience discrimination related to HIV/AIDS, we must fund a combination of activities that includes the following: advocacy and support services in organizations accessible to, and used by, populations affected by HIV/AIDS; capacity building with local lawyers to provide legal assistance with human rights complaints, tenants' complaints, grievances against employers, complaints about health care providers, and similar actions; advocacy with the provincial and territorial bar associations and the provincial and territorial governments to increase rates for, and access to, legal aid; and national, regional, or local litigation strategies. Again, this is not the work of a report or a project. It requires a sustained program.

I want to emphasize that in each of these areas we need sustained programs. The attitudes, behaviours, and systems that contribute to stigma and discrimination against people with HIV or people vulnerable to HIV simply do not change easily or quickly. We already have many things in place to help us. We have laws that protect human rights. We have a network of organizations that can take action on discrimination. We know what the issues are, having documented them in

local and national reports. What we need are sustained programs to develop and implement strategies to address these issues. This means, among other things, multi-year funding. But it also means a powerful commitment on our part to insist on and to work for these types of programs. Change will not come spontaneously from the individuals, organizations or systems we would like to change. It will come because we insist on it, sometimes nicely, sometimes loudly, usually again and again, and occasionally in court. Since the federal government is consulting right now on proposed strategic directions for the Canadian Strategy on HIV/AIDS, and since many organizations involved in HIV/AIDS have asked for substantially more funding for the Strategy, let's begin there. Let's insist on sustained funding for community activists and organizations to get more and more people in the community thinking and talking and acting about HIV in a non-judgmental way. Let's insist on sustained funding for organizations and coalitions to develop and implement strategies for change to respond to specific systemic issues of inequality and discrimination such as the ones I mentioned above. And let's insist on sustained funding for advocacy and support workers, capacity building with local lawyers, advocacy around legal aid, and litigation in order to help individuals who experience discrimination related to HIV/AIDS.

This year on World AIDS Day, the Canadian HIV/AIDS Legal Network will issue a draft plan of action on HIV/AIDS-related stigma and discrimination. The draft will be based on information gathered through research, interviews with advocacy and support workers, focus groups of people with HIV/AIDS, advice from an advisory committee, and comments from participants in a two-day workshop. The Network will be turning to you for comments and support. We'll be getting in touch with you closer to the day to say how you can do this. And in the meantime I would welcome your comments or ideas about the three broad areas of action I have discussed.