CANADIAN HIV•AIDS LEGAL NETWORK | RÉSEAU JURIDIQUE CANADIEN VIH•SIDA

Ten Years of Action for Health and Human Rights

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

Montréal (Québec)
13-15 September 2002

CANADIAN | RÉSEAU
HIV•AIDS | JURIDIQUE
LEGAL | CANADIEN
NETWORK | VIH•SIDA

417, rue Saint-Pierre, suite 408
Montréal (Québec) H2Y 2M4

Tél. : (514) 397-6828
Fax : (514) 397-8570

www.aidslaw.ca
info@aidslaw.ca

Montréal, November 20, 2002

Dean,
Thanks again!
R

Mr. Dean Wilson
#103-101 East Hastings Street
Vancouver, BC V6A 1N5

Dear Dean,

Enclosed you will find a booklet of the presentations made during the opening and closing plenaries of the Network's 2002 AGM and Skills Building Workshops.

On behalf of the Legal Network and all who attended this year's meeting, I would like to thank you once again for your valuable contribution to our 10th anniversary commemorative activities.

Sincerely,

Ralf Jürgens
Executive Director

Enclosure

The Canadian HIV/AIDS Legal Network is a partner organization of the AIDS Law Project, South Africa.
Le Réseau juridique canadien VIH/sida est un partenaire actif du AIDS Law Project de l'Afrique du Sud.

Charitable Registration Number
Numéro d'organisme de charité
141110155 RR0001

Ten Years of Action
for Health and Human Rights

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

13-15 September 2002, Montréal

edited by David Garmaise
for the Canadian HIV/AIDS Legal Network

For further information about this paper, please contact:
Canadian HIV/AIDS Legal Network
Tel: 514 397 6828
Fax: 514 397 8570
Email: info@aidslaw.ca
Website: www.aidslaw.ca

Further copies of this document can be retrieved at
www.aidslaw.ca/Maincontent/events/agm2002.htm

Partial funding for this paper was provided by Health Canada
under the Canadian Strategy on HIV/AIDS.

Ce document est également disponible en français.

TABLE OF CONTENTS

Preface
Message from the AIDS Law Project, South Africa
Page 1

Executive Summary
Page 3

OPENING PLENARY

Welcoming Remarks
Page 9

Keynote Address
Legal and Human Rights Challenges
for People Living with HIV/AIDS:
A Personal Perspective
DAVID HOE
Page 11

Presentation of the
Canadian Award
for Action on HIV/AIDS and Human Rights
to the Vancouver Area Network of Drug Users
Page 22

Presentation of the
International Award
for Action on HIV/AIDS and Human Rights
to Dr. Wan Yanhai
Page 27

CLOSING PLENARY

Act Up for Life –
A Call for a Return to AIDS Activism
RALF JÜRGENS
Page 33

Facing Down an Ugly Politics:
A Global View of HIV/AIDS and Human Rights
JOANNE CSETE
Page 41

PREFACE

Message from the AIDS Law Project, South Africa

Unfortunately, the AIDS Law Project (ALP), partner organization of the Canadian HIV/AIDS Legal Network, was unable to send a representative to the AGM. The following message was read aloud at the AGM.

Dear colleagues, comrades and friends,

We regret that it is not possible for a member of the ALP to participate in your AGM this year. I have fond memories of being in Montreal at the 2001 AGM, and of the sense of common purpose between the Legal Network and the ALP that I found there. Unfortunately, all of our staff members are involved in litigation or advocacy at this time, and it has been impossible to free anyone to travel to Canada.

However, I would like to take this opportunity to restate how highly we value the efforts of the Legal Network, which has many practical benefits for our day-to-day work. For example, as I write this message today, UNAIDS and the Office of the High Commission for Human Rights have published the revised Guideline 6 of the International Guidelines on HIV/AIDS and Human Rights, which will be immensely helpful to our struggles. This guideline would not have seen the light of day without the work of Richard Elliott and the support of the Legal Network. On another matter, we have recently been indebted to the work done by Lori Stoltz, your former president, on the HIV/AIDS testing policies of UN peacekeeping forces. Lori's work will directly feed into litigation that we are running, challenging the constitutionality of the South African Defence Force's policy of mandatory HIV testing and exclusions of recruits with HIV.

With respect to this litigation, I regret to announce that we learnt yesterday that our client in the case has died. Deaths such as this one, and the deaths of many of our friends, remind us of what our work is all about. We know that it will remind you, too, despite the fact that you live in a country where for many, but by no means for all people, the barriers for access to treatment have been overcome.

We wish you well with your AGM and look forward to a continuing relationship with the Legal Network.

In closing, I would like to congratulate the Legal Network and Human Rights Watch on giving the award on HIV/AIDS and Human Rights to Dr. Wan Yanhai. We urge you to step up the clamour of demands for his release by the Chinese government.

Yours in the struggle for health and human rights,

Mark Heywood
Head, AIDS Law Project

EXECUTIVE SUMMARY

This year the Canadian HIV/AIDS Legal Network is celebrating its 10th anniversary. "Ten years of Action on Health and Human Rights" was the theme of the Network's 2002 Annual General Meeting, held in Montréal from Friday, September 13th to Sunday, September 15th. The opening plenary of the AGM, which was held on the evening of September 21st, featured welcoming remarks, a keynote speech, and the presentation of the first annual Canadian and International Awards for Action on HIV/AIDS and Human Rights. The formal business of the AGM was conducted on September 14th. On September 15th, several skills building workshops were presented. The workshops were followed by a closing plenary which featured two presentations, one on the need for more activism in the Canadian response to HIV/AIDS, and one on international HIV/AIDS and human rights issues. This document contains a summary of the welcoming remarks, and edited texts of the presentations made at the opening and closing plenaries.

Opening Plenary

Delegates were officially welcomed by Carole-Marie Allard, Member of Parliament for Laval, representing the federal government; and Horatio Aruda, Directeur de la Protection de la santé publique, Ministère de la Santé et des Services sociaux, representing the Québec government.

In his keynote address, *Legal and Human Rights Challenges for People Living with HIV/AIDS: A Personal Perspective*, David Hoe, a person living with HIV/AIDS, said that for HIV-positive people, most of the legal and human rights challenges are formed by people who are not living with the disease. Our challenges take shape, he said, through the eyes and beliefs of others, some of whom have been dead for a century or more and who live on through systemic prejudice. For the most part, he said, society has not responded with care and compassion, but rather with prejudice and fear – prejudice and fear of such depth and power that our national and collective abilities to act freely and spontaneously, with genuine care and action for those in need, became frozen.

Fear and shame took centre stage, Mr. Hoe said – not the fear within those with the disease, or their shame, but the fear of those with the power to lead and determine opinion. This fashioned what Mr. Hoe labelled the "false character" of people living with HIV/AIDS, and became the base for all of their contemporary legal and human rights challenges.

People living with HIV/AIDS, Mr. Hoe said, are often described using epidemiological labels such as cultural identity, route of infection, practices and behaviours. But the reality of people living with HIV/AIDS, he said, is found in the lives of people with HIV who experience discrimination in housing; in the lives of women who face an interminable battle of safety and security in their relationships; in the lives of people in prisons who face complex decisions and relationships with people and with prison systems; in the lives of people who wrangle alone with injection drug use; in the lives of people with HIV who are deprived of the information and skills they need to become resourceful in disclosing their HIV status to others; and in the lives of people with HIV for whom treatment and care is not yet manageable, available or accessible.

The 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 Canadian Award was presented to the Vancouver Area Network of Drug Users (VANDU). Helping to present the award were Thomas Kerr, a health researcher with the British Columbia Centre for Excellence on HIV/AIDS, and Libby Davis, Member of Parliament for Vancouver East.

In his remarks, Thomas Kerr traced the history of VANDU from its origins in the Downtown Eastside of Vancouver in 1997. He said that with limited resources and highly dedicated peer volunteers, VANDU has found innovative ways to reach out to, care for, and advocate for, people who are among the most ill and marginalized in Vancouver. VANDU does so, he said, in an environment that can only be described as high-risk. He cited three examples of VANDU's pioneering work: starting drug user discussion groups in the heart of the city's open drug scene; setting up an alley patrol program to respond to overdoses and other emergencies; and opening a syringe exchange table during hours when the fixed needle exchange was closed.

Dr. Kerr said that VANDU has also demonstrated that drug user organizations can focus the attention of policy makers and the public on an ongoing human rights crisis. He said that VANDU has performed a critical public education function by bringing hundreds of policy makers, health-care professionals, researchers, and others face to face with the harsh realities of the Downtown Eastside. Through public presentations and back alley tours, he added, VANDU has actively countered the stereotypes that perpetuate the disabling stigmatization of people who inject drugs.

Ms. Davis called VANDU one of the most effective citizen organizations in Canada. She praised the group for the guts it has displayed, for being a model of user empowerment, and for the sense of hope that it has brought to the Downtown Eastside. She said that VANDU has changed the way people view the issue – from being an issue of criminalization to being an issue of compassion, of health care and of changing the law and the status quo. She said that one of the most remarkable things that VANDU did was to make allies of people who had viewed drug users with disdain.

Accepting the award on behalf of VANDU was Dean Wilson, a member of the board of directors, and Ann Livingston, Project Coordinator. Mr. Wilson asked for a moment of silence to remember the 3,000 people whose lives have been lost in the Downtown Eastside. Ms. Livingston said that working for VANDU is more of a calling than a job. She said that she is proud of the fact that VANDU has managed to reduce the rate of overdose deaths, and has managed to stay in existence while conditions in the Downtown Eastside were deteriorating. She said that while she believes in legal action, the people in VANDU are tired of waiting for the recommendations from the many reports that have been issued to become actions. She particularly regretted the fact that safe injection sites are not yet a reality.

The winner of the International Award for Action on HIV/AIDS and Human Rights was Dr. Wan Yanhai, an AIDS activist in China. Unfortunately, Dr. Wan was unable to be present to accept the award because he had been detained by the Chinese government. Some media reports suggested that Dr. Wan was being detained because he had leaked "state secrets" concerning the true extent of the AIDS epidemic in China, and the role of the state in helping to spread the virus through unsanitary blood collections practices in Henan province. Dr. Wan's wife, Su Zhaosheng, accepted the award on his behalf. *(Note: Dr. Wan was released from detention one week later.)* Helping to present the award were Joanne Csete, Director of the HIV/AIDS Program at Human Rights Watch, and Dr. Peter Leuprecht, Dean of the Faculty of Law at McGill University.

In her remarks, Joanne Csete said that Dr. Wan Yanhai has a long history of courageous action in the struggle against AIDS. Dr. Wan founded the AIZHI (AIDS) Action Project, an NGO that provides basic information on HIV/AIDS (a scarce commodity in China) through a widely used website. He also established the first AIDS information hotline in China, and initiated a project providing information for gay men, who are marginalized, ostracized, and sometimes criminalized, in China. Dr. Wan has also worked with women in prostitution to ensure that they have the information they need to protect themselves.

Ms. Csete said that Dr. Wan has spoken out widely in China and internationally on HIV/AIDS and human rights, as well as on the rights of vulnerable groups. In Henan province, she said, despite police harassment and threats from government officials, Dr. Wan and his colleagues have continued to visit villages; have helped affected people access services; and have brought infected villagers to Beijing and other urban centres to give talks at public forums, thus helping to reduce ignorance and discrimination. Ms. Csete said that the Canadian HIV/AIDS Legal Network and Human Rights Watch urge the Chinese authorities not to compound the terrible injustice of Dr. Wan's detention by keeping him in custody any longer.

Peter Leuprecht said that Dr. Wan Yanhai was a marvellous example of commitment and courage, and that he has been lending his voice to those whose voices are stifled, and his hands to those whose hands are bound. Dr. Leuprecht spoke about the universality and indivisibility of human rights. He said that human rights can be a living reality only in a society that practices solidarity in the defence, respect and promotion of these rights. Solidarity means seeing these human rights as the rights not only of people like us, but also of "others." Dr. Leuprecht said that the force and effectiveness of human rights must be directed towards people who are most in need – ie, those who are exposed, vulnerable and excluded. He said that this award was an expression of our profound admiration for the work of Dr. Wan Yanhai and of our solidarity with him and with his work.

In accepting the award on Dr. Wan's behalf, Su Zhaosheng said that the award means that the world is taking notice of the serious AIDS situation in China and that it wants to help. If Dr. Wan were here tonight, she said, you would see a gentle, soft-spoken and frank person who would be very happy to know that his fourteen years of work has borne fruit. She said that her husband loves China and loves the Chinese people, and wants to continue to work for them. She recounted how Dr. Wan kept photos of the villages in Henan province that were severely affected by tainted blood, and said that Dr. Wan felt he had to return to China from the university where he had been living in Los Angeles, to help these people.

Closing Plenary

In his presentation, entitled *Act Up for Life – A Call for a Return to AIDS Activism*, Ralf Jürgens, Executive Director of the Canadian HIV/AIDS Legal Network, talked about the need for governments and community organizations to change the way they are responding to the AIDS epidemic. Governments, he said, are administering the epidemic, rather than fighting it. For example, Mr. Jürgens said, rather than funding innovative harm reduction initiatives, such as safe injection sites or needle exchange programs in prisons, governments are organizing endless consultative processes. Many meetings are held, he added, where success is measured not by whether we make progress in fighting HIV, but rather by the number of participants. Mr. Jürgens said that over the years the community-based movement has become less aggressive, less confrontational and less effective. A lack of funding, he said, has meant that very few AIDS organizations can afford to undertake advocacy in a sustained fashion; many also lack the capacity to do advocacy.

Mr. Jürgens said that the experience of the blood scandal in the mid 1990s should have taught us to find ways to do things in a less process-bound manner when faced with public health emergencies; and it should have taught governments to allow non-governmental organizations to be more flexible and, thus, more able to respond quickly. Mr. Jürgens called for a new era of public policy on AIDS in Canada, an era that he said requires a return to anger and activism; that requires leadership and risk-taking by politicians, bureaucrats and community organizations; and that requires:

- that we take the principle of "greater involvement of people living with, or affected by, HIV/AIDS" seriously;
- that we link our national action with international action and solidarity;
- that we continue, and also scale up, the careful analysis of policy and legal issues related to HIV/AIDS, because this is the backbone of good advocacy; and
- that we develop a longer-term vision of where we want to be in five years and a plan for how to get there.

In her presentation, entitled *Facing Down an Ugly Politics: A Global View of HIV/AIDS and Human Rights*, Joanne Csete, Director of the HIV/AIDS Program at Human Rights Watch, discussed the ways in which AIDS is fuelled by human rights abuses, and the fact that AIDS, in turn, leaves human rights abuses in its wake. Ms. Csete identified fifteen different categories of abuse and commented briefly on three of them:

- The discrimination and abuse faced by men who have sex with men, two examples of which are the anti-sodomy laws in the Indian Penal Code, and hateful, anti-gay statements made by certain African leaders.
- Censorship and other violations of the right to information and free expression, as evidenced by the detention of Dr. Wan Yanhai in China, and the harassment of AIDS outreach workers in India.
- A wide range of violations of the rights of orphans and other children affected by AIDS, including denying them their right to education, forcing them to take up hazardous and inappropriate labour, and subjecting them to violence and sexual abuse.

Ms. Csete said that these abuses are allowed to persist largely for political reasons. The politics of HIV/AIDS, she said, are completely ugly; they include the politics of denial, the politics of cowardice, the politics of elitism and racism, the politics of moral judgementalism, and the politics of an unaccountable superpower. Ms. Csete said that the United States has had many chances to bring leadership to the global struggle against AIDS and to contribute to respecting the human rights of people, but that it has failed at every turn.

To address the situation, Ms. Csete said, we need more cross-fertilization between AIDS activists and human rights activists; we need to strengthen the global access to treatment movement and to make the link between treatment access and the realization of other human rights; we need to work harder to make global connections; and we need to overcome our cynicism about the legal, judicial, legislative and policy institutions of governments and multi-lateral institutions.

OPENING PLENARY

Friday, 13 September 2002

Welcoming Remarks

This section contains a condensed, edited version of the welcoming remarks.

Carole-Marie Allard
Member of Parliament for Laval

Over the next few days at this meeting there will be much to talk about that is complex, challenging and demanding, but that will assist all of us to strengthen the Canadian response to HIV/AIDS. This is an epidemic that permits us to gain ground here and there, but that continues to deny us victory. And yet, I believe we should not overlook the chance to celebrate success. For 10 years, the Canadian HIV/AIDS Legal Network has been active in public education, policy development and the legal and ethical examination of the complex issues surrounding this disease. The partnership with the Legal Network is one that the Government of Canada values enormously. On behalf of the Honourable Anne McLellan, Minister of Health, I want to commend you on the extremely valuable work you have done over the past decade.

As vice-chair of the House of Commons Committee that has been examining the non-medicinal use of drugs, I take a great personal interest in the work you are doing, in Canada and around the world. We share a profound concern about such vexing challenges as HIV in prisons, the growing problem of HIV among Aboriginal populations, and the need to achieve a balance between the prevention of injection drug use and the provision of adequate harm reduction facilities and services. The focus that the Legal Network has brought to the links between health and human rights is critical because this is an epidemic that continues to spread on poverty, stigma and discrimination.

As well, Canadians must begin to see AIDS and HIV infection as global problems. We cannot witness the devastation of AIDS around the world without being touched by the immensity of the problem. It is to your credit that you, as an organization, had the foresight to connect what happens abroad to what happens at home.

The issues we have to deal with – such as access to care and treatment; such as fear, stigma and discrimination – are complex and multi-layered. The Canadian Strategy on HIV and AIDS is about all these issues and more. The strength of the current Strategy is its close partnership with grassroots groups, health professionals and other frontline workers, NGOs, the private sector, other governments and international agencies. We have made considerable progress, but so much remains to be done. We must continue to work toward the development of an HIV vaccine, and to ensure that a future vaccine is distributed broadly and equitably, according to need.

In the years to come, we must also gear our research and our care, treatment and support agenda to the realities of populations most affected by HIV/AIDS both at home and abroad. In the process, we must continue to target high-risk behaviours in populations that we have not yet been able to reach in a meaningful way. At the same time, we need to examine the social conditions that support disadvantage and risk. It makes sense, therefore, to turn to people living with HIV to give us guidance and expertise. The involvement and the collaborative spirit of the partnerships that the Canadian Strategy on HIV/AIDS fosters not only empowers people living with HIV, but also enables the strategy to be more responsive to people's needs. The success of the Canadian Strategy on HIV/AIDS depends on organizations like the Legal Network. Your work on the legal, ethical and human rights perspectives will continue to inform Canadian and global efforts to confront the AIDS challenge.

Horatio Aruda
Directeur de la Protection de la santé publique
Ministère de la Santé et des Services sociaux
Gouvernement du Québec

I am pleased to see that this meeting is focussing on both the domestic and international dimensions of the epidemic. We cannot talk about AIDS today without referring to what is happening internationally. We also need to learn from the experiences of other countries if we are to meet the challenges that that we face in Québec and in Canada in dealing with this epidemic. I am also pleased to note the similarities between the issues on your agenda and the issues that we deal with in my department. The role of Public Health is to protect the health of people, and to do so in a way that respects their rights. People who are vulnerable and who live in inadequate social conditions are less likely to be in good health. The work that the Legal Network is doing to promote human rights, to improve access to care and treatment, and to reduce ignorance and inequalities, is essential to achieving good health for all.

AIDS may be less visible as a public issue today than it was in the past, but the epidemic continues to affect more and more people, and its implications are still as far-reaching and as troubling as ever. We have to make sure that our interventions – in prevention, in care, in rehabilitation – have the desired effect. We cannot do so without first making sure that legal and ethical issues – issues such as mandatory testing – are addressed. Because AIDS affects people who are already vulnerable, we find that we are now frequently dealing with dual infections. For example, many injection drug users have both HIV and hepatitis C. To be effective, we will have to be innovative in our approaches. This means that we need to consider strategies that may challenge existing laws and societal taboos.

My department is in the process of developing a new HIV/AIDS strategy for Québec, in consultation with our Public Health network and the HIV/AIDS community, to ensure that we are able to respond effectively to this evolving epidemic.

In closing, I would like to encourage you to continue the excellent work you are doing on legal and ethical issues. We cannot afford to lose the energy, the motivation and the dreams of the people who have fuelled the development of the Canadian HIV/AIDS Legal Network.

KEYNOTE ADDRESS

Legal and Human Rights Challenges for People Living with HIV/AIDS: A Personal Perspective

David Hoe
Person Living with HIV/AIDS

This is an edited, verbatim transcript of David Hoe's address.

To be asked to give this talk to the members of the Canadian HIV/AIDS Legal Network on the anniversary of its 10 years of work is indeed a privilege. I want to congratulate all of you, including those from the past (both those living and those who have died), those who have contributed to the value of the Legal Network, and those world-wide who have supported the role of the network and its work in the pandemic. Ten years of work and a strong presence in HIV/AIDS – a presence that goes beyond just the work to encompass energy, influence, vision, relationships and values – testifies to your relevance in the lives of those for whom we have concern and care. I also want to pay a special tribute to gay men and lesbians, who first brought to our attention the link between AIDS and human rights that we now view as intrinsic.

I struggled with this talk. I was invited here in my personal capacity. As some of you know, I am a policy advisor on HIV/AIDS with the federal government. There are not many of us with AIDS or HIV working on the issue in governments, but there have been several who have brought incredible knowledge to our work. One of the jobs of policy advisors is to stay clear of bias, thus enabling a good and comprehensive assessment of all influences and evidence in order to create options. However, we are also charged with developing the best possible advice. In that vein, my expertise as a person living with AIDS unashamedly augments both analysis and potential.

Today I will address, from a personal point of view, some of the constructs I see leading to legal and human rights challenges for people living with HIV/AIDS, and leading to the linking of health to human rights. Much of this will be familiar to you. I will also talk about the way a person may experience these constructs in living with HIV and AIDS, and how these constructs have created those legal and human rights challenges, all of which have, after all, been created by people. Apart from the virus, there is no catastrophe from the gods and goddesses. The other catastrophes we experience are ours, made by humans. If we wish to change them, this raises the policy world and the world with which you are concerned. I hope I have been respectful of my fellow persons living with HIV/AIDS and of the potential of the policy front.

I want to introduce two parameters and they are important ones. The first is that I am not able to describe these challenges in all of their depth, complexity and meaning. I am but one person with discrete experiences, and one with fewer challenges than most. The second is that the truest voice of such challenges comes from each person. We must acknowledge, and respond to, not only the kinds of challenges and their broad categories, but also what it means to the individual. The vitality of life lies in those meanings. With these two parameters in mind, I ask you not to take my thoughts as comprehensive or reflective of the challenges most commanding attention for each person living with AIDS or HIV.

When we consider the human rights and legal challenges for Canadians living with HIV/AIDS, we must think about the approximately 50,000 of us who are dealing with them, one third of whom are believed to be not yet aware of their infections. I put it in numeric terms at this point to emphasize the vital importance of the 50,000 human experiences of living with HIV/AIDS, and the individual nature of that. I do place us all as having these challenges because of the deep cultural construct that determines our life with the disease. This is what differentiates the Canadian experience from the Caribbean experience, and the experience of the gay injection drug user from the straight. My premise is that every one of us faces legal or human rights challenges. Of course this has little to do with our infections alone. We have a virus that makes us sick and we view death, and life.

The key is that these challenges are formed mainly by people who are not living with HIV. Their experiences determine the perception of us in society. This is where our challenges take shape, through the eyes and beliefs of others, some of whom have been dead for a century or more and who live on through systemic prejudice.

The human rights challenges of people living with HIV/AIDS take shape through the eyes and beliefs of others, some of whom have been dead for a century or more and who live on through systemic prejudice.

There is also a bigger picture. The evolution of the human rights analysis, and the absolute necessity for its place in our response, is indicative of human complexity, of how we react from deep places. Part of the human condition appears to include false beliefs about a natural capacity to care for each other over time. Not true! Throughout the planet, HIV and AIDS has met the opposite of this. From our species came prejudice and fear of such depth and power that our large, national, collective abilities to act freely and spontaneously, with genuine care and action for those in need, became frozen in fear. Though there have been, over past years, some significant shifts in Canada – such as increased access to treatment, and some human rights cases that have countered discrimination – I have yet to believe that the forces of justice, care and compassion are not restricted by the constant shadow of discrimination, able to leap on to centre stage at any time. Wherever, whenever, and for whomever there is a spontaneous act that discriminates against someone because of HIV infection, there exists the most profound confirmation that within our national consciousness lies a willingness to acquiesce to prejudicial judgement and damage to the rightful place of people living with HIV/AIDS in our society.

While this continues, we can anticipate that an environment exists for infections to continue, and for the further and unacceptable integration of the epidemic into the fabric of our society determined by citizens and our institutions, regardless of greater knowledge.

The Realities of People Living with HIV

We Canadians living with HIV/AIDS – who are we and what do we witness? We, who are part of a world of people like ourselves and among whom appears to be an inherent empathy, across national borders, of personal and collective struggles? To answer these questions, we must learn of our realities. It is most common to hear ourselves described from an epidemiological point of view. Sometimes we are known by our identity, sometimes we are known by the way we became infected, sometimes we are known because of our cultural roots, sometimes we are known because of our practices and behaviours. None of these categories describe us at all closely. They are categories to aid planning and organizing, principally for HIV prevention, or to guide research, or to facilitate clinical control over illness. We who live with HIV/AIDS must also be regarded differently because this is our life story, and in this story lies the root system of our infections, of our abilities to live with the disease, of our own definitions and analysis of what is needed for survival, and of who we are beyond and before HIV/AIDS – and because this is how we will understand the contexts for our legal and human rights challenges.

Let me give you just a few examples, not at all inclusive of all people living with HIV/AIDS. It is in these lives that the legal clinic for people with HIV in Ottawa experiences housing discrimination as the most common concern brought forward. It is in these lives that women face an interminable battle of safety and security in their relationships, when power and sex is dangerously controlled by men not conscious of how power and gender issues affect them too. It is in these lives that people in prison face complex decisions and relationships with people and prison systems. It is in these lives that people wrangle alone with injection drug use. It is in these lives that the sword of justice swooped over our heads in the Cuerrier decision, and rested potential criminality on the shoulders of all Canadians living HIV/AIDS, from the youngest to the oldest.

The Cuerrier decision rested potential criminality on the shoulders of all Canadians living HIV/AIDS, from the youngest to the oldest.

Those of us who have witnessed the epidemic over the years have seen the potential of HIV disease unbridled in the body, mind and spirit. Wrongfully and painfully so, we can still witness this in the majority of the lives of people in other countries where treatment and necessary care are not accessible, where information is sparse, and where human rights are not part of the consideration. Wrongfully so, can we still witness this in Canada. Those of us who have lived the epidemic over the years have grappled with survival in a society that has not, of spontaneous free will, come forward through its institutions, systems and leaders to show the finer values of society – values such as equal worth, care without comparison, and inclusion.

The False Character

Instead, as everyone in this room knows, fear and shame took centre stage. Not the fear within those with the disease, or their shame, but the fear of those with the power to lead and determine opinion. This void, this state of distance, this gulf of denial, became systematized, gathered momentum rapidly and, because of its massive authority, quickly became familiar and gathered status. That early beginning determined the false character of the person with HIV/AIDS, and became the base for all of our contemporary legal and human rights challenges. That construct, that demonization, rooted in fear, caused us to be perceived in almost mythological terms. Since then, in every aspect of life for people with HIV, a discriminatory and stigmatized world has been ours to deal with. The act of discrimination, or of bestowing stigma specific to HIV and AIDS, has little to do with our infection and all to do with the fears of others. Its triggering therefore has to do with the lives of others.

Let me give you an example of what I mean by a false character. It is a humorous one, taken from the International Journal of Epidemiology. It describes something called heterocopulative syndrome. The hazards of heterosexual behaviour have been well documented. They include, but are not limited to, unplanned pregnancies, penile and cervical cancer, vaginitis, a host of sexually transmitted diseases (some of them incurable or deadly), a disproportionate propensity to engage in child molestation, global overpopulation, socially oppressive gender roles, and more. A recurring pattern of these health disorders resulting from the union of the penis and the vagina has been named heterocopulative syndrome. These people could pose a serious public health threat if such practices continue unchecked and may be especially dangerous if employed as food handlers.[1]

So we deal with two aspects that make up our false character. The first is the discrimination and the stigma we receive, based upon the fears of others. We have to deal with the fear of others, their thoughts, beliefs and actions. Secondly, to survive, we may have swallowed whole those same beliefs as the truth, and see ourselves that same way. Generally, we do this at a very early age, when survival is governed by the need for emotional security regardless of right or wrong. HIV infection does not automatically give us a capacity to rise above all of this. To rise above all of this, we are called to a lofty task. We are called to define and live with an alternative. Ultimately, it affects survival.

We must rise to a world not only of the singularity of each kind of discrimination but also, in many cases, of a composite, with its intense emotional charge and systemic oppression. At its deepest levels are homophobia, sexism, violence, racism and colonialism, still alive and present in drug policy and in the discrimination of Aboriginal Canadians. We are pushed toward states of denial and the unawakened world of self-oppression, or the world of silence, for sake of self-defence.

To rise above the stigma and discrimination we receive, we are called to a lofty task.

My experience of living with AIDS is more rare than most. This is afforded to me because of sets of circumstances. I learned of my infection after I became an employee of a community AIDS organization, thus permitting open discussion. It gave me a workplace able to manage my infection and to support me. My work gave me the role to spend much of my day able to confront the prejudice of HIV/AIDS in my community. Thus, I was able to face down systemic issues on multiple levels from a collective base. I have been blessed with a community of such strength and presence that my physical care during serious illness was abundant. I have a good benefits plan and I am able to choose to pay for complementary and alternative health care and therapies. My current employer wanted to use my return to work after some years of serious illness as an opportunity to learn about the employer's responsibilities and return-to-work issues for people with AIDS, and still does. I have ease of access to information on any issue and, particularly important, I have ease of access to people to get my questions answered. Finally, I am able, on a daily basis, to contribute to policy in a number of capacities and levels.

---

[1] M Scarce. Heterocopulative Syndrome: Clinico-Pathologic Correlation in 260 Cases. *International Journal of Epidemiology* 2002; 31: 498-499.

While I use this personal example to describe my reality, I present it not as some gayly crafted narcissism, but to describe how all this contributes to the meaning I make of my realities. All of these are highly personal; yet, more profoundly, they are states of justice. What is wonderfully present in all of these is the normalcy and rightness of it all. It is right to be self-directed when well or ill, to be able to receive treatments and prevent illness, to be cared for when needed, and to stand up for that which is rightfully one's own. It is right to have safety, an economy for survival, access to treatments and information, housing, and community. Had any one of these been different, living with the disease over the past years would have been much tougher. Most definitely, with the removal of some of these, I would not be here today.

The Role of Language

Confucius supposedly said that the rectification of society starts with the rectification of its language, and that a careful use of words comes before new laws, new programs and new leaders. He said, "Laws and programs begin in words, and if the words of our leaders are entangled in garbled speech, intoned as nasal whining, bereft of inspiration and wit, and flatter than the commercials that surround them, we cannot expect a society to prosper." On the contemporary front, Paula Treischler reinforces this in her cultural analysis of AIDS. She says, "AIDS is not merely an invented label, provided to us by science and scientific naming practices for a clear disease entity caused by a virus. Rather, the very nature of AIDS is constructed through language."

The language of our experience is, most frequently, that of statistical data and science. But I think that this language is too incomplete and underdeveloped to describe the world of the person with HIV/AIDS, and is of only partial use regarding our legal and human rights challenges. Statistics are good for planning and projecting, but alone they do not carry us to action. Clearly, the human condition appears to have a capacity to adjust to the reality determined by statistics. Despite the screams coming from the figures, we appear not to have the psychic link to hear them and to take action.

Despite the screams coming from the statistics, we appear not to have the psychic link to hear them and to take action.

The scientific approach is also incomplete. Though vital in so many ways, its nature determines its separateness. The word "science" comes from the Latin "scire," which means to know. But it is only one form of knowing and, specifically, in Latin "scire" refers to that form of knowing that is cut off or separated. Other words from the same root are schizophrenia, shit and scissors, all representative of that state of separating or cutting off. Schism is another. Goethe, the German philosopher points to an alternative and though his words are over 200 years old, and appear so, to my mind they speak to the task. He writes, "It is no great matter to make a goddess into a witch, or a virgin into a harlot; but to achieve the contrary, to give the humiliated dignity, to make the fallen worth coveting, for that either art or character is needed."

While I would love to discuss the power of the aesthetic, I will take Goethe's other requirement, that of the need to invoke character. Here, I turn to James Joyce, the Irish writer. His character Stephen, as he leaves Ireland, says, " I will forge in the smithy of my soul, the uncreated conscience of my race." When Joyce wrote those words, he pointed us to a relationship between the soul and the forge. Both are places where the elements get merged, where transformation takes place, and where fire prepares one form with shape and character to be reshaped. Creating the conscience of our race equates to creating a consciousness for our work, which, in turn, creates a just character for people living with HIV/AIDS.

I often get asked why AIDS work is so hard. I believe it is because we are both fire and forge. The fire is the intense energy we infuse into our work. The forge is human, in the sense that we work on ourselves at all levels. We must expect sparks to fly when we are concerned with change and with altering the false character of people living with HIV/AIDS that is determined by prejudice and stigma.

The pre-existing consciousness and language may serve as the place where we start, but it has to be the place we leave. Our consciousness, the one for HIV/AIDS, is still in the making. We have some of the language built through empowerment, advocacy and activism – all hinged in the language of values, among which are inclusivity, respect for self determination and the rightful place of power. Words that have derived from this can be read in the International Guidelines on HIV/AIDS and Human Rights, which, of course, the Legal Network helped develop, and in the UNAIDS document "From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)."[2] Using the words in those and other documents will cause our deeper values to shift and new language to evolve. The intent of those documents is the language. Making a reality of this is the work ahead. Laws and policies need to be considered, and altered (where needed), by governments, and by all people working in the service of those of us living with or affected by HIV/AIDS, to ensure our entitlements.

We need language that elicits hope and promise, and that sits well in the soul.

As I said before, health issues are generally understood within our society through scientific terms. In many cultures, this is not so. Disease and health are considered to be based within the spirit and the ecosystem of people, place and universe. I am reminded of the comment made by a Brazilian delegate of the Pan-American Health Organization to Health Canada. I was part of a panel presenting on the Canadian response to the epidemic. "Your trouble," she said, "is that you don't know how to talk about sex. In Brazil, we love sex and everything sexual, so we do not have to battle for its rightful presence in the discussion of national planning." I think she is right! This explains why the language in Cuerrier became not the language of sexual honesty and sharing of sexual power, but rather the language of commercial and criminal fraud.

What language would speak to lives of those of us with HIV/AIDS and our human rights and legal challenges? It is the language that precedes the law and precedes the need to have human rights challenges. Whereas science cuts off, we need to have language that deals with the whole and that enhances the integration of people's experiences; language that permits the continued identification of issues; language that elicits hope and promise; and language that sits well in the soul.

---

[2] Both the International Guidelines and the GIPA document are available on the UNAIDS website via www.unaids.org.

For those of you who have seen the roller coaster of HIV/AIDS, you will know that there are myriad situations for which there is yet to be a remedy or solution. We all know this, but how much easier it is to manage when the values, words and actions are true to our experiences. Even death can be managed with empowerment and magnificence when the whole self can be present. In the absence of consciousness and meaningful language, we are left with rage, raw experience and dark humour. All of which, if not brought to consciousness and rightful place, turns life back on itself.

The Contribution of the Legal Network

Of necessity and awareness, the Legal Network was born 10 years ago to be a generator of the analysis of this deeper language. Building on the work of earlier AIDS activists, the Legal Network is now one of the symbols of Goethe's call for character and Joyce's smithy for the soul; one of our national bodies working to enable the accurate character of who we are, as Canadians living with HIV/AIDS in a global context.

The Legal Network took on this consciousness raising, this reworking of language, this character description. Over the last 10 years, it has brought an organized community, legal, ethical and human rights policy lens into the Canadian context, and in large part has enabled many of us to change our language and consciousness. What is wonderful is that the ideas challenge us all, whether we are infected with HIV or not. The work expands beyond its intentions. This is part of the language. It strengthens everyone's life, for we are not separate, no matter how much we may try.

The early work on HIV/AIDS in prisons which preceded the forming of the Legal Network still informs us and points us toward progressive directions for those in prison living with HIV/AIDS, and we know that the presence of HIV and risk is dramatically higher in prisons. The debate on the criminalization of HIV has hovered, to one degree or another, for many years. The Legal Network has been present every step of the way. You have maintained steady attention to all issues in regards to testing and associated issues, seeing this, quite rightfully, as being the beginning of knowing that one is infected. Of late, have been the policy discussions on testing of immigrants. The Network is a very strong advocate, with a clear analysis. The challenges launched by the Legal Network in its publication, *Injection Drug Use: Legal and Ethical Issues* sets out agendas for policy development. To my belief, there is not one place in that document that would signal a cautious injection drug user to doubt his or her dignity or right to self determination. An earlier piece of work on gay and lesbian issues started to set out how protection from discrimination can have positive impacts on people's health; this work will continue to be refined. Of more recent times, is the call from the Network for the country to prepare for vaccines. This is the language of consciousness. This is the language of clarity and justice. This is the confrontation to denial. This is creating an analysis which re-affirms the rightful place and the true character with which people living with HIV/AIDS in Canada can identify.

We are working to change a huge historical and systemic investment in a past world when a false morality determined rights.

As I look at the current human rights and legal challenges for Canadians with HIV/AIDS, I believe that the past vigilance will need to continue. There are far too many signposts. Because HIV/AIDS equates to our erotic selves, sexuality, homosexuality, injection drug and alcohol use – and, increasingly, to the economically poor, the politically vulnerable, those with systemic neglect and abuse, and those for whom less worth is attributed and for whom the shadows of violence and silence hang strongly – we are working to change a huge historical and systemic investment in a past world when a false morality determined rights.

I will focus on three challenges filled with signposts: the right to information, the right to treatment and care, and the right to purposeful activity, such as work and education.

The Right to Information

I want to talk about HIV disclosure, an area where the lack of information on multiple issues has painful consequences, sometimes catastrophic. Of all the issues likely to rile me, HIV disclosure is the one most likely to do so. My personal intensity is influenced by my own difficulties with this in some situations. I am astounded that, for the most part, people with HIV are deprived of information and skills to enable them to become resourceful at disclosing their HIV to others. This is a straight-forward, lifetime disease management component. No disclosure of HIV status is without risk to privacy, denial of rights and potential loss of intimacy. Intimacy, that meaningful connection with others at all levels, is one of the most undervalued aspects in the analysis of life with HIV and AIDS. On one level, it is now in the realm of criminal law (built on business law), subsequent to the Cuerrier decision of the Supreme Court. Ease of disclosure, I also believe, took another knock when the Ontario legislature set a precedent by passing a bill to assist emergency responders with their fears of possible infection. This has increased the role of law in the place of voluntary disclosure, and will subsequently impact all people with HIV and the public perception of them.

People with HIV are deprived of information and skills to enable them to become resourceful at disclosing their HIV to others.

Disclosure requires a risk analysis to inform decisions and acts. Pretty hefty business. On what seems like a weekly basis, I receive an invitation to take training in risk analysis to guide policy making. I see little difference between assessing the personal politic and the collective. The accountabilities for self with others require the same risk analysis. This analysis is paramount for those of us who are not monogamous forever, for those of us who have not developed relationship negotiation skills, for those of us who have not developed skills to manage intense erotic arousal and personal vulnerability, for those of us who carry shame from the integration of prejudice, for those managing systemic disempowerment, for those of us who live in terror of violence, and for those for whom assessing risk is new. For all of us, the lack of information and skill to manage this lifetime issue is a rights issue and a legal challenge, because of the existing laws and because of the perceptions of those who enforce and apply the law. It does not stretch the imagination too far to also see the potential benefits of reduced infections from an increased healthy and empowered disclosure.

The empowered and spiritually strong statements, “I am HIV+” or “I have AIDS,” only happen when the internal safety can withstand the outside prejudice. These statements thrive as personal statements when they claim power over all that I have discussed. It is, of course, part of managing the job of being a person with HIV and AIDS.

The Right to Treatment and Care

We are still a long way from assured treatment and care for all. Here again, we see portrayed the false character of the person whose rights have been denied. Some of the terms that are used that signal the false character raise my hackles, and I reject them as part of our character – terms such as non-compliant, non-adherent and complacent. They point to the person as a failure. They do not convey that the treatment and care is not yet manageable, accessible or available. The best treatment and care is available to people who live near an HIV clinic, who have a G.P. skilled in HIV care, who have a drug benefits plan with low administrative requirements, who do not use illicit substances, who have organized lives, who have a safe home and who are willing to take the risk of disclosure. Given who many of us are, the right to the best treatment and care is not met.

I am concerned about psychological and social care. Studies show depression among us is as high as 70 percent. Managing much of that is left to community care and support groups, where they exist and are safe to attend. I am concerned about drug plans, which differ across the country, and their current and future capacity to respond. I am most familiar with the Ontario one, the Trillium Program, which is so cumbersome that some people decide to stop taking medications. Some doctors are not able to prescribe medications when they are needed, and have to scramble to find them in others ways. Also, the Trillium Program is cash first, reimbursement second. Try that if you do not have an income that permits a cash flow of $1,500 a month, when there are pressures on food, housing, transportation and child care expenses. To ensure regularity of access to drugs, it is sometimes easier to go on social security. This is not the way to increase accessibility.

The Right to Income, Employment and Purposeful Activity

The right to income, employment and purposeful activity is strongly linked to insurance disability programs, rehabilitation programs and workplaces with appropriate accommodation policies and practices. Sustaining work, education or meaningful activity requires accommodation. Insurance programs, which could bolster the stability of someone over the long term, are generally suspicious of spasmodic or restrictive conditions that are not permanently severe. This, of course, forces people to make less empowering choices.

Rehabilitation programs are generally regarded as a luxury, and are not yet integrated into our service plans, unless one is recovering from physical disability. Much of the experience of managing the disease has to do with managing the unpredictable, and with the diversity of manifestations, sometimes short-term, sometimes long-term. Without a context to understand this, and to develop skills in this, the experience becomes, in and of itself, draining. Rehabilitation can provide this context.

Other Challenges

I would be remiss if I did not mention other influences that will impact on both rights and the law in some circumstances. We are in the middle of a national debate on health care reform which has, as one of its central themes, equity and the choice to self-determine. The Canadian Treatment Action Council warns us that the outcome of this debate will impact people living with HIV/AIDS heavily and could diminish their choices and their access to care. The ever present complexities of treatment and care are already playing out in the reduction and perceived shortage of doctors skilled in HIV care. AIDS is still not a popular career field. Some regions of the country are without such specialists, and the caseloads of skilled doctors are increasing daily.

Peter Piot, Executive Director of UNAIDS, reminds us that AIDS increases poverty. We can therefore anticipate an increased need for more supportive services. Home care is being reduced or cut to accommodate provincial priorities. Despite significant advances, I see new waves of discrimination and stigma, including in the gay community. Prejudice against newly infected men is increasing. For example, it is common to see personal ads for disease-free respondents. This is only in the gay press. It amazes me that the gay press accepts these and that we acquiesce. Imagine if these ads said, “The disabled need not apply.” As well, some AIDS organizations have a new struggle with homophobia within their organizations. Though this is not an exhaustive list, all of these signal the need to stay alert and remain responsive to each other.

Is this all dismal? Absolutely not. Greater than the challenges is the resolve – the resolve to continue to build the true character of the person with HIV/AIDS, that of someone who is able to learn to manage the disease and define changing needs; who manages uncertainty; who sees him or herself as part of a greater picture of life; who is but potential; and who, at any point, can start to determine self-direction.

Greater than the challenges is the resolve to continue to build the true character of the person with HIV/AIDS.

For the past 20 years, enormous barriers have been moved by the human spirit, and by reconstructing the false character through challenging the law and holding to rights. Words changed because our language changed. The power of the depths to which the phrase “living with AIDS” reached, in place of the word “victim,” came not because it was just a different word, but because of what it inspired. A vision of possibility was released. Life, in and of itself, had a permanent place above the disease, even in death. This depth is what defines the true character and our hope. The deeper we go, the stronger we will become, and the less we will be defined by the fear that has defined us in the past.

Until the day that AIDS is eradicated in the entire planet, the characteristics that we should be aiming for are dignity, respect, being capable of being valued, being capable of self determination, being able to face our troubles, being able to develop intimacy with others, being able to make decisions affecting us, being able to make mistakes and to learn, and being able to learn complex information if presented in accessible ways and given true worth in people’s lives. Shame will not be there, stigma will not be there, and barriers will not be thrown our way. It is clear that consciousness is still in the making, that the language is still developing, and that the culture of leadership, law and policy is still young, even after 20 years. We will increase the stories of living with justice.

There are no benefits to AIDS, but there are benefits from our experiences of AIDS, and from AIDS as the language, not the disease. We do determine what we make of those experiences, what meanings we attach to them, and how they inform our actions. This is true for those of us living with the disease, for those in service with us, and for those in positions of leadership. This will be the testament to our human capacity for compassion and justice.

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

to the Vancouver Area Network of Drug Users (VANDU)

This first annual Canadian Award for Action on HIV/AIDS and Human Rights was presented by the Canadian HIV/AIDS Legal Network and Human Rights Watch.[3] *Helping to present the award were Thomas Kerr and Libby Davis. Accepting the award on behalf of VANDU were Dean Wilson and Ann Livingston. This section contains an edited verbatim transcript of the remarks of the two presenters and of the two VANDU representatives.*

Thomas Kerr
Health Researcher
B.C. Centre for Excellence in HIV/AIDS

As a community health researcher, it is a privilege for me to have worked with VANDU. VANDU originated, and does most of its work, in the Downtown Eastside of Vancouver, a neighbourhood that is among the most impoverished in Canada. In 1997, an explosive HIV epidemic was observed in the Downtown Eastside. It remains one of the worst epidemics in the developed world. Over 90 percent of the drug users in the neighbourhood are hepatitis C positive. During the period 1996-2000, there was an average of 300 overdose deaths per year, making drug-related overdose the leading cause of death among adults between the ages of 30 and 49. Despite repeated calls for action, governments and health policy makers have failed to act, and instead have channelled funds into criminal justice interventions that have clearly failed.

In 1997, a group of individuals gathered to form a user-run organization. This group eventually became VANDU. The founders felt that little had been done in response to the health emergency, and that the voice of users had not been heard. With over 1,000 members and 800 peer volunteers, VANDU has been recognized as one of the strongest user organizations in the world. Through a broad range of activities, VANDU has demonstrated a tireless commitment to work that has a direct impact on HIV/AIDS and human rights.

VANDU combines the values of liberation theology and the methods of popular education. Through community consultations and board-directed activity, VANDU identifies and responds to gaps in support for people who use illicit drugs. Among the group's priorities is promoting low-threshold harm reduction for all users – in Canada and abroad. Recently, VANDU has become a pivotal organization in the fight to establish safe injection facilities throughout Canada.

VANDU's earliest work involved setting up drug use discussion groups. The very first discussion group took place right in the heart of the open drug scene in Oppenheimer Park. The organizers set up a discussion group and asked users to voice their concerns and needs. The first

---

[3] 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.

questions were simple and included: "What are the issues facing drug users?" and "What would most help you now?" The facilitators then documented the concerns raised on flip chart paper. The organizers continued to place notices about the meetings throughout the neighbourhood, and within a couple of months hundreds of users were attending these meetings to plan user-based actions.

Today, VANDU seeks to fill the gaps left by the inadequate response to the problems of drug use and addiction. VANDU is involved in several educational and public health interventions through direct contact with those most in need. One example of the innovative work of VANDU is their alley patrol program. After recognizing that there was a huge increase in the number of fatal overdoses following cheque issue day, also known as Welfare Wednesday, volunteers obtained CPR and first aid training and began patrolling the alleys and other locations were no health care worker would dare venture. They went out in shifts, 24 hours a day, for three days straight. They provided first aid and syringe exchange, and they responded to overdoses and other emergencies.

VANDU combines the values of liberation theology and the methods of popular education.

Because many users experienced difficulty accessing clean syringes after the fixed needle exchange closed at 8 p.m. each night, VANDU decided to open a syringe exchange table at the infamous corner of Main and Hastings. It is run by two shifts of volunteers between the hours of 8 p.m. and 4 a.m., and approximately 1,200 rigs are exchanged each night. It is particularly important to note that despite the fact that difficulty accessing syringes is the most robust predictor of HIV infection the Downtown Eastside, the police recently shut down the VANDU table. After lobbying by health researchers and activists, the table was re-opened. But he fight is not over. The police have continued to park a police cruiser next to the table each night, and have repeatedly told VANDU volunteers that they will close the table on October 3rd.

The impact of VANDU's needles exchange was recently documented in a Health Canada-funded study that examined the impact of VANDU on people who inject drugs in the open drug scene. One participant described this impact by stating:

> It keeps us safe. It tries to bring down the risk...like I've had HIV for years now. If VANDU had been going on back then, I probably wouldn't have it now, you know? Because there would have been somebody who gave a shit and I would have had a clean needle.

VANDU is also involved in advocacy and public education efforts. In the words of one local policy maker:

> You always need loud, vociferous folks out there on the edge so the centre moves ... and you can't ignore those guys. They're vocal, they're very passionate, and they are trying to hang on to the agenda until something significant occurs.

Just days after the Mayor of Vancouver announced a 90-day moratorium on the creation of new services for drug users, VANDU responded by erecting crosses on the lawn of city hall, after which they marched into council chambers and interrupted the session to deliver a coffin to our municipal representatives. They were given five minutes to express their concerns.

VANDU has also performed a critical public education function by bringing hundreds of policy makers, health-care professionals, researchers, and others face to face with the harsh realities of the Downtown Eastside. Through public presentations and back alley tours, VANDU has actively countered the stereotypes that perpetuate the disabling stigmatization of people who inject drugs. The impact VANDU has made on its members is immense and is well described by this founding member:

> It brings together a collective experience and wisdom, but also you begin to get a different feeling about yourself. To become part of something for who I am and not for who I am not. For who I am is an addict. I'm poor, I've got hep C, I live in wretched housing and all this, and then someone says, "Yeah, that all makes you a really valuable person. You have a lot to contribute to try to help people and to save other lives, and your experience can do that." Then I get a different feeling about myself.

In the Legal Network's 1999 report on injection drug use,[4] Dr. David Roy described the logic of humanity as follows: "The responsibility to care is strongest when the need for such care is for those who have become most distanced from their human dignity." He went on to say that: "The basic ethical issue is whether we endorse or whether we move far beyond the logic of exclusion." Despite the ongoing loss of members to overdose, disease, and imprisonment, VANDU volunteers continue to reach, care and advocate for those who are among the most ill and marginalized drug users in Vancouver. They do so in an environment that can only be described as high-risk and dangerous. Using limited resources and highly dedicated peer volunteers, VANDU has demonstrated that drug user organizations can focus the attention of policy makers and the public at large on the ongoing human rights crisis, while delivering effective care to those whose rights are compromised by stigmatization and neglect. VANDU has clearly embodied a logic of humanity and, in doing so, has moved many of us beyond the logic of exclusion.

Libby Davis
Member of Parliament for Vancouver East

I am pleased to be here to participate in this recognition of VANDU's work. My riding includes the Downtown Eastside of Vancouver. This award is an affirmation of a struggle that VANDU has engaged in since 1997. I have watched all of the shit that VANDU went through. I have seen the people, the groups and the policy makers who attacked the people in VANDU, who said that they were up to no good, did not know what they were talking about, and were just a rowdy group of users. I have incredible admiration for this organization because of the guts that it has displayed, and because of the sense of hope that it has brought to the Downtown Eastside, to drug users and to people who have HIV/AIDS.

I want to acknowledge the work one of the first founders of VANDU, Bud Osborne, a very remarkable poet and former drug user.

---

[4] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues.* Montréal: The Network, 1999. Available on the website of the Legal Network at http://www.aidslaw.ca/Maincontent/issues/druglaws/e-idu/tofc.htm.

The transformation that has taken place in VANDU over the past few years has been truly remarkable. I remember going to an early meeting of the organization. There were about 100 people sitting on the floor because it was so crowded and there were not enough chairs. I came to talk about what I was raising in Parliament concerning this issue. But the thing that they wanted to talk to me about, that they were most insistent about, was their human rights. They knew that they were being discriminated against and that their rights were being violated by the health care system, the cops, the judicial system and the policy makers. VANDU has changed not only that neighbourhood but also how people see the issue. It had been seen as an issue of criminalization; it is now seen as an issue of compassion, of health care, and of changing the law and the status quo. But VANDU has done more than that. VANDU has become one of the most effective citizen organizations in Canada in terms of the impact that it has had.

VANDU provides us with a wonderful model of user empowerment, organizing and mobilization.

The Parliamentary Special Committee on the Non-Medical Use of Drugs has just visited Europe to look at some of the progressive programs that are in place, and that we would like to have in Canada, such as safe injection sites and heroin maintenance. But I noticed that these countries do not involve users very much. VANDU provides us with a wonderful model of user empowerment, organizing and mobilization. They have forced people – whether they be researchers, bureaucrats, politicians or policy makers – to change their point of view. This is why, for me, their work is truly inspiring. It is so easy for us to become cynical. One of the most remarkable things that VANDU has done has been to begin to make allies of other people who, up until then, had viewed people with HIV/AIDS who were drugs users as garbage. When VANDU began to work with parents in a very middle-class neighbourhood on the West side of Vancouver whose kids were dying of overdoses – when these two groups came together, it formed an incredibly powerful force that was able to begin to change political and legal agendas.

This is a model that we can learn from. I want to wish VANDU all possible success because the struggle is far from over. There are huge battles to be fought, including the one to get safe injection sites. This is such a common sense thing, but we have yet to see it in Canada. I think that with VANDU there, and with the solidarity that is there around this issue, safe injection sites will be inevitable. As a result, lives will be saved and people will learn what it means to live with justice and to have human dignity.

Dean Wilson
Member of the Board of Directors
Vancouver Area Network of Drug Users

First, I would like to ask everyone to stand up for a moment of silence to remember the 3,000 people we have lost in our own neighbourhood. This is a tradition at VANDU.

Second, I would like to thank the Canadian HIV/AIDS Legal Network and Human Rights Watch for giving us this award. There were a lot of people who have contributed to VANDU over the years, but I think that this award is really confirmation for Ann Livingston, who has given us a voice and who has stood by us all these years.

Ann Livingston
Project Coordinator
Vancouver Area Network of Drug Users

Thank you. I wish we had more reason to celebrate. I wish that we could say that we have safe injection sites, and that the number of deaths has been reduced to a more reasonable number, whatever that is. We don't step back often in VANDU to see what we have accomplished. It is a very embattled kind of atmosphere in the Downtown Eastside because it runs day and night, and for the most part we just live it. It is not really a job, it is more of a calling. I want to encourage people who are not drug users, to tell them that it is okay to get involved with drug users. It is hell, but it is okay.

VANDU moments are very rewarding. We have done something that has not happened in most user organizations that I have read about. We have managed to stay in existence while conditions in our neighbourhood have actually deteriorated. We have managed to reduce the rate of overdose deaths, which is a terrific thing. This is what motivated us at the outset – the horror of dead bodies that were everywhere. I moved to the neighbourhood as a woman on welfare with three kids. We found someone who had overdosed This is a very difficult thing to bring into our Canadian psyches, particularly if we were raised in a middle class environment. I encourage people to visit the Downtown Eastside because it is really important that people understand what goes on there.

I want to acknowledge the work of the Legal Network. I am very keen on legal action because I think it will work, but I have to admit that we are tired of waiting for the recommendations from the many reports that have been issued to become actions. What VANDU and all drug users need is for "straight" people with reputations, with education and with some social status to stand with the poorest of the poor and say, "It's not okay to just let these people die."

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

to
Dr. Wan Yanhai of China

This first annual International Award for Action on HIV/AIDS and Human Rights was presented by the Canadian HIV/AIDS Legal Network and Human Rights Watch.[5] *Helping to present the award were Joanne Csete and Peter Leuprecht. Dr. Wan was unable to accept the award in person because he was under detention in China. Accepting the award on his behalf was Dr. Wan's wife, Su Zhaosheng. (Note: Dr. Wan was released from detention one week after this presentation.) This section contains edited verbatim transcripts of the remarks of the two presenters and of Su Zhaosheng..*

Joanne Csete
Director, HIV/AIDS Program
Human Rights Watch

Last July, when our international selection panel chose Dr. Wan Yanhai from among 50 distinguished nominees to receive the Award for Action from the Canadian HIV/AIDS Legal Network and Human Rights Watch, we did not imagine that on this occasion we would be joining with HIV/AIDS and human rights groups and concerned persons all over the world to demand his release from this shameful and unjust detention in China. But in solidarity, and with a sense of urgency, we must do that.

Dr. Wan has for many years put his personal security and his future on the line to combat HIV/AIDS. The "crime" for which is he being detained is loving his country and his people enough to try to be sure that they have access to basic information about HIV/AIDS, information that is essential so they can protect themselves and work together to stop this epidemic.

I am sure that you have read the reports suggesting that Dr. Wan's detention may be linked to his having revealed "state secrets." But the "secrets" in this case include developments that I read about in The New York Times two years ago, facts that have been known across the globe literally for years. It has been known for a long time that poor people in China, and particularly in Henan Province, have sold their blood to the biological products industry there to supplement their income. It has been known that the blood was treated to separate the plasma, which is the commercial product sought after, and that the red cells of communities of paid donors were pooled and re-injected into their arms. It has been known for a long time that this practice, conducted at government health facilities, was responsible for infecting thousands of people with HIV. Since these were government facilities, the role of the state has been understood. All of these things have been known for a very long time and have been reported in various international media. This is old news.

If it is true that Dr. Wan's rights are being violated, as his freedom has been taken from him, because of the allegation that he revealed this story as a state secret, this is more than an outrage.

---

[5] See supra, note 3, for a list of the other award sponsors.

The Canadian HIV/AIDS Legal Network and Human Rights Watch urge the Chinese authorities not to compound the terrible injustice of Dr. Wan's detention by keeping him in custody any longer. We join with hundreds of thousands of people around the world in calling for his immediate and unconditional release.

Dr. Wan Yanhai has a long history of courageous action in the struggle against HIV/AIDS.

The man we are honouring with the Award for Action has a long history of courageous action in the struggle against HIV/AIDS. Let me mention just a few highlights. Dr. Wan Yanhai is coordinator of the AIZHI (AIDS) Action Project, a non-governmental organization he founded in 1994 that provides, through a widely used web site, some of the limited basic information on HIV/AIDS available to people in China. He established the first telephone hotline providing information on HIV/AIDS in China, and he initiated a project providing the first information on HIV/AIDS targeted especially for gay men who are marginalized, ostracized and sometimes criminalized, in China. He also worked with women in prostitution to ensure that they could have the information they needed to protect themselves.

In 1993, as often happens with AIDS activists who are on the frontlines with persons at risk, government authorities accused Dr. Wan of promoting homosexuality and supporting prostitution. Many of his activities were shut down and he was fired from his government job. For many people, this would have been the end of their work, but Dr. Wan was undaunted and he found ways to continue his life-saving activities.

Dr. Wan holds the honour of being a Fulbright scholar and has held a number of visiting scholar positions in the United States. He has spoken out widely in China and internationally on HIV/AIDS and human rights, the rights of gays, lesbians, bisexuals and transgender persons, and the rights of sex workers and intravenous drug users. In the matter of the Henan blood scandal, in spite of police harassment and threats from government officials, Dr. Wan and his colleagues have continued to visit villages in Henan; have worked to bring HIV-infected villagers to Beijing and other urban centres to give talks at public forums; and have helped affected people to get access to services, in the process helping to reduce ignorance and discrimination.

Despite the crucial role it has come to play in addressing HIV/AIDS in China, the AIZHI Action Project continues to face considerable difficulties. In July 2002, the organization was evicted from its offices at a private university in Beijing after the university was pressured by government officials to shut the organization down.

We should make it clear that many government officials know that AIDS is an enormous problem in China, and that many of them admire Dr. Wan's work but are afraid to speak out as he has done. Dr. Wan's work has made people feel less alone, and has persuaded some people that they can make a difference and that only widespread awareness and public pressure will make it possible to address HIV/AIDS in China.

Before concluding, I would like also to pay tribute tonight to the courage of Ivy Su Zhaosheng, Dr. Wan's wife, who is with us tonight and who has chosen to speak out publicly for his release without regard to the repercussions she herself may face as a result. Ivy, thank you for your inspiring presence.

The Chinese government just last week made its first appeal to the international community for assistance and advice in attacking what is clearly a serious AIDS epidemic within its borders. In a constructive spirit, we offer them this advice: Do not put in prison people like Dr. Wan, who are your best allies in combating this epidemic. Do not allow this man, who loves his country and his people, to be silenced when he has done so much and can do so much more to save the lives of Chinese people affected by HIV/AIDS.

Dr. Peter Leuprecht
Dean of the Faculty of Law
McGill University

I feel honoured and privileged to be associated with this very inspiring and moving event. It is an event that encourages people to think critically and globally, and also to act. I want to congratulate the Canadian HIV/AIDS Legal Network on its 10th anniversary. The Legal Network has played a key role in this country, and beyond, in shaping policy, in overcoming prejudice and in fighting exclusion.

The theme of human dignity has run through all of the presentations here this evening. Emanuel Kant, the philosopher, wrote:

> It is every man's duty to be beneficent, that is to promote, according to his means, the happiness of others who are in need, and this, without hope of gaining anything by it. ...
>
> Beneficence towards the needy is a universal duty of man and, indeed, for the reason that man ought to be considered fellow men, that is, rational beings with needs, united with nature in one dwelling place, for the purpose of helping one another. ...
>
> Every man has a rightful claim to respect from his fellow men and is reciprocally obligated to show respect for every other man. Humanity itself is a dignity, for man cannot be used merely as a means by any man, either by others or even by himself, but must always be treated at the same time as an end.

One of the basic premises underlying the Universal Declaration of Human Rights is the idea of human dignity, the equal dignity of all human beings. This is the foundation of the entire human rights edifice. This implies that these rights are, of necessity, universal – i.e., the rights of all human beings. Human rights are not only universal, they are also indivisible. They form an indivisible whole, whether they be civil, political, economic, social or cultural rights. Only if the human being is guaranteed all of these rights, can he or she live in dignity. To this, I would add a third basic idea that., regrettably, is not found in the texts – the idea of solidarity. I believe that universal and indivisible human rights can be a living reality only in a society that practices solidarity in the respect, defence and promotion of these rights. They must be seen as the rights not only of each and every one of us, but also of others. Human rights must be seen as the rights of others. One practices human rights through encounters with others.

In this context, the increasingly important role of non-government organizations is one of the most encouraging phenomenons. NGOs practice this solidarity by lending their voices to those whose voices are stifled, and their hands to those whose hands are bound. They provide a striking example of solidarity in the defence and promotion of human rights. This is what Dr. Wan Yanhai has been doing and will continue to do. He is a marvellous example of commitment and courage. He is acting in accordance with one of the greatest principles of Chinese thinkers such as Confucius and Mencius. It is sadly significant that he should be deprived of his liberty. Perhaps this is one of the collateral damages of September 11th. More and more, I feel that the so-called (and wrongly called) war against terrorism serves as a pretext in many countries for increased repression. Among the victims of this increased repression are the rule of law and our human rights.

No one should be a stranger to the world of human rights.

I have thought for a long time that the force and the effectiveness of human rights must be directed towards those who are the most in need – ie, those who are exposed, vulnerable and excluded. But no one should be excluded from human rights, even though such exclusions have happened frequently throughout history. No one should be a stranger to the world of human rights. Among those who are exposed, vulnerable and too often excluded, are people living with HIV/AIDS. I have often read that poverty provides us with a striking illustration of the indivisibility of human rights. Almost all of the rights become theoretical if one lives in poverty. And I would say the same thing for people living with HIV/AIDS. They need all of the human rights if they are to live a life of dignity. We know, however, that these human rights are constantly being threatened.

Today, human rights risk becoming one of the victims of what I call the "pan-economic ideology" or the "fundamentalism of the market." Look around us. Is it not unacceptable that commercial accords, like the World Trade Organization's agreement on intellectual property (the TRIPS Agreement), block access to treatments that can save lives? Look also at the scandalous gap that exists in the world between the resources dedicated to the fight against AIDS and the resources being spent on armaments and the weapons of war, particularly since September 11th.

Fighting for human rights is one way to reduce human suffering. In my work in Cambodia, I have seen enormous human suffering. I have also seen AIDS in Cambodia. It is one of the most serious problems that country has to deal with, but most people there do not want to talk about it. I have seen scandalous human trafficking and sexual exploitation. I saw, with my own eyes, little girls, six, seven or eight years of age, being sold.

In is in this context – the alleviation of human suffering – that I situate the laudable activities of the Canadian HIV/AIDS Legal Network. You have made important gains, but much remains to be done. Your field of battle – in this country and around the world – is immense. I am convinced that you will continue your work in the service of human dignity.

I have the privilege to participate in the presentation of the award for Action in HIV/AIDS and Human Rights to Su Zhaosheng, the wife of Dr. Wan. This award is an expression of our profound admiration for his work and of our solidarity, particularly at this difficult moment for him and for his wife. I, too, subscribe fully to the necessity of making a strong appeal to the Chinese authorities to release him. I hope and believe that this award and the congruent publicity will help him to regain his freedom.

Su Zhaosheng
Wife of Dr. Wan Yanhai

It is a great honour to be here today, on behalf of my husband, Dr. Wan Yanhai, to accept this most prestigious award. I would like to express my deepest gratitude to the Canadian HIV/AIDS Legal Network and Human Rights Watch for the International Award for Action on HIV/AIDS and Human Rights. I would also like to congratulate VANDU on receiving the national award in recognition of its important work.

I am very grateful that my husband's work has achieved such recognition. For him, what this award means is that the world is taking notice of the serious AIDS situation in China and wants to help. I want to take this opportunity to thank everyone who has contributed so much to his work, for their time and effort, sometimes at great personal sacrifice, for their financial support and for their encouragement. Without such support, my husband's work on AIDS in China would not have been possible.

Joanne's statement has covered my husband's work, which has spanned more than a decade, extremely well. If Dr. Wan were here tonight, you would see a gentle, soft-spoken and frank person who would be very happy to know that his fourteen years of work has borne fruit. In my eyes, Dr. Wan is a dedicated and brilliant scholar, educator and researcher. He is interested in many subjects and is particularly sensitive to social issues. Dr. Wan believes that fighting the spread of AIDS requires efforts from both the public and private sectors. Within China, Dr. Wan believes that in addition to the efforts of the Chinese government, there must also be NGO involvement and community participation.

My husband loves China and loves the Chinese people, and he wants to continue to work for them. My husband was most profoundly affected by the villages in Henan province, where many families have been infected with the HIV/AIDS virus through unsanitary blood collection. My husband came from a small village no different than these villages. My husband has been an advocate for the gay communities in China for more than ten years, even when few people dared to openly support them. His work has expanded to focus on the AIDS villages because he felt that few people knew the seriousness of the problem.

Wan Yanhai loves China and loves the Chinese people, and he wants to continue to work for them.

My husband kept a file of the photos of the villages in his computer while he was living in Los Angeles. Every time he turned the computer on, he saw these images. He told me that he couldn't stay in Los Angles anymore and that he must return to China to help these people. I could see in his eyes, and by the way he would look at those photos, his total commitment to working on the frontline of fighting AIDS. When he was last seen at a gay film screening in Beijing, he had prepared a photo exhibition of AIDS orphans from the infected villages in order to raise money for them. The exhibition included photos of these AIDS children; a photo of a family in which four of the six family members are affected with AIDS; a photo of a grandmother carrying her grandchild sick with AIDS, her son having already died of AIDS; and a photo of an orphan in front of his dead parents' burial mound. These photos compelled my husband to return to China this June.

After Dr. Wan returned China, he and I kept in touch with each other regularly. On August 24th, I could not reach him, neither at our apartment in Beijing nor on his cellular phone. At 3.00 a.m. on September 5th, I received a call from an associate of Dr. Wan's in Beijing informing me that he was being detained by the Ministry of State Security and was under investigation for "leaking state secrets." The information posted on his website was collected from various reports by major news sources which are available to the public. The information is in wide circulation and cannot be considered "secret" at all. Dr. Wan is simply exercising his right to peacefully express his view and to help promote access to information and public health education.

I have not yet received any official word from the Chinese government on whether my husband is in their custody, but I believe this to be the case. This is a critical time. If the reports that we have are correct, and he is being detained, it is my hope that this misunderstanding will be cleared up and that my husband will be unconditionally released.

Dr. Wan will not do anything to hurt his country or his people. His goal is to continue co-operation with the Chinese government to help prevent the spread of this deadly disease. There is absolutely no reason why he should be detained. My focus is to obtain official word of his whereabouts and, if he is being detained by the Chinese government, for him to be released and returned to his family.

On behalf of my husband, Dr. Wan Yan Hai, scholar, AIDS advocate and volunteer, who could not be here to accept this award himself because he is being detained by the Chinese government, I want to thank the organizers for giving him such a great honour. Dr. Wan will be very happy to receive this award. I humbly and gratefully accept it on his behalf and on behalf of all who continue to struggle on the frontline.

In closing, I want to thank the Canadian people for their expression of concern for my husband. I want to express my deepest thanks to the Canadian HIV/AIDS Legal Network and Human Rights Watch for their support of Dr. Wan. This award is extremely important to both Dr. Wan and myself at this difficult time.

CLOSING PLENARY
Sunday, 15 September 2002

This section contains edited verbatim transcripts of the Closing Plenary presentations made by Ralf Jürgens and Joanne Csete.

Act Up for Life –
A Call for a Return to AIDS Activism[6]

Ralf Jürgens
Executive Director
Canadian HIV/AIDS Legal Network

This talk is dedicated to the memory of Charles Roy, one of Canada's greatest AIDS activists, who recently died of AIDS and whom we dearly miss; to my partner, Jean Dussault, without whom I could not do the work I do and who re-ignites my fire; to Wan Yanhai, the Chinese AIDS activist and recipient of the first annual International Award for Action on HIV/AIDS and Human Rights, who should be with us today but is being detained by Chinese authorities – Wan, our thoughts are with you; and to Dean Wilson, member of the Vancouver Area Network of Drug Users, for having the courage to speak out about the injustices suffered by drug users.

In their 1992 chapter entitled "Community activism, federalism, and the new politics of disease," David Rayside and Evert Lindquist give the following account of the evolution of public policy on AIDS in Canada:

> The evolution of public policy on AIDS in Canada has moved through three distinct stages. The first began in the early 1980s, as many politicians and officials ignored the epidemic or responded very cautiously. The second stage began in mid-1985, when Rock Hudson's illness became public knowledge, greatly intensifying public interest and concern in Canada, and when the development of HIV blood tests raised new issues for debate. In this period, Canadian governments began to make significant but usually ad hoc commitments to AIDS programs. As the number of AIDS cases increased, community groups grew in size and proliferated, with new militant voices broadening the range and intensity of criticism directed at governmental inactivity. The third period began in the spring of 1988, when the pressure on all levels of government to develop coherent AIDS strategies was dramatically increased by the protests of community group activists at the National AIDS Conference. Most recently, there are signs of a "normalization" of AIDS policy and the possibility that it may be reintegrated into other

---

[6] Ralf Jürgens was originally planning to talk about "Twenty Years of HIV/AIDS Law and Policy in Canada: Victories, Challenges and Opportunities." Readers interested in a 32-page summary of Canada's policy and legal response to HIV/AIDS should consult Mr. Jürgen's chapter on Canada (chapter 10.14) in DW Webber (ed). AIDS and the Law. Frederick, MD: Panel Publishers, 2000 (3^{rd} edition, 2000 cumulative supplement).

> areas of health education and care. Although it is too early to tell, this may demarcate the beginning of a fourth stage.[7]

In my presentation, I will argue that the fourth stage, that of the normalization of AIDS policy, needs to come to an end, and that we need to begin the fifth stage of public policy on HIV/AIDS in Canada – the return to activism.

Rayside and Lindquist's chapter begins with the description of a turning point in the history of HIV/AIDS in Canada:

> On May 17, 1988, Jake Epp was burned in effigy. In a country not usually given to such public dramas – a country with a tradition of political reserve and accommodation – the attack on the federal minister of health and welfare was a turning point in the AIDS epidemic in Canada.
>
> By 1988, there were more than twenty-four hundred cases of AIDS and almost two thousand deaths ... Despite the loss of life, the growing proportions of the epidemic in Canada, the extensive media coverage of the U.S. epidemic, and Canada's self-image as being more socially progressive than the United States, a national AIDS strategy had yet to be articulated.
>
> Growing frustrations with the lack of government leadership had led to radicalization of AIDS activists in Vancouver, Montréal and other major cities determined to pierce through the bureaucratic and political fog of Ottawa. The May seventeenth protest was organized by the Toronto-based AIDS Action Now! and was staged at the National Conference on AIDS, which brought together government officials, public health professionals, and representatives of community-based organizations. The display of activist anger captured national media attention and sent shock waves through the corridors of power in Ottawa.
>
> Two months later, Epp announced a $116 million [dollars in Rayside's and Lindquist's chapter are given in 1990 US dollars] funding commitment to AIDS.

Since then, the federal government's spending on HIV/AIDS has hardly increased and, because of inflation, has probably decreased. Every year, it is estimated that over 4,000 Canadians contract HIV,[8] and there can be no question that the epidemic has increasingly affected women, Aboriginal people, prisoners, people who inject drugs, and people from endemic countries, in addition to making a "comeback" among gay men.

---

[7] DM Rayside, EA Lindquist. Canada: Community activism, federalism, and the new politics of disease. In: DL Kirp & R Bayer (eds). *AIDS in the Industrialized Democracies - Passions, Politics, and Policies*. New Brunswick, New Jersey: Rutgers University Press, 1992: 49-98, at 52.

[8] An estimated 4,190 persons in Canada were newly infected with HIV in 1999. See Health Canada. HIV/AIDS Epi Update: National HIV Prevalence and Incidence Estimates for 1999: No Evidence of a Decline in Overall Incidence. Ottawa: April 2002. Available on the website of Health Canada at www.hc-sc.gc.ca/pphb-dgspsp/hast-vsmt/index.html.

Rather than fighting the epidemic, governments are administering it. Rather than funding innovative harm reduction initiatives such as safe injection sites or needle exchange programs in prisons, governments are holding endless consultative processes, involving an ever increasing number of stakeholders and costing an ever increasing number of dollars. Every excuse seems to be made to avoid having to take a decision.

In November 1999, the Legal Network released a report urging the government to act immediately to respond to the crises of injection drug use, HIV/AIDS and hepatitis C.[9] Many of the Network's recommendations were not even new, but had been issued before, including by the Task Force on HIV, AIDS and Injection Drug Use.[10]

Rather than fighting the epidemic, governments are administering it.

It took the government 632 days to respond to the Network's report. The response contained some important statements.[11] However, for the most part, it did not promise action, but further study and further consultation.[12] In the meantime, a Federal/Provincial/Territorial Committee on Injection Drug Use was set up to study the issues related to HIV/AIDS and injection drug use in Canada. The Committee acknowledged the severity of the problem, and issued another report, mapping out what governments could and should do.[13] And then, a House of Commons Special Committee on Non-Medical Use of Drugs was established.[14] Now, the Hon. Anne McLellan, the federal Minister of Health, seems to be saying that she cannot support trials of safe injection facilities or heroin maintenance trials before hearing from that committee.

---

[9] Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*. Montréal: The Network, 1999. Available on the website of the Legal Network at www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[10] Canadian Centre on Substance Abuse & Canadian Public Health Association. *HIV, AIDS and Injection Drug Use: A National Action Plan*. Ottawa: The Centre & The Association, 1997. Available on the website of the CCSA via www.ccsa.ca.

[11] The response admits that "[f]undamental changes are needed to existing legal and policy frameworks in order to effectively address IDU as a health issue." (At i) In his introductory message, then Minister of Health Allan Rock further stated: "Injection drug use is first and foremost a health issue. Involving all Canadians in a just and compassionate response means that we must dig deep in our search for solutions and not stop until we find ones that work." See, Health Canada. *Injection Drug Use and HIV/AIDS. Health Canada's Response to the Report of the Canadian HIV/AIDS Legal Network*. Ottawa: 2001. Available on the Legal Network website via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[12] For a comment on Health Canada's response, see: Canadian HIV/AIDS Legal Network. *Injection Drug Use and HIV/AIDS: The Canadian HIV/AIDS Legal Network Reacts to Health Canada's Response to the Network's 1999 Report on Injection Drug Use and HIV/AIDS*. Montréal: The Network, 2001. Available on the Legal Network website via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[13] *Reducing the Harm Associated with Injection Drug Use in Canada*. Working Document. Ottawa: March 2001. Available on the Legal Network website via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[14] On 19 February 2002, the Legal Network presented a brief to the Committee. See: Injection Drug Use, HIV/AIDS, and HCV (a 40-page brief to the House of Commons Special Committee on Non-Medical Use of Drugs). Available on the Legal Network website via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

More than five months after the Network released its report on safe injection facilities,[15] a report that showed that the federal Minister of Health can easily create the regulatory framework for the establishment of pilot projects of safe injection sites, we have not heard from the Minister. [In October 2002, three weeks after this presentation was given, the Minister did write to the Legal Network about safe injection sites.]

Lessons from the Tainted Blood Scandal

In his remarkable article, "Lessons from Krever – A personal perspective," Jan Skirrow, a former Deputy Minister of Community and Occupational Health in Alberta, discusses nine lessons that we should have learnt from the scandal of the blood contamination in the mid 1990s. Of the issues he raised, I will only mention a couple that are most important in the context of the HIV/AIDS and HCV crisis among people who inject drugs.

First, Skirrow urges us to find ways of doing things in a less process-bound approach when faced with public health emergencies. He writes ("Lesson One - The Canadian Way"):

> Canadians have developed values and a way of doing things that tolerate difference and polite dissent, emphasize agreement and consensus, but avoid the confrontation and enthusiastic discourse often found among our American cousins. Canada's ability to stay united in the face of fundamentally divisive national issues is a tribute to the power of our approach.
>
> However, the "Canadian Way" is so entrenched in our public institutions, and in ourselves, that we fail to recognize how counter-productive it can be. Our approach is not very useful when the problems are technical rather than political, develop fairly rapidly, involve matters beyond the personal experience of decision-makers, or are value-loaded. This was clearly the case with HIV/AIDS and Canada's blood supply in the 1980s. Canada has embraced a process-bound approach that has been effective at managing (but rarely resolving) our political differences, but that is patently unable to respond in a timely or appropriate manner when speedy resolution of a difficult issue must be reached.
>
> Almost anyone or anything can stop or delay action on almost any issue. Seeking consensus, much less unanimity, is very difficult. ...
>
> We must question our automatic response when faced with a difficult issue: strike a committee or task force, engage in wide consultations, set up oversight or coordinating committees, avoid conflict, postpone action until consensus is achieved, and so on. While these mechanisms are legitimate in many situations, they all too often serve only to create inflexibility, delay action, inflate cost, and drive the participants to distraction.[16]

---

[15] R Elliott, I Malkin, J Gold. *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues.* Montréal: Canadian HIV/AIDS Legal Network, 2002. Available on the Legal Network website via www.aidslaw.ca/Maincontent/issues/druglaws.htm.

[16] J Skirrow. Lessons from Krever - A Personal Perspective. *Canadian HIV/AIDS Policy & Law Newsletter* 1999; 4(2/3): 35-41, at 36. Available on the Legal Network website at www.aidslaw.ca/Maincontent/otherdocs/Newsletter/spring99/krever.htm.

Second, Skirrow urges governments to allow non-governmental organizations to be more flexible and thus able to respond more quickly. He says ("Lesson Eight - Ambivalence to Non-Govermental Organizations"):

> Non-government organizations are often thought to be more flexible and responsive to changing conditions, and thus more able to act quickly. Yet governments routinely impose on these agencies the same requirements, and sometimes methods, that make their own line operations less effective. More troubling is that government sometimes imposes accountability standards that it will not apply to itself. The result is often a non-government agency that is less effective than it could be. ...
>
> If we believe that a non-governmental agency or, for example, an operating entity within a decentralized health system offers substantial advantage over direct government operations, we must resist the tendency to impose restrictions that remove that advantage.[17]

Skirrow concludes by saying that he sees

> no reason to conclude that another preventable public health tragedy is impossible. Time will tell if we have resolved those aspects of our blood system that created the specific opportunity for disaster detailed in the Final Report. But the same forces and ways of doing things that contributed to that tragedy are still deeply embedded in our public institutions, and in many of us.
>
> Indeed, another public health tragedy may now be underway that illustrates many of the points discussed above. A marginalized community (in this case injection drug users) is experiencing an epidemic of death and disease resulting not from anything inherent in the drugs that they use, but more from the ineffective and dysfunctional methods that characterize our attempts to control illicit drugs and drug users. There is the same unwillingness to carefully analyze the problem or to depart from traditional methods and conventional thought that was integral to the blood tragedy. There is a struggle for power and control over the issue between law enforcement and public health. There is a profound lack of understanding among decision-makers and many health professionals regarding the nature of the community and individuals at risk.
>
> The hoped for national political consensus and permission to act effectively on this public health issue is unlikely to come, despite awareness by local politicians and public health professionals of the seriousness of the problem. There is little possibility of effective national action, and yet national policy prohibits the kind of local initiative that might provide useful responses. Our committees meet, the media reports the political rhetoric and the disagreements of experts, and effective program responses remain in limbo as we try to sort out what are in essence power and control issues. Yet people continue to die in alarming numbers, and no one seems to notice or care very much.[18]

---

[17] Ibid, at 39-40.

[18] Ibid, at 40-41.

Skewed Priorities

While governments can and must be blamed for the failure to fight, rather than administer, the HIV/AIDS epidemic, the community-based movement itself has had its wings cut off and has become less aggressive, confrontational and effective. Most of the early AIDS activists who challenged the governments' way of doing things have died or have abandoned the fight because they needed a break from it. Lack of funding has meant that very few AIDS organizations can afford to undertake advocacy in a sustained fashion. But there is also a lack of capacity to do advocacy, and maybe a lack of anger.[19] Reporting requirements are heavy. We often fall into the same traps as governments – asking for more consultation, more meetings, more inclusion, more mechanisms, more working groups and committees, more groups and coalitions for ever more specialized issues – rather than asking for action.

The community-based movement has had its wings cut off and has become less aggressive, confrontational and effective.

As a result, we attend meetings such as the Canadian Strategy on HIV/AIDS (CSHA) Direction Setting Follow-Up Meeting in Montréal in April 2002, where success is seemingly not measured by whether we actually make progress in fighting HIV, but by the number of participants. Where only one person is invited to represent drug users, and when that person becomes sick during the meeting, issues related to injection drug use are allowed to fall under the table. The government calls us "partners" in a pan-Canadian effort, but we are very unequal partners and we should recognize that. We should also recognize the fact that we must play different roles.

I was recently asked to be interviewed by Health Canada for the preparation of their World AIDS Day Report 2002. I was asked, in a section on "key accomplishments:"

A. "How has your organization's work contributed to scientific advancement?"
B. "In what ways have you shared information and knowledge your organization develops or acquires? Have there been new clients for your information?"
C. "Describe one or two key program or policy initiatives in which your organization has used collaboration to better reach an objective."
D. "Please provide examples of current or ongoing work your organization does to increase its capacity, or the capacity of others, to address HIV/AIDS."
E. "Describe how ... your organization has engaged a broader range of participants."

I was struck by the fact that, to a large extent, we are asked to report to Health Canada on how we collaborate, share information and include more people. It seems that with the little money

---

[19] At "Putting Third First: Vaccines, Access to Treatment & the Law," a satellite meeting of the XIV International AIDS Conference, organized by the Legal Network, the AIDS Law Project, South Africa, and the Lawyers Collective HIV/AIDS Unit (India) on 5 July 2002 in Barcelona, Spain, Justice Edwin Cameron pointed out in his opening remarks that a change in the way we think is the key to mounting an effective response to the epidemic, and that this change has been generated by principled leadership and strategic, angry activism. In her closing remarks, Sophia Mukasa Monico agreed with Justice Cameron, but wondered whether we were are angry [enough]. She said that if we are not angry, we will be powerless. She said that the community has to have outrage, anger and will, and that it has to channel this anger and will into a constructive social movement in order to turn political inaction into political action. See the proceedings of the satellite, available on the Legal Network website via www.aidslaw.ca/barcelona2002/e-barcelona2002.htm.

the CSHA has, this is all we can pretend to do. Last year, the questionnaire was similar. I responded with increasing frustration about how the Network had shared information, engaged a broad range of participants at meetings we had organized, etc. I then said to the interviewers that what I considered to be one of the key accomplishments of the Network in the year covered by the report, namely our policy work and activism around HIV/AIDS and immigration, would probably never make it into the report. I was right. The fact that all people with HIV had received a slap in the face when Health Canada initially advised Citizenship and Immigration Canada that HIV-positive immigrants constitute a threat to the public health of Canadians – and, importantly, the fact that Health Canada changed that advice, thanks to careful analysis of legal, ethical and public health issues and advocacy – these facts are not captured anywhere in the Health Canada World AIDS Day report.

We Need a New Era

Let me suggest that we need at this point to move beyond what Rayside and Lindquist called the fourth period of public policy on AIDS in Canada – the normalization period. HIV/AIDS are not normal. The poverty and human rights abuses that often result from, and create vulnerability to, HIV are not normal. The situation in the Downtown Eastside of Vancouver is not normal. AIDS continues to require what it has not received for many years, if ever: leadership, more funding, nimble responses, and thinking outside the box. We need to enter into a fifth period. I would like to describe what I see as being necessary for this fifth period.

AIDS requires leadership, more funding, nimble responses, and thinking outside the box.

First, the fifth period requires that we see a return to anger and activism.

Second, it requires that we take the principle of "greater involvement of people living with or affected by HIV/AIDS" (GIPA) seriously. But greater involvement of people with HIV/AIDS must include the involvement of people who use drugs, Aboriginal people, prisoners and ex-prisoners, and women who are HIV positive. In that regard, a lot remains to be done. Community-based organizations and governments cannot continue to pretend that they involve people with HIV unless they involve those who are most marginalized.

Third, it requires leadership and risk-taking, not only from politicians and bureaucrats, but also from ourselves.

Fourth, it requires that we link our national action with international action and solidarity. In terms of activism, for example, we have much to learn from our colleagues in countries such as South Africa, who have been angry and effective advocates over the last years.

Fifth, it requires that we continue, and that we scale up, the careful analysis of policy and legal issues related to HIV/AIDS, because it is the backbone of good advocacy.

Finally, it requires that we develop a longer-term vision of where we want to be in five years, and how we will get there. This is why I have personally been so vocal about the need to develop a five-year plan for the CSHA that clearly spells out what we need to do to fight the epidemic in

Canada, a plan that does not limit itself to current funding levels. We already know that those are not enough.

If we take our new role as advocates seriously, we may hear Maureen Brosnahan report on CBC Radio One on 1 December 2002:

> This morning in Vancouver's Downtown Eastside, hundreds of people living in the area and their supporters lay down on the streets blocking traffic to symbolize the hundreds of people who have died in the area over the last years. In solidarity, AIDS activists in Kelowna, Victoria, Calgary, Edmonton, Toronto, Montreal and other cities also blocked the traffic on major streets. Lawyer John Richardson, who represents Pivot Legal Society,[20] launched a class action suit against the federal, provincial and municipal governments on behalf of hundreds of people who use drugs and contracted HCV and/or HIV. And in Montréal, Peter Leuprecht, Dean of the Faculty of Law of McGill University, opened the proceedings of a mock Commission of Inquiry on the HIV/AIDS and HCV crisis among people who inject drugs in Canada. Members of the Commission include Libby Davies, NDP MP for Vancouver East, Joanne Csete, and other prominent and respected public figures. The Commission is expected to release its report within 30 days.

And two days later, we may hear the federal Minister of Health announce that Health Canada will support trials of safe injection sites in six Canadian cities.

Let us not wait until December 1st. Let us start activism now. Next weekend, at the AIDS Walk, let us all carry signs demanding that the Chinese government release Dr Wan Yanhai.[21]

---

[20] For more information on Pivot Legal Society, visit their website at www.pivotlegal.org.

[21] Two days before the AIDS Walk, and five days after this presentation, Dr. Wan Yanhai was released, thanks at least in part to the efforts of activists world-wide.

Facing Down an Ugly Politics: A Global View of HIV/AIDS and Human Rights

Joanne Csete
Director, HIV/AIDS Program
Human Rights Watch

I would like to begin by congratulating the Legal Network for its 10 years of courage and effective work. I am always struck by the fact that although the Network has "Canadian" in its name, it is a truly international organization, particularly in its impact. I am grateful to Ralf and the rest of the staff and the board for the chance to be part of the Network's important work.

I am happy to be here in the heroic company of the member organizations of the Network. As much as it is deeply inspiring to rub elbows with all of you, it is also deeply humbling and very daunting to think that there is something I can say about the subject at hand that you, who are on the front lines of this human rights struggle every day, have not already thought of a hundred times. But some of the thoughts I have on the subject of HIV/AIDS and human rights on the global scene make me purely miserable, and I proceed on the solid grounds that misery loves company.

With an audience where everyone in the room has been touched in some way by HIV/AIDS – in some cases, the word "touched" is clearly inadequate; more like "clobbered" by HIV/AIDS – we do not have to spend a lot of time talking about the basic facts of the epidemic – the 60 million infected so far, the 25 million already dead, most of them young adults, many of them parents, the vast majority too poor, or living in countries too poor, corrupt or misguided, to ensure that they have access to the drugs that could have prolonged their lives. We are talking about eight to nine thousand deaths a day and 16,000 new infections a day. The difference between these two numbers tells us that we are far from having seen the worst of this crisis. The 21 million deaths so far in Africa have mostly come from 18 countries of Eastern and Southern Africa that constitute five percent of the world's population, but now about 78 percent of the deaths from AIDS. At the press conference last Friday to announce the Canadian Award for Action on HIV/AIDS and Human Rights to the Vancouver Area Network of Drug Users (VANDU) – a richly deserved award I should add – Dean Wilson rightly talked about genocide in the Downtown Eastside of Vancouver. These figures from Eastern and Southern Africa inevitably bring the same word to mind.

HIV/AIDS maintains its horrible destruction around the world, riding on the back of a wide range of human rights abuses.

With respect to human rights, we know that HIV/AIDS came into the world, and maintains its horrible destruction around the world, riding on the back of a wide range of human rights abuses. It is nothing short of shocking, 21 years into this epidemic, that the way in which AIDS is fuelled by human rights abuses – and the way in which AIDS, in its turn, leaves human rights abuses in its wake – is still so little appreciated by those who have some influence on the resources that are brought to bear to combat this scourge.

Emerging Epidemics

Though the catastrophe of AIDS in Africa is so unspeakable as to be paralyzing – which we must not let it be – we are in a situation today where, frighteningly enough, there are a few emerging or already very massive HIV/AIDS epidemics that may have the potential to surpass the destruction that Africa has witnessed. To mention just three:

- The epidemic in China, about which we know very little, must be very grave. Considering only the abuses that Wan Yanhai has talked about in Henan, and similar practices in other provinces, means that the figure of one million persons living with AIDS (which is what the government admits to) is likely off by a long way. Also, we know that these deadly blunders with regard to the commercialization of blood are compounded by the cruel repression of gay men, sex workers and injection drug users, as well as persons with AIDS and their friends and families.

- In the former Soviet Union, including Central Asia, with the collapse of the Soviet structures, the associated collapse of the economy and the disappearance of jobs, came an influx of relatively cheap heroin from Afghanistan (a practice which many experts regard as having only been made worse by the recent war in Afghanistan). All of this collided with a health system, also deteriorating, that had absolutely no tradition of confidentiality in any aspect of clinical testing or record keeping. Add to this, drug laws that have long been repressive and that violate the rights of users, and you have a formula for AIDS. In Kazakhstan, where we recently did some work, all drug users are on a police "watch list," and all persons detained are tested for HIV (a policy that we hope is beginning to change).

- And then there is India, which has the epidemic that I am most worried could before too long be the worst of all. Because there we see the coming together of criminalization; deep social disdain and ostracization of gay men and drug users; a shameful history of repression of women (that is changing in some places, thanks to a strong feminist movement, but a feminism that still scorns women in prostitution); a ruling political party that is quick to dismiss anyone outside its narrow sphere of acceptable morality as anti-nationalist or, better yet, terrorist; and poverty that is so deep and wide as to be nearly unimaginable. All of the conditions are there to foster the epidemic.

All three cases involve governments that are lying or are being very evasive about numbers. In India, where the government allowed the results of one good nation-wide survey in the mid-1990s to be made public – it estimated that about 4 million persons were living with AIDS – the denials and lies since then have become more and more convoluted, to the point where some officials have said the epidemic is slowing, which is tragically untrue.

Categories of Abuse

It is a challenge for me to know how to structure a discussion of AIDS-related human rights abuses in the world when they are so many, so varied and so interconnected. I would like to share with you the fifteen categories of abuses we have identified for our research and advocacy work in Human Rights Watch. Many of them have also been central to the agenda of the Legal Network. Please note that these categories overlap a great deal; they are not as discrete as this listing will make them seem.

1. Discrimination and abuse faced by drug users (only a tiny percentage of whom have a VANDU to turn to).
2. Discrimination and abuse faced by sex workers.
3. Discrimination and abuse faced by gay men and others discriminated against on the basis of sexual orientation.
4. The subordinate status of women and girls. (This renders women and girls unable to control the terms of their sexual lives, and is often combined with laws and polices making them economically dependent on their husbands or on other men, which keeps them in marriages they might otherwise leave. NGOs in many places around the world tell us that the highest-risk group for AIDS is married women who have only ever had sex with their husbands.)
5. Sexual violence as a weapon of war (which Human Rights Watch documented in horrifying detail in the current war in the Congo).
6. Sexual violence and coercion more generally.
7. A horrific range of abuses against prisoners.
8. Discrimination on the grounds of HIV status. (We are often surprised by how much of this is embodied in national law.)
9. Immigration law and practice that limits people's entry into countries if they are HIV-positive (a pure form of discrimination based on HIV status that has no basis in public health).
10. Criminalization of HIV transmission and other criminal law issues (on which the Legal Network has contributed so much useful analysis).
11. Compulsory testing (also legal according to many national laws).
12. A wide variety of confidentiality and right-to-privacy issues.
13. Censorship and other violations of the right to information and free expression, including crackdowns against AIDS educators (writ large for us this weekend with the case of Wan Yanhai).
14. A wide range of violations of the rights of orphans and other children affected by AIDS.
15. Access to treatment and care.

I would like to say a few words about several of these kinds of abuse.

On the matter of discrimination and abuse faced by men who have sex with men: Many of you have devoted your lives to addressing these abuses, which remain so horrific in so many parts of the world. It is catastrophic that HIV/AIDS seems in some places to have hardened support of sodomy laws that must urgently be repealed. Section 377 of the Indian Penal Code is an example,[22] though the concerted work of dedicated activists working toward its repeal may yet win the day. In eastern and southern Africa, discrimination against gay men and lesbians is a almost completely overlooked part of the epidemic, which has been fed by idiotic and hateful statements by African leaders. In this regard, the case of Robert Mugabe of Zimbabwe is well known, but there is also the sainted Yoweli Museveni, who has rightly received world-wide recognition for speaking out much earlier than his peers on HIV/AIDS, but who, since then, has not distinguished himself on related human rights issues. In receiving an award for his work on HIV/AIDS recently, he took pains to point out that HIV/AIDS is transmitted only heterosexually in Uganda since the country "has no homosexuals." One wonders why it has been necessary then for so many people in his government to go out of their way to denigrate and repress gays in Uganda. In India, the director of the national AIDS program told me that the reason the sodomy law is important is that most "same-sex couplings" involve young boys, and the law is needed to protect them. No wonder it is sometimes hard to be optimistic about making a dent in the AIDS epidemic in India.

There are hundreds of Wan Yanhais out there, facing persecution and repression just because they talk about HIV/AIDS.

On censorship and crackdowns on AIDS educators: We must keep Wan Yanhai in our thoughts, and we have to remember that there are hundreds of Wan Yanhais out there, facing persecution and repression just because they talk about HIV/AIDS. Again, this is a feature of the epidemic in India, where HIV/AIDS outreach workers are being harassed, in some cases violently, by the police. But we do not need to look so far from home. The influence of religious fundamentalists in the United States is making it more and more difficult to bring basic information on HIV transmission to young people. The Bush administration's budget proposal to the Congress recommended cuts in most programs in the education sector, but asked for large increases to the budget for "abstinence only until marriage" programs. Next week, Human Rights Watch will release a report showing that these programs give young people the message not only that condoms do not work to prevent HIV (only abstinence works), but also that marriage is only for heterosexuals and, therefore, that gay and lesbian young people should never have sex at all. (I am not making this up.) I was pleased to learn that, before his detention, Wan Yanhai was about to do a study of "abstinence only" programs in the U.S. A recent United Nations report showed that even in heavily affected countries, large numbers of young people do not know the basics of HIV transmission. The U.S. is setting no example for these countries. We have to come around urgently to recognizing this as a human rights problem.

All too rarely is it recognized that HIV/AIDS has been associated with a truly atrocious crisis of human rights abuses of children orphaned and affected by AIDS. In country after country, there are laws, children's codes, juvenile justice systems and family codes that rest squarely on the assumption that a child who loses his or her parents will be cared for by members of an extended family. The cruel reality of this epidemic, of course, is that it seems often to destroy or greatly challenge the extended family, or to bring out the worst in it. Around the world, we have seen the rejection of widows and orphans of AIDS, the illegal appropriation of their property by family members, the exploitation of children by surviving family members, and so on.

---

[22] See, Indian NGO Challenges Penal Code Prohibition of "Unnatural Offences." *Canadian HIV/AIDS Policy & Law Review* 2002: 7(1): 58.

With respect to children, we are talking about a range of AIDS-related abuses that are horrific in nature and stunning in the number affected (a situation that remains under-appreciated by governments). These abuses include:

- The widespread inability of children to realize the right to education.
- AIDS-affected children having to take up hazardous and otherwise inappropriate labour as they are forced in huge numbers to become breadwinners for what family they have left.
- Discriminatory barriers to children accessing basic services.
- Violence and sexual abuse, particularly as large numbers of AIDS-affected children wind up on the streets, but also within "foster" families. In our recent work in Zambia, we interviewed about a hundred girls and heard with horrifying regularity stories about uncles, step-fathers, etc., who are the principal "care-givers" of orphaned girls, but who would coerce them into sex, sometimes saying "I'm the only one who would look after you; how could you refuse me?" or some variation on that refrain.
- Inequality before the law, as children affected by AIDS find no legal redress for the crimes committed against them.

There is little sign that any of this will get better before it gets worse.

The Politics of AIDS

How has this all been allowed to persist? Human rights violations thrive for many reasons but, in the end, the most important ones are often political in a strict sense. In this case, the politics of HIV/AIDS is completely ugly. It is, first, a *politics of denial* – the very nature of the virus and its epidemiological course give politicians and policy-makers a window of denial that they readily take advantage of. A window, most sadly, that sets the epidemic up for the enormous mortality that becomes so hard to put the brakes on in the absence of access to antiretroviral treatment. It is a *politics of cowardice* as most politicians in the world remain reticent about diving into any area in which the day-to-day struggles involve working side by side with gay men, drug users, sex workers, prisoners and others affected by AIDS.

It is difficult to find policies or programs that take their cue from the experiences of uneducated, poor and socially marginalized people.

The politics of HIV/AIDS is also a *politics of elitism and racism*. One of the main reasons that the global AIDS epidemic took so long to find a place on the global stage, and still does not have priority in global resource allocation, is that it could be brushed away as an "African problem." Moreover, in the world outside Africa, I defy you to find a policy-maker who readily embraces the idea that there are lessons to be learned from Africa. And within Africa and Asia, in spite of decades of dense and earnest rhetoric on the benefits of participation, it is equally difficult to find policies or programs that take their real cue from the experiences of uneducated, poor and socially marginalized people.

As we all know too well, the politics of HIV/AIDS is a *politics of moral judgementalism*, a politics that has thrived with the apparently growing political influence of religious fundamentalists of all kinds. One might reasonably have hoped that one result of the events of

September 11, 2001 would be a repudiation by all government of religious extremism, but the contrary seems to be the case in many places, with unspeakably terrible consequences for HIV/AIDS and human rights. The power of religious extremists, once again, has hardened support for sodomy laws, has galvanized support for cruelly repressive drug laws that violate the rights of users, and has gone to great lengths to keep women and girls in subordinate roles.

Finally, this is also a *politics of an unaccountable superpower* and its cowardly allies. The United States has had a thousand chances to bring leadership to the global struggle against AIDS and to contribute to respecting the human rights of people, and has failed at every turn. The Bush administration's response to the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria was a cynical presentation of a paltry contribution and the announcement of a program to prevent mother-to-child transmission that amounted mostly to the smoke and mirrors of reallocating insignificant amounts of money already designated to other health programs abroad. Where the big money does get pulled out is to placate religious fundamentalists with "abstinence only until marriage" programs, at the cost of denying young people in public schools access to basic information about HIV and teaching them about the immorality of homosexuality. This is from the same people who so often seem to see no moral dilemma in the casualties inflicted in wars of aggression.

How Do We Respond?

As David Hoe said in his keynote address, "Is this all dismal?" No, he said, resolve is stronger. But exactly what sort of resolve do we need to make a dent here? *How do we begin to address any of this, and how do we make the best strategic use of the respective strengths of the HIV/AIDS movement and the human rights movement?* One way is to make sure that there are more organizations in every country modelled after the Canadian HIV/AIDS Legal Network. Short of that dream, it seems clear to me that the communities of HIV/AIDS activists and of human rights activists need, if you will excuse the expression, to infect each other (or perhaps the botanical idea of cross-fertilization is more polite). Although the HIV/AIDS movement uses the language of human rights, there are few organizations like the Legal Network that have really taken on the tools and mechanisms of human rights and tried to use them. But the real need is in the human rights movement. Human rights NGOs, including my own, have been very late in coming formally to HIV/AIDS as an issue. We need badly to make up for lost time and to do much more to document and analyze AIDS-related human rights abuses and to scream like hell about them.

There are few organizations that have taken on the tools and mechanisms of human rights and tried to use them.

I think for there to be a meaningful and productive coming together of these two worlds, a lot of things need to happen. Let me highlight three:

First, we need to make maximum use of the amazing global movement for access to anti-retroviral treatment. We need to make sure that it has all the tools it needs to assert treatment as a human right, but also to make the link between treatment access and the realization of other human rights (or the reduction of human rights violations). The work of ensuring that relevant human rights resolutions and guidelines say the right thing is crucial. But we also need to bolster arguments for treatment access by reminding people that getting treatment is a key to reducing discrimination – something the UN has barely mentioned in its several reports on discrimination and stigma. We also need to make the point that extending the lives of parents with AIDS may be the single most effective way of protecting their young children from the wide range of horrible human rights abuses that I mentioned earlier. I know this is a lot to ask of the treatment access movement when their main cause is already a handful, but I think that these links can be made in ways that bolster the right-to-treatment case. Certainly, these links will help bring into treatment access advocacy more human rights activists with their documentation and analysis tools. The human rights movement, for its part, has to understand clearly that there have never (or virtually never) been successes against HIV/AIDS except where people with AIDS themselves have been able to organize to assert their rights, and that this is not going to happen – or is not going to happen as effectively – if they are persistently ill.

Second, we all need to work harder to make global connections in meaningful ways. I feel like I have been smacked in the head with the canard "think globally, act locally" ever since I learned how to read. But the sad truth is that we cannot think globally on the basis of what is in the world news, at least in mainstream media. Also, as useful as the Internet is, we all know that it too can be filled with unfiltered rubbish. We have to make partnerships with people and organizations who know what they are talking about. This is why the international program of the Legal Network is so crucial. Even if it is small and has only a few strategic priorities, it will cause the development of skills and contacts that will assist many organizations that might not otherwise be able to make those international links. It was thrilling to hear from Dean Wilson and Ann Livingston about the international attention VANDU has drawn and the links it has made to institutions in places like Iran. This is so important. The work that AIDS organizations in North America have done around the detention of Wan Yanhai has depended on contacts with people who understand China, and the Legal Network and other organizations have done well to facilitate those contacts.

We need to overcome our cynicism about the legal, judicial, legislative and policy institutions of government, and find ways to exploit these structures.

Third, and this is the hardest thing of all, we need to overcome our cynicism about the legal, judicial, legislative and policy institutions of government – city, state and national – and of multilateral institutions – and find ways to exploit these structures. This is very hard. It seems especially hard for us in the U.S. now, where, in my lifetime, to state the obvious, we have watched the progressive activism of the 1960s give way to a plutocracy run by people who too often believe that the poor and the socially marginalized and those living with HIV/AIDS deserve what they got. We also have to remember that the history of the struggle against HIV/AIDS is one where NGOs and communities of people affected by HIV/AIDS have been ahead of government in every significant battle. Given that history, it is not only easy, but also understandable, to give up on governments in all their forms. We cannot do this, of course. The small, and not so small, legal and police victories of the past – which would fill a speech in themselves and which will certainly inform those of the future – are the reason why. I am persuaded that the overturning of the "unnatural offences" section of the Indian Penal Code – the law that effectively criminalizes gay men – would dramatically alter the course of the epidemic in India. I am convinced that the work of the harm reduction movement across the former Soviet Union to get governments at all levels to approve and support needle exchange and methadone programs will pave the way for a downturn in HIV transmission there. In my better moments, I am even convinced that the U.S. government may someday come to its senses and stop spending taxpayer dollars to tell young people that condoms don't work to prevent AIDS. However, real momentum in that regard may tragically come only when more young people from privileged families contract the virus.

Conclusion

It is hard to know how to find an inspiring concluding thought for these rambling remarks, but I was lucky to stumble upon one on Sherbrooke Street not far from here the other morning. It was from a most unlikely source for people working on HIV/AIDS and human rights – Charles de Gaulle. On Sherbrooke Street East, etched into a plaque next to a very curious monument to de Gaulle, is this thought from him (in rough translation): "Let us be steady…for before us lies the greatest glory – the glory of people who never gave up." Congratulations to all of you for never giving up.