



***HIV/AIDS and Human Rights***

# ***Stories from the Frontlines***

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*Prepared by  
the International Council of AIDS Service Organizations (ICASO)*

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## About

# Stories from the Frontlines

*Non-governmental organizations (NGOs) around the world working in HIV/AIDS have had to confront a variety of human rights violations. Stories from the Frontlines describes:*

- *how NGOs have responded to human rights violations;*
- *the campaigns organized by NGOs to promote and protect human rights in the context of HIV/AIDS; and*
- *some recent examples of human rights abuses.*

*Stories contains a series of articles on access to treatment issues, immigration, housing, employment, the law, confidentiality, marriage, prisons, violence and access to care. We asked people and organizations working on the frontlines in all corners of the world to submit stories, and they responded. The names of the contributors are included at the end of each story. Some of these stories are success stories from which we can learn valuable lessons. Other stories highlight current issues that we need to address.*

*ICASO believes that it is important to celebrate our successes. NGOs and persons living with HIV/AIDS are making progress in understanding their rights and finding creative ways to ensure that they are enforced. But many challenges remain. We hope that these stories will convince you that NGOs and persons living with HIV/AIDS can make a difference. We can learn from each other and we can empower ourselves to act.*

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## The Link Between HIV/AIDS and Human Rights

HIV/AIDS is both a health issue and a human rights issue. In fact, there are close links between human rights and health. They both share the common objective of promoting and protecting the rights and well-being of people.

In the context of the HIV/AIDS epidemic, the promotion and protection of human rights is necessary to achieve the public health goals of:

- reducing vulnerability to HIV infection;
- lessening the adverse impact of HIV/AIDS on those affected; and
- empowering individuals and communities to respond to HIV/AIDS.

Care and prevention programmes that contain coercive or punitive measures result in reduced participation and increased alienation of persons living with HIV/AIDS and people at risk. People

will not seek counselling, testing, treatment and support if this means facing discrimination, lack of confidentiality or other negative consequences. Coercive measures drive away the people most in need of services.

The incidence and spread of HIV/AIDS is disproportionately high among groups that already suffer from a lack of human rights protection and from discrimination, and among groups marginalized by their legal or economic status. Lack of human rights protection disempowers these groups. However, when human rights are protected, fewer people become infected with HIV and the friends and families of those who are infected can better cope with the disease.

Protecting human rights helps to reduce societal vulnerability to HIV/AIDS.

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# Community action forces insurance providers in Israel to back down

A rapid and comprehensive response from the community sector was successful in getting health insurance providers in Israel to reverse a decision to discontinue coverage of antiretroviral medications.

## The Violation

In the spring of 1997, one of Israel's four private sector health insurance providers decided it would no longer pay for the antiretroviral medications used by persons living with HIV/AIDS. The provider claimed that because the Ministry of Health had not included these medications in the basket of drugs subsidized by the government, it was not obliged to supply them. A few weeks later, a second insurance provider joined the first and the others threatened to follow suit.

As a result, many persons living with HIV/AIDS were forced to stop their treatment in mid-stream. Some of them developed irreversible resistance to the drugs or classes of drugs they had been taking. Others were unable to start treatment. Many persons living with HIV/AIDS began to get critically ill.

## The Response

The response was initiated by the Israel AIDS Task Force (IATF), the main NGO in Israel dealing with HIV/AIDS prevention and support, with the help of Living with AIDS, a coalition of 15 human rights NGOs and HIV/AIDS NGOs initiated by IATF. A task force was established and a plan of action was developed. The following activities were organized:

**NATIONAL MEDIA CAMPAIGN** The media was given information about the problem and personal examples of the impact on persons living with HIV/AIDS. Media coverage was extensive.

**LOBBYING KEY INDIVIDUALS** Meetings were held with the executive directors of the health insurance providers; the top civil servant in the Health Ministry; the ministers of three ministries: Health, Economy and Social Welfare; and the wife of the Prime Minister (who turned out to be very supportive).

**LOBBYING MEMBERS OF THE KNESSET** Meetings were held with most of the members of the Knesset (the Israeli parliament), representing both the government coalition and the opposition. As a result of these meetings, members from both sides officially requested a change of policy on the floor of the Knesset.

**PETITION** A petition was circulated throughout the country by volunteers from human rights NGOs and HIV/AIDS NGOs.

**DEMONSTRATION** On the day of a critical debate in the Knesset, AIDS activists held a demonstration outside the building.

**LAWSUIT** Ten persons living with HIV/AIDS filed a lawsuit against the government and the health insurance providers, alleging that they had failed in their duty to take care of people's health.

**ADDITIONAL ACTIVISM** Graffiti and posters were put up in numerous locations. Faxes were sent to the person in charge of the case at the Ministry of Economy.

## Support from Abroad

As a result of efforts by IATF, the case received worldwide publicity. Hundreds of faxes and e-mails were sent to the Ministry of Economy from outside Israel from persons living with HIV/AIDS, from other people affected by HIV/AIDS, and

***Some people arriving from abroad brought in antiretroviral medications and distributed them to the people who were most critically ill. They did so in front of the eyes of the media to draw attention to the problem, even though what they were doing was illegal. The case was covered by international media, including CNN.***

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from local, national and international NGOs. Some people arriving from abroad brought in anti-retroviral medications and distributed them to the people who were most critically ill. They did so in front of the eyes of the media to draw attention to the problem, even though what they were doing was illegal. The case was covered by international media, including CNN.

IATF was concerned, however, that UNAIDS chose not to make any public statements on the issue despite being requested to do so.

### **The Outcome**

The combination of the lawsuit, the lobbying at the Knesset and the media coverage brought enormous pressure on the government.

On December 1, 1997, World AIDS Day, during a lively televised debate at the Knesset, the Minister of Health had to explain his position in front of AIDS activists who proceeded to take him apart. The activists then participated in the meetings of the Commission of Economy (a committee of the Knesset), to try to influence the government to change its policy and to approve additional funding for the antiretroviral medications. The chair of the commission declared that if the government did not resolve the problem, the commission would not approve the 1998 budget of the government. By now, the whole affair had precipitated a crisis in the Knesset and in the government.

On December 14, 1997, the tribunal in Tel Aviv that had heard the lawsuit issued an order temporarily requiring the health insurance providers to make the antiretroviral medications available. Two weeks later, the government agreed to include seven new AIDS drugs in the basket of drugs to be subsidised. In February 1998, the government

decided to categorize AIDS as a severe disease, which meant that all new HIV/AIDS treatments approved by the government would be available free of charge and would be reimbursed by the government through the health insurance providers.

AIDS activists are using the new "severe disease" classification to lobby the government for faster approval of HIV/AIDS medications and for better care for persons living with HIV/AIDS.

IATF expressed the hope that UNAIDS will review its role in this affair. IATF believes that there is a conflict between the position taken by UNAIDS that it cannot intervene in the internal affairs of a country without being invited in, and the day-to-day realities of persons living with HIV/AIDS and HIV/AIDS organizations.

### **Lessons Learned**

- **This fight was won because of the coalition that was created. Such coalitions require strong leadership, good organisation, a clear division of roles and an effective strategy.**
- **This kind of campaign can be done with limited resources, using volunteers and professionals willing to donate their time.**
- **The use of the media is critical. No government likes to be seen as the bad guys.**
- **It is very useful to provide the media with personal examples of the problem.**
- **Support from abroad is important. No government likes to have a bad image outside its borders.**

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# Hands across borders: The story of Carl and Odir

Carl in California has never met or even spoken to Odir Miranda in El Salvador. Yet he is responsible for saving Odir's life. Every two months since mid-1998, Carl (not his real name) has mailed a shipment of antiretroviral medications to a post office box in El Salvador, where a physician friend of Odir is able to pick up packages without having to be questioned by customs officials.

Carl responded to an Internet posting placed by Triangulo Rosa, the Costa Rican gay and lesbian association, asking for donated medications to save the lives of persons living with HIV/AIDS in Central America. Four persons are now being treated with antiretroviral medications sent by North American donors whom they have never met.

Carl had several months' supply of surplus anti-retroviral medications after his partner died of AIDS early in 1998. He sent these medications to Odir. There were enough medications to last until June 1998. Carl then spoke to the physician who had cared for his partner, and the physician agreed to continue writing prescriptions in order to keep Odir alive.

Triangulo Rosa, who is the intermediary in this transaction, has never asked for details of how the prescription is written or paid for.

Odir had a series of opportunistic infections early in 1998 and was hospitalized for the entire month

of February. His weight had dropped to about 45 kg. Just a few weeks after beginning to take the retroviral medications, his condition began to improve dramatically. The infections stopped and Odir gained more than 9 kg. In October 1998, he was well enough to travel to the United States to testify before the Interamerican Human Rights Commission, becoming the first person with AIDS to address the commission.

Odir's recovery on retroviral medications has been spectacular. His bravery in coming out publicly, and his work as President of Atlacatl, an association of persons living with HIV/AIDS in El Salvador, is giving encouragement and hope to the thousands of Salvadorans with AIDS who have no medications.

But Carl, in California, is an unsung hero. He has made it possible for Odir to live, thus enabling Odir to make it possible for other persons living with HIV/AIDS to have a better life. Carl is not in any newspaper, and his true identity cannot be revealed here for fear of jeopardizing the process by which he obtains the medications. But Carl, and several others like him, have made the effort to do something concrete for persons living with HIV/AIDS who cannot afford the high cost of their medications.

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# Hands across borders: The United States-Venezuela Air Bridge

Thanks to a unique, coordinated effort between two continents, about 2,000 persons living with HIV/AIDS in Venezuela have been able to gain access to life-saving HIV/AIDS medications.

The effort involves transporting medications by air through a volunteer infrastructure that includes donors, airlines, truckdrivers, customs officials, medical personnel and storage facilities. The medicine bank, or "air bridge" as it has come to be known, is organized in Venezuela by Acción Ciudadana Contra el Sida (ACCSI) and in the United States by United Against AIDS International (UAAI).

Renate Koch, Executive Director of ACCSI, began bringing medications home to her native Venezuela in 1994 following a visit to New York City where she met with representatives of a number of HIV/AIDS organizations. Around the same time, Hugh Ward, Executive Director of UAAI, who had been hand carrying medicines and supplies from his home in New York City to friends in Caracas, Venezuela, met with Koch and other NGOs in Venezuela and began to formalize the air bridge.

## Network of Organizations

A network of organizations in the United States including ACT UP! (New York), the Gay Men's Health Crisis, Unión Positiva (Miami), various coalitions of persons living with HIV/AIDS and groups of doctors assemble the medications donated to them by persons living with HIV/AIDS. The donations usually involve medications that are no longer required because a person living with HIV/AIDS has died or has gone on to an alternate treatment regimen. In addition to hand carrying the medications in suitcases, UAAI secures the help of transportation companies (including two Venezuelan airlines) to transport the medications free of charge from New York to Caracas.

In Venezuela, ACCSI successfully lobbied government officials to allow the medications to be expedited through customs with no taxes or fees. Once the medications are received, they are stored at Acción Ecumenica, the health clinic in Caracas that supervises the distribution of the drugs to persons living with HIV/AIDS.

The medications include mostly drugs to treat and prevent opportunistic infections (which are not available in Venezuela), but also some antiretroviral drugs and protease inhibitors. (As a result of pressure and legal action from groups in Venezuela, the Government is now providing antiretroviral drugs and protease inhibitors to some persons living with HIV/AIDS.)

Supplies of the medications from the United States are not as high now as they were when the air bridge started (probably because of the rapid decline in the death rate of persons living with HIV/AIDS in the United States), so the medicine bank does occasionally run out of stocks.

The air bridge also carries medical supplies and equipment, which ACCSI has distributed to eight health centres in Venezuela.

In the last year, ACCSI has also received a grant from Ensemble contre le sida, in Paris, which has enabled the organization to employ a pharmacist, to reimburse volunteers and truck drivers for meals and transportation, and to purchase some medications for emergency purposes.

## Lessons Learned

- **International programmes to develop medicine banks can and should be done.**
- **It is important to plan well in advance to find committed donor partners.**
- **Considerable patience is required while negotiating with the many players involved, including government personnel, politicians and transport companies.**
- **There is a need to budget for high communication costs to make it work.**

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Additional information taken from AIDSLink #43, published by the National Council for International Health (now the Global Health Council).

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# Advocacy campaign in France succeeds in reducing deportations of immigrants living with HIV/AIDS

Thanks to a concerted grassroots advocacy campaign, it is now illegal to deport foreigners who are living in France, who have a life-threatening illness and who are receiving treatment, unless they would be able to obtain appropriate treatment in their country of origin.

A coalition of HIV/AIDS and immigrant organizations was successful in persuading the French parliament to include the prohibition in an immigration law passed in 1997.

## Background

For years, it has been common practice in France to deport foreigners convicted of a crime while in France (for example, theft, possession or trafficking of illegal drugs, prostitution). There were also cases of foreigners being deported solely because they had entered the country illegally. Some of the people being deported were persons living with HIV/AIDS. If returned to their countries of origin, these people faced two risks:

- being imprisoned or stigmatized; and
- not being able to access treatments or adequate care.

If these persons living with HIV/AIDS were already receiving treatment in France, deportation often amounted to a death sentence. Experience has shown that treatment started in France is inevitably interrupted and rarely resumed. For many people living with HIV/AIDS, interruption of treatment carries with it a high risk of developing resistance to one or more drugs or classes of drugs.

Act-Up-Paris first began to fight individual cases of deportation in 1991. Act-Up promoted a basic principle – that people on the territory of France should be entitled to adequate treatment, whatever their status. Act-Up was able to prevent some deportations through activism (for example, blockading airports and train stations, arranging demonstrations at federal offices, writing letters to

officials). But this was a hit-and-miss approach and Act-Up resolved to fight for a policy or a law that would prohibit such deportations.

## Advocacy Campaign

An opportunity arose in 1996, when the French parliament was debating a particularly repressive immigration bill. Act-Up teamed up with a number of immigrant organizations to push for an amendment to the bill to outlaw the deportations. The members of this informal coalition shared the workload, each contributing where it was most competent. The coalition:

- wrote to all parliamentarians with arguments that were backed up with detailed facts (epidemiological statistics, reports from official bodies, etc.);
- met with key parliamentarians from all parties; and
- provided the wording for the amendment.

The government argued at the time that it already had a policy of not deporting people with life-threatening illnesses, so there was need

to legislate on the matter. The documents provided by the coalition revealed this claim to be false. Then, just before a key vote on the bill, a particular case was made public. Ali B., a Moroccan man, was deported while he was undergoing triple combination therapy and was in an advanced stage of AIDS. There was a big scandal in the media; public opinion turned against the government; and the coalition was thus able to influence many parliamentarians to support an amendment.

As a result, the amendment put forward by the coalition was introduced and passed by the French parliament.

## The Struggle Continues

While this is an important victory, the fight is not yet over. There are at least three reasons for this:

***Act-Up promoted a basic principle – that people on the territory of France should be entitled to adequate treatment, whatever their status.***

- The law only refers to people already receiving treatment. Many of the people facing deportation have not started treatment because immigrants are even more likely than most people to find out their HIV status and to access treatments late in the course of their illness.
- There are still deportations occurring that have to be fought on a case-by-case basis because some officials are ignoring the law.
- Those people who, because of the new law, are not being deported remain in a precarious social position: they cannot be deported but they do not have regular status and so cannot work, cannot benefit from social assistance and are often denied freedom of movement.
- **While it is important to educate all parliamentarians in a campaign such as this one, it is even more important to target the ones with the most influence on a particular bill.**
- **The timing of an advocacy campaign is critical. Progress in this instance was possible because public opinion was on-side and the politicians were somewhat receptive. A few years earlier, the climate was much less favourable.**
- **This fight allowed HIV/AIDS organizations to make common cause with immigrant organizations.**

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### Lessons Learned

- **While this was not a complete victory, it is important for community groups to have victories, however small.**

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## Education eliminates hostility to AIDS hostel in Ecuador

Efforts to educate the public about HIV/AIDS and discrimination successfully defused opposition to the establishment of an AIDS hostel in Quito, Ecuador.

Fundación EUDES, an NGO providing a wide variety of services in Columbia and Ecuador, runs a hostel for persons living with HIV/AIDS in Quito.

The hostel, known as EUDES, provides shelter, care, support and dietary advice. When EUDES first moved into the premises, it faced considerable hostility from the local community. People were ignorant about HIV/AIDS and were afraid of getting infected. They threatened to burn down the hostel unless it was moved outside of town. They implicitly threatened to physically harm the Director of EUDES. Residents of the hostel were verbally harassed.

***In the past, young people in the neighbourhood would not go near the house. Now, as a result of these educational efforts, they go into the hostel to attend prevention workshops.***

As this was the only hostel for persons living with HIV/AIDS in Ecuador, failure to respond to these fears would have set a pattern for discrimination and rejection in other communities.

### The Response

Fundación EUDES, with the support of COMUNIDEC Fundación de Desarrollo, a development NGO that provides technical and financial support through its AIDS

programme, mobilized NGOs and other players to respond to the problem. The response involved 20 organizations from all over Ecuador, and included AIDS service organizations, women's organizations, a theatre group, development organizations, the Ministry of Health, the faculty of medicine at the Catholic University in Quito, Glaxo Wellcome and a network of persons living with HIV/AIDS.

This informal coalition organized a health fair for the local community to raise awareness of

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HIV/AIDS and other health issues and to directly challenge discrimination. COMUNIDEC covered all of the costs involved, including the travel of NGO representatives to Quito. Only a few people from the neighbourhood attended the health fair.

However, residents had selected a person to represent them and he went to the fair. Once the facts and the issues were explained to him, the representative made a commitment, on behalf of the neighbourhood, to respect the hostel and the people who used it. He even offered to help to find a plot of land to build an additional hostel.

The health fair led to other educational efforts in the neighbourhood targeting market vendors on a one-on-one basis to explain the work of EUDES. Several neighbours became volunteers at EUDES or donated money to the hostel. In the past, young people in the neighbourhood would not go near the house. Now, as a result of these educational efforts, they go into the hostel to attend prevention workshops.

Favourable coverage of the problem and of the response from a local radio station, a national TV

network and a national newspaper was instrumental in turning things around.

### **Lessons Learned**

- **NGOs have the power to challenge discrimination and change attitudes when they work in collaboration.**
- **Working in partnership with other NGOs and stakeholders can provide invaluable support, both psychological and practical. It can help to confront issues openly and challenge prejudice.**
- **Efforts should be made to educate the local community before establishing a hostel.**
- **The health fair did not try to tackle discrimination based on sexual orientation, even though many people present at the health fair were gay and homophobia was evident. This was perhaps a missed opportunity.**

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## **Working together works: New human rights law adopted in the Philippines**

Community organizations in the Philippines worked together with other stakeholders to successfully persuade the Congress to pass a law that protects the rights of persons living with HIV/AIDS.

The new law, which was adopted in February 1998, says that

*The State shall extend to every person suspected or known to be infected with HIV full protection of his/her human rights and civil liberties. Toward this end, compulsory HIV testing shall be considered unlawful; the right to privacy of individuals with HIV shall be guaranteed; and discrimination, in all its forms and subtleties, against people with or suspected to have HIV/AIDS shall be considered inimical to individual and national interest.*

The law commits resources to a national multi-sectoral response to the epidemic; and promotes HIV/AIDS education in schools, the workplace and the community. The law also recognizes the "potential role of affected individuals in propagating vital information and educational messages on HIV/AIDS."

### **The Campaign**

The campaign to get the new law adopted, which took about five years, was spearheaded by the Senate Committee on Health and Demography, with support from the Philippine National AIDS Council, a high-level multi-sectoral council, as well as community-based NGOs, including the organization of Filipinos with HIV/AIDS and AIDS service organizations. Support for the proposed bill was received from NGOs throughout

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the country, particularly in the major cities.

The community was involved in the following activities:

- The establishment of an NGO working group to critique the bill. The groups' findings were presented at Philippine National AIDS Council meetings and Senate Committee hearings on the bill.
- Mobilization to ensure NGOs attended the Senate Committee hearings.
- Sensitization workshops in different parts of the country.
- A national consultation of NGOs and community-based organisations to discuss the bill and to prepare letters to Senate to hasten passage of the bill.
- Lobbying by some local groups with their representatives in the lower House to push for passage of the bill.

When the bill was first drafted (about 1993), there were other legislative measures before the Congress that were diametrically opposed to the bill and that were more popular among legislators. These measures included compulsory testing, maintaining records on persons living with HIV/AIDS (complete with mug shots), and quarantine for persons living with HIV/AIDS. Consequently, the campaign to get the new law passed was preceded by a long, drawn-out campaign to educate the legislators about appropriate responses to HIV/AIDS.

In the end, by making some acceptable trade-offs, proponents of the bill were able to get the backing of conservative legislators. The Catholic Bishops Conference also lent its support.

In the Philippines, the media has a significant impact on policy makers. Coverage of the HIV/AIDS situation and the response to the epidemic – both successes and failures – helped to keep the bill on the agenda of the Congress.

### **Aftermath**

The new law is being implemented in stages; NGOs are continuing the pressure to ensure that it is implemented fully and without inordinate delays.

The new law has pushed the Government and other stakeholders to give priority to HIV/AIDS. It has also provided a clear framework for the national response to HIV/AIDS in the Philippines.

### **Lessons Learned**

- **It is possible to enact a law that protects the rights of persons living with HIV/AIDS even in a conservative country like the Philippines, where it may be easier to blame people with HIV than to protect them.**
- **Working together works. Although some compromises may have to be made, support can be obtained from even the more conservative sectors of society.**

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# Court in India reverses workplace discrimination

A court in India has ruled in favour of a person living with HIV/AIDS who was discriminated against in his workplace.

Ravi (not his real name) has been working for over ten years as a casual labourer in a public sector corporation controlled by the government of India. According to the policy and practice of the corporation, casual workers were placed on a waiting list and were eventually absorbed as permanent workers if they were medically fit. Ravi was given a gamut of tests (including lung function, eyes, urine and HIV). No medical problems were found except that Ravi was revealed to be HIV positive. Significantly, the doctor who administered the tests, who was a leading physician experienced in HIV cases, certified that although Ravi had tested HIV positive he was fit for duty.

Nevertheless, for no other reason than the fact that Ravi was HIV positive, his name was removed from the waiting list.

When the HIV/AIDS unit of the Lawyer's Collective looked into the matter, it discovered that the corporation had issued written circulars making it mandatory for prospective and current employees to undergo an HIV test. (The Lawyer's Collective is a group of lawyers in India fighting for the rights of the disadvantaged in society.) The circulars stated that if employees were found to be HIV positive, they would not be hired and could even be sacked.

On Ravi's behalf, the Lawyers Collective filed a writ petition in the Bombay High Court challenging the written circulars of the corporation on the grounds that they violated his fundamental rights under the Constitution of India. The petition also challenged the removal of Ravi from the waiting list.

## Decision of the Court

The court agreed with the petitioner and rejected all of the employer's arguments. The court directed that Ravi be reinstated on the waiting list, that he undergo another round of medical tests (because three years had elapsed since the first tests), that he be given work in the meantime, and that he be taken into regular employment if the tests showed he was fit. Finally, it awarded Ravi the

amount of 40,000 Rupees as compensation for the period of his non-employment with the corporation.

In its judgement, the court:

- said that the right to livelihood was guaranteed to all persons and could be overridden only by a procedure established by law that was just, fair and reasonable; and
- that persons with an ailment who are capable of performing normal job functions and who do not pose any threat to the interests of other persons at the workplace during their normal activities cannot be denied employment or be discontinued from employment.

Many people believe that the positive decision in this case was due in large part to the fact that the presiding judges were sensitive to the issues. It is quite possible that another set of judges would have rendered a decision that was quite different.

## Confidentiality

The writ petition that was filed initially disclosed the real names of both Ravi and the corporation. Subsequently the Lawyers Collective was able to convince the court to remove from the records anything that might reveal Ravi's identity by substituting pseudonyms for both parties in the dispute. They also obtained an order preventing the publication of any matter leading to the disclosure of Ravi's identity.

## Lessons Learned

- **It is possible to use the courts to advance the rights of persons living with HIV/AIDS.**
- **It is sometimes possible to go to court to fight for one's rights without having one's HIV status revealed publicly.**
- **The judiciary needs to be educated about HIV/AIDS.**
- **The fact that another set of judges might have decided the case quite differently highlights the need for specific legislation to protect the rights of persons living with HIV/AIDS.**

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# Supreme Court of India hears a case about the right to confidentiality...

A person living with HIV/AIDS in India whose right to confidentiality was violated, and who had to leave his home state as a result, went to the courts to seek damages. His case went all the way to the Supreme Court of India, but the final outcome was not favourable.

Maneck (not his real name) was a doctor in government service from a well-known family in an Eastern state of India. He was asked to accompany an uncle of a state-level minister who was undergoing surgery in a hospital in Madras. During the surgery, the patient required blood and Maneck agreed to donate some. A sample of Maneck's blood was duly obtained for testing. However, his blood was not used in the course of the surgery.

Later, Maneck proposed marriage to a woman from his own community and the couple became officially engaged. It appears that, for no particular reason, the doctor who attended to the state-level minister in the hospital in Madras informed the minister that Maneck's blood had tested positive for HIV. The minister in turn informed Maneck's sister. When Maneck learned of his HIV status, he met with his fiancée and her family and they decided to officially call off the engagement.

That ought to have been the end of the matter. Maneck should have continued with his life and with his career in government service. However, because of the close-knit structure of the community in which Maneck lived, everyone in the community heard about Maneck's HIV status. Maneck was so severely ostracized that he felt compelled to leave his home state.

## Complaint Filed

Maneck lodged a complaint with the National Consumer Commission asking for damages as a result of the disclosure of his medical status by the hospital authorities to third parties. The complaint was filed on his behalf by the HIV/AIDS Unit of the Lawyer's Collective, a group of lawyers in India fighting for the rights of the disadvantaged in society. In July 1998, the commission dismissed the complaint on the grounds that it would be more appropriate to seek relief in a civil court.

Maneck appealed this decision to the Supreme Court of India on the grounds that the National Consumer Commission was the appropriate forum to deal with the matter. Maneck asked the Supreme Court to order the commission to hear the case. In its ruling, the Supreme Court completely ignored this issue. However, the Court did say that although doctors are bound to maintain confidentiality regarding the medical status of their patients, and although patients have a right to privacy regarding their HIV status, the right is not absolute and could be restricted for the "prevention of crime and the protection of health and rights and freedom of others." The judges said that they were concerned about the woman that Maneck was to marry and that they felt "she was saved in time by [the] disclosure."

The judges then went on to write about the right of persons living with HIV/AIDS to marry (see separate story.)

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## **...and decides that persons living with HIV in India do not have the right to marry**

In a decision that has shocked many people, the Supreme Court of India has ruled that persons living with HIV/AIDS do not have the right to marry. This is the first time that a court anywhere in the world has suspended an individual's right to marry.

One of the astonishing aspects of the decision was that the issue of the right to marry was not even before the court. The court was hearing the case of an alleged breach of confidentiality concerning the HIV status of a person living with HIV/AIDS (see separate story).

In its judgement, the court cited matrimonial laws that allow a person to divorce her or his spouse if the spouse has contracted a venereal disease. The judges said that as long as the person is not cured of the communicable venereal disease, the right to marry cannot be enforced through a court of law and shall be treated as a "suspended right," and further that if a persons living with HIV/AIDS knowingly marries a women and thereby transmits infection to that women, he would be guilty under...the Indian Penal Code.

The judges said that a doctor who remains silent in this situation would be a participant in the crime. The judges went on to say that "AIDS is the product of undisciplined sexual impulse." They added that although persons living with HIV/AIDS should not be discriminated against

sex with them or possibility thereof has to be avoided as otherwise they would infect and communicate the dreadful disease to others.

Persons living with HIV/AIDS, community-based HIV/AIDS organizations, human rights NGOs and many members of the legal profession reacted with shock and outrage to the decision.

Comparisons were made with apartheid South Africa and Nazi Germany in terms of state interference with the fundamental right to found a family. However, because of the severe gender inequity inherent in Indian society, many women's organizations applauded the decision as a way to protect women.

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# The community goes back to the courts to fight the Supreme Court of India decision

The community has decided to go back to the courts to fight a Supreme Court of India decision that suspended the right of persons living with HIV/AIDS to marry and that attacked the right of persons living with HIV/AIDS to privacy and confidentiality in medical settings. (See separate stories for details of the Supreme Court decision.)

Four persons from Mumbai affected by the AIDS epidemic, two of whom are persons living with HIV/AIDS, have filed a petition in the Bombay High Court. The petition asks the court to declare:

- that a person living with HIV/AIDS is entitled to marry and that this right is not taken away or suspended on account of her or his HIV status; and
- that doctors have a primary duty to keep information about their patients confidential except in limited, exceptional cases where it may be legally required for them to disclose.

The petition was prepared by the HIV/AIDS Unit of the Lawyers Collective.

The Bombay High Court could limit the scope of the application of the Supreme Court decision. However, the petitioners hope that the case will end up back before the Supreme Court. This is the only way to reverse the original Supreme Court decision.

## Right to Marriage

The petition accepts the premise that persons living with HIV/AIDS should inform their partners of their HIV status. It argues that in cases where a person living with HIV/AIDS wishes to get married with the informed consent of her or his prospective spouse, the person should not be pre-

vented from doing so. The petition also advances the following arguments:

- \* The right to marry is a protected right under the Constitution of India. Restricting or suspending the right to marry for persons living with HIV/AIDS is arbitrary, unjust and discriminatory in nature.
- The right to marry and found a family is a fundamental human right under the Universal Declaration of Human Rights and the International Covenant of Civil and Political Rights, to both of which India is a signatory.
- Since the right to marry is a constitutionally protected fundamental right, it can be abridged only by a valid statutory law passed by a competent legislature.

## Right to Confidentiality

With respect to a patient's right to confidentiality and the responsibilities of the patient's doctor, the petition argues:

- that in the vast majority of cases, doctors should inform the patient that she or he is HIV positive and should counsel the patient about the importance of informing her or his sexual partners; and
- that only in exceptional cases, when a third party is believed to be in imminent danger, does the doctor have a duty to reveal the information to the third party.

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# Discrimination flourishes in Russia

Discrimination against persons living with HIV/AIDS in Russia is widespread. Most of the abuses fall into three categories:

- mandatory HIV testing;
- lack of confidentiality; and
- lack of adequate care and treatment.

The Russian NAMES Fund, a national NGO involved in HIV/AIDS education, support services and advocacy, has been systematically documenting instances of discrimination and violations of human rights.

## Mandatory HIV Testing

According to Russian law, only a very limited number of people (such as health care workers who diagnose and treat persons living with HIV/AIDS) are subject to mandatory HIV testing. However, many other people have been required to undergo testing, including:

- salespersons;
- employees of restaurants and food catering businesses;
- drivers of public transportation;
- policepersons;
- patients (when entering a hospital or public health care institution);
- children and young people (as part of medical checkups required by summer camps and sanatoriums);
- students (when enrolling in colleges and universities);
- senior citizens (when entering institutions for the elderly); and
- pregnant women (including women applying for an abortion).

In most cases, people do not have the choice of whether or not to get tested. Often, they are not aware that the requirement to take an HIV test under these circumstances is illegal; as well, they know that access to the services will be denied if they refuse to take the test. Foreigners are required to provide a certificate attesting to the fact that they are HIV negative when they apply for a Russian visa of longer than three months duration.

## Lack of Confidentiality

The story of what happened to Sergei illustrates the problems around confidentiality. Sergei (not his real name) was tested for HIV while he was hospitalized and without his knowledge or consent. The test was positive. By the time the test results came back, Sergei had already left the hospital. The hospital informed the Moscow AIDS Centre (which treats all persons living with HIV/AIDS in Moscow) that Sergei was HIV positive. To get Sergei to come and register at the centre, a request was sent to his local health care clinic mentioning his HIV diagnosis and his home address. Now Sergei's diagnosis is known to all staff at the local clinic.

## Lack of Adequate Care and Treatment

Care and treatment is far from satisfactory. For example, persons living with HIV/AIDS who reside outside the largest cities cannot access adequate care. Because HIV care is usually not available in rural areas and in many cities, persons living with HIV/AIDS are forced to move to large cities like Moscow.

However, a strict system of residence registration in effect in Moscow means that these people are forced to stay in Moscow illegally and cannot get a Moscow health insurance policy.

As a result, they are deprived of their right to free medical care, and they run the risk of being harassed by the police and of being charged high rents for accommodation. This is an example of how restrictions on freedom of movement and choice of residence – two rights that are enshrined in many international human rights covenants – negatively affect the quality of care provided to persons living with HIV/AIDS.

***In most cases, people do not have the choice of whether or not to get tested. Often, they are not aware that the requirement to take an HIV test under these circumstances is illegal; as well, they know that access to the services will be denied if they refuse to take the test.***

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# Large gaps between policy and practice in Thailand

Thailand is often praised internationally for its policies and practices concerning HIV/AIDS. The current National AIDS Plan, which runs from 1997 to 2001, contains some very positive policies on HIV/AIDS and human rights.

However, the government has failed to promote these policies. Worse still, the government's own regulations and practices contradict these policies.

## Mandatory HIV Testing

### POLICY

The National AIDS Plan:

- prohibits public and private agencies from testing for HIV and using the test result as a condition of employment or admission to educational institutions;
- says that all HIV testing must be accompanied by pre- and post-test counselling; and
- prohibits nonconsensual HIV testing.

### PRACTICE

In practice:

- The regulations established by the government for university student registration in 1999 say that in order to qualify, all applicants must show the results of an HIV test.
- Regulations governing the monkhood stipulate that all males who want to become monks must provide the results of an HIV test.
- Many doctors in government hospitals conduct HIV tests on their patients without the patients' consent.
- Many private businesses and industries require applicants to take an HIV test.

The regulations concerning students and people interested in becoming monks are not routinely enforced, and there have been few reported cases of discrimination. Nevertheless, the regulations allow university officials and head monks to discriminate, and this sends out the wrong message.

## Counselling

### POLICY

The National AIDS Plan stresses the importance of pre- and post-test counselling.

### PRACTICE

None of the government's anonymous testing clinics provide any counselling.

## Clinical Trials

### POLICY

The National AIDS Plan calls for measures to protect the rights of people volunteering for drug or vaccine research trials which, in Thailand, are run by the government. The plan says that potential participants must be fully informed before deciding whether or not to participate.

### PRACTICE

For drug trials, the reality is quite different. For example:

- Participants are not given a copy of the consent form after they have signed it.
- Participants are not given information about the drug being tested (including the name).
- The trial's objectives and procedures are not explained.
- Participants are not informed about the possible side effects.
- Participants are not informed about what will happen after the trial ends.

Fortunately, the recent vaccine trials are much more respectful of the rights of participants.

## Lessons Learned

- **There is often considerable distance between writing up good policies and implementing these policies. The evidence suggests that there is insufficient political commitment in Thailand to the promotion of human rights for persons living with and affected by HIV/AIDS.**
- **Even when a government announces a policy, it is important for NGOs to monitor implementation of the policy. NGOs must remain vigilant and must follow up on promises made, especially since governments and ministers change.**

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## **While some Canadian dentists will not treat persons living with HIV/AIDS...**

Almost one in six Canadian dentists say they would refuse to treat a persons living with HIV/AIDS and more than one in six would deny treatment to homosexuals.

This information comes from a survey of about 4,000 dentists carried out early in 1999. Of those who would refuse treatment, about six in ten are concerned for their own safety; about two-thirds are afraid of losing other patients; and just under half objected to the extra costs of taking precautions with patients who have communicable diseases.

AIDS activists were shocked by the findings, given the amount of educational materials on HIV/AIDS that have been directed at health-care professionals in Canada. These materials include information on universal precautions designed to protect against infection in a health care setting. As well, refusing to treat a patient with a communicable disease is contrary to provincial human rights codes and is considered a breach of professional ethics.

SOURCE: The Globe and Mail, Canada, March 31, 1999.

## **...One U.S. dentist settles a discrimination suit**

Dr. Guillermo Recinos, a dentist in Jamaica Plains, Massachusetts, has agreed to pay \$US 60,000 and to provide free dental care to persons living with HIV/AIDS as part of a settlement with the State of Massachusetts. Dr. Recinos had been charged under several U.S. statutes for refusing to treat persons living with HIV/AIDS.

Under the terms of the settlement, Dr. Recinos will be required to provide 105 free appointments to persons living with HIV/AIDS who lack dental insurance.

SOURCE: Boston Globe, United States, April 23, 1999.

## **Travel and immigration restrictions continue**

Two decades into the HIV/AIDS epidemic, restrictions on the freedom of movement of persons living with HIV/AIDS across borders remain a serious problem in many countries.

For example:

- About 50 countries test some foreigners for HIV prior to entry.
- The United States will not allow HIV positive foreigners to enter the country (even as visitors) unless they receive special permission to visit family, seek medical treatment or attend a conference.
- Jordan says that it expelled 26 HIV positive foreigners in the summer of 1998.
- New Zealand has announced that all refugees and immigrants will be required to provide documentary evidence that they are HIV negative before being admitted.

The World Health Organization and United Nations Commission on Human Rights have strongly condemned policies of mandatory HIV screening and travel restrictions. According to the United Nations International Guidelines on HIV/AIDS and Human Rights, restrictions on liberty of movement or choice of residence based on suspected or real HIV status have no public health rationale and are discriminatory.

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# Community groups in Costa Rica develop approach for addressing human rights violations

In the course of doing advocacy work in the area of human rights in Costa Rica, community organizations have developed an approach for dealing with the problem of severe human rights violations against people living with AIDS. While this approach has been developed for a Latino cultural context, much of it may be applicable to other parts of the world.

The key elements in this approach are as follows:

THE RECOGNITION THAT because of the terrible discrimination they have suffered, persons living with HIV/AIDS are extremely reluctant to get involved in any advocacy work, even on their own behalf. Encouraging them to become involved is a very delicate process. Incredible patience is required to work with victims of discrimination in a machismo, authoritarian and patriarchal culture.

THE NEED TO draw attention in the media, on a national as well as international level, to discrimination and abuse. In Costa Rica, it has been necessary to write more than 50 news bulletins and articles over a two-year period describing the unfolding story of abuses and their impact, the actions that have been taken to respond to abuses, and the results of these actions.

THE NEED TO look for people from the target groups of persons affected by HIV/AIDS who can begin to assume a leadership role, who can draw attention to the problems of their own group, and who can serve as models for members of other affected populations.

THE NEED TO fully understand and, when possible, to utilize existing administrative and judicial resources on a national level (and, where appropriate, on an international level). It is important not to allow bureaucratic obstacles to interfere with this process. In Costa Rica, activists have continually met with and put pressure on numerous private agencies that deal with persons living with

HIV/AIDS. They have also made good use of the judicial system, which has resulted in several important victories.

THE NEED TO fully understand the nuances of the local culture and its impact on human rights, on the resolution of conflicts, and on the victims of discrimination. In Costa Rica, this has involved a thorough understanding of several elements including:

- the nature of the machismo, heterosexist culture and its impact on sexual minorities and women living with HIV/AIDS;
- understanding how bureaucracy is used to discourage and confuse persons living with HIV/AIDS and their advocates;
- differences in standards of ethics which give tacit permission to government officials to provide false or misleading information to minority group members and their advocates;
- the impact on persons living with HIV/AIDS if their families or their employers discover their HIV status;
- the basically nonconfrontational nature of Costa Rican culture, which considers publicly engaging in a dispute to be inappropriate (this ultimately works against members of minority groups because they have a great deal of trouble expressing feelings of anger and frustration);
- the importance of patience, and persistence in denouncing human rights violations in a culture where these issues are not seen as important.

It is necessary to continually reassert to persons living with HIV/AIDS that changes happen very slowly, but that it is important to persist and to continue to denounce and call attention to discrimination, even when it appears that nobody is listening.

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# Activists win Supreme Court challenge in Costa Rica

About 450 Costa Ricans are now receiving new antiretroviral medications free of charge as a result of a Supreme Court decision in 1997.

Costa Rica is a Central American country of about 3.5 million people with a universal health care system. Officially, there are about 5,600 known cases of HIV infection, but the true number is believed to be much higher.

In 1992, several persons living with HIV/AIDS filed an unsuccessful lawsuit in the Supreme Court to get AZT treatment covered by the Caja Costaricense de Seguro Social (CCSS), Costa Rica's national health care system. In rejecting the lawsuit, the Court said that AZT was not a cure and would only result in a "prolonged course of deterioration."

Because of the successes later achieved with combination therapy, an informal coalition of persons living with HIV/AIDS in Costa Rica began making representations to CCSS in 1996 to get the antiretroviral medications covered by the health care system.

The government officials did not respond to these representations, nor did they show any disposition to dialogue. This process dragged on for two years. Even though a government ombudsman organization, "La Defensoria de los Habitantes," got involved, the officials never showed any interest in supplying and paying for the medications. As a result, a committee was formed of NGO representatives and persons living with HIV/AIDS, and this led to a new lawsuit being filed in the Supreme Court on behalf of four plaintiffs – four persons living with HIV/AIDS – in August 1997. The lawsuit was prepared and argued by Marco Castillo, an activist lawyer who donated his services.

## Supreme Court Decision

This time the Court ruled in favour of the plaintiffs and ordered CCSS to provide the medications free-of-charge. The Court found:

- that there was proof that the combination of the antiretroviral medications is able to prolong life, even if it does not cure; and
- that the refusal of the national health care system to provide the medications free of charge is an illegal violation of the right to life of the plaintiffs, and is therefore unjustified.

The judges based their decision on the right to life and health, as enshrined in the Political Constitution of Costa Rica, and as endorsed by Costa Rica in international treaties, such as The Universal Declaration of Human Rights; the American Convention of Human Rights; the American Declaration of the Rights and Obligations of Men; and the International Covenant of Civil and Political Rights. The judges criticized the government's refusal to pay for the medications. It said:

*[I]f the right to life is especially protected in each modern state and, with it, the right to health, any economic criteria that pretends to deny the exercise (practice) of those rights, has to be of secondary importance because ... without the right to life, all the remaining rights would be useless. ... Of what use are all the other rights and guarantees, the institutions and its programs, the advantages and benefits of our social welfare system, if even one person is not able to count on, and be assured to, the right of life and health?*

The judges ordered CCSS to immediately develop a plan for the delivery of medications free of charge to all persons living with HIV/AIDS with severely compromised immune systems.

Although there have been short delays for some patients in beginning treatment, CCSS has complied rapidly and efficiently with the court's decision. Once persons living with HIV/AIDS are on the regimen, they have not been subjected to interruptions of their treatment. For those people receiving antiretroviral medications from CCSS, the basic cocktail continues to be AZT, 3TC and

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Crixivan, but in some cases substitutions have been made for one of more of the medications to accommodate individual needs.

The number of AIDS deaths in Costa Rica dropped from 102 in 1997 to 44 in 1998, even though the number of AIDS cases increased during this period.

Inspired by the victory in Costa Rica, activists in El Salvador have launched a similar lawsuit in the Supreme Court of that country to obtain access to antiretroviral treatments.

### **Lessons Learned**

- **It is possible to use the court system to advance the rights of persons living with HIV/AIDS. The courts are often more responsive to the needs of persons living with HIV/AIDS than government departments.**
- **Lawsuits based on fundamental human rights have a good chance of success.**

- **It is important to be familiar with the constitution of one's country and with the international conventions signed by one's country. These instruments can be used in national advocacy work and when raising issues in international forums.**
- **It is important to develop strong organizations of persons living with HIV/AIDS who will fight for their rights.**
- **It is important for persons living with HIV/AIDS to work together with physicians who specialize in HIV/AIDS to share their knowledge about treatment advances.**
- **Advances in one country can have a positive impact on other countries in the same region.**

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# Will the killing of Gugu Dlamini bring about change in South Africa?

AIDS activists in South Africa are hopeful that the tragic killing of Gugu Dlamini will be a potential catalyst for change. But they realize that real change comes slowly in South Africa, a country with the world's fastest-growing HIV/AIDS epidemic. In the meantime, Gugu's death – and the recent "coming out" of Justice Edwin Cameron – have focussed attention on the need to keep HIV/AIDS on the national agenda, as well as on the risks faced by persons living with HIV/AIDS who decide to go public.

## The Killing

Gugu Dlamini, a volunteer field worker for the National Association of People Living with HIV/AIDS (NAPWA), died on December 22, 1998. Three weeks earlier, on World AIDS Day, Gugu had gone public, speaking about her HIV infection on Zulu-language radio and on television. Her neighbours accused her of bringing shame on their community by revealing that she was HIV positive. Gugu was repeatedly threatened. The day before she died, Gugu was punched and slapped by a man who told her she should have had kept quiet about her illness, like most other people in her situation. She called the police, but they did nothing. That night, a mob attacked her house and stoned her, kicked her and beat her with sticks. She later died from the injuries.

## The Response

Very little has been done by either the government or the police to address the killing of Gugu Dlamini. After the initial flurry of articles, the media has largely ignored her story. However, two South African newspapers have started columns written by persons living with HIV/AIDS. And additional work with the media is planned for the coming year to promote more responsible journalism.

Gugu Dlamini's death has galvanized the small AIDS activist community in South Africa. Partially in response to her killing, NAPWA launched a Treatment Action Campaign in partnership with the AIDS Law Project, the AIDS Consortium and the National Coalition for Gay and Lesbian Equality.

As part of the Treatment Action Campaign, the objective of which is to improve access to treatments for persons living with HIV/AIDS, fasts and rallies were organized in four large cities on March 21, 1999, Human Rights Day in South Africa. The rallies attracted over 1,000 people and received substantial media coverage. Organizers expressed hope that these rallies would someday be seen as the beginnings of a genuine movement of

persons living with HIV/AIDS in South Africa to assert their rights.

A few days later, organizers of the campaign met with Dr. Nkosazana Zuma, the Minister of Health. Dr. Zuma pledged her support for the organizers' take-to-the-streets campaign and agreed to meet the organizers again to discuss their demands. As well, the Treatment Action Campaign was endorsed by the South African Council of Churches and a range of trade unions.

## Underlying Issues

People infected with and affected by HIV/AIDS in South Africa are becoming increasingly concerned about access to treatment. However, many people are more preoccupied by broader social and economic issues – such as the link between HIV/AIDS and poverty, unemployment and crime – and by how to get people in South Africa to talk more openly about the reality of HIV/AIDS,

***To get HIV/AIDS onto the public agenda, it is important for persons living with HIV/AIDS to speak out publicly. But, as Gugu Dlamini's death revealed all too starkly, the climate of stigma and discrimination surrounding HIV/AIDS in South Africa can make public affirmation of one's HIV serostatus difficult and dangerous, especially for members of vulnerable populations.***

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about the problems caused by HIV/AIDS, and about potential solutions.

To get HIV/AIDS onto the public agenda, it is important for persons living with HIV/AIDS to speak out publicly. But, as Gugu Dlamini's death revealed all too starkly, the climate of stigma and discrimination surrounding HIV/AIDS in South Africa can make public affirmation of one's HIV serostatus difficult and dangerous, especially for members of vulnerable populations.

In April 1999, Justice Edwin Cameron, of the High Court of South Africa, decided to publicly reveal that he is HIV positive. Justice Cameron is a candidate for an appointment to the Constitutional Court. He chose to speak out because there had been talk in the legal community about his health condition. Justice Cameron said that he was able to disclose his status because

*...I have a job position that is secure;  
because I am surrounded by loved ones,  
friends and colleagues who support me; and  
because I have access to medical care and  
treatment that ensures that I remain strong,  
healthy and productive.*

For millions of South Africans living with HIV or AIDS, these conditions do not exist. They have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave personal danger if they do so. And, most importantly, they do not have access to proper medical care and treatment. For them, in a still hostile climate, the choices are strictly limited. Their right to invoke confidentiality

remains of critical importance to them. It is only by creating conditions in which people can speak out without fear that we can begin to end the silence surrounding South Africans living with AIDS and HIV.

Activists hope that the courage of Gugu Dlamini and Justice Edwin Cameron, and others like them who have been public about their HIV status, will help create the conditions that will enable more people to speak out without fear about HIV/AIDS in South Africa.

### **Lessons Learned**

- **A tragic incident – such as the killing of Gugu Dlamini – can be used to mobilize people to address HIV/AIDS issues.**
- **Persons living with HIV/AIDS must carefully consider whether or not to disclose their status publicly, especially in communities that are ill-prepared and not properly educated to deal with the situation.**
- **NGOs need to develop strategies to help persons living with HIV/AIDS feel comfortable about disclosing their status.**
- **Change can sometimes happen very slowly, particularly in situations where people are afraid to speak out about HIV/AIDS.**

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## Prisoners in Chile subjected to inhuman conditions

Gay and transgendered inmates living with HIV/AIDS in Santiago, Chile, continue to face inhuman conditions. For example:

- They do not receive any medical attention for opportunistic infections.
- They do not receive any antiretroviral medications.
- They are held in complete isolation from the general population.
- They are not able to work during their confinement and so have no way of generating any income.

Gay and transgendered inmates have told of being lined up naked single-file, in a wet and ill-smelling corridor on the few occasions where they were medically examined, and being submitted to a cursory review after which they received no medications. Every time inmates have infections, they are treated with penicillin, with no consideration being given to how this might affect their already compromised immune systems.

The mistreatment of gay and transgendered inmates is not new. In 1996, while 37 inmates were being transported from one prison to another,

they were tested for HIV with only 10 needles being used for the entire group, despite repeated warnings that some of the inmates were HIV positive.

Activist organizations like Centro Lambda Chile and Movimiento Unificado de Minoras Sexuales have launched legal actions and pressured authorities to improve the treatment of these inmates, so far with little success. In the last two years, two inmates living with HIV/AIDS have died without receiving any HIV/AIDS medication.

The activist organizations believe that more local advocacy coupled with international pressure is required to bring about concrete improvements in the lives of gay and transgendered inmates living with HIV in Chile.

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## The Link Between HIV/AIDS and Human Rights

HIV/AIDS is both a health issue and a human rights issue. In fact, there are close links between human rights and health. They both share the common objective of promoting and protecting the rights and well-being of people.

In the context of the HIV/AIDS epidemic, the promotion and protection of human rights is necessary to achieve the public health goals of:

- reducing vulnerability to HIV infection;
- lessening the adverse impact of HIV/AIDS on those affected; and
- empowering individuals and communities to respond to HIV/AIDS.

Care and prevention programmes that contain coercive or punitive measures result in reduced participation and increased alienation of persons living with HIV/AIDS and people at risk. People

will not seek counselling, testing, treatment and support if this means facing discrimination, lack of confidentiality or other negative consequences. Coercive measures drive away the people most in need of services.

The incidence and spread of HIV/AIDS is disproportionately high among groups that already suffer from a lack of human rights protection and from discrimination, and among groups marginalized by their legal or economic status. Lack of human rights protection disempowers these groups. However, when human rights are protected, fewer people become infected with HIV and the friends and families of those who are infected can better cope with the disease.

Protecting human rights helps to reduce societal vulnerability to HIV/AIDS.

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# Persons living with HIV/AIDS are front and centre in APN+ Human Rights Initiative

Persons living with HIV/AIDS are designing and implementing the Human Rights Initiative, a research project of the Asia/Pacific Network of Persons Living with HIV/AIDS (APN+). The initiative is significant both in terms of deliverables and in terms of process.

The deliverables include documentation of cases of human rights abuse in the Asia/Pacific region that will help to identify problem areas and provide ammunition to challenge human rights violations. Because persons living with HIV/AIDS will be interviewing other HIV positive persons to document cases of abuse, the process empowers the participants and increases their skills levels. It also increases awareness of human rights issues among persons living with HIV/AIDS and other community workers.

Organizers hope that the initiative will be carried out in eight countries in the region ^ India, the Philippines, Thailand, Indonesia, Taiwan, Malaysia, China (Hong Kong), and Australia (among Aborigines). Funding for the development of the research protocol and for some other initial activities has been provided by the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Eight dimensions of human rights have been identified for the purposes of the research:

- the right to health;
- the right to privacy;
- the right to liberty and security of person;

- freedom from inhuman and degrading treatment or punishment;
- the right to employment;
- the right to marry, found a family and form significant relationships;
- the right to education; and
- the right to self-determination and association.

Some of the other significant features of this research project are as follows:

- The research protocol has been submitted to ethics review committees at all collaborating sites and at UNAIDS.
- The research team is going to great lengths to reduce any psychological or other adverse effect on the respondents of the survey.
- Unambiguous informed consent is a prerequisite for participation in the study.
- Anonymity of the participants is guaranteed.
- The interviewers are trained in offering referral services when required. Potential legal, medical and social referrals are identified by local investigators prior to any data collection.

Organizers hope to have approval from all ethics review committees by October 1999. Assuming that the necessary funding is in place, data collection will begin shortly after that. The first reports may be ready by the first quarter of 2000.

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# Final Word

*Stories from the Frontlines* describes how NGOs have improved access to treatments for persons living with HIV/AIDS by fighting in the courts, by lobbying politicians, by using the media, by organizing public actions, and by setting up distribution pipelines. Similar strategies were used to reduce the number of deportations of immigrants living with HIV/AIDS in France and to get a new AIDS law adopted in the Philippines. Education was instrumental in getting residents of Quito, Ecuador to accept a new AIDS hostel in their neighbourhood. Using the court system has been a cornerstone of the human rights response to HIV/AIDS in India.

In telling you about these events in *Stories from the Frontlines*, we have tried to describe lessons learned in the expectation that this will better inform the work you are doing to respond to HIV/AIDS. From these lessons, some common themes emerge:

- It is important to know your country's constitution and, in particular, what rights are guaranteed by the constitution.
- Be aware of what international conventions have been signed by your country and what rights are protected by these conventions.
- Make use of the International Guidelines on HIV/AIDS and Human Rights.
- The Guidelines are an excellent tool for advocacy, education and awareness raising.
- Be familiar with your national AIDS policy, law or programme. It is important to monitor what activities have been planned and implemented. It is also useful to make recommendations for new activities, particularly in response to emerging issues.
- Forming partnerships and alliances greatly enhances the chances of success.
- Use of the media is critical to the success of advocacy campaigns.
- We encourage you to obtain copies of key documents that may assist you in your efforts to better understand the issues raised in these stories. Two of these documents are the NGO Summary of the International Guidelines on HIV/AIDS and Human Rights and the accompanying Advocate's Guide. These documents are available from your regional ICASO secretariat (see listing elsewhere in this document).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has published the guidelines themselves in a booklet entitled, *HIV/AIDS and Human Rights: International Guidelines*. You can obtain copies from:

UNAIDS materials:  
UNAIDS Information Centre  
CH-1211 Geneva 27, Switzerland  
**TEL.:** (41 22) 791-3666 **FAX:** (41 22) 791-4187  
**E-MAIL:** [unaids@unaids.org](mailto:unaids@unaids.org)

The guidelines are available on the UNAIDS website at [www.unaids.org](http://www.unaids.org) and on the website of the Office of the High Commissioner for Human Rights (OHCHR) at [www.unhchr.ch](http://www.unhchr.ch). You can also check the OHCHR website to find out which international conventions apply to your country.

**Let us continue to learn from each other. And let us continue to tell our stories!**

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## Internet discussion groups on HIV/AIDS and human rights

The following Internet discussion groups have regular exchanges on HIV/AIDS and human rights:

- HUMAN RIGHTS FORUM  
human-rights@hivnet.ch
- SOUTH EAST ASIAN AIDS NETWORK  
sea-aids@hivnet.ch
- TREATMENT ACCESS FORUM  
treatment-access@hivnet.ch
- AFRICA AIDS NETWORK  
af-aids@hivnet.ch
- GENDER AND AIDS NETWORK  
gender-aids@hivnet.ch
- PLWHA NETWORK  
plwha-net@hivnet.ch
- HIV AND LAW NETWORK  
HIV-Law-Approval@web-depot.com
- HIV AND HUMAN RIGHTS NETWORK  
HIVLine-L-On@HIVLine.com

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## About ICASO

*ICASO unites groups throughout the world who have been affected by the HIV/AIDS epidemic. ICASO's recognition and respect for the human rights of all persons is central to an intelligent public health strategy to combat the AIDS epidemic.*

*ICASO's mission is to promote and support the work of community-based organizations around the world in the prevention of AIDS and care and treatment for people living with HIV/AIDS, with particular emphasis on strengthening the response in communities with fewer resources and within affected communities.*

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*This document is also available in French and Spanish.*

*Copies are available on the ICASO Web Page*  
**[www.icaso.org](http://www.icaso.org)**

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