



## Human Rights and Poverty Reduction

### *Why a human rights approach to HIV/AIDS makes all the difference*

February 2005

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#### 1. Introduction

Today it has almost been forgotten that AIDS, with its epicentre in San Francisco, was initially labelled a 'gay plague', with its consequent mental image of a disease of affluence. Africa was next declared to have been the birthplace of HIV, with racist undertones that still trigger resentment in the continent. The image of HIV/AIDS as a misery-seeking missile, and the knowledge about the vicious circle of further impoverishment it generates, came later.

The first reactions to AIDS and, later, to HIV were panicky, revealing inherent tendencies to find somebody to blame, to dissociate and protect 'us' from 'them', the carriers of a deadly infection. HIV transmission placed on the agenda sexuality and drug addiction, issues with which we cannot deal rationally even at the best of times. Fear of contagion – in its widest possible meaning – led to moral crusades. This exacerbated the panoply of discriminatory, stigmatising, xenophobic, sexist and homophobic prejudice in the 1980s. These initial years of fear were marked by rejection and exclusion: a war was waged against people with HIV/AIDS rather than against the pandemic itself. People who were infected – or suspected of being infected – were precluded from working or marrying, or were isolated in prisons for the rest of their lives as if they were dangerous criminals. They lost their identity, individuality, dignity and privacy and became 'carriers' of a deadly disease, sacrificed ostensibly to protect society.

Roll-back was engendered by human rights safeguards, which were proving necessary in order to cope with the issue. Denial led to statistics which hid the problem and, because HIV/AIDS could not be tackled, it festered. Because people with HIV/AIDS were likely to lose their rights, they avoided health authorities. HIV testing was dangerous because it could lead to the loss of livelihood or even life. AIDS-free certificates were sold on the black market because many countries required them for entry. Again, the perception was that we should keep away 'them', the foreigners, so as to prevent them by legalistic barriers from infecting 'us'.<sup>1</sup> Such measures were by definition ineffective because, unlike with people, viruses cannot be forced to observe national borders or any other legalistic barriers.

As always happens in human rights, numerous and widespread abuses prompted condemnation and the strengthening of human rights safeguards. In HIV/AIDS, these safeguards proved indispensable for both prevention and treatment. Although it took twenty years, human rights protection has finally been declared as the key to reducing vulnerability to HIV/AIDS: 'The full realization of human rights and fundamental freedoms for all is an essential element in a global response to the HIV/AIDS pandemic, including in the areas of prevention, care, support and treatment [because] it reduces vulnerability to HIV/AIDS and

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<sup>1</sup> After HIV tests became available in 1985, Saudi Arabia prohibited entry to HIV-infected people in 1986, and more than 50 countries imposed restrictions on international movement within the subsequent three years. (Duckett and Orkin, 1989).

prevents stigma and related discrimination against people living with or at risk of HIV/AIDS' (UN, 2001). The affirmation of human rights as 'an essential element' was evidence-based: the risk of infection for professional blood donors or through sexual intercourse for young girls cannot be decreased unless and until they have alternative means to secure their livelihoods. Moreover, the erroneous rationale that people who can transmit the infection will do so had led to criminalisation. The awareness of the illogic of criminalising people for the presence of HIV antibodies in their blood led to the shift from exclusion to inclusion. Involving people with HIV/AIDS proved indispensable for both prevention and care.

While prevention was the priority in the first AIDS decade, attention has now shifted to treatment. This has brought us closer to reaching a balance between prevention and treatment. The recent focus on access to medication for people with HIV/AIDS has highlighted the most controversial aspect of the human right to health – the extent to which drugs and medical services can be claimed as human rights. There is no international guarantee of free medication for people with impaired health, and country practices vary a great deal. The global consensus is that medical treatment should be affordable rather than free. Much as in all other health issues, then, the biggest health hazard proved to be poverty. To the knowledge that poverty causes ill health we have added what we learned in the HIV/AIDS pandemic: ill health deepens and broadens poverty. Factual inequalities resulting from impaired health, combined with poverty, create multi-layered obstacles to the enjoyment of all human rights.

Gradually and haltingly, we are making dents in the inverse care law, whereby 'the availability of good medical care tends to vary inversely with the need for it' (Hart, 1971: 405). Agonising debates have ensued about sharing the responsibility for life-sustaining medical treatment between wealthy and poor countries, between public authorities and pharmaceutical companies. In international law, this has required redrawing boundaries between trade law and human rights law, between commercial and public health priorities, so as to accord priority to public health emergencies and to the right to life over private-law protection of intellectual property and commercial interests.

## **2. Human rights as a corrective for public health measures**

Today we are accustomed to compulsory public health measures, such as vaccination or fluoridation of drinking water. However, each of these was the object of fierce public debate when first introduced, and their implementation was accused of infringing individual rights and freedoms. Control of communicable diseases is the oldest and most developed part of public health law. Because health education is a slow process, law is often used as a shortcut, to lay down norms of healthy behaviour and to provide for their enforcement. The aims of public health law are to reduce health hazards and prevent exposure to them, and to improve the capacity of individuals and communities to cope with such hazards whenever prevention fails. In the HIV/AIDS pandemic, the failure of public authorities to ensure the safety of blood transfusion and blood products, of hospitals and pharmaceutical products, generated a great deal of human rights jurisprudence which affirmed state responsibility and defined the rights of victims in cases where the state failed to properly discharge it.

Both international and constitutional human rights guarantees prioritise public health rather than individual access to health services. There are two facets of public health important from the human rights viewpoint:

- On the one hand, protection of public health is one of the universally accepted grounds for limiting individual rights and freedoms. Preventing the spread of communicable diseases may entail deprivation of liberty, interference in privacy and family life, freedom of movement, freedom to manifest one's religion, freedom of information, or freedom of assembly and association.
- On the other hand, such limitations have to be defined by law and can be legally challenged if they unduly restrict human rights. Any restrictions have to be legitimate, necessary and proportionate, subjected to public oversight and judicial review, as in all other areas where the state exercises police powers. Thus, human rights have been accepted as a corrective for public health measures.

Public health, especially in protection from epidemics, comprises numerous coercive, compulsory and discriminatory measures. In communicable diseases, it consists of the exercise of police powers to prevent a spread. Many such measures have been successfully challenged, and often changed, over the HIV/AIDS pandemic. Historically, public health used military terminology, abundant with terms such as surveillance, agent, defence, combat, or the vocabulary of policing, speaking about compulsory testing or contact tracing. Until the advent of human rights, public health spelled out individual obligations rather than rights. As late as 1975, WHO posited that 'the individual is obliged to notify the health authorities when he is suffering from communicable diseases (including venereal diseases) and must undergo examination, treatment, surveillance, isolation, or hospitalization' (WHO, 1983: 100). Gradually, the notion that 'the doctor always knows best' was supplanted by the rule of law, as with all other powers of the state. Nonetheless, people with communicable diseases still await an international bill of rights. Mentally ill people and people with disabilities have obtained formal affirmations of their human rights. We have not yet reached the stage where the rights of the ill are fully recognised, let alone respected and protected.

### **3. Prevention and the right to know for self-protection**

Epidemiological studies have shown that the vast majority of HIV infections worldwide result from sexual intercourse. Sexual practices are the least known and the most difficult facet of human behaviour to influence by public policies. Because a cure for HIV infection is not available, and because the infection is lifelong, it is essential to prevent its further spread. The keystone of prevention has proved to be support for informed and responsible behaviour. Informed behaviour necessitates, however, explicit information about human sexuality; it can be the case that sex education at school remains outlawed.

Endless legal changes have taken place in the past two decades. A number of countries have adopted laws to make public advertising of condoms possible. Courts in many countries have had to rule as to whether sex education can be provided to children so as to enable them to protect themselves from HIV infection. The abyss between forceful demands that schoolchildren be provided with sex education as a matter of right, and denial of this sex education in the name of their parents' rights, defines the scope of the problem. Proponents of both extremes in this debate resort to human rights language in arguing their case. Proponents of children's right to know cite the children's best interests buttressed by public health considerations. International public health experts, convened by the Pan American Health Organization (PAHO/WHO), have found that 'sexuality refers to a core dimension of being human experienced and expressed in all that we are, what we feel, think and do' (PAHO/WHO, 2001: 6). Opponents cite parental rights and public morality, claiming that children should be protected from 'immoral "sex education"' (Pontifical Council for the Family, 2003). As summed up by the government of Lesotho, 'some parents strongly feel that sexual reproduction health education empowers children to be sexually active, whereas others feel that it enables them to make informed decisions' (UN Committee on the Rights of the Child, 1998).

An explicit provision on sex education is contained in the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), which obliges governments to ensure for girls and women 'access to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning'. The Committee on the Rights of the Child has interpreted the Convention on the Rights of the Child (CRC) as affirming children's right to sex education in order to enable 'them to deal positively and responsibly with their sexuality'. It goes on to say:

The Committee wishes to emphasize that effective HIV/AIDS prevention requires States to refrain from censoring, withholding or intentionally misrepresenting health related information, including sexual education and information, and that ... States parties must ensure that children have the ability to acquire the knowledge and skills to protect themselves and others as they begin to express their sexuality. (UN Committee on the Rights of the Child, 1996)

#### 4. Multiple human rights implications of HIV-testing

The discovery and commercial application of tests detecting exposure to HIV, in 1985, triggered a veritable epidemic of laws. Never before were there so many laws relating to a disease: 104 countries, more than two-thirds of the countries in the world, adopted HIV/AIDS-specific laws during the first decade of the AIDS pandemic (Tomasevski, 2000: 198-204). Most of them authorised HIV-testing and restrictions on people identified as HIV-infected. People were susceptible to discrimination in employment, travel, and insurance, and even prohibited from going to school or from marrying. Test results were used for non-medical purposes and to the detriment of the people who had been tested. Moreover, compulsory testing was used often against prisoners, prostitutes and drug-users, who were labelled as 'high-risk groups'.

Because HIV-infected people can remain asymptomatic for a very long time, and because HIV infection can only be detected through blood tests, testing is important for public health surveillance. The lack of safeguards for confidentiality of HIV-testing and for non-discrimination of those testing positive proved the biggest disincentive for voluntary testing programmes. Requirements that people be protected from involuntary testing emerged early and forcefully. They were preceded by international pronouncements against HIV/AIDS-related discrimination, in Europe in 1983 and on the global level in 1988. These facilitated prohibitions of discrimination worldwide but, as yet, elimination of discrimination against people with HIV/AIDS remains a challenge everywhere. However, discrimination has been challenged in all corners of the world, and successfully so.

There are two opposed views on the individual responsibility to know one's own health – including infection – status. In European human rights law, the right not to know has gained a great deal of support.<sup>2</sup> On the global level, UNAIDS has acknowledged that 'stigma and discrimination continue to stop people from having an HIV test' but has nevertheless advocated routine HIV-testing in the context of sexually transmitted infections, pregnancy and 'where HIV is prevalent and antiretroviral treatment available' (UNAIDS/WHO, 2004). Whether individuals can opt out of such routine testing depends on their knowledge of this choice and their capacity to exercise it. Prostitutes are, in particular, victimised by multiple stigma. Changed vocabulary, from 'prostitute' to 'commercial sex worker', helps only a little: the latter term does not translate well into most languages. Moreover, prostitution remains illegal in many countries.

The conditions that make it possible for people to choose or refuse testing, or to refuse risky behaviour whereby they might become infected, require examination of broader legal rules, not only those related to testing. The choices that people really have are outlined by the affirmation or negation of all their rights and freedoms. Denials of women's rights impede the ability to self-protect. For girls and women, obstacles include innumerable practices, such as forced prostitution, honour crimes, life-threatening unsafe abortions, or denial of legal protection against rape on the basis of a girl's or woman's sexual life (UN Human Rights Committee, 2000). International human rights bodies have forcefully objected to the denial of choice to girls and women owing to restrictive legal provisions on access to contraceptive information and services, especially 'to penal law provisions that impede their access to essential health services' (Hendriks, 1998: 401). Prevention messages are routinely based on the assumption that girls and women are free to make choices between safe and unsafe sex: information will make all the difference. Anti-human-rights messages have not disappeared, however. Suffice it to quote an example of advocacy for child marriage: 'To safeguard young people against sexual misbehaviour, early marriages must be encouraged by solving the current social and economic problems which cause marriage to be delayed' (WHO, 1992: 32).

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<sup>2</sup> The 1997 Convention on Human Rights and Biomedicine stipulates in Article 10 (2): 'Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.'

Attempts to forge a common global standard of morality have never succeeded in history and are unlikely to be more successful in future. The guiding principle of taking responsibility for one's own health helps where individuals are free to make choices, and can therefore be held responsible for the choices they have made.

## 5. Sharing the burden of the pandemic

Whenever the burden of an epidemic is not spread evenly but concentrated in specific populations, whole populations become seen as 'sources of infection'. In the case of Africa, this was exacerbated by an early attribution of blame for the origin of AIDS, something which has resulted in African leaders still questioning scientific evidence regarding HIV/AIDS. Moreover, this uneven burden has been made painfully visible through societal, economic and medical costs of coping with the pandemic.

The absence of an enforceable claim upon a government to allocate a specific amount to health has led to a conclusion that 'the amount a nation can afford to spend on the pursuit of health is what it chooses to spend' (Townsend and Davidson, 1982: 27), confirmed by the World Bank as 'a question of political choice' (World Bank, 1992: xvii). The human rights corrective stems from the principle whereby the right to health, as with other economic and social rights, should enjoy priority in budgetary allocations. Also, inadequate or even diminished public funding assumes that disposable personal income enables people to pay for necessary health services, which may not be the case. Nevertheless, individual entitlements and corresponding governmental obligations in the provision of health care services remain an object of dispute and litigation, and there is as yet little global consensus. Generally, free health services are recommended in reproductive health and in infant and child healthcare, whereas the criterion of affordability should guide all others (WHO, 2002: 10). Reaching a balance between HIV/AIDS and other priorities is not an easy process, but is a necessary one, as illustrated in Box 1.

### **Box 1: A difficult balance: antiretroviral treatment and other health needs**

Knowledge that free medical treatment can be obtained inevitably leads to claiming it, particularly amongst people whose lives depend on it. Large numbers of demands for access to free medical treatment for people with HIV/AIDS have been filed before domestic courts and the Inter-American Commission on Human Rights in Argentina, Chile, El Salvador, Guatemala, Honduras, and Nicaragua. That people were going to die unless medical treatment and drugs were provided strengthened cases: the right to life was in question. A number of cases were successful, which encouraged additional cases.

Legal arguments debated in such cases inevitably yielded to limited budgets to finance the medication and related health services for people with HIV/AIDS. In the case of El Salvador, the Inter-American Commission on Human Rights granted temporary protective measures (*medidas cautelares*), including antiretroviral medication. It decided so on 29 February 2000, and on 15 March 2000 the government informed the Commission that clinical histories of the applicants were being reviewed with the intention of identifying optimal medical treatment, and that the necessary funds to purchase medication were being sought. Thereafter, the views of the applicants and the government parted ways. The government claimed that it did whatever it could. The petitioners argued the opposite, asserting that the government had not undertaken 'reasonable financial adjustments to permit their purchase and administration'. The Commission has decided to continue examining this case and has provisionally concluded:

The IACHR is aware of the fact that the people of El Salvador are in the midst of a very difficult period brought on by a series of natural disasters, which has placed enormous demands on the health authorities and officials. In that context, the Inter-American Commission appreciates the efforts of the Salvadoran authorities to address the needs of persons infected with HIV/AIDS in that country. The supply of anti-retroviral medications has been steadily increasing in recent months, and the State has announced that it will continue to adopt the measures necessary in that regard. (Inter-American Commission on Human Rights, 2001).

## 6. Changing law on life-prolonging drugs

A series of human rights challenges at the turn of the millennium has reinforced governmental responsibilities, and related powers, in protecting public health. This has facilitated defining the boundaries between trade law and human rights law. On 1 January 1995, the TRIPs (Trade-Related Aspects of Intellectual Property Rights) Agreement came into force. Its impact was highlighted by a court case in South Africa regarding enhanced availability of HIV/AIDS-related drugs. Thirty-nine pharmaceutical companies, who took the government of South Africa to court for breaching their property rights in 1998, had to withdraw their suit in 2001 owing to the negative publicity that the case generated worldwide (Kongolo, 2001: 601-27). Life-saving drugs are widely perceived as entitlements based on the right to health, which should be prioritised over commercial considerations. Indeed, this hierarchy of values was subsequently embodied in the Doha Declaration on the TRIPs Agreement and Public Health, which has affirmed the 'WTO Members' right to protect public health and, in particular, promote access to medicines for all' (WTO, 2001, 2003).

However, access to free healthcare services and necessary drugs as an individual entitlement does not enjoy full recognition worldwide. International human rights treaties tend to repeat the oldest definition of the right to health from the WHO Constitution as 'the enjoyment of the highest attainable standard of health', with health defined as 'a state of complete physical, mental and social well-being'. The International Covenant on Economic, Social and Cultural Rights is vague on specifying individual entitlements, obliging the states to 'create conditions which would ensure to all medical services and medical attention in the event of sickness'. The African Charter on Human and Peoples' Rights obliges states to ensure that people 'receive medical attention when they are sick'. The Protocol of San Salvador goes further and affirms that health is a public good. It obliges states to extend 'the benefits of health services to all individuals' and urges them to prioritise satisfaction of health needs of 'those whose poverty makes them the most vulnerable'.<sup>3</sup>

The reluctance of governments to guarantee an open-ended individual entitlement is understandable: health needs are limitless. As in other areas, priorities are determined through democratic processes and entrenched in law. Courts worldwide have refrained from interfering in democratically made decisions or professional medical judgements. One example comes from English jurisprudence: 'Difficult and agonizing judgements have to be made as to how a limited budget is best allocated to the maximum advantage of maximum number of patients. This is not a judgement which the court can make' (R. vs Cambridge Health Authority, 1995). Another comes from the Constitutional Court of South Africa. In the case of a terminally ill patient who needed continuous medical treatment to prolong his life, the Court declined to find for him because this 'would have the consequence of prioritizing the treatment of terminal illnesses over other forms of medical care' (Soobramoney vs Minister of Health, 1997). In a different case, which revolved around reduction of the risk of HIV-transmission to newly born babies through the administration of antiretroviral drug nevirapine, the Court has defined governmental obligations as follows:

This case concerns particularly those who cannot afford to pay for medical services. There is a difference in the positions of those who can afford to pay for services and those who cannot. State policy must take account of these differences. Here we are concerned with children born in public hospitals and clinics to mothers who are for the most part indigent and unable to gain access to private medical treatment which is beyond their means. They and their children are in the main dependent upon the state to make healthcare services available to them. In evaluating government's policy, regard must be had to the fact that this case is concerned with newborn babies whose lives might be saved. (Minister of Health vs Treatment Action Campaign, 2002)

The Court has thus affirmed the priority of prevention over cure, and of children over adults, and – most importantly – its has affirmed government's discretion in resorting to different or better methods of coping with HIV/AIDS as long as these comply with its constitutional

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<sup>3</sup> Excerpts from those and other international instruments are comprised in Alfredsson and Tomasevski (1998).

obligation to progressively eliminate or at least reduce health hazards, especially those that stem from deprivation.

## 7. A look back and a look forward

As the inability of medicine to provide a cure for AIDS or a vaccine against HIV infection has shattered unrealistic optimism in science and technology, rethinking the rights and wrongs in responding to HIV/AIDS obtains increased importance. The inability to cure highlights caring, avoiding societal responses that supplant wrongs for rights. Previous epidemics never provided a voice to sufferers. The novelty of the AIDS pandemic is that for the first time in history those infected and affected<sup>4</sup> do have the right to a voice, the right to know, the right to challenge, and the right to participate in policy-making.

HIV/AIDS became a test case for applying human rights in response to a pandemic by showing pertinent problems in their extreme, and also by forging solutions which integrated human rights faster and deeper than anybody thought possible. The best feature of HIV/AIDS is that transmission of HIV infection is preventable, and that prevention is in our hands. However, if progress has been outstanding, advances have been uneven and marred by setbacks.

During the past twenty-five years, the notion of burden-sharing has followed on from the changed knowledge about the pandemic. Initially seen as 'AIDS-free', women became the focus of attention because of their vulnerability to the infection. And yet, much of this vulnerability is manmade, literally so, and can be reduced if women's rights are fully protected, by men and women jointly. A rights-based approach to HIV/AIDS requires translating into practice women's 'right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence' (UN, 1995). Nonetheless, this almost-consensus attained at the 1995 Beijing Conference was immediately undermined by numerous reservations, and during the past decade controversies have increased.

Disagreements as to the formulation of a globally shared vision have increased, resulting from the altered policy of the government of the US. The European Parliament regretted in 2002 the lack of global agreement on 'expanding the access to reproductive health services, including information and education on reproductive and sexual health', and the Council of Europe noted in 2003 that 'clinics close and access to reproductive health services becomes more difficult for lack of funding, less poor women worldwide can afford contraception'. It is a sobering thought that we entered the third millennium without having been able to secure, globally, women's rights to self-protection against HIV infection. This remains an unmet challenge for the third decade of the pandemic.

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<sup>4</sup> The chronology of the AIDS pandemic exhibited many changes in vocabulary. Suffice it to provide one example: 'We condemn attempts to label us as "victims", which implies defeat, and we are only occasionally "patients", which implies passivity, helplessness and dependence upon the care of others. We are "people with AIDS"' (PWA Coalition, 1987)

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