

Meeting 5: Why the human rights approach to HIV/AIDS makes all the difference

Speakers: Marianne Haslegrave, Commonwealth Medical Trust
Mandeep Dhaliwal, International HIV/AIDS Alliance

Chair: Tony Barnett, London School of Economics



Meeting Summary

The first speaker, Marianne Haslegrave, opened by emphasising the importance of situating discussion and activities on HIV/AIDS within the framework of the Millennium Development Goals (MDGs). She then moved on to discuss the centrality of human rights, and in particular discrimination, to the prevention and treatment of HIV/AIDS. She outlined the obligations that governments have with respect to human rights and what this means in terms of healthcare provision. Haslegrave concluded by calling for a renewed effort to document the many examples of successful interventions based on a human rights-based approach.

The second speaker, Mandeep Dhaliwal, began by setting the scene in terms of the HIV/AIDS situation in the world today. She then established the relationship between human rights and the prevention and treatment of HIV/AIDS. Dhaliwal argued that human rights and public health approaches are mutually reinforcing and that an integrationist

approach is vital to the HIV/AIDS response. She then spoke about some of the issues relating to the scaling up of treatment from a human rights perspective, in particular routine testing and beneficial disclosure. She concluded by demonstrating how stigma and discrimination are fundamental barriers to treatment, care and prevention.

The discussion built on comments made about the obligations of developed countries towards asylum seekers. The need for better prioritisation of resources to ensure equality of treatment in the UK was suggested. The relationship between law and cultural attitudes was a focus for discussion, including the possibility for tensions within the human rights framework in relation to the rights to health and culture. The question of whether the public health agenda has been skewed too far in the direction of human rights, and whether this is in fact counterproductive, was debated.



Marianne Haslegrave

I am the Director of Commat (the Commonwealth Medical Association), which has been working for a number of years on issues related to the prevention of HIV/AIDS in Commonwealth countries. We have also been working on the right to health. My remarks will therefore concentrate on the health aspects of HIV/AIDS, which is the focus of our work. However, in setting the scene, I wish to begin by looking at the Millennium Development Goals (MDGs), which will provide the framework for all our work during the next ten years.

HIV/AIDS and the Millennium Development Goals

In the context of this meeting, I want to look at two of the eight MDGs in particular, remembering that for each goal, there are also a number of targets and indicators to measure progress made in implementing them. First, Goal 1, which is the eradication of extreme poverty and hunger, has a target of halving the proportion of people whose income is less than \$1 between 1990 and 2015. This target is going to be extremely difficult to achieve given the growth of HIV/AIDS throughout the world. Second, I want to highlight Goal 6, which is to combat HIV/AIDS, malaria and other diseases, particularly tuberculosis. Target 7 within this goal is to halt and begin to reverse the spread of HIV/AIDS by 2015.

We should also bear in mind that heads of government are going to come together at the United Nations in New York in September to review the progress that has been made in implementing the MDGs and, if we are interested in any issue within the development framework, we need to be watching what might be said and what is going to come out of that meeting. Given its present position as head of the G8 and its upcoming Presidency of the EU, the UK is going to be particularly important. If we are going to use a real human rights-based approach, we need to remember that, while Tony Blair may be focusing on HIV/AIDS in Africa, the pandemic is also happening in other parts of the world.

Vulnerability, discrimination and HIV/AIDS

When we are looking at HIV/AIDS from a human rights perspective, we must first focus on discrimination. According to last year's World AIDS Day Report (UNAIDS, 2004), women are the most vulnerable to discrimination, infection and a lack of treatment and access to care. I would also say that children and adolescents, especially young girls, are also particularly vulnerable. We also know that, when we are talking about those at high risk of infection, we must include refugees, migrants and all people living in poverty because poverty and HIV/AIDS go together. HIV/AIDS is particularly rampant amongst people living on very low incomes and who are forced to seek work in particular sectors, such as sex workers. In some parts of the world, including countries of the former Soviet Union and in Central Asia, there

is also a strong correlation between HIV/AIDS and injecting drug users. We also need to think about minorities and indigenous people, persons who are in detention and men who have sex with men, which is against the law in so many developing countries. In fact, the people who we are really talking about are those that suffer in so many other ways as far as their rights are concerned.

The one common factor for these people is that they are all likely to be discriminated against in relation to access to quality prevention and treatment services. They will also tend to be discriminated against in all areas and will probably not have access to good health services. All human rights treaties are concerned with the elimination of unfair discrimination and, at Commat, we have been examining the various adverse causes affecting health of which the worst is, undoubtedly, HIV/AIDS.

The role of health institutions in the promotion of equality

In their paper 'Poverty, Equity, Human Rights and Health' (Braveman and Gruskin, 2003), Paula Braveman and Sophia Gruskin argue that health institutions can be instrumental in dealing with poverty and health within a framework of equity. They suggest that they are crucial in terms of:

- 'institutionalising the systematic and routine application of equity and human rights perspectives to all health sector actions'. The emphasis here is on *all health sector actions* and ensuring that people who are in danger of being infected with HIV or who are already infected, have access to the relevant parts of the health sector;
- 'strengthening and extending the public health functions, other than healthcare, that create the conditions necessary for health'. Again, this is particularly important when we are looking at people who are infected with HIV because they require long-term care. This also includes interventions to try to prevent infection through, for example, the provision of condoms. We all know the story that, if you add up the number of condoms in Africa, it works out at three per man per year. This is an issue about equity of access and human rights can be used to push governments to make condoms available by pointing out that, by not making them available, they are endangering the right to life;
- 'implementing equitable healthcare financing, which should help reduce poverty while increasing access for the poor'. One of the major problems that we have to deal with is weak healthcare systems caused by a lack of financing. Given the way that donor governments are now looking at general budget support, the question will be whether health financing will go to those areas where it is needed to address the AIDS pandemic;
- 'ensuring that health services respond effectively to the major causes of preventable

'... the people who we are really talking about are those that suffer in so many other ways as far as their rights are concerned.'

ill-health among the poor and disadvantaged'. Once again, if you are not providing extra services, such as access to education or information, the poor and vulnerable will not be protected from infection because one of the major forms of protection is knowing how you get the disease. Therefore, if governments are not ensuring that there is good access to education and, even where there is access, if they are not providing sex education or family-life education or whatever it may be called (and, again, this is an area where rights are being denied), then this will increase the prevalence of HIV/AIDS;

- 'monitoring, advocating and taking action to address the potential health equity and human rights implications of policies in all sectors affecting health, not only the health sector'. This is something that needs to be taken into account when we are looking at health policies as they affect HIV/AIDS. Using the example that I have just given about access to education, it requires a much wider approach than just the health sector.

The importance of the human rights framework to the prevention and treatment of HIV/AIDS

There are seven international human rights instruments of which the most important with respect to HIV/AIDS, are the International Covenant on Economic Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and the Convention on the Rights of the Child (CRC). The CRC is important, not only because of issues to do with children who are orphaned but, if we are looking at HIV prevention, because it includes children up to age of 18 and therefore also covers adolescents.

What do human rights offer in the prevention and treatment of HIV/AIDS? Human rights guarantee the specific rights of each individual and, in order that they may enjoy those rights, they establish that the state has obligations that correspond to them. They also create mechanisms to monitor states' compliance with their obligations and allow individuals to seek redress for violations of their rights. Basically, when we are talking about human rights, we are focusing on the dignity and integrity of human beings and, the question one has to

ask is, 'are people who are affected or infected by HIV/AIDS treated with dignity?' I think the answer is a resounding 'no' in most cases because those who are infected, and also those who are affected, suffer greatly from discrimination.

Governments have three obligations in relation to human rights:

- They should *respect* human rights by not violating rights through their actions.
- They should *protect* human rights by preventing others violating human rights. This is something we need to think clearly about when we are looking at issues around HIV/AIDS.
- They should *fulfil* human rights by ensuring that they can be enjoyed, for example, by adopting appropriate legislative, administrative or other measures.

'... are people who are affected or infected by HIV/AIDS treated with dignity?'

When we are looking at obligations regarding the provision of healthcare, we need to spell out what should be provided for people who are infected with HIV in terms of clinics and health-related facilities. We must ask what they need. I have deliberately not gone into issues around access to treatment but, if we are making treatment available, the quality of healthcare services would be of concern to me and it is these types of issues that I would consider. There are two points regarding state obligations that should be highlighted, namely:

- ensuring non-discrimination in access to healthcare and the underlying determinants of health; and
- government accountability for ensuring that the rights of those who are infected are actually being taken into account.

Finally I would like to mention that there are many examples of successful interventions, such as the work of the Lawyers' Collective in India. We must now gather many other examples that show that it is possible to use a human rights-based approach in a variety of ways, whether this is through litigation through the human rights committees, as has occurred in the Committee on the Rights of the Child which has highlighted the denial of children's rights because of HIV. While it is difficult area in which to work, it is important one and one in which there is much that can be done.



Mandeep Dhaliwal

First, I would like to tell you a little bit about the organisation that I work for, International HIV/AIDS Alliance, which is an international non-governmental AIDS organisation based in the UK that supports community action on HIV/AIDS in over 25 developing countries. Much of what I will talk about today is drawn from the experience of the Alliance and the Lawyers Collective HIV Unit, where I used to work before I joined the Alliance five years ago.

A month ago, when I was putting together this presentation, I was preparing a talk for the Commonwealth Lawyers Association on migration, asylum and HIV/AIDS. I will therefore also talk a little bit about this during this presentation because I think that we often talk about HIV/AIDS as an epidemic that is out there, in developing countries, when it is actually something that affects everyone because we live in an increasingly interdependent world. I gave my presentation the title, 'Testing Times', and I think that by the end of it you will understand why. We are in particularly testing times and one that will test our commitments to the principles and values of evidence-based public health and human rights approaches to HIV/AIDS.

I am only going to talk briefly about the HIV/AIDS situation and the human rights framework as Marianne has covered this well. I will then spend some time on the relationship between HIV/AIDS and human rights and, more specifically, on what we have learnt over the years and whether these lessons can be applied to the issues that I am going to discuss in my presentation. I will then focus a little on how some of these issues manifest themselves in terms of HIV policies and programmes, which is where the Alliance's expertise is, looking specifically at issues of consent, confidentiality and discrimination.

At the end of 2004, there were 42 million people living with HIV/AIDS. There were 4.9 million new infections and 3.1 million deaths due to AIDS, with 8,000 people dying each day. Women and girls are amongst the most affected in terms of rising incidence and the burden of caring for the sick, the old or children. What have we learnt during the past 20 years of the epidemic? We have learnt that those who are in some way marginalised are the most vulnerable to HIV/AIDS and that HIV spreads in spaces of powerlessness, exclusion, poverty and conflict.

The relationship between human rights and HIV/AIDS

What are human rights? Marianne covered some of these so I will only talk about them briefly. There are also a couple of points here that I do not think we adequately reflect on. We talk a lot about state responsibilities and the rights of individuals but I do not think that we talk enough about what human rights are really supposed to be. They are supposed to be based on the principles of

humanity. People have rights because they are human. What does that mean? What does this mean in relation to promoting, protecting and fulfilling the human rights of migrants in any nation state because we know that human rights apply across all states boundaries?

Kofi Annan said: 'It was never the people who complained of the universality of human rights, nor did the people consider human rights as a Western or Northern imposition. It was often their leaders who did so'. Often, when we worked in India, we were confronted by people saying, 'this is a Western concept. Indians believe in fate so human rights don't really apply here'. But, interestingly, it was never the people at community level, people living with HIV and who were campaigning for their rights, who said that. It was always people in positions of power who made such comments.

What are some of the key rights that relate to the response to HIV/AIDS? The right to health, equality and non-discrimination, privacy, information, participation, to enjoy the benefits of scientific progress, to be free from torture, work, education, an adequate standard of living and the rights of the child. These rights were well explained in some guidelines issued by the Office of the High Commissioner for Human Rights and UNAIDS (1996), which outline state responsibilities for good HIV programming and how an effective response can be built to HIV/AIDS. These guidelines were further amended in 2002 to include the right to treatment, flowing from the right to health and the right to life.

Often, when we talk about the right to health, we hear language relating to the progressive realisation of the right to health. What does that mean? This specifically acknowledges that the right to health has a resource implication and recognises that many countries will not have the resources to put into place the health services that are required for all its population. So, when we talk about progressive realisation, we are talking about states having concrete plans to make sure that, within their resource constraints, they make the best possible healthcare available for their people in the shortest possible time.

What do we mean by human rights? It was interesting that Marianne mentioned both litigation and advocacy as strategies for promoting human rights. I would like to focus on how human rights come into play in the HIV/AIDS policy-practice continuum. There is a continuum that moves from the international covenants that Marianne outlined, and countries that have signed up to these have an obligation to enact laws at the domestic level that respect the principles found in those covenants, to practice, whereby organisations and actors have a responsibility to shape their policies, services and practices in accordance with the same human rights principles.

'... HIV spreads in spaces of powerlessness, exclusion, poverty and conflict.'

So, for example, the Alliance’s programme work is based on human rights principles. In the Ukraine, we provide anti-retroviral treatment to former and active drug users and, in Zambia, adolescents and young people are provided with condoms and information on safer sex alongside appropriate user-friendly services for HIV prevention and care. Our founding principles and strategic framework are about helping people realise the right to health, the right to information and the right to access appropriate services. Human rights also help to guide our advocacy work. We advocate for respecting bodily integrity as the basis of HIV testing, for the right to information and equity of access. We also advocate on the basis of the principles of non-discrimination and equity.

Human rights and public health approaches

What do human rights and public health have in common? They share a common objective. They are basically complementary and mutually reinforcing approaches. However, there are differences: human rights actions focus on the rights of individuals and public health addresses the rights of groups. Naturally there are therefore going to be tensions and conflicts but, as with law, these can be balanced on a case-by-case basis. There are two main considerations in terms of restricting rights for public health purposes:

- i. Is the restriction absolutely necessary in order to achieve the required public-health outcome/benefit?
- ii. Is it the least restrictive measure possible to achieve the desired outcome?

We therefore recognise that there are necessary public health measures that require the restrictions of rights. However, it must be absolutely necessary, rational and must be the least restrictive measure.

As HIV/AIDS strategies and programmes have been rolled out, we have learnt that, in order for public health programmes to be effective in the area of HIV/AIDS, the rights and dignity of the most vulnerable must be respected. Justice Michael Kirby described this as the ‘AIDS paradox’. Interestingly, at a recent session on public health, human rights and development, someone commented that this is not actually a paradox because, when you are working in the area of HIV/AIDS, it is the most obvious and fundamental thing. However, in terms of traditional public health approaches and people’s own discrimination and perceptions of the most vulnerable people, I think that it can still be called a paradox.

To summarise what I have covered so far. There are two basic approaches in responding to HIV/AIDS – the ‘isolationist’ and ‘integrationist’ approaches (see table). The isolationist approach essentially leads to exclusion and drives people underground and away from prevention and care services and, ultimately, does not lead to the achievement of the desired public health outcome by changing people’s behaviour.

Human rights in the context of scaling up treatment

I will now move on to some of the issues that we are confronting today. As treatment is becoming more available, and as there is a push to roll out treatment as quickly as possible and to achieve the target of treating three million people by the end of 2005, the scaling up of treatment can actually be used as a justification for the violation of human rights. One of the big things that we are seeing now is that, in order to put 3 million people on treatment, we have to test many millions more. However, typically, the uptake of testing has presented a challenge in developing countries for a range of reasons.

For some people, this means that we should be scaling up ‘routine testing’. What this actually means is that the specific informed consent that has been the traditional model of HIV testing, whereby people are given pre-test counselling in which they are provided with information and asked to return the next day if they wish to have the test, which is then followed by post-test counselling, will no longer be sought. What is now being said is that it is going to be the duty of the healthcare provider – the doctor, the counsellor, etc. – to say that they are offering an HIV test and the onus will be on the patient or the client to opt out.

The interesting thing here is that many of us are saying that this does not take the power dimension, the nature of the relationship between the healthcare worker and patient, into account. How many of us, when we are sick, concerned about our health or have merely ended up in a healthcare facility with a doctor or a nurse, actually have the power to say no. I wonder how many of us in this room would actually say no in that situation. A question therefore exists about how voluntary routine testing is actually going to be and we know from 20 years of experience that voluntariness is an essential component of HIV/AIDS policies and programmes.

Routine testing must also comply with human rights ethics and principles, not because it is the

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Isolationist Approach	Integrationist Approach
Mandatory testing Isolation of people who are HIV positive Confidentiality breached Discrimination against those who are HIV positive	Voluntary testing Inclusion of people who are HIV positive Confidentiality preserved No discrimination against those who are HIV positive

moral or right thing to do, but because that is the approach that is going to achieve sustained public health benefits. I think Marianne also pointed out that we are not talking about short-term gain. We are talking about something that has a short-term response but that has to be sustained. In that sense, I think that it is therefore a challenging question and we are saying that this is something we need to gather more evidence about as we roll out programmes.

I will just say something about the right to refuse treatment. In many countries, we are seeing that people do not actually believe that HIV/AIDS treatment is going to be available in the future – that the public health system may be providing it this year but will not provide it next year. They have had this experience with tuberculosis programmes. People are therefore refusing treatment but are providers actually listening or is treatment being forced on people? We have seen situations in Zambia where the right to refuse treatment has not been respected, resulting in the wastage of resources and a negative impact on the health of those who does not adhere to the treatment.

Supporting beneficial disclosure

The duty to disclose is also something that has always been a challenging issue. Is the duty to disclose a prevention tool? What impact does it actually have on the provision of care for a chronic condition? And, while we know that a person must have knowledge in order for a duty to arise, the act of omission, of not informing, can endanger another person. This is therefore similar to assessing the significant risk of foreseeable harm. The law recognises that both HIV positive and negative people have rights and duties and that the conflicts, benefits and risks that arise between them need to be balanced.

UNAIDS published a document a couple of years ago called Supporting Beneficial Disclosure, which outlines a process whereby people are empowered to disclose. I have included a quote from a person with HIV who lives with disclosure: ‘As for me, the more I am supported to follow through with the disclosure of my status and safer sex, the more I know I’m part of the solution, not the problem. That feeling empowers me. I hope it empowers others’ (UNAIDS and WHO, 2000). We often make the mistake in programmes of thinking that confidentiality and disclosure are one-time events, when they are actually something that people live with every day. I think this is really about looking at confidentiality and supporting beneficial disclosure as an important part of providing appropriate care to people.

Stigma and discrimination: barriers to prevention, care and treatment

Stigma and discrimination remain the biggest barriers to HIV/AIDS prevention, care and treatment. I think that some of the most pernicious manifestations of discrimination are the laws that criminalise particular behaviours, such as drug

use, sex work or stringent laws around migrants. These deprive people of their rights and make them even more vulnerable, driving them away from prevention, care and treatment services. Interestingly, most incidences of discrimination are experienced in the healthcare setting, such as the refusal to treat, discriminatory or sub-optimal treatment, people being charged more for treatment because they are HIV positive, forced testing, medical threats or the negative attitudes of health workers in general.

The lack of access to anti-retroviral treatment is probably the most blatant form of discrimination that I have seen in the past 20 years. I think that the culpability of the pharmaceutical industry with regard to the international patent regime, which was essentially designed in collaboration with the pharmaceutical industry, is something that we do not talk enough about. We need to really look at how we can fastidiously safeguard the public health flexibilities offered by Agreement on the Trade-Related Aspects of Intellectual Property Rights (TRIPs) and subsequent agreements in order to ensure that people have access to treatment, otherwise, in the long term, we will not be able to sustain HIV treatment or prevention.

We also need to be careful that we do not entrench existing inequalities as we scale-up treatment, for instance in terms of access. We will have to ration treatment but on what basis should we make these decisions? I think the answer has to be by involving the affected communities in the design of the criteria for deciding who gets treatment first and how it will be rolled out. In many developing countries, health workers do not have access to treatment themselves and they are being asked to provide life-saving treatments to others. So how do we ensure that they also have access as part of the scaling-up of treatment? Treatment for marginalised populations, such as sex workers, drug users and men who have sex with men, is something that is always at the bottom of everybody’s list. It is much easier to give treatment to the politician, health-worker or NGO elite, which will reinforce the marginalisation of parts of the population and adversely affect our prevention work by not providing treatment for all.

I would like to end with a warning that appeared in a book by Jonathan Mann and Daniel Tarantola (1996) that remains as relevant today: ‘Rapidly increasing numbers of people infected with HIV and people with AIDS will be accompanied by intense political, social and economic stresses. Threats to and interference with the human rights and dignity of those infected, those who are ill and those most vulnerable will increase substantially. The temptation to return to coercive public health measures will also intensify’. We probably need to also think about our own policies towards asylum seekers and migrants in the West and the requirement of testing upon entry and differential access to care and treatment. Is this sound public health practice? Are they receiving access to good quality care and treatment from the moment they set foot in the country? Is it not our human rights

‘Stigma and discrimination remain the biggest barriers to HIV/AIDS prevention, care and treatment.’

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

*Katarina Tomasevski**

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'.¹ 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 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.² 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).

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.³

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’.⁴

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'.⁵ 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'.⁶ 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.⁷

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 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 affected⁸ 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.

Endnotes

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- 1 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).
 - 2 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.'
 - 3 Inter-American Commission on Human Rights, Report No. 29/01, *Jorge Odir Miranda Cortez et al. versus El Salvador*, Case 12.249, 7 March 2001, para. 48.
 - 4 Excerpts from those and other international instruments are comprised in Alfredsson and Tomasevski (1998).
 - 5 *R. versus Cambridge Health Authority, ex parte B.* 2 All ER 129 (CA) (1995).
 - 6 *Thiagraj Soobramoney versus Minister of Health (KwaZulu-Natal)*, Case CCT 32/97, judgement of 27 November (1997), Constitutional Court of South Africa.
 - 7 *Minister of Health versus Treatment Action Campaign (TAC)*, Case CCT 8/02, judgement of 5 July (2002), Constitutional Court of South Africa.
 - 8 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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