

The HIV/AIDS Epidemic and Human Rights Responses

Mary Crewe

“The real world is endlessly fertile in its yield of sobering, wrenching, clarifying contexts for thinking about the idea of human rights”.¹

The HIV and AIDS epidemics yield sobering, wrenching and clarifying contexts for thinking about human rights and pose one of the most fascinating and challenging problems of our times. Despite the pain and suffering, the epidemic offers new and compelling ways to look at how individuals, communities, societies and states can and should respond to such challenges.

Throughout the history of the epidemic we have witnessed, in many parts of the world, acts of cruelty and horror² but also acts of support and protection.³ In the political domain there have been attempts, through legislation, to ensure that people living with HIV and AIDS suffer no discrimination or violation of their rights. At the same time there have been official acts of discrimination and violations of human rights. This tension remains between the work to get the human rights of all people living with HIV and AIDS secured and protected and the work of politicians to have HIV and AIDS as part of legislation that will restrict rights and freedoms, and is highlighted by the move of some African governments to criminalize “wilful” transmission of HIV and to put in place laws that target people living with HIV and AIDS.⁴

At the UN World Conference Against Racism in Durban in 2001, Mary Robinson declared HIV/AIDS poses the greatest challenge to human rights we have had to face.

Human rights speak in broad terms about the fundamental entitlement of all human beings to live in dignity and in conditions of social justice.⁵ The approach of human rights provides a foundation from which to mount a set of demands premised on the intrinsic worth of the person whose rights are being threatened or denied. As Connors argues, claims based on human rights require no justification, with claimants inherently entitled to human rights.⁶ Usually, an approach based on human rights promises the engagement of the state in a way that is internationally recognized and acknowledged; their denial or violation immediately raises the question, both at the national and international levels, of the legal responsibility of the state.

Is it possible that the emphasis on human rights in relation to HIV and AIDS has influenced the larger world of public health and the access of people to proper health care and support? It has been argued⁷ that this awareness of a fundamental connection between HIV and human rights has slowly but increasingly led to a new and deeper collaboration between public health officials and human rights advocates.

Initial responses to the HIV epidemic focused the blame on others: Foreigners, sex workers, gay men, injecting drug users, uneducated people, rich men, sinners, and women. Countries started to exclude foreigners with HIV, to test sex workers and to make HIV a notifiable disease.⁸

This early response to HIV was consistent with the history of disease and ways to deal with perceived threats to the general population. Wars and panics as well as epidemics have all served at one time or another in history to justify significant incursions on the rights of individuals or groups.

Between 1918 and 1920, due to fears of sexually transmitted infections (STIs) and the health of soldiers and sailors conscripted to fight in World War I, the Government of the United States promoted and paid for the detention of over 18 000 women suspected of prostitution.⁹ Earlier, when cholera struck New York City in 1832, officials rounded up alcoholics, especially poor Irishmen; and in the polio epidemic of 1916 health officials conducted house-to-house searches and forcibly removed and quarantined children thought to have polio. In short, it was common to violate the civil rights of the ill to protect the healthy – to abuse some to protect others.¹⁰

Although early responses to HIV and AIDS were based on discrimination and the application of standard public health measures such as isolation, mandatory testing, and quarantine, as the epidemic unfolded it became clear that the most effective way to address the issue was through a

protection of rights rather than allowing for any restriction of freedoms and movements, and from this developed the very strong movement that linked HIV and AIDS to human rights and the attainments and protection of such rights. HIV is no respecter of gender, nationality, sexual orientation, occupation, skin colour or age.¹¹ Rather HIV is about the risks that each of us takes and our personal ability to make choices about those risks – and some of us have far more choice than others. But it was with regard to risk and choice that many of the punitive decisions about HIV and AIDS were taken.

This point was emphasized by Jonathan Mann in 1997:¹² In HIV/AIDS, it has become clear that the traditional public health approach, combining information and education with specific health services (counselling, HIV testing, needle exchange, condom distribution) is necessary and helpful, yet clearly insufficient for HIV prevention. Vulnerability to the epidemic has now been associated with the extent of realization of human rights. For as the HIV epidemic matures and evolves within each community and country, it focuses inexorably on those groups who – before HIV/AIDS arrived – were already discriminated against, marginalized, and stigmatized within each society. Now that a lack of respect for human rights has been identified as a societal level risk factor for HIV/AIDS vulnerability, HIV prevention efforts are starting to go beyond traditional educational and service-based efforts – to address the rights issues which will be a precondition for greater progress against the epidemic.

In this way, the human rights emphasis on HIV started to strengthen work on access to health care, the position of women in society, the rights of young people to good health care and education, the rights of orphans and other young people left homeless and the rights of the elderly as they grapple with the needs of their grandchildren left in their care.

Despite this, some caution is needed. In various publications from UN agencies and from the international donor community, there are introductory paragraphs that emphasize that the work discussed is considered within a human rights framework. However, what that framework is or how it influences policy, legislation or behaviour is often quite unclear. It is as if by the mere statement of intent the right actions will follow. Some kind of nod is made in the direction of rights but measures that are discriminatory continue. This would be particularly the case, for example, in discourse about the rights of women and access to health care. The real challenge is to the

power of patriarchy, the increasing feminization of poverty, and the disproportionate burden of infection that women have to face. Stating that work about women and health needs to be in a human rights framework would be supported by most states – but seldom is there a real interrogation of what this would actually mean for state policy, action and social change.

Human rights discourse is placed within the existing status quo and has the intention of trying to make the status quo more acceptable. It is important that the human rights approach should be about challenging the status quo on all levels – no longer asking status quo questions which give status quo answers – but finding ways to ask oppositional questions which will give oppositional answers and ways to a radically transformed society.

That is what HIV and AIDS offers – a dramatic way to challenge the status quo and the prevailing patterns of discrimination and prejudice. AIDS gave us ways to challenge the status quo on issues of sex and sexuality – highlighting the needs and exploitation of those people who have sexual identities and practices outside of the mainstream. It gave us a new language to talk about intravenous drug users and the ways in which they were addressed within the status quo. We could think about sex work differently, about the position of women and young people, and it allowed for creative new ways to address how men have been marginalized in traditional public health discourse and AIDS prevention and care programmes.

Challenging the status quo is extremely complex and difficult and it is all too easy to dismiss these concerns as being outside of existing social norms and values. But it is precisely this dynamic that created the space for human rights lobbyists and activists to make the links and then the demands for greater attention to the abuse of the rights of people living with HIV and AIDS, for attention to the rights of women, attention to access to health care and treatments, and to emphasize the importance of the right to good nutrition, housing, employment and security as fundamental to an HIV and AIDS response.

While this remains fundamental to HIV and AIDS work, it is also the case that, deep within the epidemic, HIV and AIDS hold the possibility for expanded control and legislation to try to limit or prevent transmission. So while the human rights approach is acknowledged, there are also worrying signs that some governments are increasingly trying to use the law to criminalize infection, to enforce mandatory testing and disclosure, and to set back many of the human rights gains that have been made over the past two decades. And they are doing this precisely to try and buttress the status

quo against the social challenges and political action that addressing rights at all levels would entail.

Combined, the HIV/AIDS epidemic and the failure to realize and protect the human rights of both the infected and the affected represents a human tragedy and betrayal of huge proportions. Yet by using the existing conventions and protocols and by exposing how prevailing gender relations and other patterns of structural inequality are implicated in its spread, the AIDS epidemic offers the possibility of real change – change in terms of human rights being realized and along with that the real possibility to turn the AIDS epidemic around. AIDS highlights all the areas in which all of our vulnerability is increased through the failure to respect rights. In addressing AIDS, it is also possible to ensure the full protection of rights.

HIV and AIDS came into a world in which commitment to human rights was already established in the Universal Declaration and through various treaties already signed and ratified by most states. They came into a post-colonial world where the rights and dignity of previously oppressed and marginalized groups was recognized and protected and they came into a world in which equality between races, gender and nations was high on the agenda.¹³

Unlike other contagious diseases for which harsh public health interventions remained applicable, AIDS was supposedly treated in an exceptional manner. Nevertheless it was possible to try to restrict individuals' rights on behalf of overall epidemiological security. AIDS went beyond a public health issue, beyond being a contagious disease, and in the attempts to curtail the epidemic's rise – in the guise of public health – the most enduring political dilemma was how to reconcile individuals' claim to autonomy and liberty with the community's concern with safety. How does the polity treat the patient who is both citizen and a carrier of disease? How are individual rights and the public good pursued simultaneously?¹⁴

AIDS then caused a deeper analysis of instincts and attitudes lying just below the surface of expressed ideology. What AIDS forced people to confront in very real terms were their own prejudices – prejudices which before they had been able to mask. AIDS stripped bare those who were and are homophobic; those who judge sex workers and people of alternative sexual lives; of young people and how they behave and exposed in very stark forms the extent of our prejudice; our intolerance and the depth of our social hypocrisy and dishonesty. And so it was possible not to intervene as the attacks started on the gay people, IV drug users and sex workers and very

soon the attacks and the distaste were not addressed to those groups but rather to the virus itself – to the extent that anyone living with the virus moved in a slow but persistent side stream of society.

Should we, the question seemed to be, focus on the lives saved by traditional public health interventions albeit if these violate rights or focus on the rights that have been violated? Tactics adopted 150 years ago with cholera, leprosy and tuberculosis created a template for the responses to AIDS. Old mentalities and old ways of doing things remained remarkably consistent. Decisions about how to treat AIDS, and the subsequent violations of rights and dignity, were taken in accord with a deep public health ideology set in place during the last century and health is the last site where many people doubtful of the value of and sceptical of the need for human rights reside.¹⁵ This view has been echoed by amongst others Kevin de Cock who suggested:

“We think that the emphasis on human rights in HIV/AIDS prevention has reduced the importance of public health and social justice, which offer a framework for prevention efforts in Africa that might be more relevant to people’s daily lives and more likely be effective.”¹⁶

How then do we shift away from the idea that a restriction of freedoms is part of the universal good when dealing with public health crisis?¹⁷ How do we put rights first and public health second and how do we break the stranglehold of those who believe that in a time of crisis rights can be set aside and placed on the back burner?

How is it possible that in the world in which people are developing AIDS prevention and intervention programmes, various positions, for which there is very little evidence or which could clearly violate human rights, come to be taken as authoritative, and therefore to some degree socially determinant, statements about the nature of the world and the ways to address the epidemic?

According to Foucault, discourses develop and gain their determinative power as a consequence of interaction between four elements:¹⁸

- “Objects” – the things they are about
- Modes of enunciation – the way these things are spoken of
- Concepts – the intellectual constructs we need to speak about them
- Strategies – the ways in which these constructs are developed

In the field of HIV and AIDS and human rights, there are many examples of where a decision has been reached where the outcome may serve one purpose, but in execution may lead to an abuse of human rights. This analysis can apply to the ways in which routine/opt out or mandatory testing has been debated. The concept of mandatory testing was debated and discussed by people with authority and power – doctors operating from a deeply public health model, steeped in the public health history of individual rights for the general good. So skilfully did they employ their constructs that it was almost impossible for the non-medic – the community person, the human rights activist, or the AIDS worker, to challenge this – they lacked the required social authority. The strategy then became the provider-initiated test which became the routine offer, and then the mandatory test with the subsequent potential abuse and violation of rights.

Overwhelmingly the voice of testing was the medical voice, the voice of public health authority, and there seemed little ground for the non-medic – the lawyer, the judge, the teacher or the priest – to move. Through WHO, the 3x5 programme¹⁹ started and we learned that in the developing world, people required less counselling, that the numbers tested mattered, and those who were opposed to testing in this way were negatively portrayed.

Multiple social, political and economic rights were potentially rolled aside in this emphasis on testing. Reports describe increased domestic violence, losing jobs, family support and family homes.²⁰ There is now mainstreamed into public health a programme and policy counter-intuitive to the understanding of the epidemic and disrespectful of people's rights, privacy and dignity.

No one denies that treatments and treatment access are a basic and fundamental human right which should be freely and openly available to all people. When people raise concerns and questions about testing and treatment, they are not questioning the right to treatments or that people should freely choose to have them; rather they are questioning what comes with it – the very real potential for a reduction in human rights, a reduction in counselling and confidentiality, and a reduction of nuanced prevention as everything gets subsumed into voluntary counselling and testing and routine offers of a test.

A huge burden lies on treatment to succeed in ways where other ideas have failed. The urgency of the need to save lives in the face of this epidemic, and the hope that treatment would succeed where prevention seems

to have failed have led to a situation where treatments are assumed to take on all kinds of symbolic powers beyond their actual capacity to address the virus in the body.

But in Foucault's terms, testing has become a mainstreamed public and policy response leading to all kinds of rights violations that are not being challenged. Although the programme was at pains to link treatments to prevention, this instrumentalist approach seemed to close the door on research about sexuality, power, patriarchy and rights. Open and ongoing debates about sex, sexuality and modern sexual behaviour have been largely pushed to the margins.

There are similar concerns about male circumcision.²¹ Trials seemed to show that circumcision lowered the level of risk for infection in men. Experts were called in to give the social and scientific language. The strategy is to roll out male circumcision at least in the developing world with scant regard for individual choice or autonomy. Indeed examples from Kenya²² already tell us of discrimination against non-circumcized men and pressures on men presenting with a negative test result to be circumcized.

Little attention has been paid to the sexual rights of men in this regard. What of cultural, sexual and traditional rights? How will these be ensured and protected? What of the right to refuse the procedure? What about the rights of mothers in terms of decisions about their infant sons' health? Men will still have to use condoms and what about the rights of circumcized men who become infected after all. What about the sexual experiences of women? What voice do women have in this decision?

Through the WHO and UNAIDS, circumcision is to be a mainstreamed health intervention which offers no real insights into social and cultural rights and practices. So-called protection of rights is disingenuously claimed in the right of patients to choose. None but the most naive are in any doubt about how patients actually have very few rights in the face of medical authority.

There are many other examples of how, through a mainstreamed public health intervention, individual, social and community rights have been pushed aside, ignored or quite clearly abused. And most worrying of all is how this mainstreaming of an abuse of rights has been tolerated. All too often we debate the right and not the transgressor.

When confronted with these kinds of interventions we need to apply the Foucault analysis:

- What is the object?
- How is the intervention being articulated?
- Whose is the voice that is talking and why is it legitimate?
- What is the strategy?

And we need to add a fifth and most crucial point of analysis: What is the right of the individual that is being transgressed or abused and how would we move to protect it and challenge such interventions?

As South Africa's history under Apartheid showed, it is very easy to abuse rights, to deny them and take them away on the basis of a perceived public good at the time – and once rights are taken away it is very difficult to restore them.

- 1 William J. Perry, *The Idea of Human Rights: Four Ideas* (Oxford: Oxford University Press, 2000) 4.
- 2 For example, the murder of Gugu Dhlamini and other women in South Africa because of their HIV status, to people living with HIV and AIDS being rejected by their families, suffering from violence, losing jobs and housing, and young children facing exploitation and violence.
- 3 Many people living with HIV are lovingly and effectively cared for by family and volunteers; many young people have been taken in and cared for by other families and community members.
- 4 Examples of this from Africa include: From Angola, *Law 8/04 on HIV and AIDS* (2004); from Kenya, *HIV and AIDS Prevention and CONTROL Act 14 of 2006* and the *Sexual Offences Act 3 of 2006*;

- from Lesotho, the *Sexual Offences Act of 2003*; and other examples from Madagascar, South Africa, Swaziland, Tanzania, Uganda and Zimbabwe. See also the concerns raised in the Open Civil Letter to the participants of the Capacity building workshop on human rights and gender in the HIV legal framework (held in Dakar 16–18 April 2008) concerning how some of the provisions in the N'Djamena “model law” violate international human rights law and the Office of the High Commissioner for Human Rights (OHCHR) Guidelines on HIV/AIDS and Human Rights.
- 5 Jane Connors, ‘Mainstreaming Gender Within the International Framework’ in A. Stewart (ed.) *Gender Law and Social Justice* (London: Blackstone Press, 2000) at 19.
 - 6 Ibid.
 - 7 S. Gruskin, K. Tomasevski and A. Hendriks, ‘Human Rights and Responses to HIV/AIDS’ in Jonathan Mann and David Tarantola (eds.), *AIDS in the World II* (Oxford: Oxford University Press, 1996) at 326.
 - 8 A. Welbourn, ‘Gender, Sex and HIV: How to Address Issues that No One Wants to Hear About’ in A. Cornwall and A. Welbourn (eds.), *Realizing Rights* (London: Zed Books, 2002) at 99, 101.
 - 9 T. Stoddard and W. Reiman, ‘AIDS and the Rights of the Individual: Toward a More Sophisticated Understanding of Discrimination’ in D. Nelkin et al. *A Disease of Society: Cultural and Institutional Responses to AIDS* (Oxford: Oxford University Press, 1992) at 241.
 - 10 See P. Baldwin, *Disease and Democracy: The Industrialized World Faces AIDS* (California: University of California Press, 2005) at 1.
 - 11 Welbourn, *supra* note 8.
 - 12 Jonathan Mann, ‘Public Health and Human Rights’ 27(3) *Hastings Centre Report* (1997).
 - 13 It should not have been possible for the levels of discrimination around HIV to have developed over what is essentially another physical characteristic like race or gender.
 - 14 Baldwin, *supra* note 10.
 - 15 Ibid.
 - 16 Ibid.
 - 17 This is not to suggest that its an either/or scenario – either individual rights or public health – but rather to question the ways in which public health has been able, through its history and social standing, to violate human rights and defend this position.
 - 18 See this discussion in A. Woodiwiss, *Making Human Rights Work Globally* (London: Glasshouse, 2003) at 19.
 - 19 The 3x5 programme was the undertaking to get three million people in the developing world onto ARV treatments by the year 2005. This target was not met.
 - 20 Many of these are anecdotal but many are well documented and some have been dealt with through non-governmental organizations such as the AIDS Law Project.
 - 21 See the work of, for instance, Peter Aggleton and Gary Dowsett and others and the UNAIDS position papers.
 - 22 See ‘Uncircumcized pupils sent home’, BBC News, 12 February 2007, available at <http://news.bbc.co.uk/2/hi/africa/6355447.stm>; ‘Circumcision row divides Kenya town’, BBC News, 16 February 2007, available at <http://news.bbc.co.uk/2/hi/africa/6367807.stm>. See also see the effects of persecution of men in Eastern Europe in the recent ethnic struggles depending on their being circumcized or not.

standing the HIV and AIDS epidemic in South Africa through social, cultural and political theory.

Mary Crewe studied at the Universities of Natal



(Pietermaritzburg South Africa) and the Witwatersrand (South Africa) specializing in education and social and political theory. She has taught at the University of the Witwatersrand. She has worked in HIV

and AIDS since 1989 – first in the Greater Johannesburg Metropolitan Council AIDS programme, in the National Department of Health (1996/1997) and is currently the Director of the Centre for the Study of AIDS, based at the University of Pretoria (South Africa). Her research areas are focused on creating new ways of under-