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Human rights and HIV/AIDS in the context of 3 by 5: time for new directions?

Over the last decade, the success of the human rights-based approach to HIV/AIDS has been spotty, says Mark Heywood. In this feature article, the author describes the challenges that remain in implementing a human rights approach. He presents an analysis of questions raised by De Cock et al concerning the applicability of the human rights approach. The author argues that human rights advocacy needs to continue, but that new directions are required. The article outlines new directions in the areas of (a) confidentiality and openness, (b) HIV testing, and (c) health systems. The author concludes that the most serious threat to human rights remains the unwillingness of national governments to take all necessary measures to build health services and prevent epidemics.

It has been over 15 years since a “human rights approach to HIV/AIDS” was first articulated as being necessary to guarantee the success of prevention strategies that aimed to control the HIV/AIDS epidemic.¹ In 1993, Australian High Court judge Michael Kirby described this as the “AIDS paradox,” explaining that “one of the most effective laws we can offer to combat the spread of HIV is the protection of persons living with HIV/AIDS, and those about them, from discrimination. This is a paradox because the community expects laws to protect the uninfected from the infected. Yet, at least at this stage of this epidemic, we must protect the infected too.”² Kirby stated that the paradox derived from the fact that there was no vaccine or simple cure for HIV. Although there is still no vaccine or cure, since 1993 the scientific, social, and political environment surrounding HIV has changed dramatically. So has the demography

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of the epidemic. Of particular significance today are the facts that:

- The nucleus of the global epidemic has “settled” but has remained explosive in countries of the Third World, sub-Saharan Africa in particular, and Eastern Europe.³
- Projections made in the late 1980s of the potentially devastating societal impact of AIDS have been borne out, and are undermining prospects for achieving many of the Millennium Development Goals.⁴
- Antiretroviral medicines that treat HIV have nearly 10 years of proven efficacy, and drug regimens have been made simpler. In the words of Médecins Sans Frontières (MSF), “Two Pills a Day Saves Lives.” This fact, together with knowledge about which approaches to HIV prevention and treatment work, can save the lives of people already infected and could facilitate a radically different and more effective approach to HIV prevention.
- There is a growing moral outcry and recognition that HIV/AIDS is exacerbating inequities between rich and poor countries, and a conviction that the right to health and life should not be dependent on ability to pay for medicines and health services.

These realities helped create the momentum for the World Health Organization (WHO), Joint United Nations Programme on HIV/AIDS (UNAIDS), and the Global Fund to Fight AIDS, TB and Malaria to launch the Treat 3 Million by 2005 (3

by 5) Initiative in September 2003, declaring that “a growing worldwide political mobilization, led by people living with HIV/AIDS, has educated communities and governments, affirming treatment as a human right.”⁵ The 3 by 5 campaign needs the active support of human rights activists of all hues. At heart, 3 by 5 is a public health initiative, as grand in ambition as the Global Polio Eradication Initiative. But it also aims to lessen the inequity that exists in access to medicines between First and Third Worlds. However, 3 by 5 is a major risk strategy for the WHO and UNAIDS, and thus for human rights. Just as it can raise global expectations, it can also dash them. There are several scenarios for 3 by 5. It can be:

- (a) a dismal failure with only a fraction of the target reached;
- (b) a partial success, where the target is not reached but there is a significant expansion in access to treatment and a momentum and belief is built up that continues after 2005; or
- (c) a success, where the target is reached and work continues toward the ultimate goal of universal access to antiretrovirals for everyone who requires such therapy.

Finally, the success of 3 by 5 depends not only on achieving the target, but also on the sustainability of treatment access that is achieved, and evidence of an improvement in the quality and duration of life for millions of people who live with HIV/AIDS in developing countries. This will require, in a very short time, a tangible and rapid

improvement in the quality and accessibility of health-care services.

The success of 3 by 5 depends not only on achieving the target, but also on the sustainability of treatment access that is achieved.

3 by 5 and human rights

Human rights advocates can take comfort in the fact that the 3 by 5 initiative is driven by the conviction that access to health care and treatment is a human right. This is a notion that was expressed many years ago in the Universal Declaration on Human Rights and the International Covenant on Economic, Social and Cultural Rights. In recent years, globalization and the AIDS epidemic have forced national governments, the UN system, and health activists to develop a more detailed explanation of what the right to health entails and obliges governments to do.⁶ But it is also important to try to analyze the impact that the 3 by 5 campaign might have on related “traditional” human rights issues, and how human rights principles will be advanced in the 3 by 5 period and beyond. A new AIDS paradox might be that as much as 3 by 5 is an endorsement of a human rights approach to the epidemic, if its implementation leads to shortcuts around core principles such as informed consent for HIV testing, or to a weaken-

ing of patient autonomy in decisions about disclosure, it could also be a threat to human rights.

Over the last decade, the success of the human rights approach to HIV/AIDS (as first articulated by Jonathan Mann, the UN International Guidelines on HIV/AIDS and Human Rights, etc) has been patchy.

A great deal of lip service has been paid to the AIDS paradox, and it would appear that the human rights approach is firmly entrenched in the global response to HIV/AIDS. It is undoubtedly a positive development that today in many countries there is extensive legislation, policy, and case law protecting the human rights of people infected or affected by HIV. In reaction to trade liberalization, and to the WHO's Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) in particular, human rights arguments around health as a right have dramatically impacted on global thinking, pharmaceutical company conduct and, in some cases, state practice.⁷ However, the degree to which all these protections actually benefit people in affected communities depends generally either on their governments' commitment to the rights in question (which is rare), or on the extent to which activist organizations are able to draw down the rights and assert them as demands at the community level.

On the downside, a significant number of states continue to deny that HIV is a rights issue. Or they refuse to allow human rights to intrude into certain areas of HIV prevention on grounds of religion, custom, or law.⁸ In Zimbabwe, Namibia, and many other countries in Africa and Asia, discrimination against men who have sex with men prevents HIV prevention strategies from targeting or reaching millions of vulnerable people.

States' refusal to distribute condoms to prisoners in most developing countries leaves huge numbers of people vulnerable to HIV, a vulnerability heightened by overcrowding and sexual violence. Similarly, sex work remains criminalized in most countries, including those with progressive constitutions, such as South Africa. In all these instances, the force of Justice Kirby's paradox remains: failure to protect or respect the rights of the most vulnerable fuels the epidemic.

One area where the human rights approach has had little tangible impact beyond offering an analysis relates to the vulnerability to HIV of poor women in developing countries, and to the inability or reluctance of states to challenge the serial violations of women's equality, autonomy, and bodily integrity. In 2004, a Regional Report of the Secretary General of the United Nations' Task Force on Women, Girls and HIV/AIDS in Southern Africa concluded that: "The Task Force has been left to believe that the problem [of women's vulnerability] is either so large that it forces this gender paralysis, or it is so accepted that it does not warrant significant attention from governments, donors and communities."⁹ Belated recognition of this human rights crisis led to the formation of the Global Coalition on Women and AIDS in early 2004.

One area where the human rights approach risks not being successful in future is in relation to the rights of, and duties toward, children. This is an emerging human rights priority because the scale of AIDS-related death is now robbing millions of children of parents and relative security.¹⁰ In relation to women and children, the barrier is not discrimination or prejudice toward the infected or marginalized groups, but the unwillingness of

societies to alter gender relations. The paradox here may be that despite the refusal to alter the status quo by empowering women, the status quo will eventually be undermined by the erosion of the social fabric of societies that depend on women's invisible labour.

Without being backed up by resources, many human rights will be universally recognized but not fulfilled.

But generally what we have learnt over the last 15 years is that:

- without being backed up by resources, many human rights will be universally recognized but not fulfilled;¹¹
- human rights are most likely to impact on state policy or practice when they motivate social movements such as the Treatment Action Campaign (TAC) in South Africa and are integrated into their programs of actions and turned into demands; and
- bold and urgent action to demand progressive realization of the human rights to dignity, life, and the highest attainable standard of physical and mental health has to underpin all global public health strategies, in the same manner as is now taking place with 3 by 5. The right to treatment for HIV must be synchronized with advocacy that aims to reverse the gross inequalities in health spending and outcomes that are described for the umpteenth time in the 2003 World Health Report.¹²

In the post-treatment period of the HIV/AIDS pandemic, human rights advocacy must continue. The essence of the original AIDS paradox remains. Monitoring the rights of peoples vulnerable to discrimination and marginalization from access to health (and other) resources is vital. Local efforts to educate people about their rights and to redress violations must be ongoing. But on the basis of the accomplishments and failures of the last 15 years, new directions become necessary.

Defining new approaches to the articulation of human rights

There have always been opponents of a human rights approach to HIV, but these are usually persons or governments with an a priori opposition to rights. However, in 2002 and 2003, a more theorized set of questions about the applicability of a human rights approach to HIV/AIDS in Africa was posed by De Cock and colleagues in two articles published in the *Lancet*.¹³

The authors' starting point is laudable. They explain that "[o]ur philosophical and technical approaches to HIV/AIDS prevention must interrupt HIV transmission, mitigate the epidemic's clinical and social effect, reduce stigma and vulnerability, and promote the rights and welfare of HIV-infected and uninfected people." But unfortunately, in their efforts to debunk "AIDS exceptionalism," De Cock et al mischaracterize Africa and the human rights approach to HIV in Africa. They also overlook the real factors that deter HIV testing and differentiate HIV from other infectious diseases. Below, I identify some of the flaws in their arguments.

One of the central points of their argument is that what the authors refer to as high awareness of HIV in

Africa (an assertion that contradicts their own call for appreciation of the "geographical and epidemiological heterogeneity of the pandemic"),¹⁴ reduces the need for extensive pre-test counselling.

The emphasis on counselling around HIV diagnosis is unique in infectious diseases and merits discussion. Awareness of HIV/AIDS is now high in Africa, and evidence that more extensive pre-test counselling is necessary for HIV than for other infections is lacking.

On this basis, De Cock et al argue in favour of "routine testing" which, they argue, "should not require specific consent or pre-test counselling."¹⁵ However, this argument fails to take into account the fact that awareness is not the same as knowledge and understanding. High levels of HIV/AIDS awareness are often accompanied by high levels of misunderstanding, myth, and denial. High awareness does not lead to health-seeking behaviour – and the deterrent is not the human rights approach. It is important to understand pre-test counselling as both a public health intervention intended to transfer knowledge about HIV to the patient and an ethical and human rights obligation compelling the health worker to respect patient autonomy.

For example, in South Africa, which has some of the continent's largest and most expensive HIV prevention campaigns, there is now evidence that these campaigns may create awareness of an ephemeral existence of HIV, but not of one's own risk. A recent survey carried out by the Reproductive Health Research Unit (RHRU) of the University of the Witwatersrand found that 85 percent of the nearly 12,000 young people surveyed were aware of HIV/AIDS. But:

Among sexually active young people 67% continue to think of themselves as being at low risk for HIV infection. 54% of young people who indicated never using a condom with their last sexual partner feel that they are at low risk of HIV infection... Despite the high prevalence of HIV in this young age group (10.2%), the vast majority of HIV positive youth do not know that they are infected as 67% reported that they had never been tested.¹⁶

The RHRU's findings beg the question why so-called at-risk populations are not seeking HIV testing – which brings us back to the issue of human rights and stigma! If anything, this emphasizes the importance of counselling rather than the opposite.

De Cock and company create an artificial and unwarranted polarity between human rights, social justice, and public health.

De Cock and company also create an artificial and unwarranted polarity between human rights, social justice, and public health. They claim to find a new AIDS paradox in their assertion that human rights advocates deter HIV testing by insisting on autonomy via informed consent, and they conclude that "failure to prevent HIV transmission constitutes an infringement of human rights that hampers Africa's human and social development."¹⁷

Contrary to what the authors suggest, human rights both encompass and demand social justice and public health. The problem is that bad or corrupt governance by First and Third World governments prioritizes neither

social justice nor public health in many developing countries. This is manifest in the fact that it is the lack of access to health-care services, including voluntary counselling and testing (VCT) and prophylactic or curative medicines, that is the greatest deterrent to health-seeking behaviour.¹⁸ As recognized by the WHO, community mobilization around HIV/AIDS is necessary to demand the supply of VCT and other HIV-related services, as well as to create the demand in the community. Although De Cock would not believe it, the reality is that the human rights principles of confidentiality and informed consent are still widely ignored in health settings in Africa – and are therefore not the kind of obstacles they are claimed to be.

Nonetheless, in their second *Lancet* article, De Cock and his colleagues arrive by wrong means at a set of recommendations that should now be taken more seriously. These are itemized under the subheading “Messages for a serostatus approach to HIV/AIDS prevention and care in Africa.”¹⁹ In essence, they recommend that we learn our HIV status, disclose it to our sexual partners, and seek medical care if we are positive.

De Cock’s approach is too formulaic and acontextual. For example, given the reality of unequal gender relations and sexual violence in a country like South Africa, there will be many women who cannot follow his advice to disclose, or to know the HIV status of, their sexual partner. Ironically, therefore, the success of a “serostatus-based approach” depends on the synergies it builds with the human rights approach. While we can agree with the “new” messages proposed by De Cock, and concur on the need to actively build them into a new generation of messages about

HIV/AIDS prevention and treatment, it is important to remain aware of the human rights issues they present.

Some suggestions about how this can be done are advanced below.

Confidentiality and openness

In addition to the right to confidentiality, we should emphasize the right to make choices about being open, and the duty of states to actively ensure that people are able to exercise this choice without fear. This would require states to actively campaign against discrimination and to introduce laws that prohibit and penalize practices such as pre-employment HIV testing. Public messaging should promote openness and disclosure and stress that “people should not be penalized for being open,” rather than “people need not or should not be open for fear of being penalized.” This is not an argument for involuntary disclosure, but a proposal to more actively encourage openness, while still upholding the individual’s rights to autonomy and confidentiality.²⁰

HIV testing

In the past, human rights advocates insisted on recognition of the right not to be tested for HIV because of stigma, discrimination, and the absence of therapy. This right remains, but in addition we should emphasize the right to have access to HIV testing and to know one’s HIV status. Circumstances are sufficiently changed that HIV testing should be available and offered much more widely and routinely. As suggested in the Guidance Note on Scaling up HIV Testing produced by the UNAIDS Global Reference Group on HIV/AIDS and Human Rights,²¹ UNAIDS and the WHO should not reject routine testing out of hand, but should insist that the routine offer of

HIV testing be accompanied by access to both pre-test counselling and therapy where clinically indicated.

It is important to appreciate that this is not what De Cock is arguing for. He argues for “a default policy of testing unless an individual specifically elects not to have it”²² and an “emphasis on post-test counselling for those infected with HIV.”²³ Given that the problem of counselling is a systemic and structural one, rooted in government’s unwillingness to invest in this aspect of HIV care, De Cock’s formula is dangerous. It is likely that it will lead to large numbers of people being tested for HIV without even lip service being paid to the provision of pre- and post-test counselling.²⁴ Thus, as part of the 3 by 5 effort, there must be continued insistence on (a) absolute continued patient autonomy, (b) confidentiality, (c) non-discrimination, and (d) testing as an entry point to therapy where clinically indicated.

However, certain risks have to be admitted and undertaken. The risk to human rights of not scaling up HIV testing (missed opportunities for HIV prevention and treatment) must be weighed against the risks to human rights of an imperfect scaling up. Not all the key factors for the routine offer and encouragement of HIV testing, such as those set out in the Guidance Note, will be created by 2006. Therefore, UNAIDS and the WHO should work actively with governments that are committed to an ethical scale-up of voluntary testing, and encourage bodies such as the Global Fund to Fight AIDS, Tuberculosis and Malaria to dedicate funds for this purpose.

Where governments lack this commitment, support should be given to civil society groups to demand more direct investment in counselling; and better and more visible public educa-

tion about HIV, in order that the level of public knowledge and understanding of HIV testing is much higher. Success in raising the quality of public knowledge about HIV would raise the quality of counselling (and facilitate informed decision-making) by taking away some of the burden that is presently placed on counsellors to convey information, provoke questions, etc, that should already be in the public domain.

We should emphasize the right to properly funded, managed, and planned health services, and governments' positive obligations in this regard.

Health systems

Finally, integral to the right to treatment, which has now been accepted on paper, we should emphasize the right to properly funded, managed, and planned health services, and governments' positive obligations in this regard. In 2000-2001 the median per capita HIV/AIDS expenditure for six Southern African countries was US\$1. It ranged from \$29.67 in Botswana to US\$0.41 in Lesotho. The disparity in per capita spending on HIV within the same region is a travesty of the right to health. However, it reflects an unfortunate reality in which the extent of access to HIV-related care has become dependent on the foibles of government, colonial boundaries that cut across national groups, and donor decisions that favour one country over another.²⁵

The right to accountable governance and the obligation of states to take all necessary measures to prevent epidemics

However, the crux of the debate about the future focus and impact of human rights and public health arguments lies with issues of governance. What should have been learned from the last decade is that on almost every level HIV/AIDS is an expression of a crisis of politics and accountable and democratic governance that faces our world.

On the international level, a proper response to HIV/AIDS is threatened by the global impact on resource allocations of the prioritization of the "war on terrorism" over global human need by the United States, the United Kingdom, and other industrialized countries. In 2001, important recommendations were made by the WHO Commission on Macroeconomics and Health to "scale up access of the world's poor to essential health services, including a focus on specific interventions" such as HIV/AIDS. The report estimated that "by 2010 around 8 million lives per year, in principle, could be saved by essential interventions against infectious diseases and nutritional deficiencies."²⁶ But despite this there are still no serious or coordinated plans in place to check and reverse the emasculation of health services in developing countries. Instead there is pusillanimity with respect to governments whose violations of socioeconomic rights, and failures to meet duties to protect and promote health, have cost millions of people their health, dignity, and lives.

On the national level, a proper response to HIV is threatened by governments, such as those of China and

South Africa, that as a matter of politics and policy for years avoided taking the HIV/AIDS epidemic seriously. Explicit criticism of these governments, based on objective and demonstrable omissions in duties, has been left to local activists who, when they engage in such criticism, often risk persecution. Where civil society is weak or suppressed, as in many countries in Africa and Asia, governments continue to violate health (and many other) rights with impunity. A strong reason for human rights activists to develop a vigorous focus on the responsibilities of national government is that decisions and priorities decided at the national level affect government agendas and priorities both upstream (regional, international, and global) and downstream (provincial and/or municipal).

HIV/AIDS is still not an issue that is meaningfully on the agenda at international meetings of governments such as the G8, the G77, the African Union, or the Association of South East Asian Nations – as opposed to the agenda of the multilateral institutions of the United Nations. This is because except for special events like the 2001 United Nations General Assembly Special Session on HIV/AIDS, national governments have not yet made it so. Further, the problem of HIV/AIDS is still not one that is properly owned or admitted to by many governments of the worst-affected regions of the world.

At the level of local and municipal governance, in almost all high-HIV-prevalence countries, rudimentary services are not yet in place in communities, schools, municipalities, prisons, etc, that take account of the HIV epidemic. The absence of such services remains one of the major deterrents to HIV testing, disclosure, prevention, and treatment.

Conclusion

Hopefully, this article has defended the ongoing relevance of the “AIDS paradox.” The converse of the paradox is that failure to protect the rights of the most marginalized and vulnerable to HIV increases the vulnerability of the whole population – to HIV infection, but also to its social consequences. The case of prisoners substantiates this point. Prisoners are mostly young and from high-HIV-risk groups. They bring high levels of HIV infection into prison. In environments where there is no access to information, condoms, or personal security, HIV becomes a threat to the whole prison population. Prisons have a high turnover, with many people returning to their communities – once again making HIV a threat to people whose “normal” risk is low.²⁷ Thus, the failure to protect human rights creates a vicious circle of HIV infection. Similar patterns could be deduced for sex workers and gay men.

Hopefully, the article has also illustrated how, despite the evolution of the human rights paradigm into explanatory notes, guidelines, and best practices, human rights violations continue. Organizations such as the Canadian HIV/AIDS Legal Network and the AIDS Law Project have done much to advocate for human rights at national and global levels. But they cannot create a *culture* of rights, or release the investment in health in developing countries that is needed to fight this epidemic.

The ongoing failure of governments to take the world’s health crisis seriously bodes ill for human rights in general and for 3 by 5 in particular. This has already been recognized by the UN Special Envoy for AIDS in Africa, Stephen Lewis. In March 2004, Lewis called a press conference at the United Nations to “sound the

alarm” about the lack of support for 3 by 5. He explained that the WHO “needs \$200 million, over 2004 and 2005, to put 3 by 5 in place. So far – and we are into the third month of 2004 – donor governments have been unwilling to contribute the money.” The failure to invest in 3 by 5 is a human rights violation committed by governments that have lost sight, or interest, in attaining the highest attainable standard of physical and mental health for the majority of the world’s citizens.

Arguably, therefore, the time for a more vociferous but all-encompassing human rights approach to HIV/AIDS – that affirms the original paradox – has arrived. A much more concentrated focus on the human rights obligations of national governments for the provision of health care is now critical. 3 by 5 may be a global aspiration, but it will only be achieved through successful national and regional health and HIV treatment plans. Consequently, the greatest threat to 3 by 5 – and thus to human rights – remains the unwillingness of national governments to meet their duties to their populations by instituting urgent measures to build health services, social services, and provide treatment.

– Mark J Heywood

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¹ The first international consultation on HIV/AIDS and human rights was held in 1989, the second in 1996, and the third in 2002. The International Guidelines on HIV/AIDS and Human Rights were published in 1998.

² M Kirby. *AIDS and the law*. *South African Journal on Human Rights* 1993; 9: 1.

³ This is not to minimize the existence of epidemics in most industrialized countries and the danger of rising rates of infection in countries such as the US, UK, Australia, and Canada.

⁴ See the Report of the Commission on Macro Economics and Health, WHO 2001.

⁵ WHO, UNAIDS. *Treating 3 Million by 2005, Making it Happen; the WHO Strategy*, at 5.

⁶ The right of access to treatment, as a part of the right to health care, is now supported by a range of UN General Comments, resolutions, Special Reports, and Declarations. An attempt to grapple with its meaning and the obligations it creates for States is found in the UNAIDS/OHCHR *International Guidelines on HIV/AIDS and Human Rights, Revised Guideline 6*, 2002.

⁷ B Loff, M Heywood. Patents on drugs: manufacturing scarcity or advancing health? *Journal of Law, Medicine and Ethics* Winter 2002; vol 30:4: 621-631.

⁸ This was evident in the compromises on the language that were made in the negotiations around the UNGASS Declaration of Commitment.

⁹ Also: Human Rights Watch. *Policy Paralysis: A Call for Action on HIV/AIDS-Related Human Rights Abuses Against Women and Girls in Africa*, 2003.

¹⁰ *Africa’s Orphaned Generations*. UNICEF, November 2003.

¹¹ Lesotho, for example, has a model National AIDS Plan in its recognition of human rights, but there is no implementation, there are no resources, etc.

¹² Available at www.who.int/whr/2003/en/.

¹³ K De Cock, E Marum, D Mbori-Ngacha. Shadow on the continent: public health and HIV/AIDS in the 21st century. *Lancet* 2002; 360: 67-72; De Cock, D Mbori-Ngacha, E Marum. A serostatus-based approach to HIV/AIDS prevention and care in Africa. *Lancet* 2003; 362: 1847-1849.

¹⁴ De Cock et al. Shadow on the continent. *Ibid*.

¹⁵ *Ibid*.

¹⁶ HIV and Sexual Behaviour Among Young South Africans. A National Survey of 15-24 Year-Olds. 2004, at 56-57.

¹⁷ De Cock et al. Shadow on the continent, *supra*, note 13.

¹⁸ The degree of the scale-up envisaged for HIV testing by 3 by 5, and the need to create or improve 20,000 service points for VCT, is recognition of the paucity of these services on the ground at present.

¹⁹ De Cock et al. A serostatus-based approach, *supra*, note 13.

²⁰ Anecdotally, in my experience in Southern Africa, the right to confidentiality has been translated in practice by many nurses and counsellors into discouragement of disclosure and the right to keep one’s HIV status secret. Responsibility for this rests with the failure of governments to properly train health workers, particularly about ethics and human rights. De Cock criticizes “professional organisations” for failing to respect patients’ rights to an accurate HIV diagnosis and to respond to the diagnosis. But this ignores the fact that, until recently,