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Human Rights and HIV/AIDS in the Context of '3 by 5': *Time For New Directions? A Perspective from Southern Africa*

Defining the Issue

It is 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.ⁱ Since then the scientific, social and political environment has changed dramatically. So has the demography of the epidemic. Of particular importance are the facts that:

- The nucleus of the global epidemic has 'settled' but remained explosive in countries of the third world, sub-Saharan Africa in particular, and Eastern Europe.ⁱⁱ
- Projections made in the late 1980s of the potentially devastating impact of AIDS have been borne out and are undermining development.
- Medicines now exist which, together with knowledge about what approaches to prevention and treatment work, can save 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 global inequities and that the right to health and life should not be dependant on ability to pay.

These realities helped create the momentum for WHO endorsing and now leading the "3x5" campaign. This campaign needs the active support of human rights activists of all hues. However, it is important to be sober about "3 x 5". It is a major risk strategy for WHO and UNAIDS. Just as it can raise global expectations, it can also dash them. There are several scenarios for "3 x 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;
- c. A success, where the target is reached and exceeded.

It is important to note however that success depends not only on achieving the targeted numbers, but on the sustainability of treatment access that is achieved and evidence of an improved quality and duration of life for millions of people. Above all this will require a tangible and rapid improvement in the quality and accessibility of health care services in a very short time.

'3 x 5' and Human Rights

Human rights advocates can take comfort that the "3 x 5" campaign is driven by the conviction that access to health care and treatment is a human right. This notion finds expression in the UDHR and ICESCR. But in recent years globalisation and the AIDS epidemic have forced the development of greater detail about what the right entails and obliges governments to doⁱⁱⁱ. But it is also important to look at the impact that the "3 x 5" campaign has on related 'traditional' human rights issues, and how human rights will be advocated in the "3 x 5" period and beyond.

Over the last decade the success of the 'human rights approach' (as developed by Mann, the *International Guidelines*, etc.) has been patchy. Today in many countries there is extensive legislation, policy, and case-law protecting the human rights of people infected /affected by HIV. In recent years human rights arguments around health as a right have dramatically impacted on global thinking, pharmaceutical company conduct, and in some cases state-practice. However the degree to which these protections benefit people in affected communities generally depends either on government commitment to the rights in question, or on the extent to which activist organisations are able to draw down the rights and assert them at community level.

On the down side, a significant number of states continue to deny that HIV is a rights issue, or to allow rights language to intrude into certain areas of HIV prevention on grounds of religion, custom or law.^{iv} In Zimbabwe, and many other countries in Africa and Asia, discrimination against men who have sex with men prevents HIV prevention strategies from targeting or reaching these groups.

One area where the human rights approach has had little tangible impact beyond offering an analysis is in relation to the vulnerability of poor women in developing countries to HIV, and our inability to challenge serial violations of women's equality, autonomy and bodily integrity.^v

One area where it risks not being successful in future is in relation to the rights of and duties towards children, which is an emerging human rights priority because the scale of AIDS related death is now robbing millions of children of parents and relative security.^{vi}

But, generally what we have learnt is that:

- (a) without being backed up by resources many human rights will be universally recognised but not fulfilled^{vii};
- (b) human rights are most likely to impact on state policy or practice when they motivate social movements and are integrated into their programme of actions;
- (c) a recognition of human rights has underpin public health and to be much better synchronised with other responses to the epidemic – human rights advocacy needs to be inter-twined with other interventions, not running parallel.

In the new period of HIV prevention and treatment human rights advocacy must continue. Monitoring of the rights of peoples vulnerable to discrimination and marginalisation from access to health (and other) resources is vital. Localised efforts to educate people about rights and 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 to the application of a human rights approach to HIV. But in 2002, a more theorised set of questions about the 'human rights approach' to HIV/AIDS were asked by Kevin De Cock in the *Lancet*.^{viii} In his article, De Cock mischaracterized both the human rights approach to HIV in Africa and the factors that deter HIV testing, differentiate HIV from other infectious diseases etc. De Cock argues that high awareness of HIV in Africa, reduces the need for 'extensive pre-test counselling'. He fails to note that 'awareness' is not the same as knowledge and understanding, and high awareness is usually accompanied by high levels of misunderstanding, myth and denial. He also created an artificial and unwarranted polarity between human rights, social justice and public health.^{ix} Nonetheless, by wrong means he arrives at a set of recommendations that should now be taken more seriously. This is not to undermine the human rights approach, but to agree that the time is overdue for new emphases by human rights advocates, and that these should be pressed on the global response to HIV/AIDS and quickly be made part of the global language on AIDS.

I would argue, therefore, that in light of "3 x 5"; the growing toll of mortality caused by AIDS; its developmental impact; the possibility of getting medicines and medical technologies that were previously considered unaffordable or too complex to more people, a new emphasis is immediately needed in human rights advocacy. Some suggestions are made below:

- Instead of the right to confidentiality we should emphasise 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. Messages should promote openness and stress that 'people should not be penalised for being open', rather than 'people need not / should not be open for fear of being penalised'. This is not an argument for involuntary disclosure, but a proposal to more actively encourage openness, whilst still upholding individual's rights to autonomy, confidentiality etc.^x
- Instead of the right not to be tested for HIV, we should emphasise the right to have access to HIV testing and to know your HIV status. As suggested in the Summary Guidance Note on Scaling up HIV Testing UNAIDS and the WHO should not reject 'routine testing' out of hand, but insist on an agreed definition of the term and define protocols for its implementation. Circumstances are sufficiently changed that HIV testing should be available and offered much more widely/routinely. But, as part of the "3 x 5" effort, there must be continued agreement on (i) absolute continued patient autonomy; (ii) confidentiality; (iii) non-discrimination; and (iv) 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 testing, 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 Summary Guidance Note, will be created in two years. UNAIDS and WHO should work actively with governments that are committed to an ethical scale-up of testing, and encourage bodies such as the GFATM 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, better and more visible public education 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.^{xi}

- Integral to the right to treatment (which has now been accepted on paper) we should emphasise the right to properly funded, managed and planned health services, and governments' positive obligations in this regard.^{xii}

The Right to Accountable Governance: and the Obligation to Take all Necessary Measures to Prevent Epidemics

The crux of the issue of the future focus and impact of human rights argument lies with issues of governance. What we should have 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.

- On the *international level* we are challenged by the global impact on resource allocations and the prioritisation of the 'war on terrorism' etc., over global human need by the USA, UK and other industrialised countries. Despite recommendations made by the WHO Commission on Macroeconomics and Health 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 around governments whose violations of socio-economic rights, and failures to meet duties to protect and promote health, have cost millions their health, dignity and lives.
- On the *national level* we are challenged by governments, such as that in SA, that have consciously 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. Where civil society is weak, or suppressed, as in many countries in Africa, governments have violated health (and many other) rights with impunity.
- At the level of *local and municipal governance* it is a fact that 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 a deterrent to HIV testing, disclosure, prevention and treatment.

This bodes ill for "3 x 5". Arguably, therefore, a much more concentrated focus on the human rights obligations of national governments is now critical. "3 x 5" may be a global aspiration, but it will only be achieved through successful national and regional treatment plans. Consequently, the greatest threat to "3 x 5" lies in the unwillingness of national governments to meet their duties to their populations by urgent measures to build health services, social services and provide treatment.

Another reason for a vigorous focus on the responsibilities of national government in the context of this epidemic, is that decisions and priorities *decided* at the national level affect government agendas and priorities both upstream (regional, international and global) and downstream (provincial/municipal). HIV is not an issue that is meaningfully on governmental international agendas (as opposed to the agenda of multi-lateral institutions) because outside of special events like UNGASS, national

governments have not yet made it so. Further the problem of HIV is still not one that is properly owned or admitted to by governments of the worst affected regions.

This Issue Paper was prepared by Mark Heywood to facilitate discussion at the Reference Group's January 2004 meeting.

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ⁱ 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.

ⁱⁱ This is not to minimise the existence of epidemics in most industrialised countries and the danger of rising rates of infection in countries such as the USA, UK, Australia and Canada.

ⁱⁱⁱ The right 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*.

^{iv} This was evident in the compromises on the language that were made in the negotiations around the UNGASS Declaration of Commitment.

^v See Draft Regional Report of the Secretary General of the United Nations' Task Force on Women, Girls and HIV/AIDS in Southern Africa: "The Task Force has been left to believe that the problem 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." Also: 2003, Human Rights Watch. *Policy Paralysis, A Call for Action on HIV/AIDS-Related Human Rights Abuses Against Women and Girls in Africa*.

^{vi} Africa's Orphaned Generations, UNICEF, November 2003.

^{vii} Lesotho, for example, has a model National AIDS Plan in its recognition of human rights, but there is no implementation, no resources etc

^{viii} De Cock et al, Shadow on the Continent: public health and HIV/AIDS in the 21st century, *Lancet* 2002; 360: 67-72

^{ix} Contrary to what De Cock suggests 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 prioritises neither social justice or public health in many developing countries.

^x 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 your HIV status a 'secret'.

^{xi} Note that this is an important point of difference from De Cock, who argues that routine testing 'should not require specific consent or pre-test counselling provided that all clients are informed that routine testing is part of the package of services for which they are voluntarily attending.' This approach has now been adopted as policy in Botswana which has "become the first African country to implement routine opt-out testing on a national level, starting with health facilities." (*AIDS Analysis Africa* 14 (4) 2003/04).

^{xii} In 2000/01 the median per capita HIV/AIDS expenditure for six Southern African countries was US\$1. This ranged from \$29.67 in Botswana to US\$ 0.41 in Lesotho. This itself is a travesty of the right to health, when the extent of access to HIV related care becomes dependant on the foibles of government, colonial boundaries etc. See *A Comparative Analysis of the Financing of HIV/AIDS Programmes in Botswana, Lesotho, Mozambique, South Africa, Swaziland and Zimbabwe*, HSRC Publishers, October 2003.