Rights Matter: Structural Interventions and Vulnerable Communities

Dennis Altman

My original invitation to deliver this address specifically spoke of interventions for “MSM, IDUs, and sex workers,” leading one friend, a veteran activist, to dub this the perverts plenary.* The very framing of this topic shows both the strengths and the limits of the current international language of HIV prevention. It is highly important both to emphasize prevention and to recognize that some groups, because of particular behaviors, are particularly vulnerable to HIV infection. But this assertion makes two problematic assumptions. One is that we assume people can be neatly divided by behavior into discrete and identifiable groups. The second is that we assume everyone has the knowledge and the resources to make free choices —

* The acronym MSM stands for “men who have sex with men.” The acronym IDU stands for “injection drug users.”

Dennis Altman, MA, FASSA, is Professor of Politics at LaTrobe University in Australia and President of the AIDS Society of Asia and the Pacific. Please address correspondence to the author at D.Altman@latrobe.edu.au.

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whether this is the choice for sexual abstinence and refusal of drugs, or, alternatively, the choice to always use condoms or clean needles.

Interestingly, both conservatives and liberals place great emphasis on choice: the advice to “just say no” is equivalent in some ways to the advice to always follow safer sex and injecting practices. Yet this ignores the harsh reality that before we have choice, or what social scientists like to term “agency,” we need both knowledge and the means to act on that knowledge. Estimates from most parts of the poor world suggest a continuing ignorance about HIV and the basic measures to control it: one survey in Orissa, in eastern India, suggested 60% of women have never heard of AIDS.1

If there is one comment that sums up the legacy of Jonathan Mann, it is his assertion that “We must protect human rights because we want to effectively control AIDS as well as to protect rights for their own sake.”2 As the founding director of the WHO Global Programme on AIDS, Mann led us to understanding the link between health and human rights. His work lives on through the journal, Health and Human Rights, through the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health founded by Albina du Boisrouvray, and through the words of leaders such as South Africa’s Nelson Mandela and Burma’s Aung San Suu Kyi, whose absence from this conference reminds us of the indivisibility of human rights. Jonathan was willing to offend when doing so would confront people with the consequences of their actions, or, equally important, their inactions. His is a model I shall follow.

Given the gravity of the epidemic, we need go beyond a legalistic emphasis on covenants and policies to a genuine understanding of the moral and pragmatic priority of human rights. Our shared work grows out of respect for human life and dignity, which is both a religious and a secular tradition. It is closely related to the concept underlying human security, and the worst excesses of the past decades — for example, Rwanda, Cambodia, and Bosnia — remind us that without respect for human life there can be no security. In
much of sub-Saharan Africa today, societies face the literal possibility of total collapse and disintegration due to the ravages of HIV. If unchecked, HIV will undermine societies more surely than the bombs of terrorists. Yet the resources provided to check HIV/AIDS are minuscule in comparison to those being allocated to fighting terror.

Who Is Vulnerable?

Let us be careful, as we focus on youth and women, today’s theme, that legitimate outrage at the treatment of many women does not mean we forget that poverty, racism, war, and oppression also limit choices for men. Indeed, the very term “men” is itself problematic, as is clear if we think about the diverse ways in which gender is expressed. The rich transgender heritage of groups such as kathoey, waria, hijra, to take three examples from this part of the world, remind us there are many ways of acting out “maleness.” Men who deviate from the conventional assumptions of masculinity are often likely to be particularly vulnerable to HIV.

There is a parallel danger in assuming that all women are equally vulnerable. Such a view can too easily paint all women as inherently powerless, depicting them as either Madonnas or whores. This can further stigmatize the most dispossessed — and increase their vulnerability. In general, the more socially and economically marginalized a population, the greater its vulnerability to infection; and there are many groups who might also have been discussed in today’s session: refugees, migrant workers, prisoners, and indigenous and tribal populations.

Access to prevention is as significant as access to treatments, and an equally political demand, for it is about our right as healthy citizens rather than as unhealthy dependents. We need not choose between allocating resources to prevention rather than treatment, for strengthening one can only strengthen the other. Unlike the failure to provide access to treatment, it is hard to blame the rich world in general, or pharmaceutical companies in particular, for failures in prevention. Even poor countries can afford to support good prevention efforts, as Uganda and Cambodia remind us.
The greatest tragedy of HIV/AIDS is that we know how to stop its spread, and yet in most parts of the world we are failing to do so. The literature tends to emphasize immediate problems — lack of condoms or clean needles, safe sex fatigue, unwillingness to interfere with the immediate gratification of sex or drugs. There is less emphasis on the political barriers that are accelerating the epidemic — the deliberate neglect by governments, the unwillingness to speak openly of HIV and its risks, the hypocrisy with which simple measures of prevention are forestalled in the name of culture, religion, and tradition.

**What Do We Mean by “Structural Interventions?”**

Put simply, structural interventions involve policies that recognize that vulnerability to HIV goes far beyond individual choices and behaviors, and acknowledge that such behaviors are products of larger environmental factors. Structural interventions can be as ambitious as reducing economic inequalities to give people better housing and clean water, but they can also describe specific programs such as needle exchanges or the provision of condoms to sex workers and prisoners. In most cases, they will involve governments, either through their own policies or at least by not blocking programs undertaken by nongovernmental organizations (NGOs) and community groups.

Imagine a child, living on the streets in the slums of Rio or Dacca or Lagos or Kiev, forced to survive through prostitution and petty crime, often turning to drugs to numb the pain, the fear, the hunger, and the cold of everyday survival. Telling such a child to use condoms or not to share needles to ward off an illness that may strike many years hence is meaningless. Imagine a young woman, forced by family and community pressure, to marry at 13 and have sexual relations with a man older than her father, whom she has never properly met, and the possibility of her insisting on his using a condom — if, indeed, she even knows the dangers of unprotected intercourse. Imagine a young man, forced into an army or militia, having to flee his family and home to survive, perhaps in prison or a makeshift camp, introduced to drugs as a means of escape, and then imagine the chances that he will have the
means or the incentive to reject the short-term euphoria of a hit because the needle may not be clean.

Yet for millions of people in the world today struggle for immediate survival is the reality of their everyday life. As Paul Farmer has written: "For many ... choices both large and small are limited by racism, sexism, political violence, and grinding poverty ... Both HIV transmission and human rights abuses are social processes and are embedded, most often, in the inegalitarian social structures I have called structural violence."7

Unfortunately, there are more examples of political interference that have hampered sensible HIV-prevention programs than have supported them. Too many governments have applied sanctions, punishment, and repression, ignoring the reality that humans will seek both pleasure and survival in ways that often confront the traditional norms to which social, religious, and political leaders pay lip service.

Identity Versus Behavior

There is a double vulnerability involved in HIV: both economic and social factors are crucial. Someone who sells sexual services in order to survive is likely to be more vulnerable to HIV; and this is a result both of the specific behavior and of the poverty and despair that underlies that behavior. There is a critical difference between concepts of risk and vulnerability, but also between behavior and identity.8 In discussing the latter, we need be aware of oppression that results both from material inequality and from prejudice and discrimination based on identity. Here I draw on Nancy Fraser's very useful distinction between "injustices of distribution and injustices of recognition," both of which she claims have material consequences and both of which need be countered to achieve social justice.9

There is a problem in talking of "vulnerable populations," as if they are discrete and their boundaries are known. Most people who engage in the behaviors I have been asked to address do not necessarily identify themselves in these terms. Sometimes we need to name groups — and to empower them. At other times, we need to understand
that most people do not necessarily accept the terms of the HIV world and that they may be reached through other approaches — for example, through outreach to women or to street children or to unemployed youth.

The fear of stigmatizing homosexual men by linking them too closely to HIV, which was a concern for some gay men in the early stages of the epidemic, has been replaced by a frightening silence, whereby most national and international organizations working on HIV/AIDS are unwilling to even acknowledge homosexuality. In Japan, there is much talk of "young people" at risk of HIV, but little acknowledgment that many of these are young homosexual men. To always speak of HIV transmission through heterosexual intercourse without recognizing that many men will engage in sex with each other is to send the very dangerous message that homosexual intercourse is without risk. The Hong Kong Advisory Council on AIDS has recognized the need to address silence about homosexuality in schools, health care settings, and within governments as an integral part of HIV prevention. In the west, gay communities pioneered responses to HIV, particularly the development of safer-sex programs that are still relevant to most societies and populations today. Equally, as one Australian drug worker pointed out: “It was us, individually and collectively through our organizations, who developed the educational messages, trained the peer educators, taught each other safe injecting techniques, and passed on the equipment and information from person to person.”

This does not mean that we can speak of all vulnerable groups as if they resembled gay men or drug users in rich western cities. There is a political and conceptual problem in lumping together very different groups into the category of “vulnerable populations.” Where people can organize around particular identities this can be the most powerful force for prevention and action against stigma. The history of AIDS demonstrates this was true for gay men and hemophiliacs in western countries, for sex workers in groups across the developing world, for people living with or close to those with HIV, and in major social movements like TASO [The AIDS Support Organization] in Uganda or South Africa’s TAC [Treatment Action Campaign].
Some of the greatest bravery in this epidemic has come from people who have confronted the double stigma of their identity and their seropositivity, creating the community organizations without which many of you would not be at this conference. Today, their legacy is carried on in groups like the Global Network of People Living with HIV/AIDS (GNP+) and the International Community of Women living with HIV/AIDS (ICW), in organizations of sex workers, homosexual and transgender men, and drug users, who through asserting their basic human dignity and right to expression are also creating models for HIV work. As we were organizing the regional conference AIDS in Asia and the Pacific Congress in Melbourne in 2001 — held in the shadow of 9/11 — we were inspired by the bravery of young homosexual men in Lucknow, India, who were harassed and imprisoned by local authorities as they sought to provide basic information and resources for safe sex to homosexual men in Uttar Pradesh. Also in India is the extraordinary sex-worker cooperative known as the Durbar Mahila Samanwaya Committee, which seeks to empower sex workers to protect themselves and their dependents from HIV infection.12 There are examples of great bravery from people who have set up needle exchanges and done outreach work for drug users on the streets of cities ranging from New York to Beijing, risking police and government persecution and intimidation.

Just prior to this International AIDS Conference, there was a regional ministerial meeting in Bangkok devoted to AIDS, at which there was only very token participation by representatives of affected and infected communities — and that only after considerable pressure on the organizers. The lessons from countries as far apart as Brazil and Uganda, that policy work demands the full participation of infected and affected communities, seems to have been forgotten by our governments.

**What Are Good Structural Interventions?**

These include legal and social regulations that take as their starting point improving the quality of life, health, and citizenship for all. As in other areas of HIV/AIDS, Brazil stands out, with its combination of governmental and non-
governmental programs aimed at linking treatment and prevention, its willingness to promote condoms and clean needles, and the launching of a government-sponsored plan called Brazil Without Homophobia. Earlier, Brazil proposed a resolution at the United Nations Commission on Human Rights — unfortunately postponed — against discrimination based on sexual orientation.

There is growing tension between evidence-based public health and denial of that evidence, fueled by a bizarre combination of religious and ideological pressures, which often see the United States and some of its bitterest opponents united in their support of repressive legislation. This is clearest in the area of drug use. Countries such as Switzerland, the Netherlands, and Australia contained the spread of HIV in IDU populations through the early introduction of needle exchange and harm reduction. Yet this lesson is still disputed by the United States and most Asian governments, with the result that the use of injecting drugs in parts of Asia and Eastern Europe is fueling the epidemic in alarming proportions. Even in Thailand, a country many of us have long admired for its responses to HIV, the recent crackdown on drugs has greatly increased vulnerability of users to HIV. I congratulate Prime Minister Chavlit Yongchaiyut for coming close to acknowledging this in his opening remarks. Thailand might look to Portugal, which has moved to remove users from the criminal justice system, itself one of the greatest factors for harm, and has registered a corresponding decline in needle-related HIV infections.

In most countries, there are ongoing restrictions on the discussion and promotion of condoms, on sex education in schools, on recognition that homosexuality and sex for money are realities in every complex human society. Often the most significant structural interventions possible are those that remove barriers to honest discussion of human behavior. If the choice is between maintaining the demands of ancient religious superstitions — and with them the power of male clergy — and providing the information and the resources to protect young women and men from infection with a potentially lethal and painful virus, can anyone
who seriously believes in a just God, or a system of ethical standards, seriously doubt the answer?

Good interventions support genuine choice and protect people in the choices they make. In the case of sex work, this means action against the enforced recruitment of women and children into prostitution, often with the involvement of government, business, and military officials. Sex workers need genuine alternatives to prostitution as a means of livelihood, while simultaneously protecting those who survive through working in the sex industry. Extending workers rights, as is the case in some European countries and has been proposed recently by a Thai Senate committee, might be the most significant structural intervention in some cases. So too are 100% condom programs, but only when they involve sex workers themselves in the design, as has been claimed of several projects in the Dominican Republic.16

Good structural interventions will acknowledge the presence and human dignity of people who live outside conventional expectations. Often this involves the provision of safe spaces for people whose behaviors put them at risk from both state and non-state violence. Such policies would include the provision of safe spaces for injectors, as exist in Switzerland; safe street areas for prostitution; or community drop-in centers for those who identify as homosexual, as provided by the Humsafar Trust, with city and state support, in Mumbai, India.

Because effective interventions empower and remove stigma, effective interventions uphold human rights. Further, they increase the likelihood that people will do what they can to protect themselves. An empowered sex worker or drug user is more likely to find alternatives than one who is criminalized and stigmatized.

We need to think imaginatively and act boldly. In countries like the United States and Russia, where prisons are incubators for HIV, reducing the number of people imprisoned would be a very effective way to reduce the spread of HIV. In many parts of the world, only a radical shift by organized religion, and a willingness to accept that safeguarding life is more important than preserving antiquated moral precepts,
will bring the resources and the messages about safer sex to those who are most vulnerable. Moves to remove the criminal sanctions against and persecution of homosexuals and sex workers are crucial to achieving the goals of slowing HIV infection. In most of Britain’s former colonies in South and Southeast Asia, in Africa, and the Caribbean, homosexuality is criminalized because of British laws, which have been retained on the books by governments who simultaneously boast of their opposition to colonialism.

Theoretical discussion IS relevant to finding empirical solutions. As Jonathan Mann often said, how we think about and frame the question will help determine the answer. Not nearly enough attention is paid at these conferences to analyzing the barriers that religion, politics, and human hypocrisy erect against effective programs of HIV prevention. In the end, the great issues that demand research and action are political questions, in that they involve issues of power, control, and ideology.

As the epidemics grow, we have many reasons to be angry, particularly at the hypocrisies of most governments and most religious leaders. Indeed, we are so unwilling to confront these issues that we fall back on platitudes about “communities of faith,” ignoring the ways in which fundamentalists of all faiths perpetuate the gender and sexual inequalities that fuel the epidemic. We constantly hear rhetoric about leadership, rather than analyzing what it is we want leaders to do. But anger that is not supported by analysis, and that does not lead to action, is wasted and self-indulgent. As the world becomes more dangerous and uncertain, and political attention is increasingly focused on war and terror, how we respond to the challenge of halting the spread of HIV is a central test of human decency and human solidarity.

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