

## ***Rights Matter: Structural Interventions and Vulnerable Communities***

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### **Abstract**

This contribution includes a lecture delivered by Dr. Dennis Altman at the International AIDS Conference held in Bangkok, Thailand during the summer of 2004. Its main goal was to recognize Jonathan Mann for his commitment to the struggle against HIV/AIDS.

Jonathan Mann is probably best known for his work with the World Health Organization and the publication of the two volume book entitled AIDS in the World. In this address the concept of vulnerability is critically addressed in order to expose how risk behaviours are intimately linked to the environment in which they are manifested. Therefore, structural interventions that take into consideration this context are urgently needed. These structural interventions can serve to reduce the stigma surrounding HIV/AIDS and address the future of the epidemic without blaming those living with the virus.

*Keywords:* Acquired Immune Deficiency Syndrome; stigma; structural interventions; vulnerability.

### **Los Derechos Importan: Intervenciones Estructurales y las Comunidades Vulnerables**

### **Compendio**

Esta contribución incluye un mensaje hecho por el Dr. Dennis Altman en la Conferencia Internacional del SIDA llevada a cabo en Bangkok, Tailandia en el verano del 2004. Su objetivo principal fue reconocer a Jonathan Mann y su compromiso con la lucha contra el VIH/SIDA. Jonathan Mann es probablemente mejor conocido por su trabajo en la Organización Mundial de la Salud y la publicación de su libro de dos volúmenes titulado SIDA en el Mundo. En este mensaje el concepto de vulnerabilidad es críticamente abordado para exponer cómo las conductas de riesgo están íntimamente ligadas a los contextos en los cuales se manifiestan. Por lo tanto, intervenciones estructurales que tomen en consideración este contexto son urgentemente necesarias. Estas intervenciones estructurales pueden servir para reducir el estigma que rodea al VIH/SIDA y abordar el futuro de la epidemia sin culpar a las personas que viven con el virus.

*Palabras clave:* Síndrome Inmunodeficiencia Adquirida; estigma; intervenciones estructurales; vulnerabilidad.

### **The Context of this Contribution: An Editorial Perspective**

It will be evident to the reader that this contribution is significantly different than the others in this special issue. It does not concentrate on theoretical implications or specific research findings. Still, we understood it to be an invaluable asset to this journal due to its content and context. This contribution includes a lecture delivered by Dr. Dennis Altman at the International AIDS Conference held in Bangkok, Thailand during the summer of 2004. Its main goal was to recognize a man who committed his life to the struggle against HIV/AIDS.

Jonathan Mann is probably best known for his work with the World Health Organization and the publication

of the two volume book entitled AIDS in the World. Probably his most important work on a global perspective was speaking out loud about the implications of this epidemic. In his eyes HIV/AIDS was not only a biological threat, but a social epidemic of meaning. He called this the "third epidemic" which would cause of marginalization, poverty, discrimination and oppression of many who were already at a disadvantage in social hierarchies. Mann was clearly referring to AIDS stigma.

In this lecture, Dennis Altman focuses on the implications of Mann's perspectives and ideas for the development of interventions to address this "third epidemic". Structural interventions are an effective way of understanding the implications of HIV/AIDS from a perspective that does not blame or stigmatize those that are living with the virus. Due to the importance of Jonathan Mann's work for AIDS stigma, and the importance of developing structural interventions to address this epidemic, we have included this lecture in the special issue, and hope that it generates even more reflections on the topic of stigma eradication.

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My original invitation to deliver this address specifically spoke of interventions for ‘MSM<sup>4</sup>, IDU’s<sup>5</sup> 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 recognise that some groups, because of particular behaviours, are particularly vulnerable to HIV infection. But this assertion makes two problematic assumptions. One is that we assume people can be neatly divided by behaviour into discrete and identifiable groups. The second is that everyone has the knowledge and the resources to make free choices, whether this be 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 (AIDS in India, 2004).

If there is one comment which 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 protecting rights for their own sake” (Mann, 1988). As the founding director of the Global Program on AIDS, Mann led us to understanding the link between health and human rights. His work lives on through the journal, *Health & Human Rights*, through the Boisrouvray Centre at Harvard University 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 basic concept of human security, and the worst excesses of the past decades (eg. Rwanda/Cambodia/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 as surely as will the bombs of terrorists. Yet the resources provided to check HIV/AIDS are miniscule in comparison to those being put into fighting terror.

#### *Who are 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 *kathoe*, *waria*, *hijra* (eg. Boellstorff, 2002; Jackson, 1997), to take three examples from this part of the world (Asia), 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 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 stigmatise the most dispossessed, and increase their vulnerability. In general the more socially and economically marginalised 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. This argument is developed in a paper that the AIDS Society of Asia and the Pacific will release later today (McNally, 2004). Unlike failure to access 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,

<sup>4</sup> MSM = Men who have sex with men.

<sup>5</sup> IDU’s = Intravenous drug users.

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 recognise vulnerability to HIV goes far beyond individual choices and behaviours, acknowledging that such behaviours are products of larger environmental factors (Parker, 2002). 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 NGOs and community groups.

Imagine a child, living on the streets in the slums of Rio, Dacca, 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 thirteen 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 make shift 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.” (Farmer, 2003, pp. 40)

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 Behaviour*

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 behaviour and of the poverty and despair that underlies that behaviour. There is a critical difference between concepts of ‘risk’ and ‘vulnerability’ (Aggleton, Chase, & Rivers, 2004), but also between behavior and identity. 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 (Fraser, 1996).

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 behaviours I have been asked to address do not necessarily identify themselves in these terms. Sometimes we need name groups—and empower them. At other times we need understand that most people do not necessarily accept the terms of the HIV world and that they may be reached through other approaches (eg. through outreach to women or to street kids or to unemployed youth).

The fear of stigmatising homosexual men by linking them too closely to HIV, 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 acknowledgement that many of these are young homosexual men. To always speak of HIV transmission through heterosexual intercourse without recognising 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 recognised the need to address silence about homosexuality in schools, health care settings and within government as an integral part of HIV prevention (Smith, 2001).

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.” (Stafford, 2004, p. 2)

This does not mean that we can speak of all vulnerable groups as if they resembled gay men or users in rich western cities. There is a political and conceptual problem in lumping together very different groups into category of “vulnerable populations”. Where people can organise 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 haemophiliacs in western countries, for sex workers in groups across the developing world, for people living with or close to those with HIV, in major social movements like TASO in Uganda or South Africa’s TAC.

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 organisations without which many of you would not be at this Conference. Today their legacy is carried on in groups like 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 organising the last regional AIDS in Asia & the Pacific Congress (ICAAP) in Melbourne in 2001—a conference 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 (Thekaekara, 2004). 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 the 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 organisers. 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?

Good structural interventions 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 sexuality.

There is growing tension between evidence based public health and denial of that evidence, fuelled by a bizarre combination of religious and ideological pressures, which often see the United States and some of its bitterest opponents unite in their support of repressive legislation. This is clearest in the area of drug use. Countries such as Switzerland, the Netherlands and Australia contained spread of HIV by intravenous drug use (IDU) 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 IDU in parts of Asia and Eastern Europe is fuelling the epidemic in alarming proportions. Even here 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 the Prime Minister for his opening remarks, which came close to acknowledging this. 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 (Van Beusekom, Van Het Loo, & Kahan, 2002).

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 behaviour. If the choice is between maintaining the demands of ancient religious superstitions—and with them the power of male clergy—and proving 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, as has been claimed of several projects in the Dominican Republic (Kerrigan et al., 2003).

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 behaviours put them at risk from both state and unofficial 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 centres for those who identify as homosexual, as provided by the Humsafar Trust, with city and state support, in Mumbai.

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 stigmatised.

We need 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 organised 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 boast of their opposition to colonialism.

Theoretical discussion is relevant to finding empirical solutions: how we think about and frame the questions will help determine the answers. Not nearly enough attention is paid at these Conferences to analysing 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 epidemic grows 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 analysing 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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