

Abstract

This article focuses on the centrality of human rights to an effective response to HIV/AIDS. At a time when advances in medical therapy are changing perceptions about AIDS, the synergy between prevention and care which is possible in non-stigmatized situations is underlined. Examples in the Asia Pacific region of how this happens among marginalized groups, even with very sensitive issues like injection drug use and sex work, are cited. These examples show that respect for rights lead to empowerment, which enables individuals to make informed choices and act accordingly. These actions are not confined to risk reduction alone, but address how to deal with discrimination, the removal of stigma, and the building of the social and cultural fabric of once-marginalized communities. Finally, key elements to effective prevention and care are identified, recognizing that protection of human rights is the only climate in which this is possible.

Cet article traite de la centralité des droits de la personne dans l'efficacité de la lutte contre le VIH/SIDA. A une époque où les percées en matière de thérapie changent la perception du SIDA, la sinergie entre la prévention et les soins ainsi rendue possible dans des situations non stigmatisés est mise en évidence. Des exemples sont empruntés à la zone Asie-Pacifique pour des groupes marginaux, y compris dans des situations très critiques comme le recours à l'héroïne ou à la prostitution. Ces exemples montrent que le respect des droits permet la responsabilisation qui conduit les individus à prendre des décisions en connaissance de cause et à agir en conséquence. Ces actions ne traitent pas seulement de la réduction des risques mais portent également sur la discrimination, l'effacement des stigmates et la reconstitution du tissu social et culturel des communautés auparavant marginalisées. Enfin, des éléments clé d'une prévention efficace sont identifiés, dont la protection des droits de la personne qui constitue le seul environnement dans lequel sont possibles la prévention et les soins.

Este artículo trata de la centralidad de los derechos humanos en una respuesta eficaz contra el VIH/SIDA. En una época en que los avances en la terapia están cambiando las percepciones sobre el SIDA, resalta la sinergia entre la prevención y la atención que se consigue en situaciones no estigmatizadas. Se citan ejemplos de cómo esto sucede en grupos marginalizados de la región del Pacífico asiático, incluso en casos tan susceptibles como la inyección de drogas o el trabajo sexual. Estos ejemplos muestran que el respeto de los derechos conduce a un fortalecimiento que permite a las personas tomar decisiones informadas y actuar en conformidad. Estas acciones no se confinan a la reducción del riesgo, sino que se aplican a cómo se maneja la discriminación, la eliminación del estigma, y la construcción del tejido social y cultural de las comunidades que estuvieron marginalizadas. Al final se identifican elementos clave para una prevención eficaz, incluyendo la protección de los derechos humanos como la única esfera en que la prevención y la atención son posibles.

MOVING FORWARD
THROUGH COMMUNITY RESPONSE:
Lessons Learned from HIV Prevention
in Asia and the Pacific

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This article focuses on some examples of HIV/AIDS prevention programs in Asia and the Pacific that will bring out the critical elements of the quality of our collective responses to HIV/AIDS using a framework based on almost a decade of my own personal engagement with the issue.

My experience with HIV began specifically in working for sex workers in a pilot prevention project in late 1988 as part of a team led by medical professionals. It started with the provision of information on STDs and AIDS, and telling sex workers how HIV is transmitted and what to do to avoid it. It did not take long to realize that providing information alone did not work because it failed to address the complex issues that give rise to vulnerability. Hence, my involvement shifted from working *for* to working *with* and learning from diverse communities in the Philippines and in other countries in the region. I learned in very real and practical terms that the movement from "working for" to "working with" reflected a paradigm shift from one focused on interventions from the "outside" alone to a broader-based belief and con-

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viction that the key to an effective response to HIV is firmly rooted in the capacity of the people who are most affected.

At a time when advances in therapy are changing perceptions about AIDS, it is worth underlining the continuing synergy between prevention and care. This synergy is made possible in non-stigmatized situations that guarantee the rights and dignity of everyone. Communities cannot provide effective care for individuals if their basic rights are denied. Therefore, in addition to focusing on the pivotal role of affected individuals and communities, this article will draw attention to the centrality of human rights in the prevention and care continuum.

It may not be immediately obvious to everyone, but across the globe, behind the excuse of diversity used by cultures and systems to mask their inaction, it is the already disadvantaged and the marginalized who are overwhelmingly the most affected by HIV. Unless we begin to address the very situations they live and work in, we will always be several steps behind this epidemic. In reviewing the literature on interventions aimed at stopping the transmission of HIV, it becomes clear that the most effective responses to date are those that are anchored in the respect for individuals and the promotion of human rights at all levels.

In real life, HIV/AIDS prevention and human rights protection feed off each other; they are truly symbiotic. The sad fact is that people living with HIV and other marginalized groups are often denied many of these basic rights, therefore rendering prevention efforts less effective or even ineffective.

Human rights in the context of HIV prevention can be understood to focus on the freedom to choose and to assume responsibility. Choice means having knowledge, skills, options, and the means to carry out a decision to protect oneself and others. It is hard to expect, or even imagine, that people who have been marginalized, and whose rights to information (among others) have been taken away, can act on life-saving information or act "responsibly."

Prevention efforts assume that cases of HIV infection must be averted. This may imply focusing on a person who is considered to be at higher risk or vulnerable to infection. A simple way of looking at prevention can therefore be characterized as a focus on the modes of transmission on this indi-

vidual level. But in the real world, infection does not happen in a vacuum. It happens in a relationship, that is:

- every individual in this world interacts with his or her sexual partner;
- every individual is influenced by the kind of peer support available to them which is rooted in the community they belong to; and
- every individual acts within the constraints of their social, political, and economic structures.

Background

Two years ago, at the 1995 International Conference on HIV/AIDS/STDs in Asia and the Pacific in Chiang Mai, Thailand, attention was focused on Thailand's successes in responding to HIV, particularly its government's 100 percent condom strategy, as well as the emerging issues of care for the growing number of people with HIV. Even then, Justice Michael Kirby reminded us of the essence of prevention when he eloquently pointed out that the most effective strategies which promote reduction of the spread of HIV involve the adoption of laws and policies that protect the rights of the people most at risk of infection.

But lately, much public attention and interest in prevention has been side-tracked by a growing perception, fueled by media speculation, that perhaps the AIDS crisis will soon be over because of treatment advances, particularly combination therapy, or the "new cocktail" announced at the 1996 International Conference on AIDS. Let me be clear: this is still far from the truth, still far from the reality that we face in Asia and the Pacific, and indeed worldwide. In fact, it only highlights a deepening gap between rich and poor within societies and between countries.

While these new treatments have brought hope to many and have led to improving the quality of life of people living with HIV in several communities, combination therapy is not going to reach the vast majority of people now living with HIV. It is extremely dangerous and irresponsible to think that we have heard the last word about AIDS and that we can forget about prevention efforts at the individual and political levels.

Trends

Since the start of this decade, many communities and countries in Asia and the Pacific have been flagged as the emerging epicenters of the epidemic. The Asia Pacific region has the whole array of old and new stages of the epidemic. Countries such as India and China, with their enormous populations, could experience a dramatic impact if their HIV infection rates are left unchecked. What these different country scenarios show is that “contrary to popular belief, no ‘one group’ of people is intrinsically more vulnerable than another. It all depends on where you live, and at what stage the epidemic has reached.”¹ It is critical to realize that:

- we are dealing not just with a single epidemic but multiple epidemics at any given time and place;
- there is considerable uncertainty about the exact extent, course, and impact of the HIV epidemic for a number of reasons; and
- by themselves, not one of the diverse explanations and models is adequate to explain the spread of the disease or to use as the basis for response.²

Successful Responses: What is Being Done?

Some examples of successful prevention responses in the region reveal the importance of the contextual issues that place people in vulnerable positions. This recognition gives rise to the following questions:

- How are we responding to the epidemics?
- To what extent are communities and those most affected by HIV/AIDS involved in the response?
- What importance is attached to the underlying social, economic, and cultural determinants?
- How pivotal are human rights in that response?

The approach taken by the Sonagachi project in India may serve to illustrate how contextual issues can be incorporated into program design. Sonagachi has demonstrated that even in the face of extreme poverty, stigma, and other factors that contribute to powerlessness, significant breakthroughs which assist the individuals involved are possible.³ Sonagachi

has described how it shifted from research to a well-integrated community development approach.⁴ It documents that the recognition of sex workers as a professional group was crucial to encourage sex workers to gain some measure of control over their lives. This, in turn, led to an improvement in their working conditions by addressing the social and economic needs that go beyond the medical, beyond HIV and STDs, such as non-formal education for their children; the formation of their own cooperatives which provide legal training; and the capacity-building of the women to negotiate with their clients.

Freedom from the fear of violence and the attainment of better working conditions undeniably help sex workers to be more assertive. Breaking the cycle of despair and providing women with choices and the skills to carry out these choices are further exemplified by other efforts in the region. For example, USHA, a credit cooperative for sex workers, unionized 17,000 sex workers in West Bengal in order to transform the discriminatory practice of violating the privacy rights of HIV-positive sex workers. This was done by applying pressure on the government, researchers, and the media to be more responsible in their portrayal of sex workers in relation to HIV. Another example is Empower, a local NGO in Thailand, which has worked in several sites in the country for the enforcement of laws dealing with workers' rights, literacy, education, and other health-related and economic skills.

To do justice to this topic, one must also cite the successful programming found in Australia, particularly as undertaken by the gay community. Central to their prevention strategies has been a focus on the fundamental human rights of non-discrimination, equal protection, and equality before the law. As the epidemic emerged in the early 1980s, gay men, a marginalized community, bore the brunt of the pain, loss, and discrimination. Since then, the gay community has worked in partnership with other communities, incorporating a strong human rights component into their prevention activities. The rights of gay men and lesbians in Australian society are now firmly rooted, and their communities are vibrant and effective leaders in the fight against AIDS.

The lesson to be shared from these experiences is both complex and simple: when communities have their rights

respected, they are empowered; when communities are empowered, they are able to act and to make informed choices. In short, the gay communities and organizations of sex workers in many countries have been critical to the prevention of HIV/AIDS. They have done this not by concentrating only on reducing risk, but by continuing to deal with discrimination and the removal of stigma, and helping to build the social and cultural fabric of their once very marginalized communities. This has been done by participating side by side with others to influence policies and programs that make prevention work.

Injecting drug use, another sensitive issue, is also fueling the epidemic in many of our communities in Asia and the Pacific, both through the sharing of unsterile needles, and through sexual transmission from HIV-infected drug users to their sexual partners. While prevention programs have often failed to effectively address these issues, there are examples of effective prevention approaches and programs in the region targeting injection drug users. Projects in Nepal, Thailand, and northeast India have successfully documented that injecting drug users can be reached through interventions and that a reduction in risk behavior is feasible, especially if they themselves are involved in program planning and implementation. This is exemplified by an extraordinary needle exchange program run by users in Calcutta, and the Sharan program, also in India, both of which show that opiate substitution can work.^{5,6}

However, sustainability of these community efforts is constantly threatened and undermined as they face the dilemmas of continued political support. For unlike Australia, Nepal and other countries in the region do not have the legal and political environments to protect freedom of choice and access to prevention. But there are positive changes taking place. Some governments are learning that prevention programs need to acknowledge drug use in their communities and that prohibitive and criminalizing measures will not make drug use disappear. Both the state of Manipur in India and the national government of Vietnam are beginning to squarely address the factors that fuel their respective epidemics. By openly taking on harm reduction, they are showing

leadership in how to locate human rights in the response to HIV.

In addition to the central role that respect for human rights plays in the prevention of HIV/AIDS, the role of care and support of affected communities also needs to be acknowledged.

Current care and support programs for various groups, including people living with HIV, range from running hotlines to drop-in centers, from safe houses to “buddy support,” just to name a few. Even in limited and constrained settings—be it in Myanmar’s drug rehabilitation centers, or in slum communities across the region where the Salvation Army works—peer and family support programs are critical to supporting individuals who are vulnerable and at risk. Central to these support programs is the role of communities and the community-based movement. There is a need to support communities organizing by and for themselves. To prevent further transmission of HIV, we need to work with those who are now infected. This highlights specifically the role of people living with HIV/AIDS in two major areas: 1) in models of comprehensive care for people living with HIV and AIDS and their families as the link between prevention and care; and 2) in models of self-help and advocacy.

An example of comprehensive community care is the effort covering rural villages in northern Thailand run by CARE whose key strategies are focused on strengthening community participation and ownership, as well as integrated programming. Their experience has shown, for instance, that training for the provision of care and psychological support is not enough until the agencies involved develop clear policies against discrimination.⁷ Only when communities truly experience HIV in their midst and participate in the care of those infected will they have embraced the problem, and be able to add to the collective knowledge necessary to effectively think about, and act on, HIV prevention.

Our prevention efforts need to ensure that people living with HIV and AIDS are able to take measures to protect their own health and can learn to change their behaviors to protect not only their sexual partners but also other members of the community.

In 1991, GIPA, the Greater Involvement of People Living with HIV/AIDS and Community-based Groups Initiative, called upon governments to recognize the central role of people living with HIV and AIDS (PWAs) and community-based groups in the design, development, implementation, and evaluation of programs and policies that affect their lives. While there appears to be a common understanding that affected communities have a crucial role to play in mitigating the impact of the epidemic, an overview of the region shows that very little attention has yet been given to providing deliberate support to self-help groups of PWAs.

The Philippines provides one positive example, in that the inclusion and support for participation of PWAs now exists in the national policy advisory body to the Office of the President, and ongoing partnership building is occurring with Philippine legislators and the National Commission of Human Rights to ensure that human rights of affected communities are affirmed and protected. There is also movement in Bangladesh, where the state recently approved a National AIDS Policy based on a human rights framework as a result of extensive consultations that included government, NGOs, and the private sector.

Care and support anchored on human rights are integral to prevention efforts, but emerging also is the need to consider the role of networks and the need to build partnerships that incorporate community action with government action. The size of the Asia Pacific region, with its diversity, and widely distributed pockets of "multiple epidemics," still shows that while many of the effective responses have been led by the community, they remain scattered and fragmented across the region. To achieve greater impact, partnerships have to be forged. Networks and partnerships can increase the effectiveness of HIV/AIDS work through:

- ensuring that lessons learned are shared, thus widening the impact of HIV/AIDS work;
- influencing structural barriers;
- ensuring sustainability of work by gaining long-term support; and
- offering mutual support when the going gets tough.⁸

Fortunately, the HIV/AIDS community has not hidden behind the excuse of diversity; we have instead used our common goal to find ground for mutual support. Prevention projects and programs are successful when individuals have a network that will support them. When you mix clear and honest information with the promotion and protection of human rights, and add into the equation the power of a mobilized community, the impact is extraordinary. If they are to succeed, we need our prevention programs to be rooted deeply and firmly in the community. Country and regional networks such as the Asia Pacific Council of AIDS Service Organizations (APCASO), the Asia Pacific Network of People Living with HIV+ (APN+), and the Asian Harm Reduction Network are demonstrating that the cycle of isolation that leads to paralysis rather than action can be broken. It is through the solidarity of community partnerships that partnerships with governments are possible and that strength is gained.

Conclusion

The AIDS pandemic is now nearing the end of its second decade. Those of us involved in trying to address the sheer enormity and diversity of its impact in the region and throughout the world have sought to bring some coherence to our work, to ground it in frameworks which guide our actions, and to offer hope through responding collectively and effectively.

In summary, the key elements required for us to continue to deal effectively with the HIV epidemic are:

- to work with groups and individuals most affected by HIV/AIDS from the very start of any program;
- to look closely at how to integrate empowerment, care, and support in prevention efforts;
- to build capacity and support for communities affected by AIDS;
- to mobilize political will for change to happen; and,
- finally, to ensure protection of human rights, the only climate in which prevention is possible.

Lisa Enriquez has said that AIDS is a "humanizing disease."⁹ Dealing with human lives, we can settle for no less than prevention programs which integrate these key elements. Increased political will is the crying need. But political will does not come only from the top. We need now to match the fire and passion of community action with the political passion and action of the state, a passion for human life based on dignity ensured by respect for rights, so that in partnership we can look forward to more celebrations of life.

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