



Issue Paper:
***Review and Assessment of HIV/AIDS Strategies that
Explicitly Include Attention to Rights
Prevention***

Defining the Issue:

This paper reflects on the association between human rights and HIV prevention and provides some illustrations of the way different actors have interpreted the notion of “human rights based approaches to HIV prevention”. In order to do so, it begins by summarizing current thinking and practice in HIV prevention, and then associates that thinking to “human rights based approaches.” Examples are then given of prevention approaches seemingly consistent with human rights; prevention approaches that more explicitly conform with the recent UN system “common understanding” on human rights based approaches (HRBA); and finally prevention approaches that clearly violate HRBA.

How does the world understand the process of HIV prevention?

In the beginning, HIV prevention was a fairly simple notion, born on an unlikely marriage between CDC epidemiologists and American gay community activists. The epidemiologists convincingly argued that HIV/AIDS cases were linked through sexual networks and therefore, probably sexually transmitted; the activists (by and large) fought to defend their relatively new-found “right” to sexual expression by promoting “safe sex” within their community – primarily by promoting condom use. It didn’t stay that simple for long.

From the mid-1980s until today, and undoubtedly for some time to come, the theories and practices of HIV prevention have been terrains for a wide variety of practical, scientific, moral and ideological battle. Epidemiological and social analysis, programme practice and evaluation have sometimes informed each other and sometimes posed direct challenges to each other. Just as relevant for this paper, the contested terrains of HIV prevention (and its failures) have both influenced and been influenced by broader academic and ideological spheres, including thinking not just about health and human rights, but also about epidemiology, health promotion, communication, social capital, the association between socio-economic status and health, liberal versus conservative approaches to health-related law, and so on.

Despite all these debates, it is not unreasonable to assert that there is now a reasonable amount of common ground shared by most analytical HIV prevention paradigms, in particular the acknowledgement of multiple, interacting causal factors influencing the spread of HIV:

- The social or environmental influences of risk – that is, the combination of gender roles and power, violence, economic inequity and poverty, stigma (around HIV, sexuality, sexual minorities and/or drug use), discrimination, and so on. These may be understood primarily at a community level, at a national level, as a global phenomena, or some combination thereof.
- The biological influences of risk – including the date HIV first entered a population network, the date an individual was infected and his or her subsequent viral load, the prevalence within a population of other bacterial STIs, the prevalence of male circumcision, the nutritional and immunological status of the population, and so on.

- Individual or behavioural risk – including specific sexual practices, number of sexual partners and rate of partner change, sharing of needles and syringes, breast-feeding and weaning patterns, treatment-seeking behaviour in response to STIs (or lack thereof), and so on.

“HIV prevention” typically (though by no means always) involves some form of social and epidemiological analysis to identify opportunities and priorities for intervention, followed by policy and/or programmatic “interventions” to try to influence one or more of the sets of risk described above.¹ These interventions range from promoting ‘leadership’ to promoting the African potato, from eroticizing condom use and making it “macho” to challenging gender roles and stereotypes, from public pledges of virginity amongst 16 year old boys to skills building for sex workers in how to get clients to ejaculate whilst avoiding penetrative sex.

What is the association between human rights and HIV prevention?

Early in the history of the epidemic, some gay North American men and some Africans saw HIV prevention as an infringement on their “right to have sex” (obviously a lay understanding of rights rather than a legalistic one, but still relevant).²

Within the world of HIV prevention itself, human rights concerns were soon cited out of a fear that repressive, coercive or discriminatory approaches would “drive risk groups underground” and thus beyond the reach of HIV prevention efforts.³

In the United States, a social movement of self-identified people living with AIDS (PWAs) emerged as early as 1985, appropriating much of the language of “gay rights” into both a call to “come out” and a demand to duty-bearers that their human rights as PWAs be respected.⁴

Within a few years these calls had converted prominent advocates including Dr Jonathan Mann (head of WHO/SPA and then WHO/GPA) and Justice Michael Kirby, Justice of the High Court of Australia, who crucially linked these calls to prevention, arguing that “one of the most effective laws we can offer to combat the spread of HIV is the protection of persons living with 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 the epidemic we must protect the infected too.”⁵

Mann especially, to some degree his colleague Daniel Tarantola, and others (including this author and the Chair of this Reference Group), began to go even further in their arguments in the early 1990s. Mann proposed a very strong causal relationship between human rights violations and the spread of HIV, in turn arguing that the prevalence and severity of human rights abuses could be used to largely predict the future spread of the epidemic, and that the protection and promotion of human rights was perhaps the single most important preventative intervention.⁶

This human rights centred approach had its share of sceptics, particularly amongst established epidemiologists. Nevertheless, the analysis and its rhetoric became common currency in the 1990s throughout both the AIDS activist world and many AIDS-focused international co-operation specialists working in institutions such as UNAIDS, bilateral co-operation agencies and international NGOs. Moving from analysis and rhetoric to policy was sometimes straightforward (for example, in resisting proposed legislation that would violate rights or sometimes even overturning pre-existing laws and regulations that violated rights).

Moving from analysis and rhetoric to programme practice proved much more difficult, however.

A good example of the limitation of the approach in practice comes from Bangladesh in the mid-1990s, when HASAB (a local HIV/AIDS NGO support programme) promoted the use of human rights analysis to identify vulnerable populations and prioritize interventions. While some might argue that either the analytical tool they used or its execution was inadequate, it is interesting that the vast majority of community actors involved ended up prioritizing prevention interventions for rural girls and women, or urban slum dwellers, as these two population groups were seen as the most susceptible to the largest number of human rights violations. Only a very small number of groups concluded that their work should focus on sex workers, and none at the time focused on injection drug users or MSM – the groups that not surprisingly became the first to be affected by HIV.

Some current examples of “human rights based approaches to HIV prevention”:

Prevention programmes that happen to be consistent with human rights

It is reasonable to assume that the overwhelming majority of effective approaches to HIV prevention (in public health terms) are at least consistent with relevant human rights norms, and (essentially by definition) contribute to the progressive realization of the right to health. Many also contribute to furthering other internationally acknowledged rights, whether or not this is intentional.

There are many examples. Relevant interventions to reduce social and environmental risk (often called “structural” or policy interventions) include provision of HIV and sexual health education in schools and out of schools for young people; reducing the important duties and therefore the cost to end users of condoms, STI drugs and HIV drugs; including people living with HIV and other representatives of key communities in strategy development and policy oversight bodies; and so on. Examples of relevant interventions to reduce behavioural risk include ensuring the promotion and availability of condoms and needle & syringe exchanges in prisons; special efforts to provide sexual health services to underserved migrant populations; provision of responsive family planning services to women living with HIV as a means of reducing HIV infection of newborns; and so on. Similarly, any effort to promote and provide STI diagnosis and treatment services, or HIV treatment (and therefore viral load lowering), especially when such efforts make special efforts to recognize and respond to the needs of minorities and the marginalized, are arguably both biological risk-reduction and human rights based approaches.

Prevention programmes that are more deliberately human rights based

The UN system’s 2003 “common understanding” of human rights based approaches to development cooperation amongst UN agencies⁷ implies a more ambitious test of what it means to be “human rights based” than the examples cited above. How easy is it to identify HIV prevention practices in the field that are rights-based using this more ambitious or precise criteria?

The author is not familiar with any single HIV intervention or defined set of interventions currently underway that could be characterized as (1) intentionally furthering international human rights (especially the UDHR); (2) guided by human rights standards and principles; and (3) committed to capacity building of ‘duty bearers’ and/or ‘rights holders’. Several programmes come close however:

- The International HIV/AIDS Alliance's Frontiers Prevention Project (FPP) is designed around a notion the Alliance calls "empowerment for prevention". It does not fit the full definition of the UN Common Understanding framework because it does not intentionally further international human rights. However, its identification of priority populations (key populations) is based on both HIV epidemiology and rights analysis (focusing on sex workers, MSM and IDUs in five countries with concentrated epidemics); in addition to providing "standard" IEC/BCC programmes and related STI/HIV services (STI diagnosis and treatment, condom promotion and distribution, VCT, and in some cases HIV care). The intervention package also includes a great deal of attention to participatory community mobilization methodologies that are intended to both influence "social capital" within the key populations and bridging the these populations with their broader communities (arguably, paying more attention to being guided by human rights principles of participation than is the norm in health promotion and service delivery work). Finally, specific interventions are also included to support key populations to play a role in influencing and governing the service and programme delivery process, and in identifying and responding to community-level rights infringements, particularly by health services and police forces. What makes this programme of particular interest is that the evaluation framework also includes comparisons to a more "traditional" package (ie one without the empowerment, advocacy and GIPA components) in demographically matched districts, and this evaluation uses both behavioural and biological outcome measures. Interestingly, FPP also tries to address all three sets of risk factors (social, behavioural and biological) identified above.⁸
- A Brazilian attempt to adapt and update the Indian "Sonagachi" project⁹ to Rio de Janeiro provides another example that can be considered as deliberately integrating a rights approach. Three institutions collaborating together (Programa Integrado de Marginalidade, Fio de Alma and Sociedade de Estudos e Pesquisas em Drogadiccao) designed and implemented this "social capital" effort which, amongst other explicit goals, described their community mobilization process as "a right itself and a means for communities to claim their rights". Specific intervention packages at different sex work sites were designed by sex worker beneficiaries, but within a framework that was always designed to increase the prevalence of safe sex, improve health seeking behaviours, decrease the incidence of violence, and increase strategies for minimizing the impact of violence. Emphasis was also based on ensuring transparency between implementing NGO partners and the sex workers. Given the time frame, the project was not able to gather evidence to show whether interventions could actually "build" social capital (or increase rights protection and promotion). Crucially, however, evaluations showed that sex workers with higher rates of social participation and social inclusion, independent of other factors such as income, age and education levels, were significantly more likely to report consistent condom use with clients, had higher rates of health seeking behaviours, and a greater ability to avoid or to deal with the consequences of violence.¹⁰
- A third example, this time focused strictly on "policy intervention" rather than programme delivery, is an effort currently underway in Zambia to sensitize the judiciary to the gender dimensions of HIV risk and vulnerability, in the hope that subsequent legal decisions – especially in cases involving inheritance and sexual violence – will result more often in decisions that promote the ability of women to protect themselves from HIV infection. Unfortunately, no evaluation data is yet available on this programme.¹¹

The above programmes – especially the FPP and Brazil examples – are striking in that they try to address multiple dimensions of HIV risk with multiple strategies, including at least two of the three elements of the UN Common Understanding framework (being guided by human rights principles and capacity building of duty-bearers and/or rights-holders).

Prevention programmes that clearly violate human rights norms

It is also important to note that a small number of prevention programmes or strategies clearly violate human rights norms. Most often, these could probably be characterized as inadvertent violations, but there are cases where programme managers or implementers explicitly reject human rights norms in their designs or activities. Examples include:

- Some of the early efforts to adapt the 100% condom use policy from Thai to Cambodian brothels, where sex workers were forced to undergo regular STI tests with the participation of police;
- Programmes that refuse to offer sexual health and HIV information and services to minors, offering only abstinence promotion regardless of context;
- Recent Thai efforts (and earlier Nepalese efforts) to respond to HIV transmission through needle and syringe sharing by arresting and incarcerating injection drug users and shutting down harm reduction programmes.

In the vast majority of these cases, it is clear that the violation of relevant human rights (whether inadvertent or deliberate) clearly undermined the success of HIV prevention. Of particular interest are examples where violations or derogations of human rights may well be associated with effective HIV prevention, for example:

- The early Cuba policy of mandatory testing of returning soldiers and other population groups, accompanied by segregation and mandatory education;
- The potential with current technology to insist on mandatory HIV testing for an entire prison population, and the subsequent segregating of HIV positive prisoners;
- The mandatory HIV testing of identified rapists to enable victims to choose whether or not to utilize post-exposure prophylaxis.

Key Issues for Discussion:

Is it a useful starting point to first gather and synthesise evidence that shows that the vast majority of effective HIV prevention efforts are at least consistent with human rights, and that violation of human rights more often than not undermines effective prevention?

How possible – and how useful – is it to try to gather evidence that additional or special attention to human rights adds value to otherwise “standard” prevention approaches? Even if there is such a positive added effect, it is safe to assume that such efforts also promote other positive outcomes (in health beyond HIV, social justice, development and so on). A good example is the education of girls – which is a human right and clearly contributes to HIV prevention, but also contributes to reduced morbidity from diarrhoea, increased immunization, increased economic activity and so on. Are we trapping ourselves into the wrong cost-benefit parameters if we try to defend girls’ education as a rights-based HIV prevention intervention?

What political and public health analysis, legal and human rights analysis, rhetorical tools and case studies does UNAIDS need to respond to the examples of “healthy human rights violations”?

It is relatively rare to find HIV prevention intervention designs that are explicitly human rights based, and even rarer that they meet the definitions provided in the UN Common Understanding framework. Does that matter? Or is it more important to ask whether prevention interventions *consistent* with human rights are more likely to be effective than those that are not, and/or whether those prevention interventions that pay broader and deeper attention to a range of rights-related issues (eg participation, capacity building of rights-holders, etc) achieve stronger results than those that do not?

*This issue paper was prepared by Jeffrey O'Malley
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¹ It is worth noting that while single-intervention practice and research continues (including research regarding the "added value" and cost of adding one particular set of interventions to another), most practitioners now advocate some form of what Peter Piot labeled at the Geneva AIDS Conference (1998) as "combination prevention." Central to this notion is not only the idea that multiple risk factors should be addressed, but that action on multiple fronts is synergistic, or perhaps even a necessary prerequisite, to achieve HIV prevention.

² See circa 1982 copies of *The Body Politic* and the *New York Native*, and references in Africa to the "American Invention to Discourage Sex".

³ See Annex 1 "History of the Recognition of the Importance of Human Rights in the Context of HIV/AIDS," of International Guidelines on HIV/AIDS and Human Rights, UNAIDS/OHCHR, 1998.

⁴ Denver Declaration, March 14, 1998, Closing Session Of The National Gay, Lesbian & Bisexual Veterans Of America Conference, Denver, Colorado. See: <http://www.aver.us/pressrls/98-02.htm>.

⁵ Kirby cited in Heywood and Altman. *Confronting AIDS: human rights, law and social transformation*. Health Hum Rights. 2000;5(1):149-79.

⁶ J. Mann, D. Tarantola, *AIDS in the World*, T. Netter, Editors, [Harvard University Press](http://www.harvard.edu), 1992.

⁷ The Human Rights Based Approach to Development Cooperation - Towards a Common Understanding Among UN Agencies, United Nations Development Group, 2004. [<http://www.undg.org/>].

⁸ See Frontier Prevention Project, International AIDS Alliance: http://www.aidsalliance.org/res/research/FFP/Frontiers_Prevention_Project.pdf.

⁹ Cohen, HIV/AIDS IN INDIA: Sonagachi Sex Workers Stymie HIV, *Science* 2004 304: 506

¹⁰ P R Telles Dias, P Longo, H Torres, C Szterenfeld, C Castle, D Kerrigan. "Beyond health promotion: the role of community capacity building and social inclusion in reducing HIV vulnerability among Brazilian female sex workers" XIV International AIDS Conference, 2002 Abstract no. ThPeD7672. Barcelona

¹¹ O'Malley, Jeffrey. 2004. "Can this marriage work? Linking the response to AIDS with sexual and reproductive health and rights", Countdown 2015 Sexual and Reproductive Rights for All. New York: Family Care International.