Public Report

First Meeting

of the

UNAIDS
Global Reference Group
on
HIV/AIDS and Human Rights

January 23 – 24, 2003
Geneva, Switzerland

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I. Introduction

There is more than 20 years of experience showing that the promotion and protection of human rights is critical to mitigating the impact of the HIV/AIDS epidemic on peoples lives. However, the integration of human rights into HIV/AIDS work is increasingly under attack by governments and public health officials. The field is therefore now at an important juncture of it's history. There is a growing and crucial need for efforts that would highlight the effectiveness of the diverse ways in which the connections between HIV/AIDS and human rights are being understood and worked on. It is most critical to continue to keep abreast of and address current human rights issues in relation to HIV/AIDS. It is also essential to consider what is needed to collect the evidence of what has been effective; and to develop better ways to ensure that rights are genuinely integrated into the HIV/AIDS work happening within countries.

To help meet these goals, the Joint United Nations Programme on HIV/AIDS (UNAIDS) established a Global Reference Group on HIV/AIDS and Human Rights (Reference Group). This technical group has been put together to serve as an independent advisory body to UNAIDS, including Secretariat and Cosponsors and other organizations involved in policy, advocacy, programme development, implementation, monitoring, evaluation, research and training related to a rights-based approach to HIV/AIDS. In fulfilling its mandate, the Reference Group will liaise closely with other UNAIDS Reference Groups, namely, HIV/AIDS Estimates, Modeling and Projections; the International AIDS Economic Network; the Reference Group on Injection Drug Use; and the Reference Group on Epidemiology. The Reference Group will cover a wide range of topics including, but not limited to the following:

1. Stocktaking of standards and approaches to integrating human rights in the response to HIV/AIDS leading to a common methodology for analysis and terminology.

2. The development of rights-based indicators, including those to monitor HIV/AIDS risk, vulnerability and impact reduction.

3. The development of human rights and legal guidelines and methods to support countries in the design of national AIDS strategies, policies, and legislation.

4. The development of a strategic approach for integration of HIV/AIDS-related issues in UN human rights treaty bodies, charter-based bodies and other human rights mechanisms.

The first meeting of the Reference Group was held in Geneva on 23-24 January 2003, with the primary purpose of mapping current standards and approaches, highlighting the key impediments and opportunities, and identifying substantive priority issues for their future work to integrate human rights into HIV/AIDS. The discussions and recommendations are summarized in the following sections of the report.

II. Frameworks and Approaches in HIV/AIDS and Human Rights

Members noted that work in HIV/AIDS and human rights engages elements of advocacy; public education; community mobilization; litigation; normative guidance; policy development; public health programming; and implementation, monitoring, and evaluation. In discussing their work in these areas, members aimed to consider the degree to which their efforts were more focused on the integration of rights into HIV/AIDS programming, on advocacy, on legal standards, and/or on accountability.

The discussion elicited some common themes. It became clear that, although participants tend to work in a variety of ways to further work on HIV/AIDS and human rights issues, the frameworks within which they operate could be generally categorized into policy, programmatic, legal, advocacy, and bioethical frameworks. Each framework will be briefly summarized below.

Policy Frameworks:

This approach looks to institute human rights norms and standards mostly through global and national policy-making bodies responsible for HIV/AIDS from health, economic and development perspectives. One member described WHO's "corporate strategy" as an example of a shift from a theoretical commitment to human rights to operationalizing human rights work within an agency's individual programs and departments.

Programmatic Frameworks:

This approach is concerned with the implementation of rights in the programmatic responses to HIV/AIDS. This includes the design, implementation, monitoring and evaluation of HIV/AIDS programs (including what issues are prioritized and why), concerns with discrimination, and participation at every stage of the work (including the involvement of People Living with HIV and AIDS in every aspect of program implementation and evaluation).

Legal Frameworks:

A number of the presentations addressed the role of human rights law at international and national levels in producing norms, standards, and accountability in HIV/AIDS efforts. In describing their legal strategies, members noted that to ensure success, an organization must engage not only with law in the formal sense but address other approaches simultaneously, including capacity building within affected communities and advocacy. Continuity of efforts on a long-term basis was also recognized as vital. Several strategies were outlined.

- In some countries, building on the consonance between national law and international human rights norms, litigation has been used successfully to promote and protect the rights of People Living with HIV/AIDS. Members identified discrimination in relation to access to treatment as one of the main

areas where legal processes have been used successfully in the context of HIV/AIDS.

- Another successful strategy has been working with human rights structures within countries, such as national human rights commissions to bring HIV/AIDS concerns more substantially into their work.
- Working with and through the international human rights bodies and mechanisms (including the treaty monitoring process as well as other Charter based mechanisms) to promote the accountability of governments for their HIV/AIDS related actions, including ensuring human rights sensitive legislation relevant to HIV/AIDS.
- Finally, conducting research and analyzing the compliance of national law with international norms relevant to HIV/AIDS was also discussed, particularly the ways in which this analysis can help to identify entry points for action.

Advocacy Frameworks:

Advocacy was identified continuously as an important part of most organizations' work to promote human rights in the context of HIV/AIDS. Recognizing the importance in all advocacy efforts to package messages to get the greatest attention to specific HIV/AIDS and human rights issues, members described several areas of focus, each requiring different HIV/AIDS and human rights tools and strategies:

- Reaching out to policy makers and other influential groups.
- Linking with activists working on related issues (such as groups focused on violence against women, poverty and global trade issues).
- Translating international human rights norms to the work and concerns of local communities.
- Working within the paradox of the chain or web of rights (described in more detail below).
- Working from the bottom up in implementing human rights norms and standards.
- Supporting the organizing capabilities of People Living with HIV/AIDS.
- Building credibility with communities and organizations addressing various aspects of HIV/AIDS prevention, care and treatment, and impact mitigation.

Bioethical Framework:

Members recognized the relevance of this framework to work in HIV/AIDS and human rights, particularly in relation to instituting international guidelines for research via professional norm setting modes. This framework is often consonant with human rights norms even if this relationship is not explicit. The Group recognized that the similarities and differences between this framework and a human rights framework for strengthening protections in relation to HIV/AIDS work deserve further exploration.

III. Key Impediments and Opportunities in Advancing HIV/AIDS and Human Rights

Discussions raised the following issues which present both impediments and opportunities for work in HIV/AIDS and human rights. The concerns ranged from the very concrete to the very general, but it was agreed that all provide impediments and opportunities to be addressed in advancing an effective response.

The Declaration of Commitment:

Declaration of Commitment (DOC) was identified as having much potential to promote accountability at the national level, to initiate dialogue with diverse actors as an entry point, to mobilize groups at the national level, and to facilitate regional interaction.

Shortcomings in the content of the document were also addressed (for example, the ways that vulnerable groups are discussed in the document). The indicators being used to monitor compliance with the DOC were also discussed and the need to interact more with the process of monitoring compliance—both within UNAIDS and more generally.

Evidence:

Members repeatedly noted that the lack of evidence and documentation (whether epidemiological, social, or legal) of the value of integrating human rights in the response to HIV/AIDS is increasingly proving to be an obstacle in ensuring the integration of human rights in governmental and UN HIV/AIDS efforts.

Several members suggested that the collection and generation of such evidence is an opportunity that should be addressed. One member highlighted the burden being imposed on human rights activists to come up with this data and suggested a concerted effort to shift the burden of proof back on to the skeptics to demonstrate how promoting and protecting human rights has not been effective.

Rights-based Approaches to HIV/AIDS:

In attempting to implement human rights norms and standards in the response to HIV/AIDS, participants noted the lack of a unified understanding of what is meant by a rights-based approach to HIV/AIDS.

The different perceptions of the utility of human rights for HIV/AIDS work may in some part be connected to this lack of clarity and to the various and different approaches being grouped under the heading "a rights-based approach." A member also noted the futility of naming an abstract concept—a rights-based approach—in the field where the concepts may make sense even if not named as such. The Group thus saw a useful role in clarifying the different perceptions of what rights-based approaches mean to HIV/AIDS

work and advising UNAIDS on the types of activities it could undertake in supporting implementation of rights based approaches to HIV/AIDS.

UNAIDS and Cosponsor Guidelines, Tools and Methods:

Recognizing the value of the exercise to revisit Guideline 6 which took place on July2002, the Group determined that further consideration is needed as to whether the other Guidelines should be revisited, individually and to ensure coherence between them, as well as whether current and future tools, guidelines, and documents of UNAIDS and its cosponsors should be reviewed by the Group from a human rights perspective.

General Perceptions of Human Rights:

The Group noted that the lack of general understanding of human rights (what they include, what they do not, how they operate, etc.) is an impediment in bringing human rights into HIV/AIDS work. For example, the perception that some rights recognized as necessary for an effective response may be thought to conflict or compete with other rights. The members thus recognized the importance of working with UNAIDS (and its cosponsors) to clarify concepts, simplify language and collaborate with NGOs to raise awareness.

Stigma and Discrimination:

Stigma and discrimination were identified repeatedly as major issues hampering the ability of HIV/AIDS efforts. While the Group noted efforts to ensure attention to stigma and discrimination in global and national campaigns, it was recognized that increasing efforts are needed within countries to ensure, at a minimum, that legal protections exist in relation to a range of issues for People Living with HIV/AIDS (e.g. in relation to getting and keeping employment, access to education, etc.). Some members brought attention to the need also to address innate (personal and cultural) perceptions that translate into stigma and discrimination and highlighted the importance of applying human rights norms and standards to systemically overcoming the effects of stigma and discrimination.

The lack of clarity with regard to the differences between stigma and discrimination was also discussed and the need to separate their effects was highlighted (as strategies need to address them in very different ways).

Another key issue raised that intersects stigma and discrimination issues was the "paradox" of rights protection and promotion in HIV/AIDS. For example, in India, healthcare workers would not treat People Living with HIV and AIDS because of the fear of being themselves discriminated against. Advocates promoted a strategy based on the notion of protecting everyone's rights (including that of health workers), which proved successful—and may additionally provide a useful example for addressing both stigma and discrimination in national level efforts.

Poverty and Lack of Capacity:

Members recognized that many countries lack the resources, experts, and institutional capacity to comprehensively introduce human rights concepts and methods in their work to address HIV/AIDS.

Poverty was noted as one of the major impediments to implementing human rights norms even if there is commitment by officials to do so. At the individual level, the lack of access to resources may result in there being no meaningful way to realize rights even if some structures are in place.

Several opportunities were suggested, such as building relationships which emphasize the obligations of actors (like the World Bank and multi-national corporations) to provide support for realizing human rights in the context of HIV/AIDS; addressing the broader contexts of individual rights protections for affected communities (e.g. provision of affordable housing, transportation, and meals); and increasing capacity building.

Politics and Religion:

Members also pointed to the current political climate globally and within countries, the ongoing lack of awareness (or interest) of high profile officials in the majority of countries, and the concern that HIV/AIDS policy is increasingly being driven by conservative religious beliefs.

There was agreement that it is critical to give more thought to the role that the Group can play in this respect. At a minimum, it is clear that efforts are needed to work with different groups of actors (locally and globally) to try to counter these effects particularly in light of 2003 reporting on the Declaration of Commitment and 2004 ICPD +10.

The Media:

Participants agreed that there remains a general lack of awareness of HIV/AIDS and human rights issues by media and other professional groups. One member suggested a role for the Group could be engaging the media to address and educate the public on HIV/AIDS and human rights issues.

Members noted that an opportunity exists to engage different professional groups on HIV/AIDS and human rights dimensions and noted that it would be important to ensure that efforts in this regard focus not only on drawing attention to the horrors of individual cases where violations of rights have occurred but also where promotion of rights has been effective.

Vulnerable Populations:

The Group recognized that the limited engagement of vulnerable populations is an obstacle which must be overcome as it is critical that vulnerable populations are actively

engaged in every aspect of the response. The Group voiced a number of concerns that need to be addressed to ensure the engagement of vulnerable populations in HIV/AIDS and human rights issues.

The Group recognized that it is critical to ensure that the vulnerability of individuals to abuses by family, community or the state is not increased through their participation in HIV/AIDS work and that this must be considered in all efforts to secure their engagement (whether by the Group, UNAIDS, or any other actors).

Revisiting Old Issues and Being Prepared for New Ones:

The group also addressed the challenge of how best to deal with issues for which the integration of human rights concerns have been understood to be critical but where challenges to human rights continue to be raised.

The example of mandatory testing was discussed in this regard, and it was recognized that the Group had a unique role to play in providing a quick response to misinformation and taking a proactive stance in debates that raise human rights issues. The Group recognized that its membership was well situated to be able to anticipate new issues which may raise human rights concerns at national, regional and international levels and recognized this as a key responsibility both of individual members and of the Group as a whole.

IV. Standards and Approaches: What Works and What Does Not

Members discussed examples of HIV/AIDS strategies where human rights had been successfully integrated, those where they had not, and drew some conclusions as to general issues to be considered in assessing the human rights sensitivity of policies and programs concerned with HIV/AIDS **prevention, care and treatment**, and **impact mitigation**. In particular, the Group noted the implications of poverty and gender roles across all cultures and in relation to all strategies.

Prevention:

Various prevention strategies were identified for consideration by the Group in that they continue to raise human rights concerns in how they are designed and implemented:

- Awareness and information campaigns. The Group noted that efforts to withhold accurate information continue and that there are increased efforts to shift towards abstinence campaigns. One member noted that in one conservative setting where sexuality and reproductive rights are not easily discussed, reliance on human rights norms helped to ensure that the government assumed its responsibility to provide accurate information necessary for HIV prevention. The Group recognized this as a useful strategy which may be effective in other settings.

- Condom distribution. The Group noted that while condom distribution has always been understood to be central to effective prevention, there is more understanding of the complexity of what it takes to distribute condoms to all populations who need them. There is a need to consider the legal and policy environment within countries that can hinder effective condom distribution, in addition to the implications of gender for who can access condoms and in what circumstances. It was recognized that particular efforts are needed also to consider the access issues for adolescents. Members also discussed successful campaigns of condom distribution to vulnerable populations (such as prison populations).

- Voluntary testing and counseling. The Group recognized that HIV testing continues to raise the human rights concerns that have been relevant since the start of the pandemic but that, with growing possibilities of treatment, testing issues are becoming more complex. There is increasingly a need to conceptualize with more specificity the human rights concerns relevant to the different settings where testing occurs and the access to treatment that exists for the different populations offered testing. The Group recognized it as likely that this issue will require increased vigilance and significant work in the coming years.

- Needle exchange for injection drug users. Participants discussed how even though public health and human rights concerns both support the need for harm reduction approaches, it may still be difficult within countries to ensure implementation of such programs. One participant provided an example of how a range of strategies may be necessary to ensure that such services can be provided. He used the example of needle exchange in prison and the efforts that were made to ensure access that by necessity included legal, ethical, public health and human rights arguments. His group provided evidence to decision makers of the best strategies from other countries, did an analysis of the legal and policy opportunities and constraints, worked to help increase the capacity of this population to articulate their rights, worked with researchers on gathering the evidence needed to convince decision makers of the need to ensure needle exchange in prison, and supported litigation on discrimination in the access prisoners, as compared to others, had outside of prison. The Group recognized that this combination of strategies may be useful in relation to a number of "sensitive" issues raising human rights concerns in the context of HIV/AIDS.

- Peer counseling. Members noted that while peer counseling is recognized as a key to prevention efforts in hard to reach populations, as a strategy it nevertheless raises a number of human rights concerns for people engaged in illegal behaviors (sex work, drug use), as well as for adolescents (both with respect to parental consent issues and to societal recognition of adolescent sexuality). The Group noted that more attention is needed to ensure protection of the human rights of these populations in order for peer counseling to be effective.

- Mother-to-Child transmission prevention via provision of ARVs. Members noted increasing rhetorical attention to ensuring that women are able to access ARVs not only to prevent transmission, but also for the health of the women themselves. However, most programs seem still to be focused primarily on the prevention of transmission, and these raise concerns in relation to testing of women without their full consent, the lack of post test counseling, as well as to ensuring the sustained relationship of both the woman and her infant to the health care system.

- Microbicides. The Group recognized the implications of gender roles and expectations for microbicide distribution and the difficulties this may cause in ensuring access for hard to reach populations.

- Vaccines. With many vaccines in the pipeline, several members noted the importance of analyzing the human rights connotations associated with the production and testing of vaccines. While there has been attention to the ethical considerations, more work is needed in relation to the human rights implications. Attention to the human rights issues raised in relation to availability and resources for distribution will require further research and consideration.

Treatment and Care:

The Group discussed a number of key issues in relation to treatment and care:

- Connections between treatment and broader care concerns. Participants noted the need to ensure sustained pressure on governments, pharmaceutical companies and other relevant actors to move towards ensuring treatment for all people who need it. Also noted were specific concerns which can be addressed under the right to health which can impact on who is able to access treatment within a community even if it does become available, such as ensuring that women have access to comprehensive reproductive health services (and thereby can access treatment through these services). Participants recognized also that in order to ensure access, even if drugs are available, a host of rights, in addition to the right to health, will need to be realized in relation to such things as housing, food, transportation and other relevant concerns. It was noted that it is necessary to ensure that these factors are not left out of treatment advocacy and other strategies.

- Human rights issues in ensuring access. Specific issues to be considered in relation to the application of human rights norms to priority setting were emphasized, such as determining who within a population should have first access to drugs when they become available (e.g. while the human rights concept of participation would suggest leaving it to the community, reality shows women may then be the last to access), privacy concerns once treatment begins (particularly in resource poor settings), and ensuring adherence if drugs are made available in traditionally marginalized groups (e.g. drug users). The Group recognized that human rights, social justice, ethics and equity arguments have all

been used in relation to discussions about access. It was suggested that a comparative analysis of the utility and application of these various frameworks might be a useful contribution.

- Operationalizing the concept of progressive realization. It was recognized that the concept of progressive realization has not been sufficiently used either in advocacy and holding governments accountable under their human rights obligations in relation to accessing treatment, or in the operational structures for implementation. While benchmarks are compatible with both human rights and public health strategies, a concrete approach to progressive realization has not yet been sufficiently explored in this context. The human rights system can be accused of having "given up" when faced with limited resources; work by the Group towards operationalizing this concept could be useful also in this regard.

- Human rights law, intellectual property law and trade agreements. It was agreed that ensuring clarity among these various components of international law was critical to ensuring access to treatment. The Group recognized that very useful work in this regard is being done by a number of partners (such as the OHCHR). It was agreed that the Group should not duplicate existing efforts but look to see in what ways its composition and methods of work can be useful to supplement these efforts.

- Effectiveness of litigation and other well publicized strategies. Where national level legal systems provide an effective mechanism, the Group discussed the successful use of these systems to argue for increased access to treatment. The Group noted the utility of litigation strategies for raising awareness of rights within vulnerable populations, but also the concern, even in settings where litigation has been successful, to ensure that this actually translates into increased access. Similarly, the Group discussed the efforts of the Brazilian government to increase access both nationally and at the international level. While widely regarded as a success story, it was recognized that there are concerns as to whether or not this strategy has ultimately been effective—a matter that should be explored from a human rights perspective.

- Greater involvement of People Living with HIV and AIDS. It was recognized that requests have been made for formal training and capacity building in relation to the application of human rights norms and standards in ensuring access from various Groups of People Living with HIV and AIDS and that a cataloging of successful efforts might be useful and help to determine the place of the Reference Group in supporting these efforts.

Impact Mitigation:

Members identified several areas of concern where human rights perspectives have been insufficiently considered in impact mitigation efforts:

- The place of impact mitigation in HIV/AIDS strategies. The group recognized that often both the public health and human rights world's concerns with HIV/AIDS focus on prevention and treatment/care but leave out this very important dimension of the pandemic. It was recognized that the Group (as individual members and collectively) should ensure attention to this dimension of the pandemic in its work on HIV/AIDS and human rights.

- Poverty and economic impacts. The link between the neglect or violation of human rights, poverty and the economic impacts of HIV/AIDS on affected communities was noted. The group recognized that even when economic impact is considered, the human rights concerns of affected communities are generally insufficiently addressed. In this context, the group emphasized the need to ensure linkages with the Economic Reference Group and to work with them to ensure an awareness of the human rights issues connected to their work.

- Healthcare systems and providers. The group recognized the burden on health care systems as HIV/AIDS takes an increasingly prominent place in the services offered. It was noted that in making rights claims for ensuring the availability of HIV/AIDS treatment it must be made clear that systems need to ensure that access to needed drugs and services relevant to other health issues is maintained and strengthened.

- Orphan children and the resources directed towards orphans affected by HIV/AIDS. It was noted that a range of issues connected to the rights of the child have taken on new significance in light of the HIV/AIDS pandemic. For example, the right to an identity, while always critical, has taken on increasing importance as children left orphaned by AIDS require proof of their identity as they are forced to fend for themselves in relation to inheritance rights, education and access to other social services. It was recognized that a focus on support for children from affected communities will require increased attention to legal protection both at the national level and through international mechanisms.

V. The Future Role of the Reference Group

The Group's terms of reference are framed in relation to its advisory role to UNAIDS but members recognized that their function includes working with UNAIDS to strike a balance in promoting and protecting rights and ensuring respect for rights in the actions of UNAIDS partners, including governments.

The members reiterated the need for flexibility in the group's methods of work and the ways the issues are to be addressed, and recognized the capacity to work at three levels: providing ongoing support for the work of UNAIDS, cosponsors and other partners; proactively addressing issues that are not urgent but which need to be monitored both within countries and globally; and responding to emerging issues that must be dealt with immediately.