

The Next Five Years of Global HIV/AIDS Policy: Critical Gaps and Strategies for Effective Responses

UCLA Program in Global Health,
AIDS Policy Development Center

Greg Szekeres

January 2008

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Center for HIV Identification, Prevention, and Treatment Services

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This policy analysis is based on 35 interviews conducted between November 2006 and February 2007 with key informants in senior leadership positions at a variety of major organizations engaged in global HIV/AIDS work. Interviewees were drawn from major foundations, multilateral organizations, government, and non-governmental organizations engaged in multilateral and in-country efforts. This report was authored in collaboration with the following, who also conducted the interviews with key informants:

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The views expressed in this analysis are those of the author, based on interviews conducted with the key informants who graciously participated in this project, and are not necessarily those of the funders who provided support for this project or of any collaborating institution. In order to allow for interviews to be as open and frank as possible, the identities of the individuals interviewed for this project and of the organizations with which they are affiliated are not disclosed.

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Table of Contents

I. Executive Summary	4
II. Project Overview	7
Ford Global HIV/AIDS Initiative	
Goals of Project	
Interview Methodology	
III. Issues of Leadership and Leadership Development	8
Introduction	
Vision	
Maintaining Momentum	
Businesses and Faith-Based Organizations	
Leadership Development	
IV. Issues of Equity	12
Introduction	
Gender Equity	
Marginalized and Vulnerable Populations	
Regional Disparities and Access to Prevention, Treatment, and Care	
V. Issues of Accountability	16
Introduction	
Governments	
Civil Society, Communities, and Grassroots Organizations	
Funders	
Research	
VI. Issues Related to Partnerships	19
Introduction	
Fostering Collaboration	
Role of Funders	
VII. Acknowledgements	21
Appendix: Key Informant Interview Questions	22

I. Executive Summary

Overview

In 2006, the Ford Foundation launched The Global HIV/AIDS Initiative 2006-2010, in order to develop a five-year program to maximize the scope and impact of the outstanding HIV/AIDS work of the Ford Foundation. In his document, “Early Thoughts About the Ford Foundation and the Global Response to HIV/AIDS”, Jacob A. Gayle, PhD, Deputy Vice President for HIV/AIDS at the Ford Foundation, presented his vision for the Initiative to the Ford Foundation Board of Trustees. The vision for the Initiative centers on four key themes—leadership, equity, accountability, and partnerships. Thus, the Global HIV/AIDS Initiative seeks to (1) create deeper talent pools of professional and community leaders knowledgeable about best practices for preventing and treating HIV/AIDS; (2) ensure equity in access to services without jeopardizing human rights; (3) bring greater public accountability (to leaders and to global programs) for implementation of best practices in preventing and treating HIV/AIDS; and (4) conduct all work in partnership with countries, people, and organizations most affected by the HIV/AIDS epidemic.

To assist the Ford Foundation and other foundations and institutions to better understand the international HIV/AIDS policy landscape, the UCLA Program in Global Health produced a landscape analysis based on interviews conducted between November 2006 and February 2007 with 35 key informants in senior leadership positions at a variety of major institutions conducting international HIV/AIDS work, including foundations, multilateral organizations, governmental organizations, and NGOs. Key informants were asked to name the most urgent and important policy issues related to their HIV/AIDS work that they saw as relevant for the next 5 years, and to identify the issues and populations “falling through the cracks” and not receiving the resources or attention they deserved.

Issues of Leadership and Leadership Development

Informants’ responses on issues of leadership focused on four key areas:

Vision: Long-term vision is critical for an effective response to HIV/AIDS, particularly at this juncture in the epidemic. Leadership must come both from the top, as well as from grassroots movements.

Maintaining momentum: A strong, consistent, ongoing effort is necessary to retain the headway made on prevention and treatment. There is a need to be more specific about both what to do and how to do it (ie, what to implement and how to overcome barriers). Mechanisms are needed to ensure that transitions in leadership do not lead to losing ground in areas where progress has been made.

Businesses and faith-based organizations: Although businesses and faith-based groups have made progress with their involvement in HIV/AIDS, the opportunity still exists for both to assume a greater leadership role.

The need for leadership development: Long-term commitments from funders are required to support leadership development efforts, and civil society involvement in HIV/AIDS needs strengthening, particularly among vulnerable and marginalized groups. Regional partnerships may be useful mechanisms for transferring leadership skills from settings with more resources and/or experience to ones with fewer resources/less experience.

Issues of Equity

Respondents' approaches to equity primarily centered on issues of:

Gender equity: The global health community must move from rhetoric to action on gender inequality, gender violence, and related issues. It should be kept in mind that “gender” is not a synonym for “women”, but refers to a complex framework that affects both women and men in societies. Rights-based approaches that recognized the human rights of women and children are important in countering the gender disparities that can lead to increased risk for HIV infection, particularly among young women. Programs that address safety and security for girls and women can play an important role in this effort. Metrics must be developed to monitor progress on gender initiatives; the efficacy of programs cannot be determined unless change can be measured.

Marginalized and vulnerable populations: Populations that were identified as “falling through the cracks” and requiring increased attention included infants and children, adolescents and young adults, drug users (particularly IDUs), men who have sex with men (MSM), people with HIV, indigenous populations, migrant workers, sex workers, transgender people, and prisoners/former prisoners. Common themes that arose across populations included the need to decrease stigma and criminalization for many marginalized populations, as well as the need to strengthen civil society support for vulnerable populations to ensure that affected individuals and communities have a voice in the processes affecting them.

Regional Disparities and Access to Prevention, Treatment, and Care: Informants acknowledged the scope of the epidemic in sub-Saharan Africa and the continuing need to mobilize resources there. Other regions, however, were felt to be in need of increased attention, particularly Latin America, the Caribbean, and the Middle East/North Africa (MENA) region. An urban-rural divide was described, in which rural communities often lack comparable access to prevention, care, and treatment services, as compared to urban areas. In addition to the ongoing need to scale up ARV programs in low- and middle-income countries, there is also a need for affordable second-line treatments, as well as new drugs and diagnostic tools for HIV and opportunistic infections. As people with HIV in these settings develop resistance to their initial ARV regimens, this will rapidly take on critical importance.

Issues of Accountability

Informants' discussions concentrated on the need for accountability of:

Governments: National authorities of government must bear ultimate responsibility for HIV/AIDS response; local governments must also take initiative. Governments must be accountable for whether and how policies are implemented, and for judicious use of limited resources. Government can address structural factors such as human infrastructure bottlenecks, which can act as barriers to effective program implementation.

Civil society, communities, and grassroots organizations: “Bottom-up” accountability is an important concept—people need to take responsibility for understanding how HIV/AIDS affects individuals, families, and communities, for their own behaviors around risk, and for mobilizing themselves and communities to take action. NGOs can help to hold governments accountable, and must themselves also be accountable to their constituent communities.

Funders: Foundations and other donor agencies can also serve to track government actions and hold them accountable. Countries should be held accountable to their own goals, not those of the donor. Large and influential foundations were felt to be in need of greater transparency and accountability to the global community. Advisory committee or other peer-review mechanisms were proposed as strategies to help accomplish this.

Research: Research—basic science, translational, clinical, behavioral, systems/health services, policy—into all aspects of HIV/AIDS is an ongoing need. Operational and outcomes research, while less glamorous than other areas of inquiry, is particularly important at this time and requires more attention from investigators. Researchers, donors, and policymakers need to develop more efficient ways of scaling up the results of successful trials; too much time often elapses between publication of results and effective implementation. Governments and donors must also take responsibility to adequately fund research, and to ensure that disincentives to developing vaccines and other technologies are addressed.

Issues Related to Partnerships

Partnerships and collaborations can be instrumental in making meaningful progress on HIV/AIDS work. Informants had insights into building effective partnerships, including:

Fostering collaboration: Greater collaboration is needed between government departments and between governments and NGOs. Ways need to be found to ease tensions where there is intense competition for scarce resources. Regional partnerships can be useful ways for sharing ideas and transferring leadership skills from countries with greater resources and/or experience to those with fewer resources and less experience.

Role of funders: Funders can play a lead role in encouraging meaningful collaboration by promoting integrated funding streams that do not fracture public health service efforts by allocating funding by disease category. Large foundations and other donor agencies must increasingly partner with each other and work together, particularly on complex, ambitious projects. Doing so creates great potential for a lasting, significant impact on the HIV/AIDS epidemic.

II. Project Overview

Ford Global HIV/AIDS Initiative

In 2006, the Ford Foundation launched *The Global HIV/AIDS Initiative 2006-2010*. This initiative seeks to leverage the existing outstanding HIV/AIDS work of the Ford Foundation and to develop a five-year program that will capitalize on this work and maximize its scope and impact.

One of the goals of this initiative is to enable the Ford Foundation to bring its own highly respected voice to advocate for greater action in the HIV/AIDS field. It is important to the Foundation that visible voice be given to its unique values of human rights and social protection, gender equity, asset and community development, self-determination, and cultures of compassion. In his document, “Early Thoughts About the Ford Foundation and the Global Response to HIV/AIDS”, Jacob A. Gayle, PhD, Deputy Vice President for HIV/AIDS at the Ford Foundation, presented his vision for the Initiative to the Ford Foundation Board of Trustees. The vision for the Initiative centers on four key themes—**leadership, equity, accountability, and partnerships**. Thus, the Global HIV/AIDS Initiative seeks to:

- Create deeper talent pools of professional and community **leaders** knowledgeable about best practices for preventing and treating HIV/AIDS;
- Ensure **equity** in access to services without jeopardizing human rights;
- Bring greater public **accountability** (to leaders and to global programs) for implementation of best practices in preventing and treating HIV/AIDS;
- Conduct all work in **partnership** with countries, people, and organizations most affected by the HIV/AIDS epidemic.

The Ford Foundation is organized into three programmatic areas—Asset Building and Community Development; Peace and Social Justice; and Knowledge, Creativity, and Freedom. One challenge of the Initiative is to build on the Ford Foundation’s successes in HIV/AIDS, and also the strength of its organizational structure, to determine the most productive ways in which an overall strategy can be developed, and determining how that strategy can be effectively implemented using the best the Foundation has to offer—its multidisciplinary focus; its emphasis on justice, human rights, human sexuality, community and personal development; and its decentralized country office structure. A second set of challenges is to identify the issues that are likely to emerge as crucial in the next phase of the HIV/AIDS epidemic, to advance the objectives of global accountability for the work that is underway now, and to build capacity for the work that needs to continue into the future.

Goals of Project

The Ford Foundation has partnered with the UCLA Program in Global Health (PGH) to identify policy issues currently being addressed by foundations, government, multilateral organizations, NGOs, and other groups, as well as to identify ways in which foundations and other organizations might better address HIV/AIDS policies over the next 5 years. To this end, PGH has conducted a landscape analysis based on interviews with key informants from major international organizations conducting HIV/AIDS work. The purpose of this analysis is to assist the Ford Foundation and other foundations and institutions to better understand the international

HIV/AIDS policy landscape, and to formulate research and development programs that can make a significant contribution to moving important issues forward in the HIV/AIDS policy arena.

Interview Methodology

Twelve faculty and analyst-level interviewers affiliated with the UCLA Program in Global Health conducted a total of 35 interviews with key informants in senior leadership positions at a variety of major institutions conducting international HIV/AIDS work, including foundations, multilateral organizations, governmental organizations, and NGOs. Interview questions were sent to key informants in advance, and one-hour interviews were conducted between November 2006 and February 2007. All interviews were conducted via phone (with the exception of one conducted in person); all interviews were recorded with the interviewees' permission and transcribed. In order to encourage those interviewed to be as frank and open as possible, their identities and those of the institutions for which they work are not disclosed.

Key informants were asked to name the most urgent and important policy issues related to their HIV/AIDS work that they saw as relevant for the next 5 years, and to identify the issues and populations they saw as “falling through the cracks” and not receiving the resources or attention they deserved. Informants were questioned about facilitators and barriers to accomplishing their work, and about gaps in leadership (or examples of good leadership) they have witnessed. They were also asked about social inequities and other drivers of the epidemic, and what they saw as being necessary to make progress on these issues. Questions were also asked about how to strengthen accountability and promote collaboration among the players they work with. Interview questions are provided in the Appendix at the end of this report.

III. Issues of Leadership and Leadership Development

Introduction

Leadership can take many forms and may occur at all levels of society. In terms of HIV/AIDS, leadership development involves creating broader and deeper talent pools of professional and community leaders who are knowledgeable about best practices for prevention and care, and who are able to carry on the task of continuing the fight against the epidemic. There is perhaps no greater need in the HIV/AIDS epidemic, domestically and globally, than leadership development. Leadership needs to be replenished in all sectors—science, program management, community organizing, and policy and advocacy. A second kind of leadership development must also occur, namely, transfer of leadership in the fight against HIV to the countries, communities, and individuals shouldering the greatest burden of the epidemic. This will require some individuals, institutions, and countries to move away from the limelight and shift to a supporting role, in order to allow those bearing the burden of the epidemic to take charge of the response, defining both the nature and the form of the response and leading others in that effort.

For this analysis, informants were asked to identify gaps in leadership that contribute to the issues they work on, or impede progress in their work. Leadership was also an issue consistently raised by informants on their own. Numerous examples were given of both strong and weak leadership (respondents tended to accentuate the positive, listing far more examples of good leadership). Two examples of weak leadership that were frequently cited were the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the South African government. Examples of

strong leadership included the governments of Australia, Rwanda, Thailand, and Uganda; the United States President’s Plan for Emergency AIDS Relief (PEPFAR); the Bill and Melinda Gates Foundation, the Clinton Foundation, and the Open Society Institute for its work with drug users.

Our informants’ conversations on leadership tended to focus on several key themes—the importance of having vision and maintaining momentum, the need for increased leadership from the business sector and faith-based groups, and ways to foster leadership development at multiple levels.

Vision

Strong leadership requires vision. Many of our informants spoke of the need for a visionary response to the epidemic at this time. One informant expressed frustration with what she perceived to be a collective lack of vision for what is possible—we may be too willing to write off challenging yet solvable problems as impossible. Related to this, another informant noted that humans are often mired in how they look at a particular problem, and that more creativity is sorely needed in responding to the epidemic at all levels and across sectors.

The need for long-term vision in addressing HIV/AIDS was repeatedly cited as being crucial for an effective response. Due to political realities in many settings, there is a tendency to focus solely on the short-term (which often means doing what is most expedient for the next election, the next grant cycle, the next quarterly report) and avoid investing in longer-term approaches that may be riskier politically. Looking ahead and considering what the landscape might look like in 3-5 years is important for current planning, but is not always done. Long-term vision, however, must incorporate the need for mid-course evaluations and course corrections; it cannot rely solely on strategies derived from the political ideology from which it may have originated.

Leadership—both from the top and the grassroots—was cited as being necessary to address inequalities and change cultural practices and traditions that may contribute to the spread of HIV or impair delivery or uptake of programs. To do this, however, both vision and political will are necessary. Strong leadership influences societal and cultural understanding, and leadership that focuses on structural issues—policy, social inequality, etc, can influence individual behaviors. Ideological conflicts too often stifle effective leadership among those with power or influence, whether at the international, national, or local level.

Maintaining Momentum

A recurring theme during interviews with informants was the need to maintain momentum and ensure a strong, consistent, ongoing effort against HIV from those in positions of leadership. It was emphasized that HIV/AIDS is still a crisis, and that after 25 years of the epidemic, it is critically important to keep the momentum going and not succumb to “AIDS fatigue” or to become complacent in areas where gains have been made in prevention or treatment. It was expressed that HIV/AIDS needs to be accepted once and for all as a global development challenge—time and energy is periodically wasted when efforts need to be diverted to reassert it as such. To some, the concept of maintaining momentum at this point in the epidemic meant increasing specificity when addressing key issues. Repeatedly, the need for concrete recommendations and programs for addressing issues such as gender disparity and poverty in relation to HIV/AIDS was voiced. As we develop a more comprehensive and nuanced

understanding of the epidemic and its local specificities, we have greater ability to apply known interventions to specific settings. Informants stated that there was a need to get more specific about *WHAT* to do (ie, what programs to implement) and *HOW* to do it (ie, how to get programs underway and overcome policy barriers and other hurdles).

It was noted that a “leadership gap” occurs each time there is a change in leadership, whether in government, among activists, etc, and that time and resources are wasted when these transitions necessitate starting from scratch or rejustifying the work. Mechanisms at the international, national, and community levels that help to ensure smoother transition of HIV/AIDS work when leadership changes occur would be valuable in maintaining focus on the most important issues and avoiding losing ground in areas where progress has been made. One example mentioned was the need both for vision and a transition plan for upcoming changes that are likely to occur in administration of the Global Fund and PEPFAR.

Businesses and Faith-Based Organizations

The business sector and faith-based organizations (FBOs) were both recognized by several informants for the increased HIV/AIDS leadership they have taken in the last several years. While this was consistently cited as being positive, informants did have comments about the scope and nature of their leadership roles.

A number of informants noted that the business response to HIV/AIDS, while increasing, was still not adequate, and that businesses need to take responsibility for playing a larger role. One informant believed that in the United States, the business sector has much greater influence than civil society, and that its leadership role in HIV/AIDS needs to be commensurate with that level of power. Another described the need for African businesses specifically to take an increased leadership role. It was felt that businesses needed to move beyond their focus on the workplace and expand their efforts to include the communities in which their employees live (and come from/cycle back to), as well as consumers, other companies in their supply chain, and the larger society.

Similarly, some informants thought that faith-based organizations needed to assume a greater leadership role in responding to HIV/AIDS. It was pointed out that they are often an underutilized resource, and can affect change on many levels—from church leaders speaking to their constituents to the potential for FBOs to influence governments. It is possible for FBOs to initiate or support programs based on evidence, and not solely on doctrine. The Catholic Church was cited as bearing a huge responsibility and having an enormous opportunity to assume a positive leadership role in regard to HIV/AIDS.

Leadership Development

Informants repeatedly identified the need for leadership development in the HIV/AIDS field and the transfer of leadership to a new generation and to communities most affected by the epidemic as top priorities. It was noted that the current leadership structure in HIV/AIDS is aging, but that adequate plans are not in place to transfer power or develop leadership skills in the next generation, or to shift power to the places and people most heavily impacted by the epidemic.

New people and the novel ideas and fresh approaches they can bring were cited as being desperately needed at the international, national, and community levels. There is an immense

need for well-trained people of all kinds—including health care workers, program managers, advocates and activists, policy makers—and training programs are required to develop both their technical and leadership skills. Several informants singled out advocacy and activism as areas in particular need of training and leadership development globally. One respondent reflected a friend’s comment that there is no passing of the torch to young activist leaders, only “the passing of the grudge.” Another informant stated that the bottom has fallen out of the HIV/AIDS grassroots activist movement in the United States. Others noted that within the U.S., the African American community should be the focus of leadership development activities.

Informants had ideas about how to structure and strengthen HIV/AIDS leadership development efforts. Perhaps first and foremost is the need for funders to make long-term commitments to supporting leadership development work. It was expressed that participants in leadership development programs should be selected by people with activist experience, particularly from the geographic areas where the participants are being recruited. Too often, leader trainees are selected by donors or those in developed countries without adequate input from affected communities.

Several informants spoke of the need for strengthened civil society involvement in HIV/AIDS efforts. In particular, marginalized groups were identified as being in need of support so that they can be better organized and assume a greater leadership role. This may also involve addressing poverty and social inequities; organization is difficult when basic needs cannot be met. Civil society can be crucial in developing a successful response to HIV/AIDS, but groups must be able to organize effectively and may need support to do so. One informant noted that civil society groups often feel they need to be careful around power brokers (frequently government), lest they be uninvited from decision-making processes in the future. He stated that, “often we say that civil society has to choose its own people; well, we find that government chooses which civil society they will work with.”

Inconsistent leadership at the community level is certainly driven by illness and death due to HIV and to lack of resources. It was suggested that volunteerism may also play a role in the disruption. If people aren’t paid for their efforts, they may be forced to seek work elsewhere to support themselves and their families, particularly in resource-poor settings.

The development of regional partnerships was seen as a potential mechanism for transferring leadership skills from higher-resourced settings to lower-resourced settings (or from those with more HIV/AIDS experience to those with less experience). Section VI of this report focuses on partnership development.

Another focus of leadership development was the field of HIV prevention. One respondent suggested that while there were many smart people working in HIV prevention, there were only a very few that could qualify as leaders. He expressed his frustration in going to high-level HIV prevention meetings over the years and seeing the same handful of people in the room. It may be challenging to develop leadership in HIV prevention from the grassroots up. People may approach HIV prevention advocacy differently from treatment advocacy; historically, treatment advocacy was pushed forward by infected people who were fighting for their lives. Novel approaches may be needed to build a robust prevention advocacy community.

IV. Issues of Equity

Introduction

Equity with regard to HIV/AIDS means that all individuals have access to evidence-based approaches to care and prevention most appropriate to their circumstances. Such access must not be affected by geography, gender, social or economic status, sexual orientation, race or ethnicity, age, education, religion, occupation, or the way in which they may have contracted HIV. Equity means that individuals have access to HIV-related services without jeopardizing their human rights.

Our informants were asked to describe the main inequities they perceived as helping to drive the HIV epidemic and complicate their response to it, as well as discuss their ideas for addressing these inequities. The two themes most frequently discussed were gender equity and the needs of marginalized and vulnerable populations. Other topics that were repeatedly raised included the existence of regional disparities and the need for equitable access to prevention, care, and treatment services.

Several informants emphasized the need for caution when making generalizations about the role of social inequity. Social inequity is often believed to be the root of the problem driving the HIV epidemic, and in many cases it may play a very significant role. Botswana, however, was cited as an example where this may not be the case. Botswana is one of the wealthiest countries in sub-Saharan Africa, does not have a high level of socioeconomic disparity, and the role of women there is comparatively strong, yet it has close to the world's highest HIV prevalence. By contrast, Mauritania has relatively low HIV prevalence, despite being comparatively poor and having a more pronounced gender imbalance. Similarly, there is considerable rhetoric about HIV being a "disease of poverty". While poverty may indeed drive the epidemic in important ways, in some countries it is those in the middle- to low-upper-income levels that are most at risk for HIV, due to increased mobility, access to multiple partners, feelings of invulnerability, etc. There is sometimes a disconnect between the rhetoric and the data, and so it is important that discussions about social inequities and HIV avoid generalizations and be driven by data whenever possible.

Gender Equity

Gender equity was the issue most frequently raised throughout our interviews with informants. It was clear that respondents believed one of the greatest challenges in the fight against HIV/AIDS is the long, slow effort to alter the social and cultural norms that put many women in developing countries at increased risk for HIV infection. Many, however, expressed frustration that, despite there being a great deal of "talk" among the global health community about gender inequality, gender violence, and other gender issues related to HIV, there are relatively few programs geared to deal with these issues effectively. Both the discussions about the disadvantages women (and men) face and the programs designed to address them need to be more precise, many informants felt, and required greater focus on specific geographical, cultural, religious, economic, and legislative contexts.

Although it was recognized that work on gender and HIV would be unlikely to fundamentally alter gender dynamics or universally improve the lot of women, informants strongly expressed the belief that feasible interventions can be implemented that significantly reduce the susceptibility of women and men to HIV and result in a more equitable gender distribution of HIV services.

Informants described a number of gender issues to focus on more closely and strategies to address them.

An important point to emphasize about the discussions on gender inequities was that “gender” should not be used as a synonym for “women”. Many informants talked about the need to examine gender as a complex framework that deeply affects both women and men in countless ways in societies. There are indeed gender imbalances in many, if not most, societies that disproportionately put women at a disadvantage in important ways when compared to men. This disadvantage often puts women at increased risk of HIV infection. Men, however, are also affected by gender norms and dynamics, and this affects their behaviors and risk for HIV infection as well. Discussions of gender equity must take into account both men and women and the ways they interact with each other in society.

A number of informants talked about the need for rights-based approaches to gender inequality, citing an overall lack of recognition of the rights of women and children. Frequently, unequal rights for women can result in economic disadvantage that can lead to increased HIV risk. This can occur due to inability of women to control their destinies and ensure their safety, lack of negotiating power in relationships, pressure to engage in sex work, and other factors. Informants noted some of the mechanisms through which these disadvantages are manifested, including lack of educational and economic opportunities for women and girls, unequal inheritance rights for women, and loss of property rights when women or their family members are HIV infected, become sick, or die. Effective strategies that address these issues are needed. Even in settings where laws exist that promote gender equality and prohibit gender violence, the problem may be that the laws are not enforced. It was suggested by several informants that policy work focusing both on drafting and enforcement of such laws needs to be supported in many countries, and that policies can be effective in driving cultural practices. Another priority that was identified was the need to fund and support independent indigenous women’s rights groups—it was felt that their full involvement was required for success in most settings.

Many of the discussions on gender were centered on HIV prevention. It was clearly a priority to make sure that strategies are developed and policies are in place to ensure that both women and men have access to as many effective tools to protect themselves from HIV as possible. One set of strategies focused on promotion of basic safety and security for girls and women—including legal protections against sexual violence in the classroom or at home. Other approaches cited included increased resources, coordination, and civil society participation in clinical trials of female-controlled prevention technologies such as microbicides and the female condom; health systems research on ways to effectively implement male circumcision programs; and increased attention on research, implementation, and program planning of strategies for prevention mother-to-child HIV transmission (PMTCT), including breastfeeding.

Informants pointed out that programs focusing on women and girls would do well to prioritize the needs of young girls—even those in pre-adolescence. There is a need for greater recognition of the risks for young girls and their vulnerability to HIV. The policies needed to protect them are not necessarily the traditional ones that address sexual behavior, as much of their risk occurs before they choose to become sexually active, relating to early marriage and lack of safe spaces for young girls.

Lastly, the need for monitoring, evaluation, and measurement of gender initiatives was emphasized, particularly the necessity to incorporate metrics in funding decisions. There is no way to know if particular gender work is effective unless change can be measured.

Marginalized and Vulnerable Populations

Informants identified a variety of marginalized and/or vulnerable populations that would benefit from increased services and program development, and that are worthy candidates for the focus of prevention and clinical research and policy work.

No group is more vulnerable than infants and children, who routinely fall through the cracks of prevention, care, and treatment programs. One informant noted that children represent approximately 15% of new HIV infections annually, yet they make up only 7-8% of the population receiving HIV treatment. Many of these children die before they reach 2 years of age. In addition to increased antiretroviral coverage for HIV-infected children and more and better pediatric ARV formulations, there is a need for more sophisticated testing assays and widespread access to prophylactic drugs such as cotrimoxazole. It was mentioned that there are not adequate programs for HIV-infected women who do not wish to become pregnant and do not have access to effective contraception or termination of pregnancy. As noted above, more clinical and health systems research is needed on PMTCT, including breastfeeding.

Adolescents and young adults were also recognized as being in need of increased attention. While there are many small programs that focus on adolescents and youth, it was felt that large-scale programs of significant scope and impact were too few and far between.

Drug users, including injecting drug users (IDUs), were mentioned by several informants as a key population that is being ignored and is falling through the cracks globally. One informant quoted statistics that indicate that IDUs account for as many as a third of new HIV infections outside of sub-Saharan Africa, and that the virus travels most quickly through communities of injecting drug users, with prevalence going from 0% to 50% of a population in as few as six months in some cases. It was emphatically stated that HIV prevention cannot move forward with drug users until the international community and governments begin to view drug use a public health issue rather than a criminal one. There are very few reasonable programs to point to, and there has been a real failure to expand ARV access and harm reduction services to drug users, particularly IDUs. Effective policies for making clean needles and drug treatment programs available is desperately needed, particularly in Eastern Europe and Central Asia, where drug use and needle sharing is a key driver of the HIV epidemic.

Men who have sex with men (MSM) were once the focus of considerable attention in the HIV arena, but several informants felt that attention has waned and that MSM, particularly non-gay-identified MSM, have become a neglected at-risk population. Regions that were identified by informants as not adequately addressing MSM included Latin America, where the epidemic is largely driven by MSM; Africa and India, where a focus on heterosexual transmission has made MSM invisible; and the United States, where the needs of African American MSM are largely ignored.

People with HIV/AIDS (PWH/A) were named as a population that is stigmatized and marginalized. Informants called for increased funding to support ethical research on strategies to reduce stigma and its effects, and to develop indicators that can effectively measure stigma. The sexual and reproductive rights of people with HIV were cited as being discounted, and these were given as areas requiring additional policy work, as was the issue of criminalization of HIV transmission, which was seen to be counterproductive to prevention efforts.

Other populations that were noted as needing increased attention included indigenous populations, migrant workers (who may or may not cross national borders—there may be as many as 100 million in China alone), sex workers, transgender people, and prisoners/former prisoners.

Some themes and strategies were discussed that were consistently relevant across populations. First and foremost is the need for all affected populations to have a voice in the process. Stigma and criminalization (the latter being particularly relevant for drug users, sex workers, MSM, and PWH/A) are not viable means of preventing HIV. Rather, affected groups must be protected and partnered with so that they can become allies in the fight against HIV. Strengthening civil society, which is weak or nonexistent for most of these populations, was cited as being a priority. Civil society needs to be able to change the laws that perpetuate the exclusion of the marginalized groups. To do this, they need to increase their technical capacity to facilitate their ability to receive grants, which they may be competing for with their own governments. Lastly, informants described the need to build social safety nets in some countries—particularly those, such as China and Vietnam, where there are rapidly rising free-market economies.

Regional Disparities and Access to Prevention, Treatment, and Care

The disparities that exist between high-income countries and middle- and low-income countries—differential access to ARVs and prevention services being chief among them—are well recognized and have been the focus of considerable effort. Although programs such as PEPFAR seek to mitigate some of this disparity, the scope of the disparity is incredibly large and complex, and is rooted in economic, political, social, and other structural problems that extend far beyond the HIV/AIDS milieu

Sub-Saharan Africa is the region hardest hit by the HIV epidemic, and is also the region most challenged by poverty, lack of health care infrastructure, and underlying development problems, so it is logical that the region has been the recipient of a large share of attention and resources to fight HIV. While keeping Africa as a top priority, informants identified other regions they felt warranted increased attention. Latin America and the Caribbean were mentioned as being critically important regions to focus on (the Caribbean is the region with the second highest HIV prevalence), and are frequently overshadowed by the scope of the crisis in Africa. It is hoped that the next International AIDS Society conference being held in Mexico City in August 2008 will bring increased attention to these regions. The Middle East/North Africa (MENA) region was also identified as deserving greater focus. While HIV prevalence is generally believed to be low in most MENA countries, there is relatively little data available on HIV epidemiology and response to the epidemic in the region.

Within countries, informants spoke of the urban-rural divide. People in rural communities often do not have the same access to prevention, treatment, and care services as those in urban areas, and they frequently lack transportation or resources that would facilitate getting their needs met.

One informant summarized the debate around how best to address the global HIV epidemic. As HIV/AIDS is a global issue, it has been thought that a global strategy is needed—similar to responses for other transnational issues such as the environment. Others, however, see that the epidemic is quite heterogeneous. The generalized epidemic in sub-Saharan Africa is fundamentally different than the more focal, concentrated epidemics in much of Asia and Latin America. Strategies to address HIV/AIDS that are customized regionally or nationally might be more successful and should be explored.

In addition to the continuing need to scale up antiretroviral programs to bridge the treatment access gap in many countries, informants discussed the need for affordable second-line treatments and new drugs and diagnostics. In some settings, including many of those that have relatively good access to ARVs, treatment options are severely limited, and patients who break through their initial ARV regimen may have few options. One informant pointed out that middle-income countries often have an especially difficult time paying for HIV medicines, as they get less aid from donors than poorer ones. It was felt that intellectual property issues, which may complicate developing countries' ability to manufacture or access low-cost alternatives to brand-name pharmaceuticals, was a topic that required further discussion among the international community. Patient groups need to be supported to challenge their governments and demand access to prevention, treatment, and care. Support for development of advocacy focusing on access to HIV prevention was cited as a priority due to the fact that such efforts are currently lacking.

V. Issues of Accountability

Introduction

HIV/AIDS accountability means ensuring that developed and developing country governments, civil society, businesses, and global agencies make their programs accountable to everyone. It means setting specific goals, developing realistic strategies to achieve those goals, garnering the necessary resources to implement the strategies, and then holding all parties accountable for their efficient, transparent, and effective implementation.

During our interviews, informants described a deafening silence with regard to HIV/AIDS accountability, with little coordinated tracking of where money goes or how it is used. One informant expressed frustration with “letting the measurable push out the important”, meaning that there is too often a focus on what is easily quantifiable (ie, pills or condoms distributed), at the expense of what we really need to know (ie, health outcomes or behavior change).

Informants discussed the need for accountability, and strategies for increasing accountability, at multiple levels. Conversations about accountability focused on government (particularly at the national level), civil society and grassroots organizations, funders, and researchers.

Governments

Several informants identified the national authorities of government, such as the executive branch and ministries of health, as bearing ultimate responsibility for a country's response to HIV/AIDS. This, of course, highlights the need for leadership and political will to move forward effectively. Accountability at the national level requires that governments' HIV/AIDS agendas be driven by public health needs and not ideology, and that government processes and actions are characterized by transparency and openness.

One respondent noted that national-level accountability is increasingly important now that donors are recognizing that developing-country governments must be the drivers of their own priorities. Others pointed out that countries heavily affected by HIV/AIDS need to take responsibility and begin to earmark some of their own resources for addressing the epidemic, rather than relying on donor agencies. It was noted that some countries are doing this, but that it is not consistent. This

approach is important, however, in that it will help to ensure more sustainable funding. There was also criticism of some middle-income countries that were felt to spend money on other, less important issues, and then expect donors to provide resources to address their HIV/AIDS problems.

Informants expressed that governments need to be held accountable for whether and how policies are implemented. Many countries have policies about how they plan to address HIV/AIDS over a given period, but it is often unclear how, or even if, the policies can be put into action. Too often, the response depends on the individual in power (ie, the Minister of Health) and what that person is capable of or willing to do. There needs to be a greater shift towards institutionalizing the response and not relying on who is in power at the moment. Governments must also be held accountable for enforcing existing laws that protect those at risk for or affected by HIV. Many countries have laws that protect women's property rights or bar discrimination in employment and services based on HIV status, but implementation and enforcement of these laws is often weak.

Governments were also cited as bearing responsibility for addressing structural bottlenecks, such as human infrastructure capacity, that may act as barriers to implementation of prevention and care programs at the national level. Countries were urged to develop ways to move more rapidly in facilitating progress on HIV/AIDS. One example of government-level inertia cited was the drug registration process. Several drugs that have been approved by multiple regulatory agencies around the world are still not registered in many countries. Frustration was expressed at countries that have the potential for a strong response to the epidemic—literate/educated populations, decent communications and transportation infrastructure, a pharmaceutical sector, some degree of health care infrastructure—and yet still fail to respond effectively.

Civil Society, Communities, and Grassroots Organizations

In addition to government assuming responsibility, informants stressed the importance of accountability being in the hands of the people. Ultimately, it is the people of a country that must decide whether their government is spending adequately to address HIV/AIDS, and whether resources are going to the right places. Are the results of the government's efforts acceptable? If not, what will the response of the people be?

While individuals and communities need to hold their governments accountable for their responses to HIV/AIDS (or lack thereof), the people also bear responsibility for “bottom-up” accountability. People in countries need to accept responsibility for becoming educated about HIV/AIDS and how it threatens individuals, families, and communities. It was noted that, although many people know about HIV and modes of transmission, there is still a great deal of non-personalization of risk in many settings, resulting in low uptake of testing. People need to take responsibility for themselves, and need to be supported in doing so. Individuals and communities also need to become empowered and realize their potential to influence the course of the epidemic, and become mobilized and organized to take appropriate action. Funders can play a critical role in supporting these efforts, although some informants noted that many foundations are no longer supporting these types of initiatives.

Grassroots organizations and NGOs also bear responsibility, both in acting as accountability mechanisms with regard to their government's programs, and in themselves being accountable to their constituent populations and communities. Clear parameters exist for financial accountability, but some organizations may face greater challenges ensuring that financial documentation is well-

organized and transparent. Larger organizations may find this easier, as they can often afford the human resources to deal with accounting and financial management. Small NGOs often lack the skills or resources to meet these challenges, with perhaps only one person handling both program and financial management. Some informants felt the perception existed that NGOs are not really accountable to anyone, and underscored that this may contribute to why many NGOs are not well integrated into the communities they are purported to serve. Others noted that NGOs often rely heavily on volunteers, usually due to financial constraints. While there may be benefits to using volunteers, it may also be more difficult to hold volunteers accountable; accountability is more feasible when people can be paid for their efforts.

Funders

Donors were also cited as bearing responsibility both for monitoring what governments are doing, and for being transparent and accountable with regard to their own activities.

Funders, especially larger ones, have both the ability and responsibility to track what governments are doing and to hold them accountable—particularly governments that are recipients of aid from the funder in question. Informants stressed that, when donors hold countries accountable, they should ideally be held accountable to their own country plans and priorities, and not those of the donor. Some cited the example of PEPFAR funding, in which the U.S. government has promoted prevention policies that are not evidence based. Informants pointed out that increased flexibility in how programs can use their U.S. prevention funds is critical in the effort to truly enhance the use of the full range of prevention tools available to those most at risk for HIV/AIDS.

Donor agencies, particularly large and/or influential ones, were mentioned by several informants as requiring greater accountability. Given their power, foundations and agencies of this size have relatively little accountability. One respondent noted that the Global Fund has never received the amount of resources pledged to it. Who is accountable for that—donor countries?, the leadership of the Global Fund?, other foundations and organizations in a position of leadership or influence? In the case of very large donors such as the Bill and Melinda Gates Foundation, who are such funders accountable to? Informants stressed that the public and international community needs to be confident that the enormous resources such foundations possess are used appropriately. One respondent proposed accountability measures such as advisory committees or other peer-review mechanisms, which ideally would be comprised of representatives of the affected communities. This would help to create balance and prevent large foundations from becoming power brokers whose decision-making is disengaged from the communities it is working in.

Research

There has been an increased focus on international research ethics in the HIV/AIDS arena over the last several years. Studies of mother-to-child transmission and pre-exposure prophylaxis (PrEP) in Africa and Asia have received a great deal of media attention, and in some cases have been stopped prematurely; sometimes due to valid concerns about the trials, sometimes due to misunderstandings between the researchers and the communities. This attention on the role of researchers in global HIV/AIDS serves as a reminder that researchers and the agencies that fund them are accountable to both the communities they are working in, as well as the international community.

Informants stressed the importance of all types of research on HIV/AIDS—basic science, translational, clinical, behavioral, systems/health services, policy—as the more data there is about what works, the more efficiently limited resources can be allocated and mobilized to respond effectively. Several respondents, however, criticized the scientific community for not adequately focusing on “un-glamorous” areas of inquiry, such as operational and outcomes research. Questions such as how to develop a sustainable health care infrastructure do not receive the attention they deserve, respondents felt.

Researchers were also encouraged to focus on ethical issues of treatment access during and after studies they are conducting. Researchers were felt to have obligations for helping to determine the policy issues of how access to care during and after treatment and prevention studies will be provided. Informants pointed out the policy obligations of the organization that conducts the study—that they must make sure it is done in a way that the findings will ultimately be appropriately implemented within the populations that are studied. This also brings up the question of who bears the ultimate responsibility for the scale-up of study results—the research agency, national government, international donor community, or some combination thereof? With male circumcision, the studies have shown compelling efficacy, yet the scale-up has been unacceptably slow and weak.

Governments and donor agencies also bear responsibility for progress in research and must be held accountable. One issue is adequate funding of research. Another policy issue is liability—governments have not always been consistent about what protections would be provided to vaccine and pharmaceutical companies to pursue riskier vaccine development research. Doing so would encourage companies to partner more with governments and funders on research and development of such strategies.

VI. Issues Related to Partnerships

Introduction

Partnership means conducting all work in collaboration with countries, people, and organizations most affected by the HIV/AIDS epidemic in such a way that the partnership is an equal one or, even better, puts the affected country, community, or individuals into a leadership position.

Several respondents described the global response to HIV/AIDS as being characterized by too much fragmentation, duplication, and lack of coordination. Informants put forward several suggestions for developing meaningful partnerships and increasing collaboration in the HIV/AIDS field. Some of these ideas applied generally to a number of institutions and sectors involved in HIV/AIDS, while others were focused more specifically on funders and donor agencies.

Fostering Collaboration

Informants stressed the need for greater cross-collaboration, both among government departments, and between government and non-governmental organizations. This was seen to be especially true, as well as especially difficult to implement, in developing countries. In resource-

poor settings, almost every sector or structure—government, NGOs, etc—is in competition with each other for funding and resources. This is less the case in more developed settings.

A recurring theme was the need to work together, and foster a team approach to addressing the epidemic. This runs counter to the tradition in academia, where an individual or institution often works on its own. Greater responsibility needs to be taken by global players to convene meetings and work towards solutions cooperatively. It was noted that organizations often absolve themselves of their responsibility as conveners or consensus builders due to lack of interest or political reasons, and this was seen to hamper progress to forming useful partnerships and working collaboratively. In particular, respondents suggested the need for greater integration across prevention disciplines. Regional partnerships were cited as useful mechanisms for sharing ideas and transferring leadership skills from settings with more resources and/or experience to ones with fewer resources/less experience.

Role of Funders

Respondents suggested ways in which funders could be instrumental in developing meaningful partnerships, as well as encouraging them through the work that they do. One example would be helping to shape the way funding streams are designed. Prevention, care, and treatment programs would ideally be implemented in conjunction with other health services, but this is difficult to do when funding is allocated by disease category. For example, although the majority of people with HIV/AIDS die of tuberculosis, the issues of TB—stigma related to TB, challenges in diagnosis and treating TB—are often addressed separately from HIV, or go unaddressed altogether.

A major theme that emerged from interviews with respondents was the benefits that can be gained from philanthropic foundations partnering with government, NGOs, and other foundations. Public-private partnerships between government and major foundations were seen as important, as having a good track record, and as being a model that should continue to be supported. Similarly, it was felt that stronger partnerships between foundations and NGOs could be enormously beneficial. NGOs and foundations can partner together to accomplish work that governments cannot or will not do, and so this partnership model can help to fill critical gaps.

Lastly, respondents focused on encouraging large foundations and other funders (Ford Foundation, Gates Foundation, PEPFAR, Global Fund) to partner with each other and work together. How can these major players mesh with other to accomplish their goals? Informants expressed frustration that there has been unnecessary confusion and fighting over who is responsible for what and who should occupy which space in the HIV/AIDS milieu. It was felt that, if funders could work together more efficiently to address these structural issues, there is great potential for them to partner with each other to move quickly on ambitious projects that could have a large and lasting impact on the epidemic.

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APPENDIX: Key Informant Interview Questions

1. What do you think are the most important and/or urgent policy issues related to your HIV/AIDS work?
To what extent are these being addressed now?
2. In your work, which issues do you see “falling through the cracks” and not receiving the attention or resources they require?
Similarly, which populations do you see “falling through the cracks” and not receiving the attention or resources they require?
Can you help me to understand why you think they are “falling through the cracks”? (*eg, due to inadvertent effect of current policies; factors such as stigma, police actions, lack of resources, etc*)
3. What are some of the main social inequities that you think are driving the HIV/AIDS epidemic in the setting(s) in which you work?
What do you think can or should be done to help resolve these?
4. What are the main barriers to accomplishing your work and/or making progress on the areas/issues with which you work?
What are some of the key facilitators that help to move your work forward?
Who or what do you draw on for advice in addressing barriers/roadblocks? Why?
5. What gaps in leadership (at any level – government, community, multilateral, business, etc) can you identify that contribute to the problems your work addresses or that create barriers to accomplishing your work?
Conversely, can you identify examples where leadership has made a significant contribution to solving problems or eliminating barriers?
6. What could be done to strengthen accountability among the players you work with?
What effects do you think this strengthened accountability would have on the issues your work addresses?
7. In addressing the areas/issues you work on, who would need to be included in order to move forward and make progress? Why?
8. Who else should we be talking to regarding the areas/issues you work with? Why?