



# STIGMA, SCALE-UP, AND TREATMENT GOVERNANCE: STUMBLING BLOCK OR WINDOW OF OPPORTUNITY?

## WHY IS A “TREATMENT GOVERNANCE” SYSTEM NEEDED?

Recent international initiatives reflect, and are responding to, a worldwide movement for greater access and equity in HIV-related treatment. The new millennium has witnessed growing support from the global community to increase access to antiretroviral (ARV) treatment for those most in need—as evidenced by the U.S. President’s Emergency Plan for AIDS Relief, the World Health Organization’s (WHO) “3 by 5” Initiative, and the Global Fund to Fight AIDS, Tuberculosis and Malaria. By the end of 2004, these combined efforts, in addition to those of national governments, NGOs, and other donors, succeeded in providing ARVs to an estimated 700,000 people living with HIV in developing countries. This represents a dramatic increase of about 75 percent in the total number of people receiving treatment, compared with just one

year before. The global shift in support for treatment access, coupled with declining drug prices and the availability of generic drugs, has led many in the field to recognize that the barrier to treatment is no longer simply a matter of financial resources.

The President’s Emergency Plan, which by March 2005 had supported treatment for 235,000 people living with HIV, seeks to reach 2 million people with ARV treatment by 2008, while WHO had hoped to expand treatment coverage to 3 million people

by the end of 2005. Achieving these objectives requires strengthening the health and related systems necessary to deliver and sustain treatment in settings where capacity (e.g., institutions, systems, policies, personnel) is inadequate or currently unable to cope with the expected demand. In broad terms, this involves the construction or strengthening of treatment infrastructures, such as laboratory facilities, health worker recruitment and training, and community and patient involvement, as well as tertiary and community-based health systems

***The delivery of effective ARV treatment can be imagined as the most powerful instrument currently available to combat stigma and discrimination. It enables people living with HIV and their families to re-enter the mainstream of social and economic activities and relations. ...[And] as awareness of the benefits of treatment increases in the general community, the stigma of HIV as an immediately fatal virus decreases. ...The potential of increased treatment access to effect these changes in stigma, however, depends on several factors, notably the quality of services and the efforts made to integrate and involve people living with HIV in the process.***

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development, including palliative and home-based care. Importantly, while treatment programs scale up, special steps also must be taken to ensure their integration with prevention activities, as these two aspects can be mutually reinforcing or can hinder each other's success. For example, poor treatment adherence can give rise to drug resistant strains of the virus; on the other hand, lack of effective prevention programs leads to more people in need of treatment, thereby increasing the strain on overstretched treatment and care programs. Integration with more general medical care delivery also is critically important for concomitant medical problems, inpatient care when necessary, and for treatment of opportunistic infections such as tuberculosis. The identification and medical follow-up of large numbers of people living with HIV also provides the opportunity to design and implement "secondary" prevention programs that can support those accessing the system. Table 1 below sets out the basic challenge facing scale-up efforts. These numbers confront us with the urgency of access

and the critical importance of developing sustainable systems, because what lies behind the numbers are the people who will require lifelong access to treatment and care services.

In response to the emerging challenges and opportunities brought about by treatment scale-up, this briefing paper introduces the notion of "treatment governance"—a concept used here to capture and systematize the various components of an effective, expanded, and sustainable ARV treatment program. As defined below, treatment governance stresses the importance of monitoring and managing the impact of ARV treatment, particularly in settings with little ARV history and experience.<sup>1</sup> In essence, the concept of treatment governance described here aims at providing a broad framework capable of organizing treatment systems. The framework should be used to encourage governments, donors, researchers, NGOs, and activists to consider key questions about scale-up, for example: Who has access? Is access equitable? Does it reach those most in need? What is the

impact of long-term treatment on the patient? On the virus? What are the barriers to and facilitators of adherence? What is the nature of the interaction between prevention and treatment efforts?

It is not unreasonable to assume that the momentum created by the global movement for scaling up treatment can change the HIV policy and program landscape. The ultimate success of these efforts, however, depends on the ability of treatment programs to effectively attract patients and sustain them on appropriate ARV regimens. A key concern for improving treatment governance, therefore, will be to address other barriers to treatment access and adherence, particularly stigma and discrimination. The fear or experience of stigma and discrimination—including rejection by family and friends, loss of jobs or housing, poor treatment from healthcare workers, and, in extreme cases, violence—is a powerful deterrent to seeking HIV testing and treatment. In an ideal scenario, scale-up will encourage people to come

**TABLE 1. ESTIMATED NUMBER OF PEOPLE RECEIVING AND IN NEED OF ARV THERAPY IN LOW- AND MIDDLE-INCOME COUNTRIES, JUNE 2005**

| REGION                    | ESTIMATED NUMBER OF PEOPLE ... |                    |                 |
|---------------------------|--------------------------------|--------------------|-----------------|
|                           | Receiving Therapy              | Needing Therapy    | Percent Treated |
| Sub-Saharan Africa        | 500,000                        | 4.7 million        | 11%             |
| Latin America/Caribbean   | 290,000                        | 465,000            | 62%             |
| East/South/Southeast Asia | 155,000                        | 1.1 million        | 14%             |
| Europe/Central Asia       | 20,000                         | 160,000            | 13%             |
| North Africa/Middle East  | 4,000                          | 75,000             | 5%              |
| <b>TOTAL</b>              | <b>970,000</b>                 | <b>6.5 million</b> | <b>15%</b>      |

*Note: Some numbers do not add up because of rounding.*  
Source: WHO and UNAIDS, 2005.

1. It is also a framework that might usefully be applied to countries with longer treatment histories, where the impact on prevention activities is beginning to be felt.

forward to seek the treatment they need, and will help to alter the perception that HIV is an immediately fatal virus, or that people affected by it should be feared or shunned. Yet, especially in the early going, rapid treatment scale-up also may increase exponentially the potential for instances of stigma and discrimination—more people would be disclosing their status and facing possible rejection, more HIV-positive workers could be fired or denied insurance coverage, and more patients would be interacting with healthcare workers who might provide sub-optimal care or breach confidentiality.

If done properly, scale-up and measures to improve treatment governance provide the opportunity to address stigma and discrimination, to meaningfully involve people living with HIV and the most vulnerable groups, to establish the synergy between prevention and treatment, and to change fundamentally the way the world conceptualizes and responds to HIV. If we fail to do so, stigma and discrimination could be an impassable stumbling block on the path to expanded treatment access for those most in need. This paper further explores the interrelationships among stigma, scale-up, and improved treatment governance, and highlights the work that the USAID-funded POLICY Project has undertaken to involve HIV-positive people and address treatment issues in Vietnam.

## DEFINING TREATMENT GOVERNANCE

“Governance” is traditionally associated with the role of government and the operation of the state. Theorists have expanded and broadened the concept to account for shifting social, political, and economic conditions that emphasize the governance roles of new actors and sectors. The use of the concept in health, including HIV, is well established in the social science literature and as a strategic framework for HIV responses.<sup>2</sup> Governance can be defined simply as the management of the course of events in a system. It incorporates social relations, environmental factors, and resource allocation. In essence, governance practices are aimed at steering complex systems toward desired outcomes.<sup>3</sup>

In this paper, we use “treatment governance” to encompass the monitoring and management of integrated HIV treatment-related systems and practices designed to achieve optimal HIV individual and population-based health outcomes or ARV policies and programs. The concept of governance has relevance for ARV treatment

systems because of the clear need to link the management of ARV activities, practices, and events not only to each other—as in linking physician training with prescription practices and clinical skills—but also to socio-cultural and environmental factors, such as stigma and discrimination. In this sense, governance is especially relevant for HIV because of the complex interaction between personal, social, political, and economic factors. For example, it is well established that sexual behavior, economic disparity, and gender relations comprise a set of issues whose interactions clearly influence HIV outcomes (especially for women), but these interactions are not captured easily by simple models that assume static causal pathways. Similarly, tracking and understanding the impact of ARV treatment requires an approach capable of assessing the range of probable factors that may be linked to the desired outcomes. Governance is used here as a framework allowing for system change, or development, capable of attracting and retaining people as active participants in their own care and treatment, not as the governance of an individual’s behavior.

***In this paper, we use “treatment governance” to mean the monitoring and management of integrated HIV treatment-related systems and practices designed to achieve optimal HIV individual and population-based health outcomes.***

2. See Peter Soderholm. 1997. *Global Governance of AIDS: Partnerships with Civil Society*; PACT and USAID. 2001. *Survival Is the First Freedom: Applying Democracy and Governance Approaches to HIV/AIDS Work*; and United Nations Development Programme (UNDP), Bureau for Development Policy. 2001. *HIV/AIDS: A Governance Challenge*.
3. See Scott Burris. 2004. “Governance, Microgovernance and Health.” Paper presented at the Conference on SARS and the Global Governance of Public Health, Temple University Beasley School of Law, Philadelphia, PA (Draft: April 30, 2004, pp. 2-3).

**TABLE 2. COMPONENTS OF A TREATMENT GOVERNANCE FRAMEWORK**

| AREA   | ISSUE  | INDICATORS  |
|--|--|---|
| Sustainability of ARVs (this is multi-dimensional) | <ul style="list-style-type: none"> <li>Resource planning linked to estimates of ARV demand and estimates of need</li> </ul>  | <ul style="list-style-type: none"> <li>Resource plans developed</li> <li>Investment/financing strategy implemented</li> <li>Also contingent on defined ARV treatment policies and guidelines for first-, second-, and third-line regimens, and for children</li> </ul>  |
| Stigma and discrimination                          | <ul style="list-style-type: none"> <li>Equity of access</li> <li>Access for mobile populations</li> <li>Rural versus urban</li> <li>Slums</li> <li>Migrants versus citizens</li> </ul>                           | <ul style="list-style-type: none"> <li>National policy on ARV equity developed, and/ or related policies amended to include equity</li> <li>Equity monitoring system implemented<sup>4</sup></li> <li>Number of people living with HIV receiving treatment; this to include a gender analysis, as well as other relevant variables that reflect equity</li> <li>Increased HIV testing</li> <li>Qualitative research/case studies</li> <li>HIV prevention among mobile populations includes treatment component</li> </ul> |
| Involvement of vulnerable groups                   | <ul style="list-style-type: none"> <li>Representation and program involvement of people living with HIV</li> </ul>   | <ul style="list-style-type: none"> <li>National networks of people living with HIV represented on treatment governance committees, and monitoring function established</li> <li>Treatment preparedness and literacy programs for and driven by HIV-positive people implemented</li> <li>People living with HIV and affected communities involved as peer counselors and at treatment sites</li> <li>Family support systems developed and implemented</li> </ul>   |
| Delivery systems and infrastructure                | <ul style="list-style-type: none"> <li>Human resources adequate to meet need</li> <li>Health systems strengthened to meet expected demand</li> </ul>   | <ul style="list-style-type: none"> <li>Number of healthcare workers trained and able to meet demand</li> <li>ARV management and program systems coordinated</li> <li>Laboratory and clinical facilities adequate</li> </ul>   |
| Compliance and adherence                           | <ul style="list-style-type: none"> <li>Healthcare workers and patients understand and patients adhere to treatment regimes</li> </ul>  | <ul style="list-style-type: none"> <li>Reported compliance</li> <li>Reduced morbidity and mortality</li> <li>Biosurveillance of viral suppression</li> <li>Biosurveillance of viral resistance</li> <li>Qualitative research/surveys</li> </ul>   |
| Prevention   | <ul style="list-style-type: none"> <li>Prevention and treatment integrated</li> </ul>  | <ul style="list-style-type: none"> <li>Number of patients receiving integrated prevention and treatment</li> <li>Activities to promote prevention among HIV-positive people implemented</li> <li>HIV prevalence and behavioral surveillance data linked to treatment provision</li> </ul>   |
| Monitoring and evaluation (M&E)                    | <ul style="list-style-type: none"> <li>One national M&amp;E system and database</li> <li>Strategic information system</li> </ul>   | <ul style="list-style-type: none"> <li>One national M&amp;E system established</li> <li>One national ARV database established</li> <li>ARV policies and guidelines</li> <li>Relevant information from national, state, and local levels compiled and analyzed</li> </ul>  |
| Coordination                                       | <ul style="list-style-type: none"> <li>National and international ARV initiatives linked and synchronized</li> <li>Awareness of the impact of treatments raised among national and local stakeholders</li> </ul> | <ul style="list-style-type: none"> <li>Policies and protocols synchronized under M&amp;E system</li> <li>One national Treatment Governance committee established under national HIV committee</li> <li>National treatment awareness campaign</li> </ul>   |

4. Defining equity in relation to access to ARVs cannot be resolved through the use of a simple formula; policymakers have to make difficult decisions regarding who is granted access when the demand for ARVs exceeds the supply. UNAIDS and WHO have developed a guidance paper which reviews the major debates and offers a framework. See UNAIDS and WHO. 2004. *Guidance on Ethics and Equitable Access to HIV Treatment and Care*.

It is clear from worldwide experience with ARVs so far that several factors are critical to achieving successful treatment programs. Table 2 illustrates eight broad areas of action for effective treatment governance. These issues are presented as a starting point for discussion of a treatment governance approach, rather than as a comprehensive list.

## PUTTING TREATMENT GOVERNANCE INTO PRACTICE

We have outlined, in a broad sense, the conceptual framework for treatment governance. The next question posed is what this would look like in practice. Ideally, treatment governance will increase the linkages among HIV-positive people, healthcare workers, program managers, policymakers, donors, and others involved in the delivery of treatment, and will facilitate a greater capacity to access, measure, and monitor the progress of treatment scale-up. At a minimum,

operationalizing an effective treatment governance program requires the following elements.

**Strengthen comprehensive treatment monitoring.** ARV provision on a scale that will meet the Emergency Plan treatment targets requires a system capable of tracking access and impact across multiple levels. Treatment governance is a conceptual framework designed to capture and comprehensively systematize monitoring and evaluation of ARV programs. It is the basis for a system, currently lacking in the area of HIV treatment and care, which will operate parallel to and complement surveillance systems and other prevention activities. In practice, treatment governance will link target-based data evaluation systems with broader but equally vital data on, for example, community levels of access and adherence (this information is central to monitoring the impact of ARV scale-up on viral resistance and, therefore, on forecasting ARV second-line requirements). However, the

framework of governance moves beyond the management and analysis of data because it allows for an expanded frame of reference that incorporates issues of equity, transparency, and accountability, and provides a forum for guiding data utilization and feedback to key stakeholders.

### **Use an interdisciplinary approach.**

Effective treatment governance is more than the management of HIV-related health systems; it must also incorporate and link with social issues. Castro and Farmer (2005) provide the basis for developing these links, as presented in Table 3. While they acknowledge that the analytical integration of issues as diverse as stigma and gender with behavioral and biological data is underdeveloped in practice, the solution lies in designing an approach that is a “novel synthesis” of biological and social frameworks, drawing on the full range of disciplinary methods from epidemiology to ethnography, all of which are organically engineered into the program.

**TABLE 3. ASSESSING THE IMPACT OF A COMPREHENSIVE HIV PROGRAM: POSSIBLE DATA POINTS**

| INDICATORS  | SOURCES OF INFORMATION NEEDED TO EVALUATE INDICATORS |
|---|--|
| Impact on patient outcomes                            | Patient charts, weight, activities of daily life     |
| Impact on burden of disease                           | Prenatal screening                                   |
| Response to local calls for equity                    | Community forums, focus groups                       |
| Reduced mortality                                     | Chart review, community health workers' reports      |
| Reduced rates of hospitalization                      | Daily reports, chart review                          |
| Reduced stigma  | Ethnographic inquiry, case histories                 |
| Improved staff morale                                 | Staff meetings, ethnographic study                   |
| Increased demand for voluntary counseling and testing | Laboratory registers, daily reports                  |
| Meeting public health goals                           | External Ministry of Health evaluation               |

Source: Castro, A.C., and P. Farmer. 2005. “Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti.” *American Journal of Public Health* 95 (1): 53–59.



**Encourage multisectoral collaboration.** The most challenging aspect of the treatment governance approach outlined here is the absolute necessity for coordination and collaboration among government, civil society, the private sector, and donors. The development of parallel systems of ARV treatment becomes a very real possibility without this coordination; this would not only overburden healthcare workers and managers, but also would make the task of data collection and, therefore, overall national management of ARVs, almost impossible. Wider discussion of this issue will be critical in determining appropriate national coordination mechanisms and the policy and legal environments capable of addressing and resolving access and equity imbalances in the provision of ARVs.

**Link prevention and treatment.** The integrated nature of a treatment governance framework recognizes the need to link and build synergies between prevention and treatment. Treatment scale-up changes the relationship between prevention and treatment. It provides new opportunities for better prevention and dissolves the traditional divide between the two domains (e.g., through clear links between testing and access to treatment, and through better access to HIV-positive communities for prevention activities). In many countries, including those with experience of ARVs, the impact of ARV treatment on the long-term progress of the epidemic has not, until recently, been the subject of much research. Treatment has been developed and delivered with only a partial acknowledgment that it represents a major shift in the way HIV is conceptualized (from fatal to chronic, for example). Specifi-

cally, the question of how sustainable long-term access to ARVs will affect prevention programs is only now being addressed, and this remains mainly at a theoretical level in countries with generalized epidemics. Hogan and Salomon (2005) argue that treatment and prevention integration requires a much more sustained and rigorous monitoring of impact to achieve the balance required for successful individual and population-based outcomes. Related to this are many outstanding questions, including how to effectively link and re-orientate (or sustain) prevention programs when the emphasis of the national response is shifting to treatment. For example, how do we strengthen voluntary counseling and testing to meet both testing and treatment goals (Global HIV Prevention Working Group, 2004; Lamptey and Wilson, 2005)? Mathematical modeling of the potential impact of increasing treatment coverage suggests that effective integration of prevention and treatment provides the best outcomes in both areas (Salomon et al., 2005).

**Involve people living with HIV and the most at-risk populations, and understand their treatment and prevention needs.** In most developing countries, rapid scale-up systems designed to deliver new HIV treatments require the creation of entirely new systems, policies, and programs aimed at ensuring optimum benefits from their introduction. There is also the need to monitor treatment awareness and knowledge among at-risk populations to re-orientate prevention programs so as to account for this new dimension—for example, to sustain safe behaviors. In developing countries, treatment scale-up represents one of the largest increases in invest-

ment in health systems development. Scale-up should bring a far larger proportion of vulnerable and at-risk individuals into contact with health-care providers, creating an unprecedented opportunity to increase prevention coverage and impact (Lurie et al., 2005). However, it appears that, in many cases, countries are not taking advantage of this opportunity. This point is underscored by a report from South Africa that quotes Manto Tshabalala Msimang, the health minister, who voiced the concern that efforts to scale up ARVs are “working in the dark,” with little systematic capacity to monitor what patients are doing, track how they are adhering to the regimes, or understand why some people stop treatment (PLUSNEWS, 2005). The implications of the lack of a systemic monitoring for ARV scale-up in relation to treatment compliance and side effects are huge; several likely results of not monitoring treatment include the development of drug-resistant strains of HIV and increased costs for replacement therapy. Promoting meaningful, active participation of people living with HIV and vulnerable groups is the best way to ensure that treatment programs do not scale up “in the dark,” but to include these populations in a meaningful way, one must first address stigma and discrimination.

### **A SPECIAL CONCERN FOR EFFECTIVE TREATMENT GOVERNANCE: STIGMA AND DISCRIMINATION**

Stigma and discrimination have been constants for those living with HIV. This is true in developing as well as developed nations, and in concentrated as well as generalized epidemics. Stigma and discrimination affect

***If policies and programs are not designed to address stigma, they will not work and they will not reach the communities and people that are at the heart of the epidemic.***

women, men, orphans, youth, care providers, and the most at-risk populations. A failure to understand and address this problem represents a failure of imagination across the spectrum of prevention, treatment, and care, and, ultimately, in our ability to shape an effective response. Understanding the roles of stigma and discrimination depends on our ability to think through the difficult and complex social and emotional dimensions of the epidemic. We must look through the eyes of those most affected and try to understand how stigma operates as a structural barrier to program and policy implementation.<sup>5</sup> If, for example, programs and policies do not involve those most affected, then at minimum they will have little impact, and it is more likely they will have a negative effect on the conditions they seek to alleviate (Stephens, 2004). Put simply, if policies and programs are not designed to address stigma, they will not work and will not reach the communities and people that are at the heart of the epidemic. Policies and practices that actively stigmatize and discriminate against people living with HIV are counter-productive, alienate affected and at-risk populations, and can encourage a false sense of safety among the general population.

***Impact of stigma and discrimination on individuals.*** Stigma and discrimination—including both the individual internalized feelings regarding HIV status and external experiences with discrimination—are significant barriers to expanding testing and treatment access. Fear of judgment from healthcare workers and family members and fear of disclosure prevents many people from seeking voluntary counseling and testing. Upon learning their HIV status, people may lose hope, isolate themselves, or avoid social interactions and opportunities, as the following testimonies from HIV-positive men and women in South Africa illustrate:

“Some [people living with HIV] just cannot find it in themselves to disclose because of the stigma that might follow. They just have so much to lose—the respect of their community and family. Their friends will reject them. So they live in silence.” (POLICY et al., 2003, p. 22)

“Even if there is an offer of a job, I would not apply. It’s hard because you think that they will draw blood or look at your urine and see if something is wrong.” (POLICY et al., 2003, p. 21)

Actual experiences with stigma further reinforce the desire of people

living with HIV to isolate themselves. Stigma and discrimination in the healthcare system are major barriers to access. A recent study in Vietnam found that many people living with HIV had experienced negative attitudes and actions from healthcare workers (Khuat et al., 2004). Too often, the desire to avoid possible negative reactions causes people to delay seeking treatment until they become symptomatic with an AIDS-defining illness, limiting the efficacy of ARV treatment. A report from Malawi notes that many pregnant women choose not to undergo HIV testing, despite the promise of free ARV drugs, because of the social stigma surrounding the virus (Sumbuleta, 2005). Once on treatment, stigma becomes a barrier to adherence. If a woman fears disclosing her status to her husband, for example, she may have to hide her pills or may not be able to visit clinics for regular check-ups. While a study of treatment adherence in Soweto, South Africa, showed that most people achieved an adherence rate of 95 percent or higher, “fear of stigmatization (rejection or violence or both)” by a patient’s partner significantly decreased the likelihood of maintaining adherence at 95 percent or above (Nachega et al., 2004, p. 1054). For treatment to be effective, treatment governance must address the internal stigma felt by people living with HIV and vulnerable groups and reduce stigma and discrimination within the community. This underscores the importance of developing innovative, flexible, and sensitive adherence programs and approaches that address social and cultural constraints, as well as medical

5. For an overview of HIV-related stigma, see P. Aggleton and R. Parker. 2002. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination (Revised)*. Geneva: UNAIDS.

demands. Even if these programs produce modest gains, they also will improve cost effectiveness (Lucas et al., 2004).

**Impact of stigma and discrimination on families.** The role of the family is pivotal in the care and treatment of HIV-positive people. In countries like Vietnam, the absence of well developed institutional-based care facilities, as well as an existing culture of family-based care and support, highlights the central role of the family in HIV care and treatment. For most people living with HIV, the family is the only resource they can turn to and is the primary means for receiving economic support and healthcare. A study of the causes and effects of stigma in Vietnam found that stigma and discrimination affects families caring for people living with HIV in profound and multiple ways (Khuat et al., 2004). The economic impact of HIV infection, through lost income and high treatment costs, imposes a heavy burden from which it is hard to recover. Stigma limits opportunities to access credit and loan facilities needed to replenish family finances. While many families do support relatives who are living with HIV, others find the shame of HIV an insurmountable barrier to accessing HIV treatment and services. People living with HIV report that families will withhold support for fear of the shame and loss of family honor associated with HIV.<sup>6</sup>

**Impact of stigma and discrimination on policymaking.** Structural, institutionalized stigma is pervasive and difficult to address. One area in which stigma is a factor is in relation to decisions regarding which groups get access to treatment resources. How people become infected and the degree to which they are deemed to be culpable (or not) has, from very early on, structured debate and decisions about access to resources. A classic formulation is the distinction between those who are deemed “guilty” and those who are “innocent.” ARV treatment raises new questions about the social and economic dimensions of access, which are seldom discussed and rarely if ever presented in a format that provides some guidance to HIV treatment services, potential beneficiaries, or communities.<sup>7</sup> For example, in Vietnam, a significant proportion of clinically treatment-eligible people living with HIV also have a history of injection drug use. Historically, injection drug users (IDUs) have experienced profound difficulties and discrimination in accessing and using HIV services. The country’s current approach of compulsory rehabilitation has struggled to incorporate effective treatment, care, and support for HIV-positive IDUs. The dominant view of IDUs as socially unstable places them at a distinct disadvantage in relation to equitable access to ARVs. Discussions about ARV access at the provincial level already have involved the

development of social criteria which suggest that the mode of infection and perceptions of behavior and lifestyle are real and influential factors in decisions regarding treatment eligibility.

**Impact of treatment scale-up on stigma and discrimination.** The idea that the availability of effective treatment will reduce stigma or help people overcome reluctance to seek HIV testing has not yet been proven. Castro and Farmer (2005) argue that the provision of treatment in Haiti has made progress in reducing stigma. However, a report from the Centers for Disease Control and Prevention estimates that more than 40 percent of people in the United States who may be eligible are not accessing treatment, and that stigma remains a factor in people’s reluctance to be tested for HIV or use HIV services once a positive test has been confirmed.<sup>8</sup> While the availability of treatment provides an incentive to seek testing to confirm or allay fears about HIV status, this potential depends on the quality of the services available. Critical questions regarding the accessibility of testing services and their capacity to offer services in a non-judgmental manner must be addressed.

In sum, the delivery of effective ARV treatment can be imagined as the most powerful instrument currently available to address stigma and discrimination. It can enable people living with

6. Focus group discussion with people living with HIV in Hanoi, Vietnam, February 28, 2005.

7. For an exception to this, see D.P. Wilson and S.M. Blower. 2005. “Designing Equitable Antiretroviral Allocation Strategies in Resource-constrained Countries.” *PLoS Med* 2 (2): 0132–0141. Retrieved April 14, 2005, from [http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/10.1371\\_journal.pmed.0020050-S.pdf](http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/10.1371_journal.pmed.0020050-S.pdf).

8. Teshale, E. 2005. “Estimated Number of HIV-infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States” (Abstract 167). Paper presented at the 12th Conference on Retroviruses and Opportunistic Infections, Boston, MA, 22–25 February, 2005. The study indicated that of the people living with HIV in the U.S., about 212,000 people—44 percent of the total—who should be eligible for ARVs are not getting them. About 42 percent of these individuals—89,000 people—are undiagnosed and do not even know they have HIV. Approximately 34 percent of this group are receiving care for HIV, but are not being prescribed antiretroviral therapy, and about 24 percent of them know they are HIV-positive, but have not sought medical help. Reported in *Doctors Guide*. Retrieved October 26, 2005, from <http://www.docguide.com/news/content.nsf/news/8525697700573E1885256FB6004B73A8>.



HIV and their families to re-enter the mainstream of social and economic activities and relations. In theory, the availability of treatment should increase the uptake of testing and counseling services as people who are at risk begin to see that there are real health benefits when they access HIV services. As awareness of the benefits of treatment increases among the general community, the stigma of HIV as an immediately fatal virus decreases. It is probably overstating the case to assume that this pattern will result in “normalization” of HIV and the complete elimination of stigma and discrimination. However, at least in terms of the shift of the disease from fatal to chronic status, and in the ability of HIV-positive people to maintain employment and other social and economic activities, there should be a decrease in stigma levels. The potential of increased treatment access to effect these changes in stigma, however, depends on several factors that must be addressed by treatment governance mechanisms, notably the quality of services and the efforts made to integrate and involve people living with HIV in this process.

## **REDUCING STIGMA AND IMPROVING TREATMENT ACCESS THROUGH MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV: MAKING PROGRESS IN VIETNAM**

People living with HIV “remain a major under-utilized resource in the fight against the global epidemic” (Global HIV Prevention Working Group, 2004, p. 19). For many people working in HIV prevention, treatment, and care, the essential truth of this statement is all too familiar. For

others, the assertion that the role of HIV-positive people is critical to an effective response remains at the level of rhetoric, but is not to be taken seriously (Stephens, 2004). What we know about the importance of involvement of people living with HIV in prevention, treatment, and care should, however, galvanize innovative activities and responses around the world. It should be a call to include and support organizations of people living with HIV as real partners in a comprehensive response. It is often the case that HIV-positive people are the first architects and initiators of activities designed to support and educate communities affected by HIV. The statement and call for the Greater Involvement of People Living with HIV/AIDS (GIPA) is now 11 years old. The principle was established from the very beginning of the epidemic through the importance of activism, prevention, and care and support activities by people living with HIV. It is a principle that is constantly renewed and kept alive through the work of HIV-positive individuals and communities around the world.

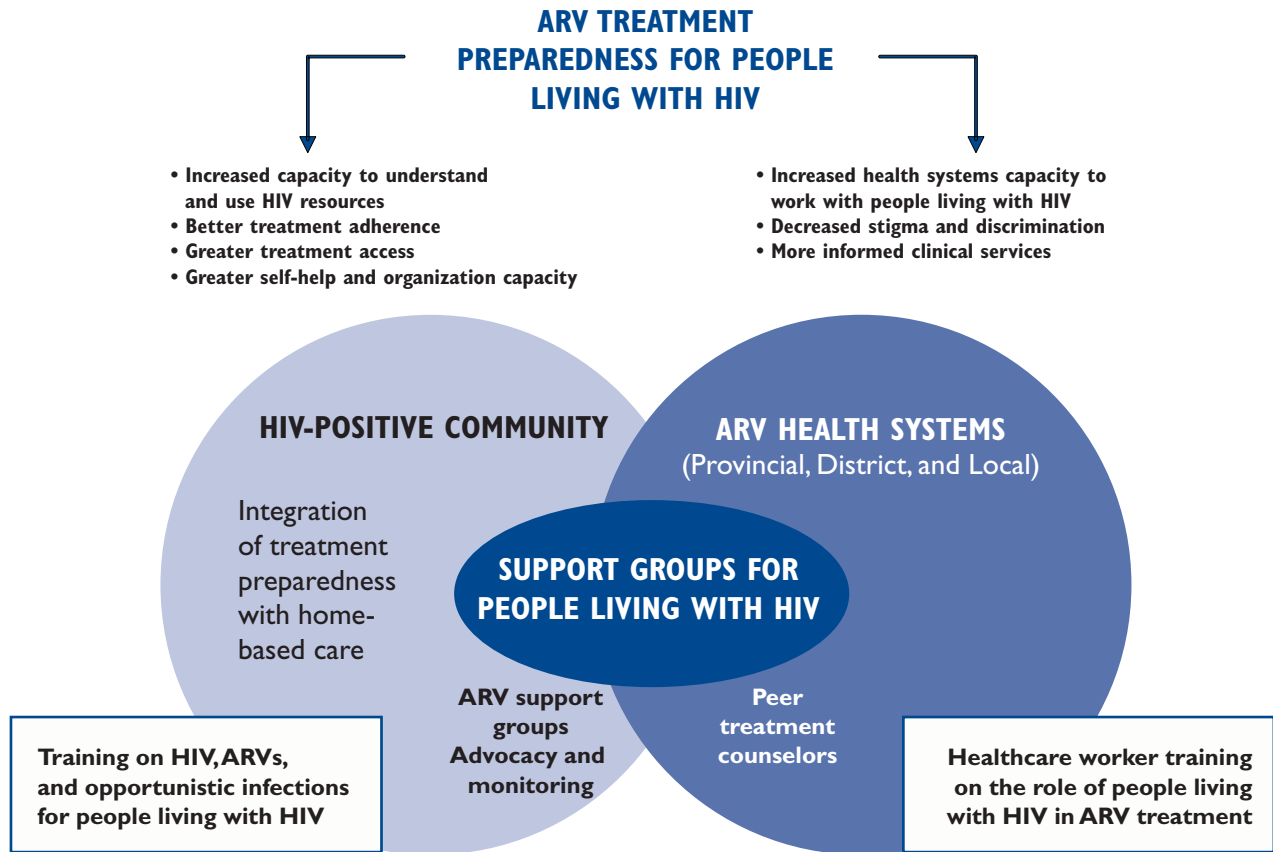
Unfortunately, and to the detriment of better outcomes in prevention, treatment, and care, GIPA remains an ideal that is largely ignored when we consider the role of HIV-positive people in the global response to HIV. In Vietnam, increasing and supporting the involvement of people living with HIV and addressing the stigma surrounding the virus are critical components of the POLICY Project’s approach to creating an enabling environment for improved HIV prevention, treatment, and care. Our work has involved a series of activities designed to support the development

of capacity among people living with HIV and link meaningful involvement with the evolving national response. The development of organizational capacity is a cornerstone of meaningful involvement and it provides the necessary foundation for people living with HIV to be able to actively address stigma and discrimination.

The introduction of wider scale access to ARV treatment provides an opportunity for increasing the level of engagement of people living with HIV with the systems designed to address their needs. POLICY actively supports the involvement of people living with HIV in treatment programs in Vietnam. One activity is the development of a treatment preparedness program for HIV-positive people that is designed to raise awareness of the new treatment options among people living with HIV and, at the same time, involve them as partners in the evolving treatment system. Figure 1 (see page 10) describes in graphic form the development and implementation of a treatment preparedness program. This program is aimed at increasing knowledge and capacity to manage ARVs among people living with HIV, and at introducing and establishing HIV-positive treatment counselors as necessary partners in ARV treatment sites.

A key aspect of treatment preparedness is outreach to communities that lack access to services and information. This is an area where people living with HIV are leading the way in Vietnam. For example, a core group of HIV-positive people from the Bright Futures Group based in Hanoi has made independent links and contacts with affected communities in several northern provinces in Vietnam. With

**FIGURE I. TREATMENT PREPAREDNESS IN VIETNAM**



Source: D. Stephens, POLICY/Vietnam.

support from POLICY staff, the Bright Futures Group has brought more than 300 people to Hanoi to access HIV services. Without this initiative, these people living with HIV, their families, and communities would have remained isolated and without access to HIV information and services. This activity has stimulated the creation of several provincial self-help and support groups that enjoy the trust and respect of the community. The impact has been a reduced reported level of felt stigma and discrimination in the community, as well as increased access to essential services.

**THE WAY FORWARD**

Emerging national and international initiatives that complement the multitude of ongoing grassroots efforts to expand treatment access have the potential to dramatically change the way in which the world conceptualizes and responds to HIV. The new treatment era brings with it the need to develop mechanisms to monitor and manage large-scale treatment programs—including understanding behaviors that support adherence, tracking drug-resistant strains of the virus, linking prevention and treatment activities, and ensuring equitable access. To help manage the

challenges and opportunities brought about by expanded treatment, we have proposed the concept of “treatment governance” and have explored its relationship to two components that are essential for effective treatment scale-up: reducing stigma and discrimination and actively involving people living with HIV and vulnerable groups. Stigma reduction and GIPA strategies must work hand-in-hand with efforts to strengthen treatment governance. We have used stigma reduction and GIPA as examples, because while these issues are more often than not peripheral to the development and implementation of

treatment, the emerging evidence suggests that reduction of stigma and the involvement of people living with HIV are critical to successful scale-up efforts, and their incorporation provides a “bridge” that can help link prevention and treatment activities.

Successful treatment scale-up will be contingent on the capacity of national and international actors to rethink the landscape of HIV prevention, treatment, and care. In our view, the concept of treatment governance

merits more attention, both as a conceptual framework and as the basis for improving the management and monitoring of HIV responses. The development of this approach requires a phased introduction, beginning with national-level forums that examine the potential for prevention and treatment integration and the articulation of a treatment governance strategy. We also acknowledge that this introduction and the examples given here do not provide a comprehensive over-

view; however, we hope that they do provide the basis for discussion and development. If treatment governance is done successfully, countries will be better positioned to eliminate the barriers to treatment access and adherence, as well as to better understand the needs of the people that treatment programs are designed to reach. If not, countries will continue to struggle “in the dark” and miss the opportunities afforded by expanded treatment.

## REFERENCES

- Aggleton, P., and R. Parker. 2002. *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination* (Revised). Geneva: UNAIDS.
- Burris, S. 2004. "Governance, Microgovernance and Health." Paper presented at the Conference on SARS and the Global Governance of Public Health, Temple University Beasley School of Law, Philadelphia, PA.
- Castro, A. C., and P. Farmer. 2005. "Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti." *American Journal of Public Health* 95 (1): 53–59.
- Global HIV Prevention Working Group. 2004. *HIV Prevention in the Era of Expanded Treatment*. Seattle, WA, and Menlo Park, CA: Bill & Melinda Gates Foundation and Kaiser Family Foundation. Available at <http://www.kff.org/hivaids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=36967> [accessed April 14, 2005].
- Hogan, D. R., and J. A. Salomon. 2005. "Prevention and Treatment of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome in Resource Limited Settings." *Bulletin of the World Health Organization* 83 (2): 135–143.
- Khuat Thu Hong, Nguyen Thi Van Anh, and J. Ogden. 2004. *Understanding HIV and AIDS-related Stigma and Discrimination in Vietnam*. Washington, DC, and Hanoi, Vietnam: International Center for Research on Women and Institute for Social and Development Studies.
- Lamprey, P., and D. Wilson. 2005. "Scaling Up AIDS Treatment: What Is the Potential Impact and What Are the Risks?" *PLoS Med* 2 (2): 0102–0104. Available at [http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/0.1371\\_journal.pmed.0020039-S.pdf](http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/0.1371_journal.pmed.0020039-S.pdf) [accessed April 14, 2005].
- Lucas, G. M., A. W. Wu, and L. W. Cheever. 2004. "Adherence to Antiretroviral Therapy: An Update of Current Concepts." *Current HIV/AIDS Reports* 2004 (1): 172–180. Available at <http://www.biomedcentral.com/1548-3568/1/172/abstract> [accessed February 24, 2004].
- Lurie, M. N., C. Akileswaran, and K. H. Mayer. 2005. "Opportunities for Preventing HIV in Treatment Settings in Developing Countries." *The Lancet Infectious Diseases* 5 (2): 66–68.
- Nachega, J., D. Stein, D. Lehman, D. Hlatshwayo, R. Mothopeng, R. Chaisson, and A. Karstaedt. 2004. "Adherence to Antiretroviral Therapy in HIV-Infected Adults in Soweto, South Africa." *AIDS Research and Human Retroviruses* 26 (10): 1053–1056.
- PACT and United States Agency for International Development (USAID). 2001. *Survival Is the First Freedom: Applying Democracy and Governance Approaches to HIV/AIDS Work*. First Edition. Washington, DC: PACT.
- POLICY Project, Centre for the Study of AIDS/University of Pretoria, USAID, and Chief Directorate: HIV/AIDS & TB/Department of Health. 2003. "Siyam'kela: Measuring HIV/AIDS-related Stigma—A Report on the Fieldwork Leading to the Development of HIV/AIDS Stigma Indicators and Guidelines." Washington, DC: POLICY Project/Futures Group. Available at [http://www.policyproject.com/Special/SA\\_research.pdf](http://www.policyproject.com/Special/SA_research.pdf) [accessed June 15, 2005].
- PLUSNEWS. 2005. "South Africa: Monitoring ARV Patients Like 'Working in the Dark'." UN-OCHA Integrated Regional Information Networks PlusNews. Available at [http://www.plusnews.org/DSreport.asp?ReportID=4515&SelectRegion=Southern\\_Africa](http://www.plusnews.org/DSreport.asp?ReportID=4515&SelectRegion=Southern_Africa) [accessed April 14, 2005].
- Salomon, J. A., D. R. Hogan, J. Stover, K. A. Stanecki, N. Walker, P. D. Ghys, and B. Schwartländer. 2005. "Integrating HIV Prevention and Treatment: From Slogans to Impact." *PLoS Med* 2 (1): 0050–0056. Available at [http://medicine.plosjournals.org/archive/1549-1676/2/1/pdf/10.1371\\_journal.pmed.0020016-S.pdf](http://medicine.plosjournals.org/archive/1549-1676/2/1/pdf/10.1371_journal.pmed.0020016-S.pdf) [accessed April 14, 2005].
- Soderholm, P. 1997. *Global Governance of AIDS: Partnerships with Civil Society*. Chartwell-Bratt, Lund, Sweden: Lund University Press.
- Stephens, D. 2004. "Out of the Shadows: Greater Involvement of People Living with HIV/AIDS in Policy." *POLICY Working Paper Series No. 14*. Washington, DC: POLICY Project/Futures Group. Available at <http://www.policyproject.com/pubs/workingpapers/WPS14.pdf> [accessed April 14, 2005].
- Sumbuleta, A. 2005. "Mums-to-be Shun Malawi HIV Tests." *BBC World Edition Online* (May 17, 2005). Available at <http://news.bbc.co.uk/2/hi/africa/4551767.stm> [accessed July 25, 2005].



Teshale, E. 2005. "Estimated Number of HIV-infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States" (Abstract 167). Paper presented at the 12<sup>th</sup> Conference on Retroviruses and Opportunistic Infections, Boston, MA, 22–25 February, 2005.

UNAIDS and World Health Organization (WHO). 2004. *Guidance on Ethics and Equitable Access to HIV treatment and Care*. Geneva: UNAIDS and WHO. Available at [http://www.who.int/ethics/en/ethics\\_equity\\_HIV\\_e.pdf](http://www.who.int/ethics/en/ethics_equity_HIV_e.pdf) [accessed June 15, 2005].

United Nations Development Programme (UNDP), Bureau for Development Policy. 2001. *HIV/AIDS: A Governance Challenge*. New York: UNDP.

Wilson, D. P., and S. M. Blower. 2005. "Designing Equitable Antiretroviral Allocation Strategies in Resource-constrained Countries." *PLoS Med* 2 (2): 0132–0141. Available at [http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/10.1371\\_journal.pmed.0020050-S.pdf](http://medicine.plosjournals.org/archive/1549-1676/2/2/pdf/10.1371_journal.pmed.0020050-S.pdf) [accessed April 14, 2005].

World Health Organization (WHO) and UNAIDS. 2005. *Progress on Global Access to HIV Antiretroviral Therapy: An Update on "3 by 5"—June 2005*. Geneva, Switzerland: WHO. Available at <http://www.who.int/3by5/fullreportJune2005.pdf> [accessed July 25, 2005].

World Health Organization (WHO) and UNAIDS. 2005. *Progress on Global Access to HIV Antiretroviral Therapy: An Update on "3 by 5"—June 2005*. Geneva, Switzerland: WHO. Available at <http://www.who.int/3by5/fullreportJune2005.pdf> [accessed July 25, 2005].

STIGMA, SCALE-UP, AND TREATMENT GOVERNANCE 13





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