

## A Global Disease and Its Governance: HIV/AIDS in Sub-Saharan Africa and the Agency of NGOs



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This article provides a theoretical assessment of the agency attributed to nongovernmental organizations (NGOs) within the emerging international governance of HIV/AIDS. The analysis, which focuses on the pandemic in sub-Saharan Africa, responds to the question of how effectively NGOs are able to function in policy interventions in the long term. It looks at the nature of the emerging governance system and the role it attributes to NGOs, then raises questions for this system by looking at the operational characteristics of NGOs in context. In conclusion, it suggests that although NGOs have been important actors in this field, they do not have the sort of agency required for sustainable long-term policy interventions in the HIV/AIDS context. **KEY-WORDS:** HIV/AIDS, Africa, agency, NGOs, governmentality.

The HIV/AIDS epidemic is a catastrophic phenomenon—one of the most devastating ever—that has and will continue to impact people's lives in sub-Saharan Africa. In 2005, approximately 29 million people are living with the disease in the region. In 2002, 3.5 million people contracted HIV.<sup>1</sup> The epidemic, generalized largely in eastern and southern Africa, influences all aspects of society. The problem has been given importance in international development and aid policy agendas for most of the last ten years. Although international policymakers believe that the intervention mechanisms in place are providing correct channels for policy interventions, they have recognized lack of funding as one of the most important challenges they are facing in scaling up these existing mechanisms to deal with the more generalized disease. In this, taken as a part of the existing intervention mechanisms, civil society organizations—nongovernmental organizations (NGOs)—have been at the center of the international policy interventions for the HIV/AIDS pandemic in the region. Therefore, it is timely at this juncture, when many countries are pledging new HIV/AIDS-targeted funds, most of which will be channeled through the existing mechanisms, to ask the following questions: *how efficient is the role*

*played by these organizational forms,<sup>2</sup> and do they have the agency to bring about long-term sustainable change to deal with the HIV/AIDS pandemic?* It opens up an important problem in the field, namely the agency required to positively address people's needs. By examining this problem, the distinction between claimed and actual agency of NGOs can be scrutinized.

In this article, I argue that this international system, or governance system, not only manages but also constitutes the agency of certain actors and relevant domains of policy. This is done according to a particular domain of governance whereby people with the disease are constructed in a manner independent of their everyday lives, allowing them to be governed in a particular domain, that of international HIV/AIDS policy produced by certain languages and technologies. The overall analysis is based on the outcomes of my ongoing research on the impact of international policy on HIV/AIDS in sub-Saharan Africa conducted in the last three years in Uganda, Zambia, Botswana, and Rwanda. The article is a theoretical look at the issues; the empirical claims related to this debate are analyzed in depth elsewhere. The first part articulates the conceptual concerns of the present study by looking at the idea of agency and governance. The second part examines the context of governance and articulates the peculiarities of the system in relation to the international policy environment on HIV/AIDS. This section points out those issues that exacerbate the disjuncture between the policy context and the needs expressed by the infected and affected. This is followed by a section that locates NGOs within this system whereby they have become the main actors in the implementation of policies on the ground. The following part looks at the characteristics of NGOs as civil society actors. The aim here is to assess whether these characteristics can provide the right capacity for NGOs to address people's needs in times of HIV/AIDS in sub-Saharan Africa as it is assumed by international actors. In the conclusion of the article, I respond to the original question, suggesting that although NGOs have provided important help, they do not possess the sort of agency required for sustainable long-term HIV/AIDS interventions.

### **Conceptual Elaborations**

In engaging with this issue of agency, I look at the international policy environment of HIV/AIDS from a particular theoretical perspective on governance that allows one to better understand the relationships among organizations and people and therefore better assess the agency of civil

society in this context. Let me comment on what is meant by agency before the discussion moves on to look at the idea of governance. I take Norman Long's general view on the issue that "agency attributes the capacity to process social experience and to devise ways of coping with life to individual actors."<sup>3</sup> Linking this with Anthony Giddens's position that "agency refers not to the intentions people have in doing things but to their capability of doing those things in the first place," it is possible to consider the relationship between the governance structure and the way an agency is assumed in this structure as a capability to deal with the HIV/AIDS pandemic.<sup>4</sup> The governance system is considered here as a structure that then becomes the locus of active production of certain agency in relation to an actor—civil society in the present case—through a dynamic process of engagement.

HIV/AIDS is considered to be a global problem. In this, the globality of the disease is mostly related to its occurrence in multiple country contexts across the world. The interpretation of this globality puts policy formulations into a certain global context whereby global intervention policies supported by global funding and other resources are formulated. Alongside this formulation process, certain practices for coordination, communication, and implementation are established as a particular language game.<sup>5</sup> This formation around the HIV/AIDS pandemic is very much in tune with Leon Gordenker and Thomas Weiss's definition of global governance: "efforts to bring more orderly and reliable response to social and political issues that go beyond capacities of states to address individually." They go on to say that "like the NGO universe, global governance implies an absence of central authority, and the need for collaboration or cooperation among governments and others seek to encourage common practices and goals in addressing global issues."<sup>6</sup> Therefore, the theoretical lens used in this study considers the international policy environment as an incipient governance system that consists of various international organizations, bilateral agencies, and private foundations.

Following Gordenker and Weiss, the concept of governance used here is more interested in governance as a process of developing common aims and practices. This markedly differs from, for example, the World Bank, which focuses on promoting governance issues through its good governance agenda that ties in largely with "increasing popular participation, reducing poverty, and improving project performance."<sup>7</sup> In this, the Bank attempts to achieve its developmental aspirations through initiating policies to change governance-related practices in developing countries. My concern here is to critically examine a particular governance system by looking at it as an agent that influences the form of interventions and practices. Elke Krahmann defines governance as "the

structures and processes that enable governmental and nongovernmental actors to coordinate their interdependent needs and interests through the making and implementation of policies in the absence of unifying political authority.”<sup>8</sup> Although this definition allows us to overcome a certain conceptual confusion about the idea of governance by focusing on, in general, a fragmented process that includes various actors, it is in danger of setting out an image that is too comfortable. The important imbalances among actors trying to coordinate their interdependent interests have important consequences for the policy outcomes and the way governance is constituted through the process of negotiation. In this process, the idea of power is critical—power that is exercised through the everyday practices of negotiations and project management among various actors constituting their organizational subjectivities. Therefore, in the present study, the governance of HIV/AIDS is considered to have an impact both on the way policies are articulated and on the actual outcomes as experienced by people. From this perspective, not only can the agency of particular actors such as NGOs within the governance structure be defined, but an assessment of the impact of actors on each other and on the disease can also become meaningful.

Thus, the international policy environment as it pertains to HIV/AIDS will be considered as a particular “practice of governance” that looks at the forms of governing put into practice.<sup>9</sup> James Tully argues that these forms include “the language games in which both governors and governed are led to recognize each other as partners in the practice, communication and coordination of activities; to raise problems and propose solutions; and to renegotiate their form of government, including languages of administration and normative legitimation.”<sup>10</sup> In this sense, the concept of governance here involves not only policymakers that exercise power in managing the disease as a technical issue, but also the relations and context in which the HIV/AIDS field is constituted as a policy intervention domain in a productive process. In this, practices of governance articulate ways of managing the structure of the institutional arrangements, decisionmaking processes, and the capacity for implementation within the context. Considered from this perspective, HIV/AIDS governance becomes a set of complex interconstitutive relations creating legitimacy for civil society actors.

### **Governance Context**

The definition of *governance* I used in the introduction differs from a rather technical and instrumental usage common in recent years with the

emergence of new thinking on development—thinking based on Comprehensive Development Frameworks and on Poverty Reduction Strategy Papers (PRSPs)—among the leading multilateral and bilateral organizations involved in development. The idea includes altering public sector management to initiate more citizen participation, to ensure government accountability, and to ensure transparency of public policy in order to be able to move on achieving higher goals of development. As a result, the role of civil society has become very pronounced in increasing citizens' voices and in establishing demands for public accountability and transparency.

As suggested earlier, the perspective here is not related to the idea of good governance as an instrument for achieving such developmental aims; it is more about practices that create a particular way of governing international HIV/AIDS policies and interventions. Therefore, the role that civil society organizations (NGOs and community groups) now play in the HIV/AIDS epidemic can be analyzed in relation to the general governance of the disease—that is, practices of governance. It allows the analysis to take explicitly into account the processes leading to the establishment or acceptance of a certain system as a governance structure whereby certain influences are institutionalized in relation to the internal processes. This way of looking at the processes takes into account the conceptual feedback created by enabling actors to be active participants who are the focus of development initiatives and, in terms of the present study, the focus of HIV/AIDS interventions.

The perspective applied here follows an understanding that considers the issue of governance as “the forms of reason and organization through which individual and groups coordinate their various activities, and practices of freedom by which they act within these systems, following rules of the game striving to modify them.”<sup>11</sup> The governance structure I am considering, in relation to the HIV/AIDS interventions, involves the following: international organizations (such as the World Bank, the Joint United Nations Programme on HIV/AIDS [UNAIDS]); individual donor countries (such as the United States, Britain, Norway, Sweden, and the Netherlands) and their aid organizations (such as the U.S. Agency for International Development [USAID], and the UK's Department for International Development [DFID]); national governments and their existing policy intervention channels; and national civil society. At the local level, community groups and local and international NGOs work with national or transnational NGOs. Although it is clear that many multilateral and bilateral organizations have individual priorities, depending on their particular expertise and mandate, it is possible to observe that a *de facto* governance regime in relation to HIV/AIDS

has emerged. This has been partially facilitated by the establishment of UNAIDS as the coordinating body for the involvement of UN-related organizations in HIV/AIDS interventions; UNAIDS is cosponsored by:

- United Nations Children's Fund (UNICEF)
- World Food Programme (WFP)
- United Nations Development Programme (UNDP)
- United Nations Population Fund (UNFPA)
- United Nations Educational, Scientific and Cultural Organization (UNESCO)
- World Health Organization (WHO)
- World Bank
- United Nations Office on Drugs and Crime (UNODC)
- International Labour Organization (ILO).<sup>12</sup>

Furthermore, this emergence is bolstered by the inclusion of HIV/AIDS as one of the main policy areas in comprehensive development frameworks, such as the Millennium Development Goals. The UN also played a leading role in organizing a General Assembly meeting on the pandemic in June 2001, placing the disease prominently in the international policy agenda for development and human rights.

Civil society, in this system, is by and large constructed into a resource category to be utilized as an efficient and effective way to deal with the disease at the community level. In terms of this policy context, the role of civil society is to act as a conduit between policy structures and the people. Prevalent in this are a few central assumptions that are both justified by and justify the practices of governance: (1) civil society is related to people or reflects their needs; (2) civil society is effective in reaching people; (3) civil society should be brought more into service delivery; and (4) the involvement of civil society increases the accountability and the transparency of governments in line with their development aims and restructuring plans. On the one hand, the status of civil society within the policy context is considered in reference to the context of international policymakers. On the other hand, the idea of civil society in relation to people is also implied. The problem, however, is understanding the possible impact of civil society and assessing this impact in relation to HIV/AIDS by attributing a certain success to the process deriving from the former consideration, that is, using the assumed aspirational status of civil society within the policy context, on the basis of asserting the naturalness of the latter, its link to people. This makes civil society appear nearly independent of the global policy context although it clearly is not only part of this governance structure I

have been discussing but also constituted by this structure in its present role as the agents of intervention. In this the structure equates civil society with people, implicitly establishing an intimate relationship between the two. Then, naturally, the increased NGO and community activity is taken (or asserted) to reflect people's participation in the process of dealing with the disease, a process that will ultimately produce positive outcomes.

### *NGOs in Context*

In this multiplicity of structures, decisions are based on international actors arriving at decisions about policy priorities that are then turned into intervention frameworks—for instance, on prevention based on certain tools like condoms or voluntary counseling and testing (VCT). For such interventions, the funding is then added to the general aid packages. Once the dispersal of funds is initiated, civil society is called on to carry out the policies using the predetermined tools. Therefore, NGOs and community organizations are brought in to localize global policies as free agents, although they will frequently represent the global frameworks. In this process, local particularities are not captured by the global policies. Although NGOs participate in this global system to coordinate and achieve their aims and thus to participate in the formation of a certain governance structure, there is a deflection or rearticulation of the particular aims of NGOs under a global perspective.

The global and transnational part of the governance structure is similar to what Martin de Graff<sup>13</sup> designates as an environment over which NGOs, for various reasons, have no control and are only able to relate to it. Although this situation might create a challenge for the policy context, which is broadly global in attempting to produce interventions in highly localized settings, the situation is not as rigid as this might suggest. There have been arguments about NGO strategies for dealing with these sorts of external power relations that work by relying on their location within communities as assets and that are used for rethinking and influencing their funding relations. Significantly, these arguments, like de Graff's argument, rely on a certain assumption of closeness between people and civil society, which may be true. But once located in the analysis here, the impact of this closeness in the actual policymaking process loses its significance for the HIV/AIDS context in sub-Saharan Africa. The claimed closeness needs to be explained more in relation to the enculturation process within the governance structure, whereby NGOs "acquire a specific form of subjugation or practical identity, a habitual way of thinking and acting within the assignment relations and

languages of reciprocity.”<sup>14</sup> Therefore, the idea of closeness is more about the perception of the policymakers that is produced in their relations with NGOs than about the actual relationships of NGOs with particular communities. Arguably in this process, although the discourse of closeness is used as a legitimating argument, a certain disassociation between NGOs and communities can be observed.

In the governance framework leading to interventions by NGOs at the international level, multilateral policymakers and experts take decisions within preexisting development parameters (that give direction for the recognition of relevant partners) and available aid structures (that decide what is feasible).<sup>15</sup> In this sense, the governance of HIV/AIDS is located within preexisting understandings among international actors.<sup>16</sup> One important nuance that needs to be clarified in this relationship is the link between a donor and a policymaker. It is clear that donors such as the World Bank, DFID, or even an international nongovernmental organization (INGO) such as OXFAM or foundations such as the Bill and Melinda Gates Foundation, are not merely funders but have comprehensive perspectives on what the problems are and how they should be tackled. As a result, the donor also becomes the policymaker. The position of INGOs is interesting in this respect, since theirs is a balancing act between having specific country programs and acting as contractors for larger, internationally funded projects for which they are given a mandate. Therefore, their relationship with NGOs and community groups presents a divided scenario; for example, while working with local groups, an INGO might also be contracting out particular aspects of its projects and acting as a donor in many respects. Though some coordination activity is performed by UNAIDS, on the basis of its foundational mandate within the UN system, as it tries to inform the policymaking in the HIV/AIDS field by expert analysis of needs and methods, the international outcomes mostly reflect other policymakers’ concerns.

Hundreds of NGOs are working in prevention, support, and care projects funded by international donors. Typically, in this context, an NGO is involved in either a single activity or some combination of activities, which might include implementing prevention programs, such as sensitization; distributing condoms; producing posters; or caring for and supporting people living with HIV/AIDS (PLWHA). In addition, NGOs often conduct small workshops to promote these activities in the larger community where they are working. Note that many of these interventions use tools that have proved to be effective at the international policy level. Some of these groups establish local and regional networks by scaling up their work and cooperating to increase the impact of mostly small individual programs. Through these efforts, NGOs, in fact, constitute the



largest implementation component of the governance structure.<sup>17</sup> An interesting question to ask is: which NGOs are incorporated into the practices of governance and thereby become producers of particular practices of governance in their own activities?

The link between NGOs, community groups, and the international component of the governance structure does not provide for much NGO participation in deciding which policy approach should be followed. NGOs, participating in funding relationships in which they are regarded as service delivery tools, gradually internalize certain ways of relating and thinking that are independent of their community relationships. Not only do funding relationships create this, but the process of know-how transfer also gradually leads NGOs into a particular way of thinking. Most of these processes are aptly called *capacity-building* programs. This seems to indicate a need for NGOs to function in a particular manner in this system. For instance, endless training sessions provided by international donors or INGOs to teach the correct implementation of tools include, among other things, establishing the correct language for communication with their target groups when conducting sensitization meetings. It is in this process that the transfer of cognitive maps of international policy thinking occurs. One good example relates to gender-specific interventions in the region; although it is clear to many local activists that unless they bring men into the debate, most of these interventions are not going to produce any results, they are unable to produce projects to engage with this issue. Such projects require long-term involvement that would lead to an understanding of the state of gender relations and the state of men's thinking, which are not included in the existing governance priorities, some of which are set according to funding cycles and to reporting requirements of certain agencies to their auditing authorities. Arguably, the NGOs and community groups that are incorporated for service delivery in this context are incorporated as a result of their organizational characteristics that are seen as relevant for this governance system. In other words, it is by *not* challenging the international policy frameworks that NGOs have a significant role.

### Characteristics of NGOs

NGOs work typically in the context of poverty and poverty-related issues. David Lewis notes these as “the delivery of new or improved services to sections of communities which are in need; efforts to catalyse social, economic and political change processes at the level of group or individual action; and the attempt to create ‘synergies’ among different

agencies and initiatives through the building of ‘partnerships.’”<sup>18</sup> However, the organizational nature of NGOs makes their position in the governance structure difficult. By and large, partnership schemes suggest that NGOs are conditioned to conduct “themselves in regular and predictable ways” to be located within those relations. In most cases, NGOs working in the field are small organizations with small staffs managing the everyday operations. The staff may be largely volunteers, from inside or outside the area of activity, or they may even be foreigners. It is not uncommon to have many PLWHA volunteering. Some of them work as general office staff, whereas others work as project officers or training consultants, which allows them to share their experience with others.<sup>19</sup> Since the number of NGOs dealing with disease is very large, it is difficult to conclude whether the interventions are coherent or sustainable and whether they will have a societal impact. The small size of individual NGOs makes them attractive to donors for their interventions but, in terms of outcomes, the results are fragmented and unsustainable.<sup>20</sup> This is partially related to the changing donor policy frameworks, which need to be followed in order for an organization to survive. But, this situation is primarily related to the nature of NGOs, which are taken to be the implementers of most policies in many instances.

The question about the role of NGOs in this governance structure is intimately related to the nature and characteristics of these organizational forms, because these particularities affect the outcome of their interventions in relation to HIV/AIDS. The particularities of NGOs are well documented in what Alan Fowler refers to as NGO capacities. He identifies five key NGO capacities:<sup>21</sup>

- organizational “set up”
- leadership and human resources
- managing external relationships with “primary stakeholders”
- mobilizing funds (of a “quality” to allow the NGO to pursue its work properly)
- “managing through achievement”

Note that these capacities reflect some of the assumptions used to understand why civil society is seen as relevant to the interest of international policymakers. Capitalizing on these capacities would be the preferred way of delivering services to people from the policymaker’s perspective. From the NGO perspective, however, these capacities reflect particular characteristics of NGOs in their organizational setup that are conditioned by the larger context. Therefore, NGOs in the HIV/AIDS context need to be analyzed within this governance structure in order to

be evaluated in regard to what they can do rather than be taken as an abstract organizational form to be constituted as reified civil society. Nonetheless, the identity created in the discourse of civil society for NGOs depends on these characteristics, since they have allowed NGOs to become used to doing things in a certain way and gradually to become a part of the form of governance. Although the size of NGOs and their closeness to their communities are important aspects of their nature, it is not clear whether these are positive characteristics when dealing with HIV/AIDS in the long term. The problems pointed out by Caroline Sahley are relevant to the HIV/AIDS discussion. She notes that partnership debate in this field focuses on details, not horizons; on individual donor agendas imposed on organizational remit; and the impact of insecure funding on the way an NGO plans its activities.<sup>22</sup> The general external funding-based resource dependency as a central organizational characteristic of NGOs is one of the reasons for this situation. Again, I would like to reiterate that in this case, funding does not mean just finances but also includes a set of policy prescriptions that specifies the nature of interventions. This creates an operational and existential uncertainty in the management of resources that are central to an organization and central to the matching of the self-proclaimed vision of an NGO with the aims of donors who are providing the funding for the interventions. Several arguments have raised questions about the impact of this funding relationship on an NGO's work. It is suggested that replacing government services<sup>23</sup> or, in the absence of a central authority in conflict zones,<sup>24</sup> performing a service delivery role is leading to a certain disconnect between people-as-citizens and the state in the long term.<sup>25</sup> Furthermore, given the international resource base of NGOs, this disconnect is also creating two processes that are consequential for the welfare of the people benefiting from NGO services: (1) an external resource dependency is created for people; and (2) considering the political distance—that is, the lack of direct accountability between international donors and the people benefiting from the services—people are depoliticized as receivers of aid.<sup>26</sup>

If the assumption about the link between NGOs and community is considered to be a real asset for policy implementation, paradoxically this link becomes disarticulated in the policy context. Although a strong case is usually made for the importance of a value-based vision of NGOs in relation to poverty interventions, a certain deflection of purpose seems to be inevitable. In the governance of HIV/AIDS, discussed earlier, arguably most NGOs working in the field choose interventions based on the available funding structure that reflects international policymakers' perspectives on the disease.<sup>27</sup> Otherwise, their participation would be questioned according to the particular language and rules structuring the

governance, leading to their exclusion from the system. As a result, some of Fowler's capacities that allow NGOs to be effective and efficient are transformed into imminent problem areas as potential vulnerabilities. The flexibilities allow NGOs to adapt to the needs and requirements of the international system whereby they themselves survive as organizational forms; but in relation to achieving their aims to deal with poverty in general and with HIV/AIDS in particular, these qualities become debatable.

The last capacity, managing through achievement, becomes an issue because the more integrated NGOs become in the governance structure, the more their work is evaluated according to donor priorities based on demonstrable outcomes within a given project cycle. As a result, they do manage through achievement, but then we must ask: What does this mean? What is the measure of achievement? And who decides this? It is a particularly important problem for HIV/AIDS interventions, as it favors and limits what can be done in such activities as condom distribution, VCTs, posters, training workshops, and other tools that can be evaluated on the basis of exact numbers distributed, tested, and trained. These reflect donor interests in concrete measurable outcomes for accountability purposes within a limited project or program cycle independent of an assessment of the actual long-term impact of an intervention. In this way, the relationship between the policymakers and the implementers once again influences the way the latter function. Therefore, it is important to consider capacities as nominal rather than actual, as they are realized within the power relationships implicit in the governance structure discussed earlier. Even with this, one might take a further step and suggest that the actualization of these capacities within the limits of a power structure depends on how far an NGO is able to adapt to the international policy frameworks. In some ways, it is possible to agree with Fowler and suggest that NGOs are rich in potential capacities but very much limited in their capabilities, which, according to Giddens, is creating a poverty of agency. As a result, NGOs are mostly pushed into the first area in Lewis's schema, service delivery, leading to a limited ability to deal with the expressed needs of people while performing the activities in the second and the third areas he noted to implicitly promote the vision of the policymakers.

### *A Different Role?*

This analysis could be criticized on the grounds that it focuses on funding and service delivery roles while ignoring advocacy functions, a situation

that has become a cause célèbre as regards NGOs. This critique could be supported by Adil Najam's concept of policy entrepreneurs that attributes several roles to NGOs in monitoring, reviewing, and innovating existing policy for important social issues.<sup>28</sup> However, I agree with Alison Van Rooy that NGO success in this respect is related to noncontroversial, "low" policy international issues, whereas high politics related to economics and human rights proves to be a harder task.<sup>29</sup> Also, beyond this juxtaposition, HIV/AIDS presents a rather complicated picture for advocacy. Most of the programs are based on sensitization and information distribution or have large components of advocacy attached to other tools. Therefore, advocacy in HIV/AIDS is a project priority for NGOs as a result of their assumed ability to be closer to the people. The advocacy in this manner is in conflict with the advocacy role suggested by Najam that requires a critical engagement to change or influence the parameters of policy frameworks. The latter requires active confrontation at local, national, and international levels. Apart from the Treatment Action Campaign in South Africa, this model is not observable in the region. Again, advocacy as an abstract capacity of NGOs should be considered within a context. In the case of HIV/AIDS, this capacity is exercised with the limitation I have already mentioned. Therefore, although NGOs are seen as advocacy groups in relation to people, they remain as service providers for the international policymakers. Advocacy in the latter realm is usually left to INGOs. This does not mean that there is no critical understanding of the issues in the region, as most local NGO workers and PLWHA are aware of the problems in terms of both the needs and the issues associated with many interventions. But according to many activists, voicing these views is considered to be controversial and unproductive, as it would influence the support and funding arrangements of some INGOs, arrangements that resemble a competitive market whereby international donors are choosing those NGOs that are willing to accept and implement their procedures and priorities. In short, there is no doubt that interesting and effective interventions are created and implemented by NGOs. In many of these instances, interventions seem to have worked because the NGO in question provided what international policymakers were looking for. Nonetheless, the demand for evaluation according to the outcomes accrued to the people still remains largely unanswered. In this sense, the agency of NGOs is questioned both in their capacity to effect long-term sustainable changes and in their relationship with the governance structure creating them as agents that are not well located to produce policies informed by the contextual nature of HIV/AIDS problems.

### What Should Be Done?

So far, I have argued that there is a mismatch between the policy context of HIV/AIDS as constructed in a particular form of governance and the way people experience the disease in their everyday lives. Also I have argued that it is the perspective articulated in this governance system in relation to HIV/AIDS that is dominating the interventions. In this perspective, the role of NGOs and community groups is seen as central in implementing many policies. Furthermore, with respect to the desirability of this situation, I have pointed out that despite the central role that these organizations play, they present characteristics that make them vulnerable vis-à-vis the donors and international policies that determine how these organizations function. Therefore, their assumed or ascribed role in terms of the civil society identity claimed for them becomes implicitly disarticulated whereby people are distanced from contributing to policy processes. It has also been suggested that technologies of governance, such as certain administrative processes and policy priority areas set in the international domain, help this process by embedding NGOs and community groups into a space outside communities. In doing so, these organizations by and large begin to consider PLWHA in terms of patients or particular individuals in risk groups rather than as members of a certain community within which they experience the disease.

Thus, the short response to the original question is that civil society, whereby NGOs are incorporated as the implementers, lacks the right agency to influence the psychosocial conditions of the epidemic. In other words, although civil society's contribution is important, it cannot influence and sustain a social change to address people's needs in the long term within the present international governance of the disease. This also suggests that under these conditions, there are questions about how effectively the U.S. funds pledged in 2003 will be used.<sup>30</sup> The disease, both in its causes and consequences, requires sustained and persistent localized support of interventions if a long-term change is to be realized.

This conclusion could be criticized on pragmatic grounds. One could say that there is a major emergency and we have to do something; in the absence of other mechanisms, this is imperfect but it is the best we can do. It is absolutely true that what people are facing in Africa is a disaster of a scale and pace probably unseen for many generations. However, this objection is also located within the particular governance structure that has been discussed. It reduces the scale and the impact of the disease to the immediate present. Although it is clear that people

require immediate help, their needs can be satisfied only if the disease is considered within a larger psychosocial and cultural context. Otherwise, while relief-based needs are served, albeit insufficiently, the needs for long-term survival in a certain sociocultural context are ignored. Therefore, it is rather shortsighted to keep considering the issues as an emergency. This would motivate only emergency interventions/relief, and NGOs would be considered as deliverers of service and goods at the point of need, and not addressing the causes that are creating the need for these services. In most cases, these deliveries are based on information and materials for sensitization without those responsible for disseminating them understanding how to use them in a particular context to effect a change in behavior. This requires an agency that would have the capacity to coordinate, implement, and improve a given program, and above all to sustain the efforts over the long term to eliminate the causes of the disease while at the same time dealing with the immediate problems. Such agency can be seen in relation to governments that can build on the existing interventions and act as social leaders for positive change.

In the absence of this understanding, most of the effort is targeting short-term interventions through the assumed agency of NGO interventions. As a result, most efforts are anchored in cyclical campaigns with homogenized tools that center on the distribution of posters, condoms, or information about the spread of the disease and other activities that in turn often create profound fatigue among the infected and the affected. People are being constantly told that they are facing a grave disease and that to save themselves they should to be loyal to one partner, use condoms, or abstain from having sex. Also, many are tired of being subjects of workshops and training programs, only to be told these things again and again. Knowledge is important, but clearly HIV/AIDS requires long-term vision that includes influencing societal changes without breaking down communities; in fact, the spread of the disease appears to be positively correlated with, among other things, community collapse.

International policymakers need to understand the contexts in which they are targeting people, the projects for which social and economic resources are provided, and the constraints on people for action. By targeting only the sick and the HIV-positive individual, the interventions are not only creating stigma, but they are also making redundant the capacity of existing coping mechanisms available to people. Therefore, agency for change needs to be articulated beyond interventions based on tools that are, externally, deemed appropriate and feasible. Change will be possible only by considering sociocultural contexts and by providing actors that can influence and sustain change in such contexts. At the

moment, neither the short-term relief-based vision implicit in many NGOs in the region nor the governance system supporting this vision, which is based on perceived common sense among the major development actors, is providing the agency for such change. 🌐

## Notes

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1. *Report on the Global AIDS Epidemic: Update 2002* (Geneva: UNAIDS, 2002).

2. Particularly, in the last few years, large pledges such as the Bush administration's U.S.\$15 billion pledge to twelve African and two Caribbean countries for HIV/AIDS interventions over the next five years makes this question rather important. The pledge was approved in the U.S. Congress on 21 May 2003.

3. Norman Long, *Development Sociology: Actor Perspectives* (London: Routledge, 2001), p. 16.

4. Anthony Giddens, *The Constitution of Society: An Outline of the Theory of Structuration* (Cambridge: Polity Press, 1984), p. 9.

5. Here the idea of language game is used in Ludwig Wittgenstein's sense. He argues that "language game is meant to bring into prominence the fact that the speaking of language is part of an activity, or form of life." Ludwig Wittgenstein, *Philosophical Investigations* (Oxford: Blackwell, 1977), p. 11. Also see Hakan Seckinelgin, "Civil Society as a Metaphor for Western Liberalism," *Global Society* 16, no. 4 (2002).

6. Leon Gordenker and Thomas G. Weiss, "Pluralizing Global Governance: Analytical Approaches and Dimensions," in Gordenker and Weiss, eds., *NGOs, the UN and Global Governance* (Boulder: Lynne Rienner, 1996), p. 17.

7. Paul Nelson, "Whose Civil Society? Whose Governance? Decision-making and Practice in the New Agenda at the Inter-American Development Bank and the World Bank," *Global Governance* 6, no. 4 (2000): 405–431.

8. Elke Krahmann, "National, Regional, and Global Governance: One Phenomenon or Many?" *Global Governance* 9, no. 3 (2003): 331.

9. James Tully, "Political Philosophy as a Critical Activity," *Political Theory* 30, no. 4 (2002): 538.

10. *Ibid.*, p. 539.

11. *Ibid.* Tully here is summarizing Michel Foucault's various discussions on governmentality.

12. See [www.unaids.org/en/about+unaids/cosponsors.asp](http://www.unaids.org/en/about+unaids/cosponsors.asp) (accessed April 2005).

13. Martin de Graff, "Context, Constraint or Control? Zimbabwean NGOs



and Their Environment,” *Development Policy Review* 5 (1987).

14. Tully, “Political Philosophy,” p. 539.

15. On this, see John Dengbol-Martinussen and Poul Engberg-Pedersen, *Aid: Understanding International Development Cooperation* (London: Zed Books, 2003), pp. 158–159.

16. Within this broad thinking, bilateral donors decide their own intervention priorities and at times coordinate their policies with the international frameworks.

17. Note that here I am not suggesting a very static relationship; on the contrary, these relationships are dynamic and influence each other at various levels.

18. David Lewis, *The Management of Non-Governmental Developmental Organisations* (London: Routledge, 2001), p. 3.

19. For instance, the Centre for Youth and Hope (CEYHO) in Botswana, created by young PLWHAs and operating out of a small office, made from a container and located in the garden of a local hospital in Gaborone, provides counseling and support. Another example is the Mother of Mary Hospice in Chilanga Lusaka, which is supported by Polish Catholic nuns and managed by a medical student intern from the United States. They are providing residential medical care for about twenty people and also assisting in home-based care for HIV/AIDS infected and affected in the Lucy compound, which comprises over 400,000 people.

20. See Richard C. Riddell et al., *Searching for Impact and Methods: NGO Evaluation Synthesis Study* (Helsinki: Ministry of Foreign Affairs, 1997).

21. Alan Fowler, *Striking a Balance: A Guide to Enhancing the Effectiveness of Non-Governmental Organisations in International Development* (London: Earthscan, 1997), pp. 43–68.

22. Caroline Sahley, “Strengthening the Capacity of NGOs: Cases of Small Enterprise Development Agencies in Africa,” INTRAC Management and Policy Series No. 4, Oxford, 1995, pp. 149–160.

23. For example, see Kassahun Berhanu, “The Role of NGOs in Promoting Democratic Values: The Ethiopian Case,” in Bahru Zewde and Siegfried Pausewang, eds., *Ethiopia: The Challenge of Democracy from Below* (Uppsala: Nordiska Afrikainstitutet, 2002).

24. The context of conflict zones and emergencies presents important challenges for NGO work as well. It is argued that NGO interventions to bring resources to people have at times allowed central governments with resources and freedom to continue fighting or to channel funds for military and other uses rather than helping their own citizens. See Jenny Edkins, *Whose Hunger? Concepts of Famine, Pictures of Aid* (Minneapolis: University of Minnesota Press, 2000); Alex de Waal, *African Issues: Famine Crimes: Politics and the Disaster Relief Industry in Africa* (London: Villiers Publications, 1997); Peter Uvin, *Aiding Violence: The Development Enterprise in Rwanda* (West Hartford, Conn.: Kumarian Press, 1998), especially chap. 8.

25. See Geoff D. Wood, “States Without Citizens: The Problem of the Franchise State,” in D. Hulme and M. Edwards, eds., *Too Close for Comfort? NGOs, States and Donors* (London: Macmillan, 1997). This argument has also been made in terms of the increased role played by voluntary sector organizations in the UK.

26. See Stephen Commins, “NGOs: Ladles in the Global Soup Kitchen?”

*Development in Practice* 9, no. 5 (1999); Monica K. Juma and Astri Suhrke, eds., *Eroding Local Capacity: International Humanitarian Action in Africa* (Uppsala: Nordiska Afrikainstitutet, 2002); Karuti Kanyinga, "The Politics of Development Space in Kenya: State and Voluntary Sectors in the Delivery of Basic Services," in J. Semboja and O. Therkildsen, eds., *Service Provision Under Stress in East Africa* (London: James Currey, 1995); Anthony Bebbington and Richard Riddell, "The Direct Funding of Southern NGOs by Donors: New Agendas and Old Problems," *Journal of International Development* 7, no. 6 (1995); Edward A. Brett, "Voluntary Agencies as Development Organisations: Theorising the Problem of Efficiency and Accountability," *Development and Change* 24 (1993); Sarah C. White, "Depoliticising Development: The Uses and Abuses of Participation," *Development in Practice* 6, no. 1 (1996); Alex de Waal, ed., *Who Fights? Who Cares? War and Humanitarian Action in Africa* (Lawrenceville, N.J.: Africa World Press, 2000), especially chap. 6.

27. See Jude Howell and Jenny Pearce, *Civil Society and Development: A Critical Perspective* (Boulder: Lynne Rienner, 2001), p. 113.

28. Adil Najam, "Understanding NGOs as Policy Entrepreneurs," in D. Lewis, ed., *International Perspectives on Voluntary Action: Rethinking the Third Sector* (London: Earthscan, 1998).

29. Alison Van Rooy, "The Frontiers of Influence: NGO Lobbying at the 1974 World Food Conference: The 1992 Earth Summit and Beyond," *World Development* 25, no. 1 (1997).

30. The Bush administration pledged U.S.\$15 billion to twelve African and two Caribbean countries for HIV/AIDS interventions over the next five years. The pledge was approved in the U.S. Congress on 21 May 2003.