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OUT OF THE SHADOWS:

*Greater Involvement of People Living with
HIV/AIDS (GIPA) in Policy*

by

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Acknowledgments

The idea of GIPA is still a work in progress. It is clear from this research and other studies on the subject that the involvement of PLHA in HIV/AIDS policy is still weak in many if not most countries. Despite this, the concept has become an animating principle for PLHA activists and leaders and is gaining a foothold among others concerned with developing and implementing effective HIV/AIDS policies.

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Executive Summary

The Greater Involvement of People Living with HIV/AIDS (GIPA) principle has become the most enduring legacy of the Paris Declaration. GIPA has been incorporated into national and international program and policy responses and taken up as a model of best practice in the response to HIV/AIDS. Since the Paris Summit in December 1994, GIPA has been endorsed in numerous international statements, most recently by the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS in its Declaration of Commitment on HIV/AIDS (United Nations, 2001).

Ten years after the Paris Summit, the issue of meaningful involvement of people living with HIV/AIDS (PLHAs) in policy development remains largely unexplored. A number of questions linger:

- Has GIPA become a “bandwagon” policy slogan without significant meaning?
- What are the benefits of adhering to the GIPA principle and does this lead to better policies?
- How do PLHAs and others measure and determine progress?

To answer these questions, the POLICY Project conducted a study of PLHA involvement in five countries. This report seeks to address how PLHAs are meaningfully involved in policy formulation by exploring key issues related to the GIPA principle and its effects.

Study Countries

The five countries that took part in this project provide a series of contrasting HIV epidemics, national responses, and PLHA communities.

- *Benin*, despite being one of the poorest countries in the world, has demonstrated an impressive commitment to participatory processes involving community sectors, NGOs, PLHAs, bilateral organizations, and the U.N. system. In the 15–49 age bracket, Benin has an estimated HIV prevalence rate of 3.6 percent (UNAIDS, UNICEF, and WHO, 2002), but this is a rate that is expected to increase rapidly in the next few years.
- *Brazil* has embraced the often discussed but seldom practiced unification of prevention and care through a policy of universal access to antiretroviral therapy (ARVs). A relative stabilization of AIDS incidence in Brazil has been observed since 1997. A national law defines AIDS as a public responsibility in terms of prevention and care. There is legislation against discrimination, supporting the human rights of PLHAs.
- *Cambodia* has one of the highest rates of HIV prevalence in Asia, estimated at 2.7 percent among its adult population (UNAIDS, 2002). The epidemic is mainly heterosexual and is characterized as a general epidemic.
- *South Africa* is a nation devastated by the epidemic, with an estimated 4.5 million people living with HIV/AIDS, in the continent most affected by the global epidemic. In 12 years, HIV prevalence in 15–49-year-olds rose from less than 1 percent to about 20 percent. The demographic group most affected by HIV/AIDS is female, aged 15 years and over, African in racial origin, and living in urban, non-formal dwellings.
- *Ukraine*, along with the rest of Eastern Europe, is experiencing one of the fastest growing HIV epidemics in the world, with an estimated 400,000 PLHAs, an increase of 200 percent over five years. It is also significantly affected by ongoing stigma and discrimination. One of this survey’s findings indicates that almost 50 percent of Ukrainians believe PLHAs should be separated from the rest of society.

Methodology

The research process was designed to collect information on the influence of GIPA on the development and implementation of national HIV/AIDS strategies, legislation, and other relevant HIV/AIDS policy instruments. A document review in each country assessed the legislative and policy commitment in relation to GIPA. The review included national AIDS strategies, HIV/AIDS legislation, and other relevant policies and literature relating to PLHA involvement. Interviews were conducted with senior policymakers responsible for HIV/AIDS. The leaders of the national PLHA movement or network in each country were also invited to take part. A total of 25 interviews were conducted in five countries. Researchers used a semi-structured interview format organized in sections that addressed the following areas:

- participants' awareness of GIPA;
- the formal or institutional level of PLHA involvement in national HIV/AIDS planning;
- benefits of involvement to national HIV/AIDS policies and programs; and
- barriers and challenges to PLHA involvement.

Findings

Awareness of GIPA. The majority of those interviewed were aware of the principle of PLHA involvement that GIPA represents. While there are differences in interpretation of the term GIPA, the respondents understood the meaning as relating to PLHA involvement and participation in HIV/AIDS policy and program design, planning, implementation, and evaluation. More specifically, respondents pointed to the need to have PLHA opinions and voices heard and integrated in decisionmaking processes.

Involvement. In Benin, two PLHAs representing the national association of PLHAs were invited by the government to take part in the design and planning of the national HIV/AIDS strategic framework.

In Brazil, PLHA groups and networks have been able to achieve consistent (although not unproblematic) involvement in national HIV/AIDS planning and strategy development structures and processes.

In Cambodia, PLHA involvement in national HIV/AIDS planning only became formalized with the establishment of the Cambodian Network of Positive People (CPN+) following the development of the country's national HIV/AIDS strategy.

Levels of involvement varied among the countries in the study. In South Africa, a PLHA was involved in drafting the first national AIDS strategic plan. The involvement of PLHAs remains the first guiding principle of the country's HIV/AIDS and STD Strategic Plan for 2000–2005. The United Nations first developed the GIPA Workplace Model in South Africa as an expression of the GIPA principle. Half a dozen HIV-positive people were subsequently placed in government departments, as well as in parastatal organizations and corporate and NGO workplaces.

In Ukraine, PLHA involvement in national planning began in 2000 through the advocacy of PLHAs. From 2002 on, PLHA involvement has become formalized in a number of national HIV/AIDS structures.

PLHA Identity and Representation. The legitimacy of PLHA involvement rests on a number of factors. Key among these is the question of PLHA representation. The small number of publicly active PLHA leaders struggle to represent the diversity of PLHA. Tension also exists between an individual's right to confidentiality and personal considerations regarding how and when to disclose HIV status on the one hand, and the pressure to publicly disclose in order to openly promote GIPA on the other hand. At the same time, PLHAs are also recognizing the need to collaborate with non-HIV-positive allies and partners.

The Brazilian experience of PLHA involvement and representation, for example, relies on serological status and a “seropositive identity,” a category that includes seronegative people who are committed to a core set of ethical, political, and ideological principles supported by PLHAs. This consensus of representation is based on the idea of solidarity between seropositive and seronegative people, as well as the concern that representation based on PLHA visibility forces people to disclose their status when they may be unwilling.

Benefits of GIPA. For people with HIV/AIDS, involvement—even at its most basic level—can overturn feelings of shame and stigma, depression, and the social isolation that often accompanies HIV/AIDS. For the individual with HIV/AIDS, involvement helps re-establish social relations and feelings of self worth.

The majority of respondents in this study noted that policy involvement improves the quality of prevention and care interventions by creating a direct link (provided by PLHA involvement) between policy development and the implementation of services.

Respondents pointed to a range of areas where the benefits of involvement flow directly into improved policy and programs including creating greater awareness of HIV/AIDS at all levels of society, more focused research, and more effective HIV/AIDS communication strategies.

The advantages of GIPA at the policy level flow beyond the immediate concerns of prevention, care, and treatment issues and improve the capacity of various sectors, such as education and employment, to respond to HIV/AIDS.

Involvement also increases the legitimacy of PLHA organizations with PLHA constituencies and with other HIV/AIDS stakeholders and increases participation in the management of health policy.

Barriers. In all five countries, stigma remains the major disincentive to the promotion of GIPA and a fundamental barrier to greater PLHA involvement.

Even before gaining policy negotiation skills and a level of familiarity with the national HIV/AIDS response, PLHAs require basic knowledge and awareness of the impact and effect of HIV/AIDS at both personal and policy levels. Understanding and being able to articulate the personal experience of HIV/AIDS is a prerequisite to coming to terms with the more technical knowledge domains that dominate policy development.

The GIPA principle is unsupported by, or ill-defined, in policy and legal frameworks leading to uncertainty in defining and interpreting responsibilities in implementation.

A more detailed understanding and rationale for GIPA at the policy level is still elusive. While the principle of involvement may enjoy significant support among some policymakers, promoting it as an effective instrument of the broader HIV/AIDS response is problematic.

Recommendations

1. Support GIPA as a broad and dynamic process

The GIPA principle is dynamic and broad. Institutional promotion and support of GIPA needs be linked to both PLHA social movements and organizational development. In essence this requires that GIPA initiatives be linked to PLHA movements and organizational responses. Ideally, this involves the development of representative PLHA structures that are empowered to act as full partners in the development of HIV/AIDS policy.

2. Support PLHA leadership

PLHA leadership is also central to establishing a voice in the policy process. PLHA leaders generally have to accept the heavy burdens imposed by the physical and social experience of living with HIV/AIDS. Leaders often emerge because they are among the first people in their country to speak openly about living with HIV. The limited number of openly positive people creates huge demands on those who have taken the step to be public about their status. A critical element in sustaining such public leadership remains the provision of ARVs for those who lack sustainable access.

3. Support PLHA network development

PLHA groups and particularly networks are crucial to establishing PLHA involvement at the policy level and to articulating the views of the PLHA sector. PLHAs should decide how these structures should be managed.

4. GIPA should be harnessed to the needs of all people living with and affected by HIV/AIDS

Achieving the meaningful involvement of people living with HIV/AIDS who are also sex workers, men who have sex with men (MSM), or injecting drug users (IDUs) requires related activities that build a supportive environment. For example, analysis of the relationship and influence on HIV/AIDS of legislation and statutes concerning drug use, sex work, and human rights is a good starting point. GIPA should also be harnessed to articulate issues specific to individual PLHA communities.

5. Publicize the contributions of PLHAs

Support education and publicity about the valuable contributions PLHAs can and do make to a country's response to the HIV/AIDS epidemic. Positive images of PLHAs and the contributions they make are an effective method of countering negative stereotypes and providing role models for other people living with HIV/AIDS. To increase the impact of this approach, campaigns and information, education, and communication (IEC) publicizing PLHA contributions should be endorsed by political leaders and well-known personalities.

6. Integrate GIPA with PLHA services

Link GIPA empowerment components and strategies directly to services for PLHAs, such as voluntary counseling and testing (VCT), so that individual PLHAs can be immediately made aware of both the health issues involved in living with HIV and their rights as citizens with HIV, as well as the resources available to assist them.

7. Develop multisectoral and local-level GIPA policies and activities

As important as it is to establish a nationally coordinated response to GIPA, it is equally critical that GIPA-friendly policies and activities be encouraged in a wide range of domains beyond health and between the public and private sectors at national, regional, and local levels.

8. Support and develop PLHA policy capacity

PLHAs require support to increase skills and abilities to make effective contributions to the HIV/AIDS policymaking process. Support for PLHA policy capacity can be framed, or divided among, three inter-related categories, each of which reflects necessary skills and capacities and corresponds to a gradient of involvement.

Foundational. The foundational category includes a series of fundamental attributes that will help support basic awareness of the impact and response of HIV from an individual perspective. These include awareness of HIV/AIDS and its impact at a personal level, awareness of stigma and discrimination and of the human rights dimensions of HIV/AIDS, peer support, and support for self-esteem management.

Organizational. This category includes those skills and attributes required to support effective community involvement and organization. These include organizational management, public speaking, advocacy, and networking skills.

Operational. This category includes a series of operational skills acquired through training and the practice of actual policy involvement. These include specific technical skills, for example, knowledge of current antiretroviral treatments and human rights instruments as well as broader competency in areas such as policy analysis and advocacy. While it is not necessary for all PLHAs to become technical experts in HIV/AIDS medicine or law, it is important they are supported to become conversant with the major developments in these and other related technical areas. It is also important to provide proper support and advice to PLHA policy advocates while they establish themselves as policy actors, for example, through a well resourced and sustainable mentoring program.

9. Recognize PLHA expertise

Increasing the role of PLHAs in the policy process requires not only the development of policy skills and expertise but also the recognition that PLHA experience constitutes expertise in its own right. This is perhaps the most sensitive area of PLHA involvement because it requires harnessing that experience so that it leads to more direct PLHA control of HIV/AIDS resources (both financial and intellectual). When PLHAs have some control over information and knowledge relating to, for example, care and support or HIV education, other policy actors are likely to seek increased PLHA involvement. In other words, substantially elevating PLHA involvement in the policy process requires allocating a degree of control to PLHAs over HIV/AIDS resources.

10. Monitor and evaluate the progress and impact of GIPA

There is an urgent need to sustain support for and, in most cases, stimulate programs and projects that aim at creating instruments that monitor and evaluate PLHA involvement. More specifically, there is a clear need to identify appropriate indicators to measure levels of representation and involvement of people with HIV/AIDS and/or their organizations in policy and planning processes. This report contains a simple framework or checklist that can be adapted and used to measure progress toward achieving GIPA. An important next step is to assess the impact of the GIPA principle and PLHA involvement on HIV/AIDS policies. To do this requires effective monitoring and evaluation of policy involvement, and it is strongly recommended that PLHA impact on policy be evaluated in relation to changes in policy content and policy development processes, as well as program implementation.

Abbreviations

AIDS	Acquired immune deficiency syndrome
ARV	Antiretroviral therapy
CBO	Community-based organization
CCM	Country Coordinating Mechanism
CPN+	Cambodian Network of Positive People
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater involvement of PLHAs
GNP+	The Global Network of PLHAs
HIV	Human immunodeficiency virus
IDU	Injecting drug use(r)
IEC	Information, education, and communication
MSM	Men who have sex with men
NAP	National AIDS Program
NGO	Nongovernmental organization
PLHA	Person living with HIV/AIDS
RNP+	Rede Nacional de Pessoas Vivendo com HIV/AIDS (Brazil)
STD	Sexually transmitted disease
TAC	Treatment Action Campaign (South Africa)
TB	Tuberculosis
U.N.	United Nations
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
UNGASS	United Nations General Assembly Special Session
VCT	Voluntary counseling and testing

Introduction

In December 1994, at the Paris Summit, 42 nations declared their support for the greater involvement of people living with HIV/AIDS (PLHAs)¹ in prevention and care, policy formulation, and service delivery. Signatory governments to the Paris Declaration undertook to

support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all national, regional and global-levels, this initiative will, in particular, stimulate the creation of supportive, political, legal and social environments (Paris Declaration, 1994).

The greater involvement of PLHA (GIPA) principle has become the most enduring legacy of the Paris Declaration. GIPA has been incorporated into national and international program and policy responses and taken up as a model of best practice in the response to HIV/AIDS. Since the Paris Summit, GIPA has been endorsed in numerous international statements, most recently by the UNGASS Declaration of Commitment on HIV/AIDS, which acknowledges

the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects and recognizing that their full involvement and participation in design, planning, implementation and evaluation of programs is crucial to the development of effective responses to the HIV/AIDS epidemic (United Nations, 2001, paragraph 33).

As well as continued activism and advocacy, GIPA has increased a commitment to ensuring that PLHAs are involved in, and have some control over, HIV/AIDS research, program development, and policymaking. The argument for the importance of GIPA in promoting the health, rights, and well-being of PLHAs, as well as in the overall improved response to the HIV/AIDS epidemic, makes intuitive sense. GIPA is also supported by human rights principles and precedents and progressive public health policy. The GIPA principle now refers to “more meaningful” rather than simply “greater” involvement of PLHAs.

Despite agreement that GIPA makes a meaningful contribution to the public health agenda, there has been little research to date on how GIPA is being implemented, or its impact on HIV/AIDS policy. The most relevant and similar initiative to the activity described in this report was a pilot project focusing on five South Asian countries—Bangladesh, India, Nepal, Pakistan, and Sri Lanka—initiated in 2001, and named the Greater Involvement of People Living with HIV/AIDS (GIPA) Project.² The project aimed at meaningful participation of PLHAs in response to HIV/AIDS in South Asia and was implemented jointly by Sahara—a nongovernmental organization (NGO) based in New Delhi—and the United Nations Development Program (UNDP), through the establishment of a close partnership with 17 PLHA groups in the subregion. This was the first regional project aimed at raising the profile of GIPA in South Asia. The project provided an opportunity for PLHAs to network and implement small-scale activities together and signaled the beginning of extensive networking among PLHAs across the Asia and Pacific region. The pilot phase had made it apparent that PLHAs did not view GIPA as an end in itself but as a tool to achieve the objectives they had set for themselves and their networks. This distinction was crucial in formulating

¹ The term “people living with HIV/AIDS” is abbreviated in a number of ways: people living with HIV/AIDS (PLWHA or PLHA), positive people, and people living with AIDS (PWA). The abbreviation used throughout this report is PLHA.

² See the Interim Report of the GIPA pilot project at <http://www.plwha.org/Resources/gipabackground>

the next phase of the project. Named the Asia Pacific Initiative for Empowerment of PLHAs, the second phase of the GIPA project was conceived as a three-year effort and initiated in summer 2002.

GNP+ released another relevant study in early 2004 that synthesizes 74 completed questionnaires received from 13 countries about the involvement of PLHAs in Country Coordinating Mechanisms (CCM) and specifically attempts to capture the relationship between CCMs and PLHAs, how they are working together, the challenges they face, and the institutional reforms needed.³ A four-country study conducted by the Horizons Project and the HIV/AIDS Alliance analyzed the involvement of PLHAs in the activities of NGOs and community-based organizations (CBOs) (Horizons, 2002). Stover and Johnston (1999), in reviewing HIV/AIDS policy development in Africa, note the significance of a wide spectrum of interest groups, including PLHAs.

Despite these efforts, ten years after the Paris Summit, the issue of meaningful PLHA involvement in policy development remains largely unexplored. This dearth of analysis of PLHA involvement in the social science literature is especially surprising given that PLHAs have been prominent leaders in the HIV/AIDS response in the majority of western democracies. A few authors have discussed the move to involve PLHAs in service delivery and policy development (e.g., Altman, 1994), but little attention has been focused on the details of efforts to promote their meaningful involvement (for notable exceptions, see Roy, 1995; Epstein, 1996; Ariss, 1997; Stoller, 1998; Roy and Cain, 2001). The lack of published literature on PLHA involvement is perhaps more reflective of the fact that the vast majority of PLHAs still live in countries where active PLHA involvement in policy development remains difficult, if not impossible.

Nonetheless, even where commentary has focused on PLHAs in the most affected areas of the world, GIPA remains a relatively unexamined topic. Several critical questions have yet to be effectively debated, let alone resolved. Has GIPA become a “bandwagon” policy slogan without significant meaning? What are the benefits of adhering to the GIPA principle and does this lead to better policies? How do PLHAs and others measure and determine progress? To answer these questions, the POLICY Project conducted a preliminary study in five countries. This report seeks to assess the extent of PLHA involvement in policy formulation by exploring key issues related to the GIPA principle and its effects.

³ The Final Report of this GNP+ study can be downloaded at www.gnpplus.net/files/multi_country_study.pdf

Background to GIPA

To a practitioner or student of international health policy, GIPA represents one element of an ongoing historical shift that is moving broader views of what constitutes ‘health’ to the forefront of health policy development. This process has been marked by the emergence of several international statements that articulate a holistic understanding of health issues and departs significantly from the closed, traditional medical model.⁴ The social model of health seeks to ensure that the social and economic dimensions of health are more prominently considered in health policy. A significant theme in this new paradigm is an increasing demand for more meaningful consumer participation in health programs and policy development. This does not mean that medical expertise has been relegated to the margins, as it still dominates the technical arena. But medical science, as the principal domain of expert knowledge on health, has been forced to make room for compelling evidence that identifies critical environmental, social, and economic forces influencing well-being, morbidity, and mortality.

A vivid example of this shift has been the entry of human rights experts and advocates in the health arena, and an expanded concern with medical ethics and the doctor-patient relationship. This has led to a broader view of the human rights dimensions of health. The global HIV/AIDS pandemic is a standard bearer for this shift. The ways in which HIV is transmitted, the complex social taboos attached to the major modes of transmission, and the rapid spread of the virus in many countries have demonstrated the need to refresh traditional public health knowledge and expertise and engage a wide spectrum of stakeholders. Similarly, a shift in HIV/AIDS activism has led to more informed patient treatment education. While not usurping the role of the medical establishment, HIV/AIDS advocates have helped to show that, without direct patient involvement in medical service provision decision making, responses to HIV/AIDS are suboptimal.

In this context, the idea of GIPA begins to appear less radical and more in tune with the demands of the HIV/AIDS pandemic. To a person living with HIV/AIDS, and to people who live with and work with infected people, what GIPA represents does not seem extraordinary at all. The global HIV/AIDS pandemic is demonstrating the social and economic dimensions of disease on multiple levels. The need to harness all the most potent responses and initiatives in HIV/AIDS policies and programs remains the most basic challenge in stopping the spread of HIV and supporting and involving people living with HIV/AIDS.

While policymakers and PLHAs have made headway in many countries in adopting and implementing principles of involvement, a considerable divergence exists between the principle and practice of greater involvement (O’Loughlin and Murni, 1997). A lack of clarity over what constitutes “meaningful involvement” hampers efforts to further the vision articulated by GIPA.

⁴ The Ottawa Charter for Health Promotion, a framework for international health promotion declared in 1986, defines the prerequisites for health as “peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity.” The 1997 Jakarta Declaration on Health Promotion into the 21st Century extends and updates the health promotion mission to include issues of more central relevance to developing countries including the impact of environmental degradation, urbanization, and global economic integration. The general thrust of these documents emphasizes the role of political, social, and economic conditions in relation to health status.

Defining GIPA

In 1999, UNAIDS published a paper analyzing the levels of PLHA involvement in the response to HIV/AIDS. These levels are shown in Table 1.

Table 1. Levels of PLHA Involvement

<p>Decisionmakers: PLHAs participate in decisionmaking or policymaking bodies, and their inputs are valued equally with all the other members of these bodies.</p>
<p>Experts: PLHAs are recognized as important sources of information, knowledge, and skills who participate—on the same level as professionals—in design, adaptation, and evaluation of interventions.</p>
<p>Implementers: PLHAs carry out real but instrumental roles in interventions (e.g., as caregivers, peer educators, or outreach workers). However, PLHAs do not design the intervention or have much say in how it is run.</p>
<p>Speakers: PLHAs are used as spokespersons in campaigns to change behaviors or are brought into conferences or meetings to “share their views” but otherwise do not participate. (This is often perceived as “token” participation, where the organizers are conscious of the need to be seen as involving PLHAs but do not give them any real power or responsibility.)</p>
<p>Contributors: Activities involve PLHAs only marginally, generally when the PLHA is already well-known. For example, using an HIV-positive pop star on a poster or having relatives of someone who has recently died of AIDS speak about that person at public occasions.</p>
<p>Target Audiences: Activities are aimed at or conducted for PLHAs, or address them as a group rather than as individuals. However, PLHAs should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as “patients” at this level. They can provide important feedback which, in turn, can influence or inform the sources of the information.</p>

Source: UNAIDS, 1999

The Horizons/Alliance study (Horizons, 2002) provides a similar evidence-based framework that helps to clarify meaningful involvement in practice. The study identifies four categories of involvement as summarized in Table 2.

Table 2. Categories of PLHA Involvement

<p>Access to Services: This level of involvement—access to services—is defined as PLHAs taking part in NGO activities as beneficiaries of services. It was most typically observed among the 17 NGOs that took part in the study.</p>
<p>Inclusion: Inclusion is characterized by PLHAs acting as support staff for HIV/AIDS NGOs and as volunteers in HIV/AIDS service delivery. The research found that PLHA involvement at this level is not formally supported by structured training or wage remuneration.</p>
<p>Participation: Participation moves PLHA involvement into a more structured and recognized role within NGOs. In this category, PLHA expertise is recognized and work is financially rewarded.</p>
<p>Greater Participation: Greater participation is defined as the most advanced stage of PLHA involvement. This level is characterized by PLHAs working in management and as significant policy and strategic organizational actors. At this level, PLHAs may also have a significant representative role outside the NGO.</p>

Source: Horizons, 2002 (More information about the Horizons/Alliance study is available at www.popcouncil.org/horizons)

The models developed by the Horizons/Alliance study and UNAIDS represent GIPA as a hierarchy of involvement. Progress is measured by the degree to which PLHAs are able to influence and ultimately direct HIV/AIDS policy. GIPA is also a process that reflects a way of thinking. Implementing GIPA requires a partnership approach on the part of all stakeholders working with PLHAs. In this partnership, those affected by HIV/AIDS have an equal role and are included in all policymaking and programs.

This study aims to broaden the criteria that define GIPA-related activities. Although the purpose is to focus on the policymaking arena at the national level, it is important to recognize that the concept of GIPA is broad, dynamic, and related to the interests of the people it is designed to advance.

As this report illustrates, the application of GIPA varies from country to country. There are, however, many common experiences regardless of the setting. Numerous conferences and workshops (Stephens, 1999; UNAIDS, 2000a; UNAIDS, 2000b; Kasente, 2002; Low, 2002; Gray, 2002; Ortega, Gonzales, and Liwanag, 2002) have addressed the challenges facing PLHA involvement. A list of key barriers is summarized in Table 3.

Table 3. Barriers to PLHA Involvement

<p>Leadership: The small number of people who are involved as leaders of PLHA groups and networks are invariably overburdened. This has obvious health implications for individuals bearing the major responsibility of representation and public advocacy.</p>
<p>Sustainability: Illness and death create severe problems for sustaining organizations and organizational responses. Leaders and activists are lost and the continuity of PLHA representation and involvement is disrupted.</p>
<p>Lack of Capacity: PLHAs generally require extensive support in order to engage with the policymaking and strategic planning process; if this support is not forthcoming then the capacities required to create meaningful involvement at the policy level will remain undeveloped</p>
<p>Resistance to Involvement by Other HIV/AIDS Stakeholders: Despite the GIPA rhetoric, many HIV/AIDS stakeholders both in the governmental and nongovernmental sectors remain unconvinced or unwilling to support involvement. The reasons for lack of support are many. The small number of research studies that have attempted to look at this, together with evidence from PLHAs, suggest that stigma, discrimination, and lack of understanding of the role of PLHAs remain significant barriers.</p>
<p>Lack of Evidence: The evidence needed to convince stakeholders of the value of PLHAs is still lacking. As noted above, research on the issue is limited.</p>
<p>Stigma: Involvement is also constrained by the prevailing environment of stigma and discrimination. The ability of individuals and organizations to become involved demands the creation of a space in which this can happen. Stigma and discrimination effectively close off and limit the ability of PLHAs to organize and develop a response in a supportive environment.</p>
<p>Public Voice: PLHA involvement should not be premised on public HIV status. However, the ability to speak openly about the personal experience of HIV/AIDS is a powerful strategy for assisting others with HIV/AIDS as well as providing a public voice. While barriers in the form of stigma and discrimination remain, the number of people willing to speak openly will remain low.</p>

HIV/AIDS and the Policy Process

Policy development is generally concerned with setting the framework and vision that will create an enabling environment to achieve national goals. This includes measures aimed at defining roles and responsibilities, legal and regulatory frameworks, resource allocation, and monitoring and evaluation. There are many approaches to policy formation: evidence-based, participatory, highly centralized, and non-participatory.

The HIV/AIDS policy environment is complex. The challenges of finding effective policy responses to HIV/AIDS have meant that a range of expert knowledge domains are vital in contributing to developing and implementing comprehensive policy approaches. In the brief history of the disease, at least at the global level, U.N. leadership on HIV/AIDS has been the province of the Joint U.N. Program on HIV/AIDS (UNAIDS) since the mid-1990s. The creation of UNAIDS reflected the need to involve the widest partnership and range of expertise within the U.N. system to cope with the challenges presented by HIV/AIDS.

In a review of policy formation in nine African countries, Stover and Johnston (1999) found that a high level of participation in the policymaking process from a wide range of interest groups resulted in policies that enjoyed a higher level of political commitment as well as support from civil society actors. While the process of participation may lengthen the policy-drafting period, it can, according to Stover and Johnston, shorten the overall period required for approval, because momentum and support for policy content has already been established. Even when progressive national policy is developed, it often fails at the local level (Divan, 2002).

The complex social, economic, and political factors that fuel the HIV/AIDS epidemic require a multisectoral response. HIV/AIDS policy development should reflect this breadth. The literature on GIPA and the findings of this study point to the need to build the skills and capacities of PLHAs to enable them to participate in the policy process. The list of requirements identified by PLHAs and others interviewed are consistent across the project countries. It begins in many cases with the need to address the basic psychological and emotional stresses of living with HIV/AIDS, as well as organizational and management skills. Gaining the confidence that training and skills development bring is seen as a necessary platform for greater involvement. However, policymaking is not always the outcome of a rational public health process, and PLHA involvement in the policymaking process does not necessarily guarantee favorable policy outcomes for PLHAs. HIV/AIDS policies in many countries, if not in all countries at some point, have been driven by a range of moral and political agendas.

The Study Countries: Benin, Brazil, Cambodia, South Africa, and Ukraine

The countries represented could not, of course, feature all the conditions and environments that need to be considered in relation to the application of the GIPA principle in HIV/AIDS policymaking. HIV is a complex epidemic. Social and economic conditions—including national culture, history, and politics—exert an influence on the trajectory of the epidemic and, therefore, on the meaning and possibilities of GIPA. For example, national political conditions and cultures of social mobilization (to name only two factors) create a broad framework within which civil society groups and organizations, including PLHAs, are able to maneuver. The opportunities available to PLHAs marginalized by poverty and systemic stigma in the developing world present a different set of challenges to those facing PLHAs in the richer western nations. How GIPA develops is not only an outcome of historical forces, social and economic conditions, or even the nature of the epidemic. The will, energy, and activism of the people most affected by the disease provide the most compelling force for GIPA.

The countries that took part in this project provide a series of contrasting HIV epidemics, national responses, and PLHA communities. The five countries are profiled below.

Benin, despite being one of the poorest countries in the world, has demonstrated an impressive commitment to participatory processes involving community sectors, NGOs, PLHAs, bilateral organizations, and the U.N. system. Benin is among the few African countries where HIV prevalence rates have remained relatively low. However, UNAIDS projections into 2025 estimate the HIV prevalence rate in Benin could reach 10 to 20 percent. In the 15–49 age bracket, Benin has an estimated HIV prevalence rate of 3.6 percent (UNAIDS, UNICEF, and WHO, 2002), a percentage that is expected to rapidly increase in the next few years.

Brazil has embraced the unification of prevention and care (often discussed but seldom practiced) through a policy of universal access to antiretroviral therapies (ARVs). A relative stabilization of AIDS incidence has been observed since 1997. A national law defines AIDS as a public responsibility in terms of prevention and care. There is legislation against discrimination, supporting the human rights of PLHAs.

Cambodia has one of the highest rates of HIV prevalence in Asia, with an estimated 170,000 PLHAs in 2001 and 2.7 percent prevalence among its adult population. The epidemic is mainly heterosexual and characterized as a general epidemic, with particularly high rates of infection among sex workers and young adult women. There is a low reporting rate for HIV (8%). Cambodia is also a nation recovering from the tragedy and trauma of civil war and genocide.

South Africa is a nation devastated by the epidemic, with an estimated 4.5 million people living with HIV/AIDS. In 12 years, HIV prevalence in 15–49-year-olds rose from less than 1 percent to about 20 percent. The demographic group most affected by HIV/AIDS is female, aged 15 years and over, African in racial origin, and living in urban, non-formal dwellings. The scale of the epidemic in South Africa has catalyzed a dynamic response from people living with and affected by HIV/AIDS, and GIPA initiatives are relatively advanced.

Ukraine, along with the rest of Eastern Europe, is experiencing one of the fastest growing HIV epidemics in the world, with an estimated 400,000 PLHAs, an increase of 200 percent over five years. In fact, Ukraine seems to be in the midst of three large and interlocking epidemics that serve to fuel and spread each other: high rates of injection drug use, sexually transmitted infections, and HIV. GIPA activities

have to negotiate the difficult and complex issue of drug addiction and drug injection-related stigma. It is also significantly affected by ongoing PLHA stigma and discrimination. One of the survey's findings indicates that almost 50 percent of Ukrainians believe that PLHAs should be separated from the rest of society.

Methodology

The research process was designed to collect information on the influence of GIPA on the development and implementation of national HIV/AIDS strategies, legislation, and other relevant HIV/AIDS policy instruments. A document review in each country assessed the legislative and policy commitment in relation to GIPA. The review included assessing national AIDS strategies, HIV/AIDS legislation, and other relevant policies and literature relating to PLHA involvement. The most relevant findings from this document review are taken into account in this paper's final discussion and recommendations.

Twenty-five interviews were conducted with senior policymakers responsible for HIV/AIDS, and were limited to those most senior and familiar with the subject of inquiry. The leaders of the national PLHA movement or network in each of the five countries were invited to take part. The researchers also interviewed other influential policy actors where possible. All interviews were audio-taped, transcribed, and translated into English. Where feasible, and in most cases, interview transcripts and summaries were sent back to interviewees for verification. Researchers used a semi-structured interview guide organized in sections that addressed the following areas: participants' awareness of GIPA, the formal or institutional level of involvement of PLHAs in national HIV/AIDS planning, benefits of involvement to national HIV/AIDS policies and programs, and the barriers and challenges to PLHA involvement. The interview guides are included in the appendix.

Analysis of the Interviews

Unpacking GIPA

Probably the most well-known, widely-used, and simplistic expression of the GIPA principle is the process of public disclosure, often referred to as the “Hello, my name is ... and I’m HIV positive” speech. (South African respondent)

GIPA is most often understood as a visible and public acknowledgement of living with HIV infection. Awareness of the origins of the GIPA statement at the Paris Summit of 1994 was not high among the majority of policymakers interviewed for this study. However, while policymakers may be unfamiliar with the origins of the statement, most of those interviewed were aware of the principle of PLHA involvement that GIPA articulates. Not surprisingly, PLHAs were more familiar with the Paris Declaration. While there were differences in interpretation of the term GIPA, the majority of respondents understood the meaning as relating to PLHA involvement and participation in HIV/AIDS policy and program design, planning, implementation, and evaluation. More specifically, respondents pointed to the need to have PLHA opinions and voices heard and integrated in decisionmaking processes.

Some respondents questioned the value of promoting PLHA involvement using the terminology of GIPA. South African respondents also noted that the term GIPA created a label known only to a small circle of people directly involved in HIV/AIDS and created the expectation noted by a South African respondent:

You are expected to behave like a person who’s positive, whatever that means. (South African respondent)

Levels of involvement varied among the countries in the study, although all the countries provide examples of PLHA participation in policymaking. In South Africa, a PLHA was involved in the drafting of the first national AIDS Plan. The involvement of people with HIV/AIDS remains the first guiding principle of the country’s HIV/AIDS and STD Strategic Plan for 2000–2005. South Africa is the country in which the United Nations developed the GIPA Workplace Model. Half a dozen HIV-positive field workers were subsequently placed in government departments, as well as in parastatal organizations and corporate and NGO workplaces. The workplace model was established to demonstrate the practical application of GIPA. In the view of those involved with the model, its wider impact on national HIV/AIDS policy has been limited, although the value and expertise of the HIV-positive workers have stimulated debate and raised awareness of PLHA issues and rights within the world of work.

In Brazil, PLHA groups and networks have been able to achieve consistent (although not unproblematic) involvement in national HIV/AIDS planning and strategy development structures and processes. In Cambodia, PLHA involvement in the implementation of the national strategy only became formalized with the establishment of the Cambodian Network of Positive People (CPN+). In Ukraine, PLHA involvement in national planning began in 2000 through the advocacy of PLHAs. From 2002, PLHA involvement has become formalized in a number of national HIV/AIDS structures. In Benin, the government invited two PLHAs representing the national association of PLHAs to take part in the design and planning of the national HIV/AIDS strategic framework.

Institutionalizing GIPA

Responses to the question on PLHA involvement in national planning and strategy suggest that GIPA is actively implemented at the policy level in the countries represented in this report. However, as the

following section highlights, perceptions of the quality, depth, and meaning of PLHA involvement in the policy process vary considerably depending on the position and perspective of the respondent.

National HIV/AIDS programs are under increasing pressure by international agencies to demonstrate a commitment to GIPA. The UNGASS Declaration of Commitment calls for governments to actively pursue PLHA involvement. The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) requires Country Coordinating Mechanisms (CCM)—the national bodies responsible for administering the funds—to include a PLHA representative. Although GIPA activities may become more institutionalized in government programs and policies as a result of international pressure, this does not guarantee that representation becomes anything more than tokenistic.

The [GIPA] principle has not yet seen the light of the day. Often, the government authorities recruit infected persons to give an image of HIV, so that people can testify on the TV network. That's not GIPA. The right persons, based on their skills, should be used so that they can contribute something new. (Benin respondent)

Importance of a Network

While issues of representation raise difficult questions regarding legitimacy, a network of PLHA organizations does provide a powerful platform from which PLHAs can advance claims for greater involvement. A strong network plays an important role in advocacy, sharing of experiences, and mobilization of resources (Kamdar, Noor, and Maseeh, 2002; Kithinji, Ilinigumugabo, and Chirchir, 2002). An important step to achieving greater involvement of PLHAs is an acceptance of the principle by key national actors. Building support for GIPA requires working toward a critical mass that will create the momentum and provide the resources for PLHA involvement. The central hub of this critical mass has to be people living with HIV/AIDS.

Building a PLHA-driven advocacy movement presumes the existence of a cohesive community of activists ready to raise their voices. How does such a community evolve, how does a movement emerge? (Suwannawong, 2002)

The question posed by Suwannawong is one of critical importance in understanding the processes that support GIPA. The Cambodian Network of Positive People (CPN+) was formed in 2001. Prior to its formation, representation of PLHAs in HIV/AIDS policy was ad hoc. Despite its newness and its struggle to build capacity, CPN+ provides a national framework for representing the views of PLHAs to government and other actors. This is clearly a situation more comfortable for policymakers charged with involving PLHAs in the policy process. Being able to deal with a representative network, however fragile, relieves policymakers of the obligation to consult with multiple PLHA groups.

In Benin, government policymakers looked to the established PLHA network as a partner in designing the national strategic framework.

We chose those that were organized; we have to work with structures already set up and are organized. (Benin respondent)

Representative networks can also deal more effectively with factional disputes that are potentially destructive to government attempts to construct HIV/AIDS policy as well as to the unity of PLHAs. The Director of the AIDS Law Project and Secretary of the Treatment Action Campaign in South Africa argues that strong lobby groups are an essential precursor to meaningful PLHA involvement which:

...partly depends on having strong lobby groups or organizational voices for people with HIV because involvement in drawing up strategies doesn't mean having one person on the National AIDS Council or consulting three people in the drawing up of a strategic plan. It means much more serious consideration of the perspectives of people with HIV in the drawing up of those plans as well as sustained consideration in the implementation of those plans. (South African respondent)

This view was supported by the experience of PLHAs in the Ukraine:

When the PLHA Network was established as a big, powerful organization and it claimed publicly ...that PLHAs were people with specific needs and they wanted to live and we expected our country to help us. And the situation has changed radically... they invite us, they respect us. (Ukrainian respondent)

GIPA: PLHA Identity and Representation

The question of how PLHA organizations and movements claim representative legitimacy (internally within PLHA communities and externally with other actors) is one that typically faces all PLHA organizations seeking a greater role in HIV/AIDS programming and policymaking. PLHA representation raises questions regarding the extent and coverage of the representative voice. One observer (Stern, 2001) has noted that PLHA involvement, particularly within international organizations, has the potential to create elite tendencies and dependence on international funding, that can lead to a lack of motivation and energy when it comes to representing issues related to the very poor. The legitimacy of PLHA involvement rests on a number of factors. Key among these is the question of PLHA representation. The question raised by GIPA, and indeed by the larger debate over PLHA involvement, is: To what extent, and how should the idea of GIPA promote PLHA representation?

The Brazilian experience of PLHA involvement and representation relies on serological status and a "seropositive identity," a category that includes seronegative people who are committed to a core set of ethical, political, and ideological principles, supported by people with HIV/AIDS. This consensus of representation is based on the idea of solidarity between seropositive and seronegative people, as well as the concern that representation based on PLHA visibility forces people to disclose their status when they may be unwilling. HIV/AIDS in Brazil resonated with existing social justice and developmental concerns, and catalyzed people affected to mobilize both socially and politically. Mobilization was based not only on HIV/AIDS but also on other socially excluded identities, in particular homosexuals, sex workers, transgender people, and injecting drug users (IDUs). Representation of PLHAs is an important theme from the Brazilian perspective. Respondents argued that the application of the GIPA principle in Brazil is not restricted to people with a positive serology but applies to every person that lives with, and is affected by, the epidemic. When commenting on the serological criteria for the inclusion of representatives in some committees, a Brazilian respondent stated that:

...the controversy about the inclusion of a seropositive person in these spaces is due to the position of the Brazilian AIDS Program, which is against obligatory or induced testing. Thus, there are doubts on demanding the condition of seropositivity for participation, because of this principle. He concluded with quote from a Brazilian AIDS activist who said that the establishment of these criteria would be like an "ambush to initiate a process of identification of people based on their serology." (Brazilian respondent)

The representative from RNP+, a Brazilian organization that involves only seropositive people, highlighted the fact that there are only a few leaders of seropositive people prepared to disclose their condition. Moreover, there is little perception among seropositive people of the importance and need for

visibility to legitimize their representation. The RNP+ has been discussing the possibility of admitting seronegative people who are connected to seropositive people within the organization.

Overt PLHA involvement in policy can be fraught with emotional and other risks for participants. A seropositive interviewee from Group Pela Vidda was emphatic on this issue when discussing representation criteria based on serology arguing that:

...there is no evidence that the representation of a seropositive person guarantees better results in the process of planning and implementing policies. Therefore, Pela Vidda works based on the principle that all members of the organization must be able to represent people with AIDS. (Brazilian respondent)

Significant policy change on HIV/AIDS is rarely driven solely by PLHA groups. In South Africa, policy change on key issues such as mother-to-child transmission were brought about by a coalition of organizations, some of which involved people with HIV/AIDS. Participants in the South African study believed that public disclosures—which they acknowledged involves significant personal risks—were nevertheless vital to raise awareness and educate audiences about HIV/AIDS, particularly in the early stages of the epidemic.⁵

Out of the Shadows: The Benefits of Involvement

The benefits of greater involvement of PLHAs flow first to people living with HIV/AIDS and their lovers, families, and friends. For PLHAs, involvement at its most basic level can overturn feelings of shame and stigma, depression, and the social isolation that often accompanies HIV/AIDS. For the individual with HIV/AIDS, involvement helps re-establish social relations and feelings of self worth. A respondent from Benin described how he was initially rejected by his family for over a year after informing them of his diagnosis. His involvement as a leader of the PLHA association has helped him reconnect with his family, gain employment, and even begin his own family.

I won esteem for myself. In the beginning it wasn't easy. I said I was lost. But now, I am proud of myself, of my person. I have given a new meaning to my life, a new orientation. That is what I value most. (Benin respondent)

The majority of respondents in this study noted that policy involvement improves the quality of prevention and care interventions by creating a direct link (provided by PLHA involvement) between policy development and the implementation of services. Involvement provides firsthand information on issues that may not come to the notice of policymakers. More specifically, respondents pointed to the advantages that PLHAs bring to prevention activities. The Vice Chair of the National AIDS Authority in Cambodia described how the openness of PLHAs had brought HIV/AIDS out of the “shadow” of public denial thereby increasing public awareness of the reality of the epidemic. Other respondents noted that open PLHA involvement qualitatively enhances the impact of HIV/AIDS education activities.

NGOS use positive speakers in their educational messaging and have seen what a difference in fact that can make. So you've often had the situation whereby an NGO will do training over one or two days and then the feedback will be that the most powerful component was the positive speaker because that made it become real and whatever. (South African respondent)

⁵ This was tragically evident in South Africa in 1998 when Gugu Dlamini was stoned and beaten to death by a mob after she spoke on national television about living with HIV.

Research analyzing the educational impact of HIV-positive educators, people who speak openly about their experiences, is scant. Susan Paxton (2002) conducted an extensive study of the impact of HIV-positive people as HIV educators. Paxton concludes that PLHAs have a significant and measurable impact in a number of critical areas, including reinforcing the messages about protective behavior and breaking down negative stereotypes of people with HIV/AIDS. Paxton's research confirms what many PLHAs and others working in HIV/AIDS have known for a long time.

Involvement also increases the legitimacy of PLHA organizations with PLHA constituencies and with other HIV/AIDS stakeholders and increases participation in the management of health policy. The advantages of institutionalizing GIPA flow beyond the immediate concerns of prevention, care, and treatment issues.

For example, we come across a situation where the children of HIV-positive women are not admitted to the kindergartens, and we should know. But the manager of the kindergarten or district department of public education or whoever, won't tell us about it. Involving PLHAs in our work, we get to know their needs and demands directly. (Ukrainian respondent)

As the findings outlined above show, lack of progress in GIPA principles is not only detrimental to the well-being of people living with and affected by HIV/AIDS, it is also a major barrier to activities aimed at reducing HIV transmission. Respondents in this study noted the general benefits of involvement in creating more credible and insightful policy. Involvement is also seen as an approach in line with human rights principles and the requirement to empower people affected by HIV/AIDS. For policymakers, this is also part of their responsibility to ensure that policy decisions are directly informed by what is happening at the grassroots level. Respondents pointed to a range of areas where the benefits of involvement flow directly into improved policy and programs including creating greater awareness of HIV/AIDS at all levels of society, more focused research, and more effective HIV/AIDS communication.

While the principle of involvement may enjoy significant support among some policymakers, promoting it as an effective instrument of the broader HIV/AIDS response is problematic. The methods developed to analyze GIPA have so far relied on establishing the level and quality of PLHA involvement. Less attention has been paid to how this affects the major concerns of programs and policy, particularly prevention of HIV transmission. While this aspect of GIPA remains underdeveloped, even sympathetic institutional supporters have difficulty convincing others of the benefits of PLHA involvement in policy.

My broad feeling is that the general principle has lots of support. But ... there's a lack of detailed understanding. People always agree 'yes, it's important' but there's not really a full understanding. I've got a strong commitment, but sometimes I struggle to really argue it. All my arguments are based on general principles and on the alternatives to it. One of the strong arguments is that it's almost like making sure that you don't go too much wrong—it protects you from making rather wrong decisions. That's one of the arguments. But I think that there's still a poor knowledge base among stakeholders, including myself and probably more amongst others, in terms of being able to define the benefits. (South African respondent)

GIPA and Stigma

The social repercussions of HIV/AIDS became clear early in the epidemic. The stigmatization and discrimination of people infected and affected has been a universal experience that people with HIV/AIDS around the globe have shared. The extent of HIV/AIDS-related stigma and the quality of the response to this stigma are perhaps the central factors determining the progress of GIPA. The findings from this report confirm that addressing stigma is central to working toward meaningful involvement.

Stigma also operates to retard the efficacy of prevention efforts at every level. The need to address stigma in HIV/AIDS on a structural and policy-related level is equally apparent (Parker and Aggleton, 2002).

While the principal goal of stigma reduction is to increase the life opportunities and well-being of people with HIV/AIDS, the claim has also been advanced that reducing stigma will lead to greater gains in prevention activities. Although the link between stigma reduction and more effective prevention is difficult to quantify, there is mounting evidence that addressing the relationship is pivotal to enhancing HIV prevention efforts. A recent literature review of HIV-related stigma stated, "...both actual discrimination and fear of stigmatization affect transmission patterns and contribute to determining the success or failure of prevention and care and support efforts." (Busza, 1999: 1) Another review of HIV-related stigma (Malcolm et al., 1998) found that the durability and success of HIV/AIDS prevention programs depend on the ability to understand and overcome stigma and discrimination. In the five countries in this study, stigma remains a fundamental barrier to greater PLHA involvement. In Cambodia, the leader of CPN+ stated that poverty and stigma combined to limit the number of effective PLHA advocates.

To properly address stigma and discrimination requires the involvement of PLHAs. If the need to address stigma remains at the center of efforts to reduce the spread of HIV, and the role of PLHAs in stigma reduction is acknowledged, we can begin to see the public health rationale for more fully incorporating and working with PLHAs as essential partners in the response to HIV/AIDS.

Knowledge Barriers

A fundamental requirement and an implicit demand of GIPA is to increase the knowledge base of PLHAs. Engaging with experienced and skilled policymakers requires a level of expertise that many PLHAs do not possess. While it is difficult to establish the socioeconomic profile of PLHAs involved in organized HIV/AIDS responses, PLHAs who come to the attention of the public health community working on HIV/AIDS in resource-poor settings are typically from low socioeconomic strata with only basic education.⁶

Even before gaining policy negotiation skills and a level of familiarity with the national HIV/AIDS response, PLHAs require basic knowledge and awareness of the impact and effect of HIV/AIDS at both personal and policy levels. Understanding and being able to articulate the personal experience of HIV/AIDS is a prerequisite to coming to terms with the more technical knowledge domains that dominate policy development. One respondent, who was present at the South African national summit for people with HIV/AIDS, was

...struck by the functional illiteracy of 90 percent of the participants there. Their lack of knowledge on treatment issues for people with HIV, despite the fact that quite a number of them were visibly symptomatic, their lack of knowledge in my section on basic human rights and legal questions. And if you don't empower people on those issues, then you can't expect them to engage properly on policy processes because policy processes require a basic level of knowledge and information. (South African respondent)

⁶ This assertion is based on observation. Nevertheless, it is not unreasonable to assume that PLHAs who are employed and have the financial means to access healthcare in the private sector, with some exceptions, constitute a minority of the membership of most PLHA organizations in the developing world. A higher level of socioeconomic status allows PLHAs to access healthcare and other goods in the private sector. Greater socioeconomic status also creates greater disincentive to identify as a person living with HIV/AIDS.

In countries with a large number of poor people affected by HIV/AIDS, demands on PLHA groups and organizations can be intense. In Brazil, the Group Pele Vidda has to respond to the demands of PLHAs who are largely poor, have little education, and lack experience of how civil society groups operate in a political context. This creates pressure on the small number of PLHA leaders to respond to the basic health needs and at the same time empower group members to recognize the need for collective PLHA advocacy and political action. The challenge for PLHA organizations is now to balance these competing demands and foster the ability to transform individual needs into collective demands.

Legal Awareness

Even when the GIPA principle is supported by legislation, as is the case in the Ukraine, there remains the uncertainty of clearly defining and interpreting GIPA in relation to law and the related problem of designing and activating its implementation.

There is a problem of legislative definition...of this principle. And there is a problem of law implementing activity... It's difficult for me to say to what extent it is being observed. Well, as a matter of fact, there are no such data. Such data may exist only when these people will defend their rights actively, i.e., appeal to court, appeal to the bodies of pre-forensic appeal. (Ukrainian respondent)

For PLHAs, the lack of legal power and enforcement of GIPA-related programs and principles is a major source of frustration. One respondent from the Ukraine recounted a case where the national program failed to purchase a sufficient quantity of antiretroviral drugs to cover the needs of PLHAs for 2001.

What would you call such an attitude? And what would an HIV-positive person think about it? I would not call it a serious attitude. The problem is that all our rules and regulations, all programs and documents in this field are simply recommendations. I mean they just recommend, not oblige to do things. It means that you can easily do nothing if you have a "good" reason, like lack of money or of lack of resources. (Ukrainian respondent)

Leadership

Political leadership on GIPA provides crucial high-level support and punctures institutional hesitancy. Leadership statements on PLHA issues and a close interest in HIV/AIDS are often provoked by personal experience of a friend or family member with HIV/AIDS. King Norodom Sihanouk of Cambodia became aware that several of the palace staff were living with HIV/AIDS. From the perspective of policymakers, the king's actions and the support of other political leaders for PLHA issues helped create a supportive environment.

No community or institution has shown a reaction or bad behavior toward PLHA involvement...This is due to the top institutions. The king hosts and supports PLHA representatives. Other leaders like the prime minister, the president of the Senate and National Assembly provide support so we see it is no longer a barrier. (Cambodian respondent)

Another Cambodian government official concurs with the view of his colleague; however, he is more circumspect on the question of GIPA in practice, in spite of commitment from national leaders.

I think until to date, many things changed in a positive way. Yet, as I mentioned, we have prepared policy on paper but the real practice is still limited and will not advance unless the private or business sector allows PLHAs to participate in or amend policy and also show a clear commitment. (Cambodian respondent)

PLHA leadership is also central to establishing a voice in the policy process. PLHA leaders generally have to accept the heavy burdens imposed by the physical and social experience of living with HIV/AIDS. Leaders often emerge because they are among the first people in their country to speak openly about living with HIV. The limited number of openly positive people creates huge demands on those who have taken the step to be public about their status.

Once PLHAs acquire the organizational capacity and individual skills required to take an active lead in HIV/AIDS responses, their associations compete with other NGOs for a limited pot of HIV/AIDS funding. On the one hand, the promotion of GIPA can result in a tension between HIV/AIDS NGOs and PLHA groups. On the other hand, non-PLHA organizations are aware of the advantage they gain in the competition for funding by involving PLHAs. As the following quote from South Africa makes clear, this may not be to the advantage of PLHAs or the promotion of GIPA.

Many people are actually threatened by PLHAs, not only government... How do you justify a situation where you have a home-based care organization in a township [and] within its leadership there are no PLHAs, but it is trying to provide care to PLHAs. So in each and every NGO PLHAs must be employed, PLHAs must be involved—but the moment these NGOs and CBOs should involve PLHAs they become scared that “I’m going to lose my job because funders will fund PLHAs directly.” Also the involvement of PLHAs in some of these organizations has been used as a tokenism in a certain way, because people will say “In my organization, I’ve got three people who are positive and we are helping them”—so PLHAs are being used as moving automatic teller machines. (South African respondent)

Discussion

There is an emerging awareness of GIPA among HIV/AIDS policy actors and people living with HIV/AIDS. There are, however, considerable differences over interpretation and implementation and the quality of commitment by national bodies to supporting PLHA involvement. The majority of the respondents to this survey were in agreement regarding the key benefits of involvement for HIV/AIDS policies. The fundamental advantage of a GIPA approach is the improvement to policy through a greater awareness of the impact of HIV/AIDS, and greater integration of the people most affected by the epidemic.

The history of the epidemic illustrates the two interlinked but delineable strategies aimed at securing PLHA involvement in the program and policy response to HIV/AIDS. In simple terms, these can be described as GIPA as a social or grassroots movement and GIPA as a more institutionalized component of HIV/AIDS public health strategies.⁷ Social movement strategies are aimed at shifting policy positions by mobilizing communities and activists through coordinated campaigns, usually focusing on a single issue. South Africa provides examples of both these approaches. The Treatment Action Campaign (TAC) in South Africa is a current example of a publicly conducted social mobilization campaign aimed at changing government policy on antiretroviral therapy. In contrast, the GIPA workplace program in South Africa was developed by PLHAs, international actors, and government officials. Described as a variant of an affirmative action program by one of the South African respondents, the GIPA Workplace Model aims to create greater workplace and institutional awareness of the role PLHAs can play. Neither approach is solely driven by PLHAs.

While there are many activists and institutional actors who bridge the community-institutional divide, the key difference between the approaches sketched here is GIPA advocacy through social movement pressure, and the institutionalization of GIPA through a more structured, and in many cases, donor-driven process.⁸ This distinction was noted by several of the PLHA respondents and is used to make strategic decisions on advocacy strategies.

Institutionalizing GIPA through the appointment of PLHAs to policymaking bodies may satisfy the formal requirement of GIPA and create a more visible PLHA presence, however, without a parallel process aimed at creating more representative PLHA networks, GIPA may become a source of tension rather than a viable program and policy response.⁹ GIPA activities that insert PLHAs into positions of policy influence without connecting them to a supportive organizational anchor are important but can leave individuals isolated. This form of GIPA activity will not, unless it is connected to a larger effort to support PLHA originations, satisfy the demand for a more representational PLHA voice in the policymaking process.

The role of civil society in national policy debate and development remains perhaps the most important factor in determining the underlying conditions for the promotion of GIPA. In South Africa, the

⁷ Even at the Paris Summit, dissenting voices from the HIV/AIDS NGO/CBO sector questioned the value of institutionalizing the concept of involvement fearing that GIPA would lead to PLHA co-option by non-PLHA HIV/AIDS actors.

⁸ For example, the United Nations Volunteers program aims to create greater PLHA involvement by placing PLHAs in national health bureaucracies or U.N. agencies.

⁹ The issue of representation of people with HIV/AIDS (as for all the identity-based groups affected by HIV/AIDS) is not without some tension. Although national coalitions or networks exist in many countries, including those in this study, claims to representative status are vulnerable to the charge that the vast majority of people with HIV/AIDS are not connected to organized PLHA groups.

HIV/AIDS epidemic and the national response have been coterminous with major political transition and the emergence of a vocal and vibrant civil society freed from the restraints of apartheid. In Brazil, democratic transition in the 1980s and the enactment of a new constitution guaranteed citizen rights to health and welfare assistance as well as creating the framework for consumer participation in health policy. In both of these countries, the changing political environment has influenced the direction and ability of PLHAs to advocate for involvement. Policy change through the application of GIPA, however meaningful, will fail to achieve optimum results if the principle is applied without an understanding of national conditions, particularly the capacity of PLHAs to take part in policy dialogue.

Creating effective policy changes that improve the lives of people with HIV/AIDS should not be the sole responsibility of people with HIV/AIDS. While GIPA activities should advance the views and involvement of PLHAs, the principle does not relieve others (government, U.N., NGOs) of their responsibility to work toward policy that improves the life chances of PLHAs.

While it may be the case that the GIPA principle is reflected in an increasing number of international and national policy statements, it is the mechanisms, processes, and resources that support this involvement that are at the core of meaningful involvement. The essential elements of this involvement vary markedly from country to country.

The value of GIPA is that it allows the human face and voice of the epidemic to be present and heard in all analyses, planning, and discussions about the epidemic. More effective policies and programs can be developed because they have arisen from a full and clear analysis of needs, and from informed discussion about their likely success and implications.

GIPA can have a profound impact at the programmatic level. PLHAs can be effective educators. Many evaluations of behavioral and attitudinal change programs show that a presentation by a person affected by HIV can have the most impact in making people realize that HIV is real and a potentially serious threat. These presentations can also assist listeners to change and improve their attitudes and beliefs about PLHAs. In this way, GIPA can be effective in addressing the silence, fear, stigma, and discrimination that characterize the HIV/AIDS epidemic.

At the primary level, GIPA is critical for breaking the isolation and trauma with which many PLHAs live. The foundations of GIPA lie in bringing PLHAs together in support groups. At this level, the basic needs of PLHAs can be addressed. People can share experiences and feelings, they can provide practical and emotional support, and they can assist with home care for those who are ill and dying. Activities that are intended to support people, to build their self-esteem and sense of personal health and well being, can also assist in building skills and knowledge that encourage responsible personal behaviors.

Apart from the activities of PLHA groups and networks, support for GIPA from the wider array of HIV/AIDS actors, including international organizations and funding agencies, is a fairly recent phenomenon. The Paris Summit was held in 1994, yet financial and technical support on a large scale for PLHA groups is still a marginal element of most national and international HIV funding. The reasons for ignoring or sidelining GIPA as a central element of a national response or as a necessary component of international activities are varied. The literature on GIPA is currently underdeveloped, and it is not a prominent theme in the social science literature on HIV/AIDS. As a consequence, the findings from the small number of studies reviewed in this report and our own research conclusions should be viewed as illustrative of the major factors inhibiting a more vigorous and large-scale effort to integrate and involve PLHAs.

GIPA relates to people living with and affected by HIV/AIDS. The formulation of the statement from the Paris Summit and subsequent literature does not distinguish between PLHAs on the basis of identity or

behavioral attributes. GIPA is a crucial policy tool but remains, at this stage of the pandemic, a blunt one. The stigma of injecting drug use, sex work, and non-normative sexuality underlie and compound the stigma of HIV/AIDS where people identified with these attributes are significantly affected by the epidemic. The question for policymakers and people with HIV/AIDS is how to develop GIPA to address these issues without adding to already virulent institutional and community-based stigma and discrimination. Achieving the meaningful involvement of people living with HIV/AIDS who are also sex workers, men who have sex with men, or injection drug users requires a related set of activities that build a supportive environment. Analysis of legislation and statutes concerning drug use, sex work, and human rights is a good starting point. In many countries, PLHA groups are caught between the tension produced by GIPA and repressive policy and legal environments that limit the capacity to speak out on issues of sex work, drug use, and homosexuality.

It is also clear from the findings of this study that PLHAs struggle to build the skills that will equip them to participate as policy actors on an equal footing with government. The view that PLHAs require more intensive support to acquire policy advocacy abilities was voiced by most respondents. Building the necessary skills through training and greater exposure to the environment in which policy is formulated and decisions made is an essential step toward greater involvement for PLHAs. Influence over the policymaking process also comes from expertise and recognition of that expertise by other policy actors. The expertise of PLHAs is generally understood to be founded in the personal experience of living with the disease. However, as many of the respondents in this study argued, personal experience alone, however articulate, will not move PLHA involvement beyond the 'token' stage. The need to support a collective PLHA view is the next essential step. At this level, PLHA organizations are able to represent a broad range of issues. Moving PLHA input even further, however, requires developing not only policy skills and expertise but also the recognition that PLHA experience constitutes expertise in its own right. This is perhaps the most sensitive area of PLHA involvement because it requires harnessing that experience so that it leads to more direct PLHA control of HIV/AIDS resources (both financial and intellectual). When PLHAs have some control over information and knowledge relating to, for example, care and support or HIV education, other policy actors are likely to seek increased PLHA involvement. In other words, substantially elevating PLHA involvement in the policy process requires allocating a degree of control to PLHAs over HIV/AIDS resources.

Monitoring GIPA

The findings from this study illustrate that GIPA is, however problematically, a real concern for PLHAs and an increasing number of other policy actors. As GIPA moves from theory to practice, debates over application and implementation become increasingly complex. The findings from this research also suggest that the measurement of PLHA involvement in policy, and particularly successful involvement, is currently more art than science. What should GIPA indicators in fact measure? This is a difficult question that demands further analysis. The findings of this study warn against simple indicators that fail to go beyond a head count of the number of PLHAs at the policy table and instead suggest a more sophisticated and refined approach that might more effectively identify PLHA activity and influence at a range of levels. Undoubtedly, the indicators suggested by Horizons and UNAIDS (cited in Tables 1 and 2 above) provide for baseline measures. However, in order to effectively assess progress toward GIPA, new tools are required. The difficulty of measuring GIPA lies in defining specific indicators that capture the concept of meaningful involvement.

With these limitations in mind, Table 4 represents a simple framework or checklist from which to assess progress toward GIPA at the level of HIV/AIDS policy. The categories are illustrative rather than fixed and should reflect the range of policies, forums, structures, and processes that constitute the HIV/AIDS policy environment in each country. Further detail, for example regional and provincial GIPA assessments, may need to be incorporated to reflect in more depth the GIPA context in each country. The framework attempts to capture the different levels of inputs—personal, organizational, and operational—identified in this report. The checklist then addresses levels of representation of PLHAs in the HIV/AIDS policy structure and the wider enabling environment.

Charting the level of program support for GIPA as well as actual representation provides a baseline from which to assess the level of national commitment to GIPA. It does not directly address the impact of PLHA involvement on HIV/AIDS policies. To do this requires effective monitoring and evaluation of policy involvement, and it is strongly recommended that PLHA impact on policy be evaluated in relation to changes in policy content and policy development processes, as well as program implementation.

Table 4. GIPA Framework

GIPA Framework	
Individual Level (Resources required to strengthen personal coping mechanisms)	<ul style="list-style-type: none"> • Availability of peer support • Knowledge of HIV/AIDS (for example, living with a diagnosis of HIV/AIDS) • Treatment literacy • VCT • Human rights awareness
Organizational	<ul style="list-style-type: none"> • Public speaking • Advocacy training • Organizational management skills • Income-generation assistance • Support for local and national PLHA groups and networks
Operational	<ul style="list-style-type: none"> • Policy analysis training • Technical support (for example, HIV/AIDS treatments/human rights advocacy and social research skills) • Mentoring support for policy involvement • ARV provision
PLHA Representation	
<p>Policy Structures:</p> <ul style="list-style-type: none"> • National HIV/AIDS Program and other relevant committees/mechanisms • Global Fund to Fight AIDS, TB and Malaria, Country Coordinating Mechanism • Other <p>Is PLHA involvement articulated and promoted in the national strategy?</p>	<p>Is policy involvement supported? Who is represented?</p> <ul style="list-style-type: none"> • The national PLHA network • PLHA individuals • Other <p>Is a cross-section of PLHAs represented (e.g., sex workers, IDU, women, MSM, etc.)?</p> <p>How is involvement supported?</p> <ul style="list-style-type: none"> • Training/capacity building • Mentoring • Funding • Other
Supporting Environment	
Support for National PLHA Network/Forum	Does the government provide support for a national PLHA network, managed by PLHAs?
Anti-discrimination Legislation	Are there appropriate anti-discrimination legislation and enforcement mechanisms?
Government/NGO/INGO Resources for PLHA Self Help and Support	What proportion of the national HIV/AIDS budget is allocated to supporting GIPA?

Appendix: Interview Guides

Interview Guide: National AIDS Program Managers and Policymakers

Section A: Personal Information

Name:

Title and position:

Date of interview:

Section B: Knowledge of GIPA

Are you aware of the principle known as the Greater Involvement of People with HIV/AIDS (GIPA)?

If so, what is your understanding of this principle?

How do you think the GIPA principle applies to your country? Please give examples.

In your opinion, how do other stakeholders feel about the greater involvement of people with HIV/AIDS in the policymaking processes of your country? For example, stakeholders can include the following:

- Government officials
- NGOs
- Health workers and the medical establishment
- Donor organizations
- Members of the academic community

Section C: Involvement of People Living with HIV/AIDS

Does your country have a national AIDS strategy or plan?

Please describe how the plan was developed, for example:

Who is responsible for developing it (for example, which government agency)?

Who was consulted in the process (for example, donors, international NGOs, consultants, local NGOs, and other civil society organizations)?

Were people with HIV/AIDS involved in the development of the national AIDS strategy/plan?

If so, please describe how this occurred (*interviewer please prompt for the following*):

How did PLHAs become involved?

For example, did government invite them or did they request involvement?

Were PLHAs invited to participate as individuals or as representatives of constituent PLHA organizations or as members of HIV/AIDS NGOs?

Which PLHA organizations were asked to be involved?

Were some PLHA organizations or individuals invited and not others?

If yes, please describe why certain groups were chosen over others.

How often were PLHAs involved in the development of the strategy or plan? For example, PLHAs involved in the entire process or only in certain phases of its development?

Which areas of the draft plan/strategy were they asked to comment on?

Was there a specific PLHA committee within the body/group that developed the strategy/plan?

Were PLHAs given support to be involved? For example,

- Did they receive help organizing and refining PLHA input (for example, a workshop or facilitated discussion group)?
- Did they receive help in gathering views and suggestions from other groups/PLHAs in the country?
- Training on policy development?
- Financial assistance?

Please describe the implementing mechanisms and coordination structures for the strategy/plan (for example, steering committees/advisory committees).

Are PLHA groups or individuals represented on any of these committees?

If yes, please describe how. For example, is there a position for a PLHA on the coordination committee?

If so, how is this position chosen?

What support does this person receive to take part in the committee?

Does the NAP describe measures for monitoring the continued involvement of PLHAs throughout its implementation?

If yes, please describe what these are and who is responsible for implementing them.

Section D: Benefits of Involvement

In your opinion, is it important to involve people with HIV/AIDS in the policy and planning process?

In your opinion, are there benefits to involving people with HIV/AIDS in the HIV/AIDS policymaking process and the national AIDS strategy/plan in particular?

Please tell me what you think these benefits are?

Interviewers please prompt in the following areas:

- Other people with HIV/AIDS
- The general community
- The national response to HIV/AIDS

Please describe your experience of working with PLHAs in the policymaking process.

Are there challenges for you in working with PLHAs as policy partners?

If yes, please can you describe what these challenges are and how you think they can be overcome?

Do you think involving people living with HIV/AIDS assists your country's response to the epidemic?

Interviewer, please prompt for examples of the benefits of involvement, in the following areas:

- care and support
- treatments
- stigma and discrimination
- HIV/AIDS prevention interventions

Section E: Barriers to PLHA Involvement

Please describe what you consider to be the major barriers to involving people with HIV/AIDS in the development and implementation of the national plan and in policymaking more generally?

Interviewers please prompt in the following areas:

For example, how do general community attitudes toward people with HIV/AIDS impact on or influence PLHA involvement?

Is there institutional resistance from within the National AIDS Program (NAP) or other government agencies and policymaking circles to PLHA involvement?

Which institutions and individuals are reluctant or resistant to involving PLHAs?

Please can you describe why you think certain individuals or institutions are resistant to PLHA involvement?

How does capacity and skill level on the part of people with HIV/AIDS and PLHA organizations affect their ability to become involved in the policy process?

For example, do you think that PLHAs have the necessary skills and capacities to take part in the processes?

If not, please can you describe what skills and capacities you consider PLHAs need to participate effectively?

Please describe any other factors or challenges that you consider to constrain PLHA involvement in the policymaking process.

How do you think these challenges can be overcome?

Section F: Assistance Needs

What kind of assistance (for example technical advice or training) do you think NAP officials and other stakeholders need to help promote and implement GIPA? Please list as many examples as you can.

What kind of assistance (for example, technical advice or training) do you think the PLHA community and their organizations need to become more fully involved in the development and implementation of the NAP? Please list as many examples as you can.

Is there anything you would like to add on the involvement of PLHAs in the policy process, or about other issues that you feel are important?

Thank you for taking the time to speak to me today.

Interview Guide: People Living with HIV/AIDS

Section A: Personal Information

Name:

Organization and position:

Time and date of interview:

Section B: Knowledge of GIPA

Please describe your organization, for example, geographical coverage, nature of activities, and number of members.

Are you aware of the principle known as the Greater involvement of People with HIV/AIDS (GIPA)?

If so, what is your understanding of this principle?

How do you think the GIPA principle applies to your country?

In your opinion, how do other stakeholders feel about the greater involvement of people with HIV/AIDS in the policymaking processes of your country? For example, stakeholders can include the following:

- Government officials
- NGOs
- Health workers and the medical establishment
- Donor organizations
- Members of the academic community

Section C: PLHA Involvement in National Strategy/Plan

Does your country have a national AIDS strategy or plan?

Were you, your organization, or other people with HIV/AIDS involved in the development of the national AIDS strategy/plan?

If so, please describe how this occurred (*interviewer please prompt for the following*):

How did you or other PLHAs become involved?

For example, were you invited by the government or an NGO, or did you request involvement?

Which PLHA organizations were asked to be involved?

Were some PLHA organizations or individuals invited and not others?

If yes, please describe why you think certain groups or individuals were chosen over others.

How often were you or PLHAs involved in the development of the strategy or plan? For example, were you asked only for comment on the draft or were you more fully involved throughout the process?

Which areas of the draft plan/strategy were you or other PLHAs asked to comment on?

Was there a specific PLHA committee within the body/group that developed the strategy/plan?

Were you or other PLHAs given support to be involved? For example,

- Did you (or other PLHAs) receive help organizing and refining PLHA input (for example, a workshop or facilitated discussion group)?
- Did you (or other PLHAs) receive help in gathering views and suggestions from other groups/PLHAs in the country?

- Training on policy development?
- Financial assistance?

Do you know if the national strategy or plan has an implementing committee or group, for example steering committees/advisory committees?

Are you or other PLHA groups or individuals represented on any of these committees?

If yes, please describe how. For example, is there a position for a PLHA on the coordination committee?

If so, how is this position chosen?

What kinds of support does this person/people receive to take part in the committee?

Do you feel that the government and other stakeholders take PLHA involvement in the national strategy/plan seriously?

For example, are PLHAs actively encouraged to take part in these processes?

If yes, please describe how PLHAs are encouraged.

Section D: Benefits of Involvement

In your opinion, is it important to involve people with HIV/AIDS in the policy and planning process? Please describe why you think it is important.

In your opinion, are there benefits to involving people with HIV/AIDS in the HIV/AIDS policymaking process and the national AIDS strategy/plan in particular?

Please tell me what you think these benefits are? *Interviewers please prompt in the following areas:*

- Other people with HIV/AIDS
- The general community
- The national response to HIV/AIDS

Does involving people living with HIV/AIDS assist your country's response to the epidemic? *Interviewer, please prompt for examples of the benefits of involvement, in the following areas:*

- care and support
- access to treatments
- stigma and discrimination
- HIV/AIDS prevention interventions

If you have been or are involved in the development of the national AIDS strategy/plan, please can you describe your experience.

For example, what were or are the challenges for you and other people living with HIV/AIDS in being involved in the development or the implementation of the strategy/plan?

Please can you describe what these challenges are and how you think they can be overcome?

What do you think you gained personally from being involved?

Please list as many benefits as you can think of.

What do you think other people with HIV/AIDS gained from involvement?

Please list as many benefits as you can think of.

Section E: Barriers to PLHA Involvement

Please describe what you consider to be the major barriers to involving people with HIV/AIDS in the development and implementation of the national plan and in policymaking more generally.

Interviewer please prompt in the following areas:

For example, how do general community attitudes toward people with HIV/AIDS impact on or influence your involvement and other PLHAs?

Is there institutional resistance from within the National AIDS Program (NAP) or other government agencies and policymaking circles to PLHA involvement?

Which institutions and individuals are reluctant or resistant to involving PLHAs?

Please can you describe why you think certain individuals or institutions are resistant to PLHA involvement?

How does capacity and skill level of people with HIV/AIDS and PLHA organizations affect their ability to become involved in the policy process?

For example, do you think that you or other PLHAs have the necessary skills and capacities to take part in planning and policymaking processes?

If not, please can you describe what skills and capacities you consider you and other PLHAs need to participate effectively?

Please tell me how you think the personal experience of HIV, for example illness, affects your ability and that of other PLHAs to be involved in the NAP or policymaking more generally?

Please describe any other factors or challenges that you consider to constrain your involvement and that of other PLHAs in the policymaking process?

How do you think these challenges can be overcome?

Section F: Assistance Needs

What kind of personal assistance do you think people with HIV/AIDS need to help promote and implement GIPA? Please list as many examples as you can.

What kind of assistance (for example, technical advice or training) do you think the PLHA community and their organizations need to become more fully involved in the development and implementation of the NAP? Please list as many examples as you can.

Is there anything you would like to add on the involvement of PLHAs in the policy process, or about other issues that you feel are important?

Thank you for taking the time to speak to me today.

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