The Heart
of the Matter

Findings from a Study on the Greater Involvement of People with HIV/AIDS in Nepal
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The Heart of the Matter

Findings from a Study on the Greater Involvement of People with HIV/AIDS in Nepal
Foreword

The Greater Involvement of people Living with HIV/AIDS (GIPA) principle is one of the most substantial contributions made by Paris Declaration in 1994. This has been adopted by many nations to respond to the epidemic and has got further recognition when recently endorsed by the UNGASS (United Nations General Assembly Special Session). Nepal is also the signatory to UNGASS and has shown its commitment at various levels. Our commitment towards GIPA principle and its application has been prominently reflected in the National HIV/AIDS Strategy (2002-2006). However, it is necessary in identifying the ways of implementing, strengthening and monitoring GIPA in HIV/AIDS policy processes.

"The Heart of the Matter": explores the understanding of Greater Involvement of people with HIV/AIDS in Nepal. This has been one of the most useful initiations of NCASC, USAID, and the POLICY Project. I am confident that this work will be able to draw attention of concerned individuals and organizations towards the importance of GIPA in HIV/AIDS prevention to care continuum.

On behalf of National Center for AIDS and STD Control (NCASC), I would like to congratulate the study team for their recommendable work.

Dr. Ram Prasad Shrestha
Director
Foreword

Kevin Osborne and David Stevens are a few people who have really inspired me in my work on HIV/AIDS. These two people have enabled me to understand the greater depths of GIPA. Thus it gives me a pleasure to write a foreword of this book as both of them have somehow contributed to this book, either in the past or in the present.

Soon after I attended my first AIDS conference in 1999 and learnt about GIPA, I tried to explain that concept in a meeting held in Kathmandu afterwards. No one had ever heard the acronym before, so I ended up explaining to them what it meant. This short personal testimony of mine itself should be enough to understand the history of greater involvement of people living with HIV/AIDS in Nepal.

Though the first PLWHA group was established in 1997 the PLWHA movement did not take much momentum until 2002 in Nepal. It was due to a few avoidable and numerous unavoidable circumstances. Some of the unavoidable circumstances would include the sad demise of Manisha Singh who had been a source of all inspiration in establishing the first group though herself not a PLWHA. And some of the avoidable ones would be the lack of funding and leadership. However now I am happy that it has finally gained momentum and with a mature outlook.

Even before going to this book I would like to express few of my viewpoints. Firstly, I feel that GIPA is a process that could take several years of PLWHA movement to reach its best levels thus it is important to see it as a process than an end product. Where there are no groups of people living with HIV/AIDS and where people do not feel represented, GIPA will never reach its highest levels nor be any effective. Secondly, it is very difficult to measure the impact of GIPA and thus to be effective people living with HIV/AIDS themselves have to develop a evaluation tool to monitor its effectiveness and it can vary according to the PLWHA movement in different countries or communities.

One of the greatest barriers of GIPA is an assumption like this one which is also quoted in this study. "One or two positive might have the skill but they don’t represent the whole country.” In my opinion and also to quote the famous anthropologist Margaret Mead who
said "It is not that a big crowd of people who change this world but rather a small group of committed individual who would do so." In other words, I think it is the donors’ and the state’s responsibility to build the capacity of the individuals who would then come out with their respective issues and advocate. However statements such as the above will only devalue and discourage individuals who have committed their lives in advocating for the issues that is benefiting everyone. However to disguise the failure of the programs that have been implemented, mostly INGOs have been reinforcing such statements that are generally counterproductive. As a result even people who have actively been involved are discouraged.

I was once talking to Kevin Osborne who was then working with Policy Project. He asked me a rather simple question and that in fact triggered my whole concept of GIPA. I have several answers to that question now but it is still partly unanswered. He asked me "What evidences do you have that can suggest that GIPA works?" And really that is a very strong question and needs a lot of self assessment to be able to answer it. Unless every one of us try to find concrete answer to this simple question GIPA will merely remain tokenistic.

Thank you.

Rajiv Kafle
Coordinator
Nava Kiran Plus
The "Greater Involvement of People Living with HIV/AIDS" (GIPA) principle, a global commitment emanating from the Paris AIDS Summit in 1994, is a recognition of the important contributions people infected or affected by HIV/AIDS can make in response to the HIV/AIDS epidemic. Nepal is one of the many countries that acknowledge that people living with HIV or AIDS (PLHAs) have to be actively involved in all aspects of the response to the epidemic. Stigma attached to HIV/AIDS creates barriers that often block the participation of PLHAs. These barriers also prevent those vulnerable to infection from coming forward to access the services and education that they require. PLHAs have limited access to care and support services, treatment, and opportunities to create sustainable livelihood and participate in decisionmaking regarding the HIV/AIDS response. The involvement of PLHAs in policy issues has thus far been largely tokenistic; PLHAs are not cultivated as the policy actors they should be.

The present study has been conducted to assess perceptions of the GIPA principle and provide preliminary recommendations for increasing PLHA involvement in Nepal. We are confident that implementation of the recommendations will help to realize the goals of the GIPA principle in Nepal.

On behalf of the study team and POLICY Project/Nepal, our sincere appreciation goes to all the respondents who have contributed their time, effort, and views in making the study happen. We would like to express our special gratitude to the National Centre for AIDS and STD Control (NCASC) for partnering with us to conduct this important study that directly affects all the effort invested in a meaningful response to the epidemic.
We would also like to thank Mr. David Stephens of the POLICY Project/Viet Nam for the technical guidance provided to conduct this study and for his valuable input in finalizing this report. We are thankful to Ms. Badana Rana for conducting the study.

Our special thanks to the USAID/Nepal HIV/AIDS team for its invaluable support, comments, and feedback while carrying out this study. Finally, we would like to thank the Quality Assurance Team in the POLICY/Washington, DC office for its guidance and final editing of this document.

Bhojraj Pokharel
Country Director
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Abbreviations

AIDS  Acquired immune deficiency syndrome
ARV  Antiretroviral (treatment or therapy)
CBO  Community-based organization
CCM  Country coordinating mechanism
EDP  External development partner
GIPA Greater involvement of people living with HIV/AIDS (principle)
HIV  Human immunodeficiency virus
IDU  Injection drug user
IEC  Information, education, and communication
INGO  International NGO
MSM  Men who have sex with men
NCASC  National Centre for AIDS and STD Control
NGO  Nongovernmental organization
OI  Opportunistic infection
PLHA  Person living with HIV or AIDS
UNAIDS  Joint United Nations Program on HIV/AIDS
UNGASS  United Nations General Assembly Special Session
The greater involvement of people living with HIV/AIDS (GIPA) is being promoted as a cornerstone of HIV/AIDS prevention and care and support. The concept of GIPA emerged as a formal statement at the Paris Summit on AIDS in 1994. However, the concept of PLHA involvement expressed by GIPA has been a feature of community responses to HIV/AIDS from very early in the epidemic. This research analyzes the perceptions of GIPA in Nepal from the perspective of policymakers, international organizations, NGOs, and people living with HIV/AIDS (PLHAs).

**Methodology**

PLHAs, government agencies and officials, nongovernmental organizations (NGOs), and External Development Partners (EDPs) have all expressed a desire to work collaboratively towards implementing a strengthened GIPA response in the kingdom. The need for a clearer understanding of the context for GIPA in Nepal provides the rationale for the study. The research was designed to describe perceptions of GIPA from a range of stakeholders in Nepal. Interviews were conducted with senior policymakers responsible for HIV/AIDS. This category was selected according to seniority and familiarity with the subject of inquiry. Representatives of national NGOs and international agencies took part. Two leaders of the national PLHA movement were also interviewed. All interviews were audio-taped, transcribed, and translated into English. All together 15 interviews were conducted in Kathmandu. A semi-structured interview guide was used for all the interviews. The interview guide was organized in sections that addressed the following areas: the participants’ awareness of GIPA, the formal or institutional level of involvement of PLHAs in national HIV/AIDS planning, the benefits of involvement in national HIV/AIDS policies and programs, and the barriers and challenges to PLHA involvement. The interviews also contained questions relating to the involvement of injection drug users (IDUs).

The findings of this report should be read as illustrative of views on GIPA in Nepal among a small sample of government, NGO, international, and PLHA actors. Most the interviews for this research were carried out in Kathmandu, as it was not possible for the interviewer to journey to other regions of Nepal. While this is clearly a limitation and highlights the
need for further work with broader geographical coverage, the respondents do represent a sample of influential HIV/AIDS stakeholders who are all, in different ways, engaging with the demands of greater involvement. While the research sample is small, the findings we report here are thematically consistent with similar research conducted by the POLICY Project.¹

Key Findings

The findings of the study are summarized below.

- There is a broad consensus, what might be called an agreement, among those interviewed that the involvement of PLHAs in the response to HIV/AIDS in Nepal is important and should be incorporated in the national response to HIV/AIDS.
- PLHAs feel that GIPA remains at the tokenistic level and that government support is inadequate and does not address GIPA as a serious HIV/AIDS policy and program issue.
- Among the non-PLHA respondents, there are diverging views regarding the level of involvement that programs and policies should promote; for example, some respondents do not see a role for PLHAs in HIV/AIDS policymaking processes and structures.
- Most respondents agreed that GIPA needs to be contextualized in Nepal, at the macro level in terms of existing policies and governance practices and at the micro or community level in relation to culture, norms, religion, traditions of caste and class, and the varied needs of those affected by HIV/AIDS.
- There is a need for government and donors to deal with a collective and, as much as possible, a representative PLHA voice; therefore, there is a need to support a strong and active network of PLHA groups.
- While most stakeholders support the involvement of PLHAs, there is less unanimity regarding the role of IDUs.
- There is a gap in translating the needs of PLHAs into policy statements; several people expressed this as the difficulty in translating individual needs into a collective expression understandable in policy and program terms.

### Summary of Findings: Perceptions of Respondents

The table below highlights the key perceptions of the respondents.

<table>
<thead>
<tr>
<th>Knowledge of GIPA</th>
<th>PLHA involvement</th>
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<tbody>
<tr>
<td>National PLHA leadership has a clear understanding of origins of GIPA and has identified GIPA as a central strategy for PLHAs in Nepal. Less clarity or understanding by PLHAs outside Kathmandu. Women remain significantly marginalized.</td>
<td>PLHA involvement in national operational and strategic planning and the country coordinating mechanism (CCM). Little involvement of PLHA outside Kathmandu. Involvement is not well coordinated or broadly representative, and there is little support in assisting PLHAs to increase involvement. PLHAs report that they feel government efforts to involve them are motivated by donor pressure and that their involvement has not reached beyond the level of tokenism.</td>
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<tr>
<th>Government</th>
<th>NGOs</th>
<th>EDPs</th>
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<tr>
<td>Those working closely on HIV/AIDS and with affected communities have a good understanding of the principle of involvement. Described GIPA as inclusive of affected (family, friends) as well as those living with HIV/AIDS. Significantly less knowledge and understanding in sectors of government not working directly on HIV/AIDS.</td>
<td>Most NGOs working in HIV/AIDS have a working knowledge and understanding of the principle. Most NGOs described GIPA as inclusive of affected communities and individuals.</td>
<td>Most agencies are well versed in the international statement and the principles of community-based participation and involvement and are supportive of GIPA and a greater role for PLHAs in the response to HIV/AIDS.</td>
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<tr>
<th>PLHAs</th>
<th>Government</th>
<th>NGOs</th>
<th>EDPs</th>
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<tr>
<td>PLHAs are involved, and involvement is respected. Concerned that GIPA needs to evolve in the cultural, political, social, and economic context of Nepal. GIPA has limits, and these should be determined by what the national program requires from PLHA involvement.</td>
<td>Views in this sector are varied. Some stated that PLHA involvement is at an early stage but to a higher degree than might be expected given limited PLHA capacities and the lack of understanding of GIPA in Nepal. In contrast, others perceive PLHA involvement still at the tokenistic level.</td>
<td>Perception that GIPA is being implemented in Nepal, but there is skepticism about the motivations of government and other actors to involve PLHAs.</td>
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<tr>
<td>Benefits of involvement</td>
<td>PLHAs</td>
<td>Government</td>
<td>NGOs</td>
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<tr>
<td>Personal level: Increases confidence, builds skills, and helps foster acceptance of PLHAs by family, friends, and community.</td>
<td></td>
<td>Personal level: Enhanced relationships with PLHAs and greater understanding of the issues. Enhanced policy and program design and effectiveness.</td>
<td>Personal/PLHA level: Increased capacity for PLHAs and care and support programs.</td>
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<tr>
<td>Policy and program level: More realistic policies and programs, wider participation in the response to HIV/AIDS and, therefore, greater trust and ownership on the part of PLHAs.</td>
<td>More effective communication strategies, reduction in stigma and discrimination.</td>
<td>PLHA involvement creates more reach in service delivery (wider coverage).</td>
<td>General community: More effective information, education, and communication (IEC), reduction of infections.</td>
</tr>
<tr>
<td>General community: Greater visibility of PLHAs and, therefore, awareness of the epidemic, reduction in infection, and reduction of impact and stigma and discrimination.</td>
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<tr>
<th>Barriers to involvement of PLHAs</th>
<th>Widespread stigma limits the number of people available to become active.</th>
<th>The GIPA principle is not adequately defined in policy and legal frameworks.</th>
<th>Lack of understanding of how to operation-alize GIPA in Nepal.</th>
<th>Lack of effective PLHA networks.</th>
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<td></td>
<td>Lack of serious commitment by government and other HIV/AIDS actors.</td>
<td>Lack of understanding across government sectors.</td>
<td>Existing opportunities for involvement have not been utilized effectively.</td>
<td>Lack of support to build PLHA capacities.</td>
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<td></td>
<td>Low capacities of PLHAs.</td>
<td>Difficulty in designing a coordinated GIPA response that meets the needs of different communities affected by HIV/AIDS, for example, rural women or urban IDUs.</td>
<td>Institutional resistance in some government sectors, particularly health and education.</td>
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Recommendations

The recommendations below describe a series of activities that will enhance the GIPA response in Nepal. The recommendations reflect the views of the respondents. While we have attempted to be as inclusive as possible, it is important that in setting priorities for the GIPA response in Nepal these recommendations are discussed and reviewed by all stakeholders and that a leading role is delegated to PLHAs in the design and implementation of any GIPA strategy or activity.

1. Create a multisectoral GIPA Advisory Group under the leadership/chair of a PLHA network. This group should be empowered to monitor and evaluate GIPA in Nepal and provide advice to government and HIV/AIDS organizations. This group should be given oversight of this report and the implementation of the recommendations.

2. Implement GIPA awareness-raising activities (including publicizing the contributions of PLHAs) with government and NGO stakeholders and use these activities to continue to build a policy rationale for GIPA.

3. Support PLHA leadership through expanding training opportunities and supporting health needs. Capacity development as well as support for policy-level engagement are urgently required in the following areas:

   - **Foundational.** The foundational category includes a series of fundamental activities that will help support basic awareness of the impact 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 (ARV) treatments or human rights instruments as well as broader competency in areas such as policy analysis and advocacy. While it is not necessary for PLHAs to become technical experts in HIV/AIDS medicine or law, it is important that they are supported to
become conversant in 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.

4. **Increase popular and political commitment for GIPA.** Acceptance of the value PLHAs bring to the national response will be considerably enhanced through activities designed to heighten awareness of GIPA. In particular, the endorsement of PLHA involvement through advocacy with, and by, high-profile public figures including the monarchy is an important step toward gaining wider acceptance of PLHAs in Nepal.

5. **Increase access to treatment, care, and support, including opportunistic infections (OIs) and ARV therapy.** Meaningful involvement relies on providing the means for people to stay well and able to make a contribution. This is a fundamental requirement if PLHA involvement is to be supported.

6. **Provide suitable financial reimbursement for PLHA involvement.** Where PLHA advice and expertise is sought, financial reimbursement should be commensurate with standard practices (for example, consultant fees). At a minimum, provision should be made to cover transportation, meals, and expenses.

7. **Develop a GIPA monitoring and evaluation system.** This should include the design of instruments that monitor and evaluate policies. Identify appropriate indicators to measure levels of representation and involvement of PLHA and/or their organizations in policy and planning processes.

8. **Support PLHA networking** to expand the coverage of PLHA representation across the country, and increase the involvement of groups and individuals currently less active. This should include activities aimed at developing functional and sustainable network structures.

9. **Support the development of an HIV/AIDS women’s network/group.** Women remain marginalized by gender roles and in general shoulder a higher burden of care and support in the family than men.

10. **Harness GIPA to meet 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 IDUs requires a related set of activities that build a supportive environment. For example, greater human rights support and changes in legislation that criminalizes drug use and sex work may be important considerations.²

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² Neither USAID nor the POLICY Project supports the legalization of drug use or prostitution. They are, however, committed to supporting effective strategies to prevent the spread of the HIV/AIDS epidemic and mitigate its impacts. Risk for HIV infection is one of the harms associated with injection drug use, and the sex industry is often one of the primary mechanisms through which HIV spreads in a country. POLICY recognizes that respecting the dignity and rights of sex workers is essential for developing effective HIV/AIDS prevention and care programs. The use of the terms “sex work” and “sex worker” in this report does not imply support for prostitution as a legal form of employment; rather, they are used as a way to reduce the stigma and discrimination faced by sex workers, who may be vulnerable to exploitation and lack access to health-related and other types of information and services.
11. Utilize the skills of positive people in HIV/AIDS prevention and care. In Nepal, as in other countries, people with HIV/AIDS have played a significant role in bringing a human face to the epidemic. The value of this in prevention activities is slowly being recognized. Speaking openly as a person living with HIV/AIDS has been shown to have a significant impact on public attitudes toward HIV/AIDS and perceptions of personal vulnerability. Those working in the field recognize this.
Introduction

HIV/AIDS is the most stigmatized of diseases. The history of the epidemic is replete with examples of prejudice and discrimination. It is also a history of the courage and endurance of the people and communities most directly affected by the disease.

In Nepal, the number of reported HIV cases is 3,432 (NCASC, February 2004); however, it is estimated that nearly 60,000 people are infected with HIV (National Estimates of Adult HIV Infections, NCASC, 2003). Nepal is vulnerable to HIV/AIDS for numerous reasons. Poverty and low levels of education and literacy in addition to gender inequalities and discrimination fuel the progress and impact of HIV. This is compounded by the problems of unsafe sex and drug injection practices, a weak public health infrastructure, political uncertainty and unrest, and internal and external mobility. HIV prevalence is concentrated among vulnerable and marginalized people and communities. Research has shown that HIV prevalence among female sex workers in the Kathmandu Valley increased from 2.7 percent in 1996 to 15.6 percent in 2001 (FHI/SACT, 2000). Among IDUs in Nepal, approximately 40 percent are HIV positive (UNAIDS/NCASC, 2004). HIV prevalence among IDUs in the Kathmandu Valley is much higher at 68 percent (UNAIDS/NCASC, 2004). In the Far West, a recent study in Doti district found that 10 percent of men who had migrated to Mumbai were HIV positive (UNAIDS/NCASC, 2004). The burden of HIV/AIDS is high in these marginalized communities. While there is a dynamic response underway in Nepal, a comprehensive response is urgently needed to address major gaps, including a technically stronger and long-term program for IDUs and a cross-border program for labor migrants and affected communities. Underlying this complex and challenging environment is the pervasive stigma of HIV/AIDS, which acts to limit the access and involvement of PLHAs and other vulnerable and marginalized groups.

As in most other countries in Asia, Nepal PLHAs face similar if not greater levels of HIV/AIDS-related stigma. This creates barriers that keep PLHAs and others who are vulnerable to infection from coming forward to access the services and education that they require. In Nepal, it is estimated that 42 percent of the population live below the poverty line. There is a high incidence of poverty in rural areas. Poverty pervades the life of low-caste people, the so called Dalits in society. Women are highly affected by poverty (The Tenth Plan, 2002–2007, Nepal). The rapid increase of HIV in recent years among IDUs, female sex workers, and male sex workers means these socially marginalized groups face additional stigma and
discrimination. Stigmatization and discrimination of those infected with HIV coexists with existing stigma related to drug use and sex work, resulting in limited access to treatment, care, and support services. This situation makes it more difficult for PLHA to participate in decision-making processes as well as in responses to HIV/AIDS. There is limited space for people to take part in the policy decisions that affect them directly, and there is, as yet, little practical support for PLHAs to be major policy actors. This situation underlines the urgent need for a powerful and supported PLHA voice in Nepal.

Despite the present situation, PLHAs have responded to the challenge of HIV/AIDS in remarkable ways. They are educators and carers and advocates. They work together to support each other, and they work with others to reduce the impact of the epidemic on all levels of society. They do this in an environment where they often have to struggle against illness, hostility, and discrimination. While there is, as this report argues, a clear need to increase and deepen support for GIPA in Nepal, the value of the contribution PLHAs are making is beginning to be recognized by some sections of the government as well as by the international community.

Nepal is a signatory to a number of international declarations, the most recent being the United Nations General Assembly Special Session (UNGASS) declaration agreed to in June 2001. Nepal is party to the “Melbourne Manifesto” developed at the Sixth International Congress on AIDS in Asia and the Pacific in October 2001. The government of Nepal has endorsed the GIPA principle through its participation and approval of the UNGASS and Melbourne documents and other international agreements. HIV/AIDS is also addressed in Nepal’s sixth Millennium Development Goals, with the target of “halting and reversing the spread of HIV/AIDS by 2015.” These international commitments to GIPA are reflected in national HIV/AIDS policies, specifically, the National Strategy on HIV/AIDS and the National Operational Plan for HIV/AIDS Control.

There are active PLHA groups in the country whose leaders are prominent advocates for a greater role for people with HIV/AIDS in the national response. Donor agencies and international and national NGOs have also become more active in engaging with the concept and practicalities of PLHA involvement. These developments indicate that GIPA is gaining a foothold in the national HIV/AIDS agenda. The research on which the findings of this study are based grew out of these developments. The findings reported here are aimed at assessing perceptions of GIPA and providing some preliminary recommendations for progressing PLHA involvement. The findings of the study are illustrative of the perceptions of key HIV/AIDS actors in Nepal; however, they are consistent with similar research conducted in Asia, Africa, and Latin America. 

Background to GIPA

GIPA is a term that describes an international commitment to ensure that people infected and affected by HIV/AIDS are encouraged and assisted to play as full a role as possible in the response to the epidemic. In Paris in 1994, an international conference representing 42 governments declared the concept of the greater involvement of people living with HIV/AIDS. GIPA has been incorporated into national and international program and policy responses and has been taken up as a model of best practice in the response to HIV/AIDS. GIPA calls on governments 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 (Reprinted from the Paris Declaration in ICASO 1996).

The GIPA principle is also reaffirmed by the UNGASS Declaration of Commitment on HIV/AIDS, which recognizes the role of,

people living with HIV/AIDS, young people, and civil society actors in addressing the problem of HIV/AIDS in all its aspects (United Nations 2001, paragraph 33).

GIPA can be expressed in many ways. At the core of the idea is the need to create an environment free from fear and stigma in which people with HIV/AIDS have the means to live their lives in dignity and care for themselves and their families. GIPA also means a commitment to ensuring that people living with HIV/AIDS have meaningful involvement in HIV/AIDS research, program development, and policymaking.

In 1999, UNAIDS published a paper analyzing the levels of PLHA involvement in the response to HIV/AIDS (UNAIDS, 1999). 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). The study provides a
valuable framework for understanding the various levels at which PLHAs are involved in NGO and CBO programs. The models developed by the Horizons/Alliance study and UNAIDS are combined in Figure 1 below to 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 and program responses. 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. It should be noted that although GIPA calls for a progressive approach to involving PLHAs, the extent and level of involvement must necessarily be one that meets the needs of all stakeholders and adheres to basic principles of equity.

At the very primary level, GIPA is critical for breaking the isolation and trauma that many PLHAs live with. The foundations of GIPA lie in bringing PLHAs together in support groups. At this level the very basic needs of PLHAs can be addressed. People can share experiences and feelings, provide practical and emotional support, and assist with home care for those who are ill and dying. Activities that are intended to support people and 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.

GIPA can have a significant impact at the program level. PLHAs can be very effective educators. Many evaluations of behavioral and attitudinal change programs show that a presentation by a person living with HIV can have a profound impact on the audience, helping them realize that HIV is real and can be a serious threat to them.

At the level of policy development, the meaningful involvement of PLHAs is a necessary step toward creating policies that are informed by, and respond to, the needs of the people they are designed to serve. Involvement at this level also helps to create greater links and trust between communities (often highly marginalized and difficult to access) and policy and program managers.

**Rationale for the Study**

While there is compelling international advocacy for GIPA, at the national level GIPA remains an area of some confusion and often tension. There is little evidence on which to base GIPA policy and strategy or convince skeptical policymakers that GIPA is an effective arm of the larger public health response to HIV/AIDS. Nevertheless, PLHAs, government agencies and officials, NGOs, and EDPs have all expressed a desire to work collaboratively toward implementing a strengthened GIPA response in the Nepal. GIPA is not a new concept. PLHAs have been at the forefront of efforts to prevent the disease and to assist others affected. In Nepal, commissioning and implementing this research constitutes an important
step along the path to greater partnership between PLHAs, affected communities, and HIV/AIDS policymakers. We hope that the findings reported here will assist all those working in HIV/AIDS in their efforts to reduce the impact of the epidemic.

Interviews

To assess the GIPA environment in Nepal, the POLICY Project conducted interviews with key stakeholders from government agencies, international organizations, NGOs, and PLHA networks. Interviews were conducted with senior policymakers responsible for HIV/AIDS. This category was selected according to seniority and familiarity with the subject of inquiry in consultation with the POLICY Project. Two prominent leaders of the national PLHA movement were also interviewed. All interviews were audio-taped, transcribed, and translated into English. Fifteen interviews were conducted in Kathmandu. A semi-structured interview guide was used for all the interviews. The interview guide was 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 interviews were analyzed according to themes, which were suggested by the categories of the semi-structured interviews and those emerging from the interviews. It is also important to note that the findings presented below reflect the views of the respondents, and this report has attempted to render them as accurately as possible. Findings are presented in themes and illustrated by quotes from the interviews.
Findings from a Study on the Greater Involvement of People with HIV/AIDS in Nepal
Findings

Knowledge of GIPA

The majority of those interviewed were aware of the principle of PLHA involvement that GIPA represents, although theoretical knowledge about the principle was limited. While there were differences in interpretation of the term, the majority of respondents agreed that the involvement of PLHAs in the response to HIV/AIDS in Nepal is important and should be incorporated in national program and policy activities. Five of the respondents interviewed stressed that the GIPA principle should reflect activities aimed at involving not just the infected but also the affected. In this broader sense, GIPA encompasses a range of issues at the community level as well as involvement in national planning and policy.

*My understanding of GIPA is involvement of the main actors of HIV/AIDS who are not only people who are infected but also those who are affected by it.*
(NGO representative)

*So in the case of GIPA it means the involvement of people living with AIDS, their family and others dear to them. This is a simple translation of what GIPA means.*
(International NGO (INGO) representative)

The majority of the policymakers interviewed were not aware of the origins of the GIPA statement and the discussions that led to it at the Paris AIDS Summit of 1994. One government official declined to make any comment on his knowledge of GIPA. However, most of those interviewed were aware of the principle of PLHA involvement that GIPA expresses, and one policymaker added that GIPA involved attention to respect for the rights of PLHAs. The PLHAs interviewed were familiar with the Paris statement.

GIPA in the Context of Nepal. The majority of the respondents felt that GIPA was a difficult challenge for Nepal. The major barriers identified were stigma and discriminatory behaviors, which discourage PLHAs from coming forward and severely limit opportunities for involvement. This limits the number of PLHAs who are willing to be publicly open about their HIV status and develop the skills and capacities necessary to engage in public policy advocacy. The few who have come forward do not reflect the spectrum of PLHA experiences or issues and, therefore, it is difficult to develop, on this basis, a representative national
picture of PLHA views and experiences. This is particularly the case for women, who face a number of additional barriers preventing them from speaking openly. While international statements and commitments on GIPA do not require public visibility as a prerequisite to involvement, it is difficult for many to imagine how PLHA involvement can develop without a greater number of open PLHA spokespeople and representatives.

The bigger problem in Nepal is to find people who are not afraid to speak up as infected or affected. (EDP representative)

There are only some PLHAs who can effectively participate. I work with women positives, and from my experience I can say that they are not able to come forward and work with others in the policy and decisionmaking level. That is the challenge for Nepal. (NGO representative)

It was also felt that the issue was very diverse and that there was not enough experience in working with different groups to say what approaches work. A significant number of the respondents felt that government officials had little or no knowledge of GIPA and should be sensitized—particularly those in the health sector—to deal appropriately with the issue.

While many of the people interviewed understood the conceptual elements of GIPA and spoke in depth about the need for meaningful as well as greater involvement, some participants also pointed to the need to understand what GIPA means in Nepal, for example, how the meaning of involvement is shaped by cultural context, class, religion, and the differences between urban and rural settings. These factors should be considered in operationalizing GIPA. One NGO representative felt that the GIPA principle was a foreign import and may not necessarily apply fully to the Nepali context, with the capacity of PLHAs constituting the main constraint to extending involvement beyond the realm of program activities.

This concept came from foreign countries. I agree to some extent greater involvement is necessary. But the capacity of positive people here is not up to the mark to be involved in policymaking. They can be involved in peer counseling and in providing support system. This is very effective. (NGO representative)

Almost all the respondents were of the opinion that HIV/AIDS planning and programs should be designed and implemented in Nepal based on the needs of the PLHAs to ensure the success of the HIV/AIDS program. However, several respondents from the international, NGO, and PLHA sectors expressed the view that current government activities in relation to GIPA amounted to little more than token efforts aimed at fulfilling policy obligations and lacked commitment to ensuring meaningful involvement.
For people at the policy level, the meaning of GIPA is different. In practice they feel that inviting a positive to a meeting fulfills the principle of GIPA, but this is not so. (NGO representative)

The PLHAs interviewed were of the view that the issue was considered only because of the pressure exerted by international actors; otherwise, neither the NGOs nor the government was serious about their involvement.

But it is only limited to this—a three-day workshop happens and that is that. They still do not understand that the involvement of PLHAs will make the programs more effective and the response will be better. (PLHA representative)

NGOs are supportive because most of the NGOs are donor driven and the donors have their mandate, and if they have GIPA on their mandate, then NGOs have to follow it. There has to be more investment in involving PLHAs in GIPA policy and qualitative participation rather than tokenism. Commitment at the highest level is also required. There has to be trust. (PLHA representative)

A number of the respondents endorsed the PLHA view, noting a lack of commitment to involve PLHAs in all processes at the government level. In addition, some respondents felt that while PLHAs were being involved to a limited extent, this represented pressure from the EDPs rather than a genuine desire on the part of national government actors. In contrast, government officials interviewed expressed an understanding of the principles of GIPA and voiced commitment to involving PLHAs as equal partners in all planning and implementation processes. However, they were also of the view that the scope of understanding across the government sector in relation to PLHA involvement, and GIPA specifically, was very narrow and limited to the few who are directly involved in HIV/AIDS programs.

Those of us who are conducting HIV programs are very positive and fully understand the importance of their involvement. But I cannot say about other officials who are not working in this area because they don’t have the knowledge. (Government representative)

Reflecting a position somewhere between these views, most of the NGO respondents felt that positive changes were taking place in terms of the perception of concerned government ministries and officials. However, they felt that community stigmatization was very strong.

The government, for example, has been more open and willing to involve them, much more than they have been in the past. (INGO representative)
They are still heavily stigmatized and discriminated against in the community level; the government is becoming more positive. There is no problem with donors. (EDP representative)

In the view of several respondents, efforts by the government to consult and involve PLHAs, while sometimes flawed, demonstrated an important beginning and commitment to GIPA. This was seen as significant in the context of the continuing conflict in the country and the demands of other competing issues on the national agenda.

Involvement

Responses to the question on PLHA involvement in national planning and strategy suggest that a GIPA response has been implemented at the policy level, at least since 2002 and particularly in the development of the HIV/AIDS operational plans. However, perceptions of the quality and depth of PLHA involvement in the policy process varied considerably depending on the position and perspective of the respondent.

At present there are several committees providing advice to the HIV/AIDS program, including the National AIDS Council under the chairmanship of the Prime Minister, a further committee under the chairmanship of the Health Minister, and other task forces and executive committees. PLHAs are represented in the National Council and CCM for the Global Fund through an individual PLHA chosen by the government. Government officials stated that at the time of choosing the PLHA, no network or representative body of PLHA existed. Currently there is no steering committee for the National Operational Plan for HIV/AIDS Control (2003–2007). However, the government believes that by including a PLHA as a member in the CCM and the council, they have fulfilled the criteria of involvement of PLHA. It should be noted that while this may address GIPA in a technical sense, it does not address issues of meaningful involvement or representation.

All the government representatives who had been involved in the development of the operational plan felt that the involvement of the PLHAs in the formulation of the plan was at a very high level. PLHAs were invited individually as well as through NGOs working in HIV/AIDS, and they participated in meetings specifically convened for them. Government respondents who participated with PLHAs recalled that PLHAs were extremely vocal and voiced their needs and demands strongly and were able to provide inputs in all aspects of the plan, demonstrating, in their view, a high level of involvement and capacity in relation to HIV/AIDS policy discussions. The government also held regional meetings in five development regions where they claim to have involved PLHAs through local NGOs.
However, a small number of people with HIV/AIDS capable of voicing their opinions is only one measure of capacity. The NGO representatives who were interviewed had more varied views. Some felt that the involvement of PLHAs was at the level the NGOs expected. Other NGO respondents were more skeptical and felt that PLHA involvement was not taken seriously and that little effort was actually made to inform and encourage PLHAs to be involved in the process.

*Everyone is talking about GIPA; therefore, the PLHAs were brought to the meetings, but there is no sentimental binding. This feeling is not internalized among the concerned officials.* (NGO representative)

NGO respondents also felt that there was no follow up on the decisions made with civil society representation (including PLHAs). They did not know how much of their input was incorporated or if any follow-up action was taken. Several government representatives from line ministries also admitted that they did not know about the update of the operational plan. One of the NGO representatives stated that the consultation in the districts was very poor. The government cited security and political reasons for this, but the NGOs felt that this could have been conducted in a more effective and participatory manner through NGOs. The NGO representatives interviewed felt that monitoring and evaluation of the operational plan should be a responsibility of the NCASC. However they also argued that the NCASC should not be involved in the implementation, which should be the responsibility of the NGOs.

*In my perception, the inner motive and interest of NCASC and its staff is to try to get the funding through their organization for implementation. I may be wrong, but that is what we have felt. We cannot work in that way. NGOs should be the implementers and NCASC should do the monitoring and evaluation.* (NGO representative)

Representatives of international organizations were of the view that the formulation of the operational plan followed a broadly consultative process. Consultation was clustered around the main topic of future national plans and included all major actors in the area. The draft was posted on the internet, and anyone interested was invited to participate or send written comments. They felt that the involvement of the PLHAs in whatever small way was a good start. However, some also felt that the government might not have gone through this consultative process if they were not subject to external pressure.

*I know that there has been some consultation because the government realizes that this is very important. But had they had their own way, they may well have developed the policy on their own.* (EDP representative)
The PLHAs interviewed were less than satisfied by government efforts to involve them. They said PLHA participation amounted to only one or two meetings, and they felt consultation required more PLHA representation from outside the capital. They also complained about the process, which included little encouragement beyond initial email contact. They noted that no materials or drafts of the operational plans were sent to them beforehand to comment on and neither were they given any kind of support for pre-consultative meetings among themselves.

**Involvement of PLHA IDUs.** The series of meetings that took place during the formulation of the operational plan revolved around various key issues related to vulnerable communities. A key theme was IDUs. Respondents were asked to comment specifically on PLHA IDU involvement. The rationale for a focus on IDU was not to distinguish between PLHA groups on the basis of injection drug use but to address what was perceived by the research team during the preliminary stages of the research as a strong level of resistance to IDU involvement in Nepal based on highly stigmatizing views of IDU capacity. Responses relating to IDUs were varied. Some respondents felt that IDUs were integral partners in the response; other respondents reflected a more stereotypical view of IDUs as dysfunctional and unstable. This latter view remains, unfortunately, the dominant image of people who inject drugs and sets the parameters for discussions on IDU involvement. Where IDU involvement has been promoted, for example in the Indian state of Manipur (Sharma, 2003) and Australia (Godwin, 2004), it is credited with changing people’s attitudes towards drug users and increasing the reach and efficacy of harm reduction services and information.

The involvement of IDUs is at the heart of GIPA in Nepal. While the principles of involvement that GIPA promotes do not distinguish or discriminate between PLHAs on the basis of mode of HIV transmission, identity, or behavior, many who work in the field of HIV/AIDS do make these distinctions. Several of the respondents in this study were of the opinion that it was very difficult to involve active IDUs. The major reasons cited were the level of stigma and discrimination from their families and the priority they give to using drugs. Other respondents felt strongly that it was necessary to develop innovative ways to increase IDU participation in order to increase the effectiveness of programs and policies.

> Their involvement is necessary to understand why they are using it, where do they get drugs from, how do they use it, what effect does it have on them, and what treatment and control mechanism do they need. They are aware of these issues better than we are. (Government representative)

The struggle to increase the level of PLHA participation and meaningful involvement rests on the ability of GIPA advocates, governments, and other actors to face the challenge of creating the means for marginalized people to become partners in the response. When, as
is the case with IDUs, people face the burden of multiple stigma, hostile legislation, and services designed without regard for their needs, this challenge can seem insurmountable. Nevertheless, it is clear that the promotion of GIPA must be configured to account for the conditions that are central to HIV/AIDS and people living with the disease. IDU involvement is therefore important, first as a commitment to protecting and promoting the human rights of people who inject drugs, and second in relation to improving policies and programs. In a different way, IDU involvement is necessary to expand the framework of who are understood as legitimate actors in relation to HIV/AIDS policy involvement. It was also clear from the research that the stereotype of dysfunctional IDUs is an enduring construction posing a significant barrier to increasing the involvement of PLHAs with an IDU background. It is, however, a stereotype not supported by the high level of active self help and peer support among IDU in Kathmandu.

Limited Representation of PLHAs. Despite the limited representation of IDU issues, it is PLHAs who are former IDUs that comprise the majority of publicly open HIV-positive people in Nepal. This is a concern to some of the respondents working with PLHA who worry that HIV/AIDS program and policy development is not sufficiently informed by, or oriented to, the issues and experiences of non-IDU PLHAs. For example, in Nepal there are many migrants, particularly in the mid-west and far western regions who are infected. The voices of these affected people are seldom heard and so may not be addressed by policies.

_The involvement of different groups of PLHAs (other than from the drug users’ background) will help to understand the different sectors and have specific programs and policies for each group rather than a unified policy for everyone._ (INGO representative)

The questions relating to IDUs also elicited concerns about the scope and breadth of involvement and how to manage multiple voices from different individuals, communities, and groups. Several respondents cautioned that it was necessary to draw a line or set boundaries on who to involve and to what degree, as expectations will expand as involvement increases. To address this, several respondents pointed to the need for rising community expectations of involvement to be linked to a realistic GIPA system that is able to manage the demands of differently infected and affected groups. While such a system has not yet been outlined in Nepal, the major challenge, or task, in the view of many respondents is to satisfy the demands of various groups within a framework of expectations that are understood as realistic and achievable by all stakeholders.

_It would be best to involve everyone, but it becomes too big a group, so drawing a line is necessary._ (Government representative)
Concerns over how to manage GIPA activities and the related question of how to involve the largest possible number of people raises the important question of who is responsible for drawing the line and establishing limitations on involvement. It seems clear that in the current context, attempts by any stakeholder to set further boundaries on PLHA involvement will result in tension between PLHAs and the government. While the problem of managing demands is a real one, it should not be seen as insurmountable or used to restrict efforts by PLHAs to have their opinions and issues represented in HIV/AIDS policy and program activities. A resolution can be found in efforts that support PLHA to decide who represents them and how they are represented.

Nepal Plus, Navakiran Plus—all formed groups and worked for support. But, since a strong voice was required to reach the government and to talk about our rights, we formed a national network for unity. We are trying to change the perception of the society that PLHAs cannot work, they are dying or very weak; we are trying to prove that they are normal. (PLHA representative)

Benefits of GIPA

In this section of the report we describe the benefits of involvement from the perspective of those interviewed. Respondents described benefits at the individual, community, and national levels and discussed how PLHA involvement permeates HIV/AIDS activities from grassroots community development to national policymaking. The impact of involvement on stigma and discrimination was perceived by many of the respondents as highly significant.

This will help us to bring out things related to discriminatory legislation to resolve the problem of stigma and discrimination. (PLHA representative)

The majority of respondents in this study noted that PLHA involvement in policy and programs improves the quality and coverage of prevention and care interventions. While it is difficult to describe how this actually happens, perceptions are related to the links created between vulnerable communities and policymakers and program managers, the increase in understanding between these sectors, better-designed and more appropriate policies and programs, and greater ownership by beneficiaries.

It benefits everyone, like those who are discriminated; the infected and affected; those who live around these environment and in their community; those who provide service from the community level to central level; those who make programming, like the health department; and those who contribute directly or indirectly to the policy level. So it benefits all these communities. (Government representative)
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, research, and more effective HIV/AIDS communication strategies. The advantages of GIPA at the policy level accrue beyond the immediate concerns of prevention, care, and treatment issues and can improve the capacity of sectors such as education and employment to respond to HIV/AIDS.

*The involvement of PLHAs in developing school curriculum will make the program effective and help in sustaining our response to the epidemic.* (Government representative)

The value of involvement begins with the advantage that personal experience with HIV/AIDS services and community attitudes brings to designing informed policies.

*The doctor at the health department would know less about the disease than the drug users in the street because they are facing the difficulty on a day-to-day level. So the drug user would know better as to what policy would be effective to stop this. So the information that PLHAs and IDUs provide is more vital than information provided by people who have gone to America and Europe. Policy will only be effective if it matches the needs of PLHAs and IDUs.* (NGO representative)

*Since they are the target group, their involvement helps in understanding their problems, and this will be reflected in the policy. So the policy made with their input helps in implementing the programs for addressing and tackling the problems of the vulnerable or the target group.* (Government representative)

At the personal level, involvement contributes to a greater sense of personal well-being and assists people to stay active and economically viable.

*It keeps the young motivated, alive, and involved, which means it has an economic contribution.* (INGO representative)

Involvement also marks ownership. This will create a greater sense of commitment toward the policy or program that is developed, which will help develop trust between the beneficiaries and the project and a greater understanding of the programs and policies on the part of the beneficiaries.

*If the beneficiary group is involved in planning and implementing the program, then there is going to be 100 percent trust. So it will result in the success of the program, and its impact is also direct and greater.* (NGO representative)
Consultation makes people own it, and that’s the most important thing.
(EDP representative)

The benefits of GIPA are not easily measured to show a causal effect on policy or program activities. Indicators that measure the quality of involvement and move beyond simple quantitative measures (for example, the number of people with HIV/AIDS involved in policy forums or employed in HIV/AIDS programs) rely more on in-depth qualitative social science methods than the public health tools that are more commonly associated with monitoring and evaluating HIV/AIDS policies and programs. Nevertheless, the views of the respondents in this study clearly suggest that involving PLHAs provides a significant benefit to the HIV/AIDS response in Nepal.

Barriers

Stigma and Discrimination. All the respondents interviewed stated that stigma and discrimination was the major disincentive to the promotion of GIPA and a fundamental barrier to greater PLHA involvement. The level of felt stigma and enacted stigma (discrimination) is a fundamental factor in the ability of a PLHA to initiate and sustain involvement.\(^4\) In addition, people with HIV/AIDS are subject to other stigmatic barriers in relation to poverty, sexuality, IDU (as noted), and gender. For the individual this can, and does, lead to severe problems related to self esteem. The central role of stigma and discrimination in undermining effective responses to HIV/AIDS across the continuum of prevention, care, and treatment was eloquently described by one of the study participants.

Stigma and discrimination is the cornerstone of the whole fight against HIV/AIDS. I am saying this because unless and until we fight this stigma and discrimination, nothing is really going to change here. Once you have stigma and discrimination, HIV/AIDS is definitely going to be socially submerged. Once it is totally submerged, then they are not going to come out. If they are not going to come out, then how are we going to plan the responses? For example, if we go to Dhangadi and give medicines, then no one is going to come and take it because it is totally submerged there. So it will be difficult for us to give services and monitor. If it is totally submerged, then people will never talk about HIV/AIDS. If they do not talk about it, they would not know how to protect themselves against HIV/AIDS. They would not discuss and know the precaution and the tools to protect themselves. Another important thing is if PLHAs don’t come out, then how are we going to protect their rights, which is the basic principle of GIPA? If they are thrown out of a job and if you just keep it to yourself, then how can we fight?
(Government representative)

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\(^4\) Stigma is understood as both the way a person sees him or herself and the way in which others feel toward the person. Thus, felt stigma is the way in which a person internalizes the stigma of HIV/AIDS. Enacted stigma or discrimination refers to the actual experience of stigma and discrimination. See Aggleton, P. 2001. Comparative Analysis: Research Studies from India and Uganda: HIV and AIDS-related Discrimination, Stigmatization and Denial. Geneva: UNAIDS.
Many PLHAs, particularly women, are thrown out of their houses as soon as they reveal their status. It is during this time they require crucial and critical support. The lack of support centers or institutions that could provide such care and shelter discourage PLHAs from coming forward and disclosing their situation.

*If that transition period can be designed well by us, PLHAs will start opening up. If they know that there is a place where they can stay for six months or one year with stipend, they will definitely come. Therefore, there should be institutions that can provide support for that certain time.* (Government representative)

*It becomes difficult for them to disclose their identity. Once they reveal it, they have to face discrimination. There is no law or policy to support them if they face discrimination.* (NGO representative)

**Capacity of PLHAs.** Engaging with experienced and skilled policymakers requires a level of expertise that many PLHAs who have come forward do not possess. The majority of the PLHAs who have revealed their status are from low socioeconomic strata with only basic education. 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 a personal level. Understanding and being able to articulate the personal experience of HIV/AIDS is an important foundation for coming to terms with the more technical knowledge required to engage in policy development. It is also the case that in many consultative situations, the involvement of PLHAs requires some command of English, at least in relation to donor activities and other policy activities that involve international actors. While there may be educated PLHAs in Nepal and who have the ability to learn how to negotiate in a policy environment, too few have come forward.

*One or two positive might have the skill but they don’t represent the whole country. They represent their particular group, and it’s not enough.* (INGO representative)

*Most of the PLHAs are illiterate—only three or four have come forward, and even they don’t have all the knowledge. We cannot talk at high level.* (PLHA representative)

*There are positives with brilliant ideas, but they are not able to express their ideas because of language gaps. There are meetings where they say “you can speak Nepali but we will conduct it in English”. People will definitely feel uncomfortable to speak up in Nepali in these kinds of meetings.* (PLHA representative)
There is need for capacity building and training. Maybe they need a little more investment for this. In Nepal’s context, I think they need to strengthen a small group. Let’s be more qualitative than quantitative. (PLHA representative)

The few PLHAs who have taken up the leadership in bringing the issue to the forefront have to accept the heavy burdens imposed by the physical and social experience of living with HIV/AIDS. The limited number of openly positive people creates huge demands on those who have taken the step to be public about their status.

Even now I feel so stressed after talking for long at meetings. My head starts aching because you have to think while you are speaking. I am not a tape recorder; I have to go through things and present them with logic. So I do feel stressed out at times. (PLHA representative)

There has to be clinic and counseling support. We cannot just let them die. So treatment is very necessary. I think there is no GIPA unless there is treatment. (NGO representative)

The next thing we have to provide is care and support because until a person knows that he is going to get good care and support he will not come out. (Government representative)

There were several respondents who stated that capacity and skill was not necessarily the most significant. Rather, the attitude of people toward PLHAs and the lack of opportunities for involvement posed more immediate barriers to increasing the quality and quantity of PLHA involvement.

If we can involve them in areas where they can contribute, then capacity and skill does not act as barrier. (Government representative)

I think they have the capacity in knowing what they want. I think the critical thing is to provide them the opportunity when implementation is underway, to fully involve them even more than they have been involved up to now. (EDP representative)

In Nepal, the GIPA principle is not adequately defined in policy and legal frameworks, leading to uncertainty in defining and interpreting responsibilities in regard to implementation. Government officials who were interviewed revealed that an in-depth understanding and rationale for GIPA at the policy level is still elusive. While the principle of involvement was basically understood by the majority of policymakers, promoting it as an effective instrument of the broader HIV/AIDS response does attract significant support.
I still feel that those in the high position have not understood the need of involving them and its implication to the society and the country. As long as this gap cannot be addressed this remains as a major barrier. (Government representative)

Lack of political commitment is also very less in regard to involving PLHAs. Maybe they don’t feel this issue as their own problem (PLHA representative)

That way is for His Majesty to give patronage to this whole program. Just imagine the impact when His Majesty comes out and talks about HIV/AIDS, meets PLHAs, and shakes hands with them. Imagine the impact of this then and look how popular His Majesty is going to be in the national spotlight. And this is what I am really fighting for. (Government representative)

A further barrier is the lack of PLHA experience in operating strategically in a political context. The needs of PLHAs tend to be expressed as individual and primary. There is a need to empower the group to recognize the value and methods of collective PLHA advocacy and political action through effective networks.

The main challenge is that they get the network running and that they find one or two issues that they really want to do together and they want to make a difference. Another big challenge is how to provide information for people who are not living in Kathmandu. (EDP representative)

As long as there is only individual voice from the positives this issue cannot be well addressed. The voice of the group relating to their needs and concern should come out. I feel the voice of the group will be much respected than the individual voice. So what they lack now is a network and knowledge in the making of the policy. (Government representative)

Institutionally based fear and ignorance of HIV is also a significant barrier to expanding the GIPA response. Respondents cited the health and education sectors as particularly resistant to the idea of PLHA involvement.

When we were conducting a study on HIV/AIDS, one school headmaster directly refused to let us in his school. I was never allowed inside another school in Lalitpur. I had a government letter, still I could not go in. (Government representative)
Findings from a Study on the Greater Involvement of People with HIV/AIDS in Nepal
Discussion

This research highlights the varied perspectives of policymakers, PLHAs, and other key stakeholders. While there is a broad consensus regarding the value of GIPA, there are substantive differences over activities and approaches. In the view of several respondents, the efforts the government and other agencies have made to consult and involve PLHAs, while sometimes flawed, demonstrate an important beginning. This was expressed as significant in the context of the continuing conflict in the country and the demands of other competing issues. In contrast, PLHAs felt that little attempt has been made to recognize the value of GIPA or support PLHAs to move beyond a tokenistic level of involvement.

While there is a broad consensus regarding the value of GIPA, there are substantive differences over activities and approaches. The response to HIV/AIDS in Nepal would benefit from further research aimed at gaining a better understanding of the needs and challenges affecting PLHAs, for example, how to support disclosure of HIV status, the need to recognize and involve IDUs, and the status of women and the particular burdens they face. There is a clear need for greater dialogue and interaction in order that all stakeholders learn from each other. Figure 2 represents the core components required to support GIPA activities.
As noted earlier in the report, the development of GIPA does not require that PLHAs acknowledge their status publicly; however, the limited number of people in Nepal currently willing to be “open” about HIV has created, in the view of several of the non-PLHA respondents, a narrow idea of the range of PLHA experiences and issues and places a heavy burden on those who are open. The view that involvement should reflect the participation of those affected as well as infected is one step toward building a broader and more inclusive approach to GIPA in Nepal. However, to ensure the legitimacy of an expanded GIPA response, PLHA control and representation must remain a fundamental guiding principle. Sensible discussions of GIPA must also encompass the capacity needs of people marginalized by their health status and multiple layers of stigma. If the value of PLHA involvement in policymaking is to move beyond current levels, attention must be paid to treatment access and skills/experience development. The concept of PLHA capacity, or lack of it, should not detract from efforts to involve PLHAs in activities where there is demonstrable skill and experience (as noted by several respondents). In other words, significant opportunities for involvement currently exist but are not being fully utilized, particularly in counseling, peer support, and HIV/AIDS education. Nor should capacity issues be used to withhold support to PLHAs to gain the skills and experience necessary to play a meaningful role in HIV/AIDS policy and program activities.
References


UNAIDS. 1999. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA).* Geneva: UNAIDS.


### Appendix A: GIPA Models

This table is reproduced from the UNAIDS report *From Principle to Practice*.

<table>
<thead>
<tr>
<th>Role Type</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>Decisionmakers</strong></td>
<td>PLHAs participate in decisionmaking or policymaking bodies, and their inputs are valued equally with all the other members of these bodies.</td>
</tr>
<tr>
<td><strong>Experts</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Implementers</strong></td>
<td>PLHAs carry out real but instrumental roles in interventions, e.g., as carers, peer educators, or outreach workers. However, PLHAs do not design the intervention or have little say in how it is run.</td>
</tr>
<tr>
<td><strong>Speakers</strong></td>
<td>PLHAs are used as spokespersons in campaigns to change behaviors, or are brought into conferences or meetings to &quot;share their views&quot; but otherwise do not participate. (This is often perceived as &quot;token&quot; 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.)</td>
</tr>
<tr>
<td><strong>Contributors</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Target Audiences</strong></td>
<td>Activities are aimed at or conducted for PLHAs, or address them on mass 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 &quot;patients&quot; at this level. They can provide important feedback which in turn can influence or inform the sources of the information.</td>
</tr>
</tbody>
</table>


The Horizons/Alliance study provides a similar evidence-based framework that helps to clarify what meaningful involvement is in practice. The study identifies four categories of involvement. These are summarized in the table below.

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access to services</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Inclusion</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Participation</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>Greater Participation</strong></td>
<td>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.</td>
</tr>
</tbody>
</table>

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

  - 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 national AIDS program 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 their 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:
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 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 national AIDS program 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 national AIDS program? 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 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 national AIDS program 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 national AIDS program? 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.
The GIPA principles were established at the Paris AIDS Summit in December 1994, and were articulated in the Paris AIDS Summit Declaration. In this Declaration, representatives from 42 countries committed to support the total involvement of people living with HIV/AIDS (PLWHA) in the common response to the epidemic at all levels. The main commitments of the Declaration were to:

- Support the greater involvement of PLWHA through initiatives to strengthen the capacity and coordination of networks of PLWHA and community-based organizations (CBOs), stimulating the creation of supportive political, legal and social environment
- Fully involve PLWHA in decision making, formulation and implementation of public policies
- Protect and promote the rights of individuals, particularly those living with or most vulnerable to HIV/AIDS, through legal and social measures
- Make available necessary resources to better combat the epidemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalized populations
- Strengthen national and international mechanisms that are concerned with HIV/AIDS, human rights and ethics

*Source: Regional Human Development Report - HIV/AIDS and Development in South Asia 2003, UNDP*