The National Forum of PLHA Networks in Uganda

PROMOTING **GIPA/MIPA** Principle

Uganda AIDS Commission
Civil Society Fund

Together for a positive Difference

Contents

Foreword

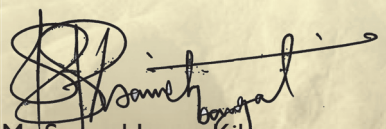
The GIPA principle is the backbone of many HIV interventions and is critical to ethical and effective national responses. This booklet seeks to elaborate the phenomenon of Greater Involvement of People living with HIV/AIDS (GIPA) principle in the national HIV/AIDS response in Uganda. The booklet provides information on the history of GIPA, current progress on the involvement of PLHIV in the national HIV/AIDS response at social, individual and organization level, the level of involvement of PLHIV in the national HIV/AIDS response; the challenges of operationalising the GIPA principle and meaningful involvement of PLHIV; the potential role of PLHIV in unblocking the barriers to scaling up universal access to prevention, care and treatment, and support, among other issues.

The involvement of PLHIV has been at the lower levels of the six-level UNAIDS GIPA involvement pyramid, including being involved as beneficiaries of project activities, as contributors, as speakers, or as implementers. Few organizations involve PLHIV at higher levels of the organization such as having PLHIV as paid staff, managers, or as experts and decision makers.

Therefore, organizations that implement HIV/AIDS programmes and activities should include activities to sensitize government leaders and program managers in addition to civil society leaders and the general population on the needs of PLHIV and the value of including them in policy development and programs to prevent the spread of HIV/AIDS and mitigate its impact. The commitment of policymakers and program managers, in addition to donors and implementing organizations, is crucial to the effective implementation of GIPA.

This booklet may not provide you with all the answers on GIPA but it contains a wealth of information and resources, and includes references to appropriate organizations/references that can provide further assistance. We must work together collectively in order for GIPA to be effective and workable and to have a positive impact on our nation.

'Together for a positive difference'



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Together for a positive difference.

Acronyms

ACORD	Agency for Cooperation in Research and Development
AIC	Aids Information Center
AIDS	Acquired Immune Deficiency Syndrome
ANE	Asia/ Near East Bureau
ART	Anti Retroviral Treatment
ARV	Anti Retroviral Drugs
ASO	Aids Service Organization
CAO	Chief Administrative Officer
CBO	Community Based Organization
CHAI	Community- led HIV/AIDS Initiatives
CSO	Civil Society Organization
CSW	Commercial Sex Worker
DAC	District Aids Committee
DART	Development of Antiretroviral Treatment
DAT	Districts Aids Task Force
DMO	District Medical Office
DFP	District Focal Person
IDP	Internally Displaced Persons
FAO	Food and Agricultural Organization
FBO	Faith Based Organization
FGD	Focus Group Discussions
FOCAGIFO	Friends of Canon Gideon Foundation
GFATM	Global Fund to fight HIV/AIDS, TB and Malaria
GIPA	Greater Involvement of Persons Living With HIV/AIDS
GLIA	Great Lakes HIV and AIDS Initiative
GNP+	Global Network of People Living with HIV/AIDS
HPAC	Health Policy and Advisory Committee
HIV	Human Immune Deficiency Virus
ICASA	International Conference on HIV/AIDS and Sexuality Transmitted Infections in Africa
IGA	Income Generating Activities
INGOs	International Non Government Organizations
JAR	Joint Annual Review
KABP	Knowledge, Attitudes, Beliefs and Practices

KI	Key Informants
LC	Local Council
MAP	Multi- Country Aids Program
MIPA	Meaningful Involvement of persons living With HIV/AIDS
MoH	Ministry of Health
NACWOLA	National Community of Women Living With HIV/AIDS
NAFOPHANU	National Forum of People Living with HIV/AIDS Networks in Uganda
NAP+	Network of African People Living with HIV
NGEN+	National Guidance and Empowerment Network
NGO	Non Governmental Organisation
NMS	National Medical Stores
NSF	National Strategic Framework
NSP	National Strategic Plan
NUSAF	Northern Uganda Social Action Fund
PC	Palliative Care
PLHIV	People Living with HIV/ AIDS
PMTCT	Prevention of Mother to Child Transmission
TWG	Technical Working Group
UAC	Uganda Aids Commission
UACP	Uganda Aids Control Project
UN	United Nations
UNAIDS	United Nations Joint Programme on AIDS
UNGASS	United Nations General Assembly Special Session dedicated to HIV/AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations Children Fund
UPDF `	Uganda People's Defense Forces
USAID	United States Agency for International Development
UYP	Uganda Young Positives
VAT	Village AIDS Taskforce
VCT	Voluntary Counseling and Testing
WFP	World Food Program
WHO	World Health Organisation

What is GIPA

GIPA means the Greater Involvement of People living with and affected by HIV/AIDS, and derives from a principle embedded in the Paris AIDS Summit Declaration[1] of 1994. The Declaration acknowledged the central role of People living with and affected by HIV (PLHIV) in HIV/AIDS education and care, and in the design, implementation, monitoring and evaluation of national and international policies and programs, in order to successfully tackle HIV/AIDS.
It also acknowledged that, for HIV positive people to take on a greater role in the response, they need increased skills, capacity, empowerment and support.

The Declaration committed governments to develop and support structures, policies and programs to facilitate the greater involvement of people living with HIV and AIDS. UNAIDS has broadened GIPA to include those most directly affected by the epidemic, based on the consensus reached at the Nairobi Consultation (UNAIDS 2004).
This is done with the understanding that no one can speak for a person living with HIV better than a person living with the virus. Nor can anyone speak for the bereaved widow or someone lost to AIDS, except someone with that experience (which is not necessarily that of all PLHIV).

History of GIPA

In 1994, during the Paris AIDS Summit, 42 national governments declared the principle of GIPA (Greater Involvement of PLHIV is critical to effective national response to the epidemic. This becomes

1 Article 1 of the Declaration resolved to facilitate this greater involvement of persons living with HIV and AIDS. It states that: "The success of our national, regional and global programmes to confront HIV/AIDS effectively requires the 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... By ensuring their full involvement in our common response to HIV/AIDS at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments".

an official position of these 42 governments who has committed themselves to supporting full involvement of persons living with or affected by HIV/AIDS.

This principle has yet to become a reality even at the governmental and country level and GIPA is often promoted by individuals with HIV "going public" about their serostatus in order to give a human face and voice to the epidemic which was never meant to be in the first place.

It is recognized that the understanding and realization of effective GIPA may be different over time and space. However, such contextualization of GIPA should not be at the cost of denying persons with a personal experience with HIV/AIDS to be heard, or an opportunity to participate in the response.
In Abuja at ICASA 2005, it was noted that GIPA principle needed to move from emphasizing numbers but also to place emphasis on the quality of PLHIV and their capacity to advocate and influence critical actions in the HIV response. This denotes Meaningful Involvement of PLHIV (MIPA) and thus the use of the term GIPA/MIPA was born.

In countries where PLHIV have been involved in the HIV/AIDS response, a positive and significant correlation between the level of PLHIV involvement and effectiveness of the response to the epidemic has been noted.

Evidence shows that PLHIV involvement makes programmes and policies more effective and development focused, no matter whether these programs and policies are targeting HIV-positive persons specifically (e.g. support, care and treatment) or a broader audience such as prevention (Horizons 2003; UAC 2004; UNAIDS 1996; UNAIDS 2006; Paxton 2002a). The involvement of PLHIVs provides a role model for other HIV-positive persons; helps to empower them, helps to counter stigma and reduce discrimination; and it brings a sense of urgency to the AIDS response (Garmaise, 2003).
The PLHIV have contributed in areas of peer support, peer education, advocacy, public education, sensitization and community mobilisation, programme planning and implementation, public policy and legislation (ANE, 2004, UAC 2004, NAFOPHANU 2006)

In 2003, PLHIV lobbied for a new GIPA initiative, one that shifted the focus from increased involvement to a more expansive vision for meaningful involvement of PLHIV, focusing more on the overall empowerment of PLHIV.

Extent/Level of involvement of PLHIV

The principle of Meaningful Involvement of People Living with HIV and AIDS (MIPA) in all aspects of HIV and AIDS programming, seeks to promote the integration of People Living With HIV (PLHIV) in the planning, implementation, and monitoring and evaluation of interventions addressing HIV and AIDS.

Such an approach is critical to the ethical, efficient and effective response to HIV and AIDS.
It is essentially a policy position which rationalises and secures the position of PLHIV as legitimate participants in policy and decision making.

The concept is further anchored on "Denver principles" of 1983 where positive activists announced a set of principles destined to revolutionise the way the world responded to the HIV epidemic. The "Denver principles" set forth standards for human rights and self-empowerment of PLHIV.
Inadequate implementation and popularisation of GIPA, resulted in some stakeholders questioning its appropriateness and effectiveness, and adopted a reinvention of the term to Meaningful Involvement of People Living with HIV and AIDS (MIPA).

Below are the general categories of level of involvement;

Social level - This involves breaking the silence. PLHIV Publicly acknowledging that involvement helps reduce stigma and discrimination and tells society regarding the acceptance and recognition of the importance of PLHIV in the HIV response.

Organizational level

It serves as a powerful tool for breaking down barriers, whether subjective or objective. This helps to clear preconceived ideas which are misinformed about PLHIV. This is possible and can be facilitated through setting up HIV work place policies.

Human level

Working with HIV+ people and having a name and face to associate with the concept of a "person with HIV/AIDS" helps people overcome their fears and prejudices and change their perception towards PLHIV. This promotes VCT, care and treatment, social support, as well as individual self esteem.

By providing a human face to the epidemic, involvement of PLHIV breaks down barriers, changes the image of AIDS from that of a terrible fatal disease, and reduces stigma and discrimination (conscious or otherwise).

Partnership

The partnership concept breaks down the simplistic concepts of "service giver" (non-PLHIV) and "service receiver" (PLHIV). Involving PLHIV exposes the organization to the unique perspectives that PLHIV direct experience bring in the following areas:

A) Reinforcement at the level of general morale and team-building
B) Substantive improvements in the way an organization actually works.

Policy and Programming

GIPA improves HIV/AIDS related policies and programs: PLHIV involvement in policy formulation and program development and implementation makes it more ethical, needs-based, credible, efficient, relevant and sensitive.

PLHIV contribution within organizations:

Within organizations, PLHIV involvement can be a powerful tool for breaking down barriers. Organizations are made up of individuals,

and individuals who are neither infected nor affected by HIV/AIDS often have preconceived ideas and misconceptions about PLHIV. Involving PLHIV can break these and can be reflected in change in the organizational policies or practices.

In Prevention, Treatment and Care:
Involving PLHA in all prevention strategies will lead to effective control of the epidemic across the nation. The involvement should primarily be at the level of evaluating the efficacy of the BCC messages. Of course, PLHIV are often the best message creators!

PLHIV Support Group provides more effective and structural care for psychological care of PLHIV. The principle of GIPA becomes more effective to care giving and its response especially in PLHIV Peer Counseling and Care.

International Declarations, Policies and Guidelines on the GIPA Principle

At the International level, the 2006 Political Declaration of HIV/AIDS in paragraph 20 commits UN member states to;

"pursuing all necessary efforts to scale up nationally driven, sustainable and comprehensive responses to achieve broad multi-sectoral coverage for prevention, treatment, care and support with full and active participation of People Living with HIV……., towards the goal of universal access to comprehensive prevention programmes, treatment, care and support by 2010"

It recognizes the important contribution PLHIV can make in response to the epidemic and to creating a space at all levels-locally, nationally and globally-for their involvement and contributions (UNAIDS, 1999). This further acknowledges the fact that universal access will be scaled up when prevention, treatment, care and impact mitigation is linked, planned and delivered with full involvement of PLHIV as equal partners.

The United Nations General Assembly Special Session dedicated to HIV/AIDS (UNGASS) makes explicit commitment to the involvement of PLHIV. It is envisaged that such a high level international commitment will provide a conducive environment for negotiations and campaigns for action by national policymakers and donors on issues of PLHIV involvement in the HIV and AIDS response.

The Global Network of People Living with HIV/AIDS (GNP+) international office was established to coordinate, lobby, link, and share through capacity building of PLHIV, in planning, implementation, monitoring and evaluating of the AIDS response.
This was after having realized that the Worlds' responses to the epidemic are strengthened by the active engagement of PLHIV, but they remained the most underutilized resource in the epidemic (GNP+, 1998). UNAIDS has a program for promoting PLHIV involvement at all levels in the response (UNAIDS, 2003)

At the regional level, the Network of African People Living with HIV (NAP+) evolved to coordinate the involvement of PLHIV in regional HIV planning, implementation, monitoring and evaluation. Similarly the Great Lakes Initiative on HIV and AIDS (GLIA)2 has set targets to reach PLHIV (GLIA, 2004).
Some international non-governmental organizations have already kept their promise by moving a step further to empower PLHIV. Action Aid International (Uganda) provides advocacy skills for PLHIV to influence people and organizations in power to create an environment which protects the rights, health and welfare of PLHIV and those affected (Action Aid, 2006)

GIPA in Practice

Articulated in a declaration issued at the Paris AIDS Summit in December 1994, GIPA principles are now recognized as a fundamental cornerstone to effective responses to HIV/AIDS by the Joint United Nations Programme on AIDS (UNAIDS), USAID, and the Global Fund

2 Article 7 clearly states that GLIA will ensure the full participation of PHAs in the region and will guarantee for human rights, gender and cultural sensitivity and commit to eliminate all stigma and discrimination of PHAs and other vulnerable groups

to Fight AIDS, Tuberculosis (TB) and Malaria (GFATM) and the Uganda NSP 2009/10-12.

Consensus on the importance and validity of GIPA is reflected by its endorsement in numerous international statements, most recently, the Declaration of Commitment on HIV/AIDS, signed by the 189 member states of the United Nations in 2001.

USAID identifies GIPA as one of the 10 crosscutting program components by which the agency implements its HIV/AIDS strategy. USAID "believes that the involvement of people living with HIV/AIDS in designing and implementing prevention and care activities is essential to these activities' sustained success. People living with HIV/AIDS have a critical role to play…"4

While there is broad consensus on the importance of GIPA as a principle, little programmatic experience and research is available to guide policymakers and other stakeholders, including PLHIV, in implementing GIPA. Key questions to consider to ensure GIPA include;

What activities can be considered GIPA-focused? Should organizations working on HIV/AIDS be required to incorporate GIPA into policy and decision-making bodies in addition to program delivery?
What is "meaningful" participation? How can GIPA be measured and what are benchmarks of achievement? Beyond these questions, issues pertaining to "meaningful" involvement of PLHIV at all levels of the policy and programmatic response are gaining increased urgency.
At what levels of the decision-making processes are PLHIV involved? Are PLHIV serving as advisors, but have no decision-making power? Within the NGO sector, at what levels of are PLHIV involved?

Are PLHIV only used as occasional volunteers and/or models for posters and publications of HIV prevention communication campaigns? Do PLHIV have a face but no voice? Is there a danger that PLHA participation may become tokenistic and co-opted.

GIPA Assessment in Uganda 2007

According to the findings, the team established that in Uganda there has not been any focused education on the GIPA principle and how it can be fully incorporated in programming and service delivery.
The respondents with more knowledge about the principle had attended conferences and workshops outside the country specifically focusing on GIPA. A number of district officials in the South-Western region said they were involving PLHIV in their activities but not as a conscious and deliberate effort to put into practice the GIPA principle.

Effective implementation of policies and other legislative frameworks requires a clear understanding of the context and commitment from the would-be implementers. In the local governments DFP have a responsibility of supporting the involvement of the PLHIV among other things in the HIV/AIDS response. However, DFPs have substantive positions and responsibilities in the local governments for which they are appraised which tends to affect their new roles in HIV/AIDS coordination and thus PLHIV activities and GIPA in general.

The assessment found out that institutional barriers limit the involvement of PLHIV and thus the ability of PLHIV to influence decisions in the local government decision-making fora.
The institutional weaknesses are a result of the institutions within which the PLHIV operate and which institutions shape the incentives that drive behaviour, performance and expectation about rights and obligations, roles and responsibilities.
These are the rules of the game which include written and implied laws, policies and cultures that have major influence on universal access to HIV and AIDS services. According to North3 institutions "…. consist of formal rules, informal constraints- norms of behaviour, conventions, and self imposed codes of conduct- and their enforced characteristics".

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3 North D (1991) Institutions, Institutional change and economic Performance, Cambridge, Cambridge University Press

The assessment found that in some districts PLHIV representatives handpicked by the district officials seldom represent the views/ consensus of fellow PLHIV networks and associations. It was noted that many times the PLHIV are sidelined on HIV and AIDS activities that comprise monetary gains or that have a remuneration attached to them.

PLHIV are mainly involved in activities as volunteers, and this is one of the reasons why PLHIV professionals are not willing to offer their services to the PLHIV networks or the response. Programmes that involve remuneration are designed for or in the name of PLHIV but implemented with less of PLHIV participation or involvement. Some of the focus group discussion participants had this to say.

PLHIV are encouraged to engage in activities that are voluntary like counseling. But even then when there is money to be paid they are thrown out. (PLHIV rep-Moyo district)

MSF in Arua district provided training to PLHIV in counseling and the PLHIV do it on a voluntary basis. But when the work is to be paid for/remunerated, the PLHIV are pushed out (PLHIV-Arua district)

This practice of voluntarism must stop immediately. We have the skills and have to be rewarded accordingly. We the youth lack motivation to participate because some of them do not have even transport to the meeting places (Young positive-Kampala District)

PLHIV are not called upon to participate in workshops where a lot of money will be given inform of per diem and allowances exceeding Uganda shillings 5,000- (PLHIV rep – Kabale)

The programmes that have money on them are designed for the PLHIV and not with the PLHIV as is the requirement with meaningful involvement of PLHIV (PLHIV rep-Arua district).

As long time serving counsellors/volunteers in TASO and AIC, we were the first ones to be thrown out when restructuring came.

In fact there were no terminal benefits for us even after working for more than 10 years at these organisations. Despite our contribution over the years we were not considered for any other placements in the organisations despite our vast experience and resource in HIV and AIDS response (PLHIV-Mbarara district)

It was further reported that activities that concern PLHIV are budgeted for every year in local governments, but these activities are not funded or implemented. Budget allocations are made to other sectors that are said to be more critical as decided upon by the district and endorsed by the councils. Respondents had this to say:

PLHIV are not very much involved and are very rarely represented at the district and sub-county levels. Mostly the HIV anonymous people are involved to carry out activities that could be effectively done by the PLHIV (FGD- participant- Lira District))

It is common practice for district to keep on postponing the implementation of PLHIV activities. I was a councilor and this used to happen in those meeting (PLHIV rep- former LC V Councilor – Mbarara)

The activities of the PLHIV are postponed and not funded every year. District officials need to be sensitised so that PLHIV activities are given priority (Local government official-Kitgum district)

Policies, Guidelines and Initiatives on GIPA in Uganda

Initially in Uganda, individual PLHIV and national PLHIV networks played an important role in stimulating openness and greater number of citizens' social support and access to prevention, care and treatment services.

The involvement of PLHIV in the nationhgal response started long before the term GIPA was invented. Pioneer PLHIV like Mr. Philly

Lutaaya (RIP), Ms. Ofwono Elizabeth (RIP), Major Rubaramira Ruranga, Ms. Beatrice Were, and Reverend Gideon Byamugisha4, took early bold steps to give a human face to HIV.

Networks such as AIC-PTC/PLI, TASO, National Guidance and Empowerment Network (NGEN+), National Community of Women Living with HIV/AIDS in Uganda (NACWOLA), Positive Men's Union (POMU), have made tremendous contribution. However the scramble for resources and internal conflicts in the PLHIV constituency affects the level of involvement of PLHIV and their ability to influence policy, planning, implementation and access to available services.
Nevertheless with their 20 years history in supporting PLHIV and building their confidence and empowering PLHIV to live on, it is apparent that PLHIV networks have a lot to offer and learn from. They have contributed to national and international best practices such as the International Memory Project (IMP) of NACWOLA.

In addition, The National Forum of PLHA Networks in Uganda was established in May 2003 after identification, acknowledgement and recognition of gaps among PLHIV initiatives in the national response. This was reached through a process that involved joint consultative meetings of PHA from PHA initiatives in Uganda, with support from UNAIDS and the HIV/AIDS Partnership of the Uganda AIDS Commission (UAC).
Since its inception, NAFOPHANU has been in close partnership with the Partnership Committee as a Self Coordinating Entity of the PLHAs and gets funding to run part of its activities. NAFOPHANU has eight functional constituencies; Central I &II, Greater East, West I &II, North, West Nile, and Karamoja regions.

Vision- NAFOPHANU envisions a community of people living with HIV realizing their full potential through mutual support, respect of human rights and positively influencing the HIV/AIDS response at all levels.

4 Namirembe Diocese is credited for championing the involvement of PHA in the HIV and AIDS response when it accepted Rev. Gideon Byamugisha to continue in the service of the Church even after declaring he was HIV positive. Byamugisha was later ordained a Canon of the Church of Uganda.

Mission- To unite, support building of capacities and coordinate all networks and groups of PHA in Uganda for a concerted effort to the HIV and AIDS national response

Goal- To enhance the capacity of the networks and member organizations of PHAs through training, coordination, information sharing, advocacy and resource mobilization by 2012

Strategic objectives

- To strengthen advocacy capacities of the National Forum of People Living with HIV Networks and groups to ensure their wellbeing
- Manage PHA specific information through research, documentation and dissemination at all levels
- To enhance resource mobilization through strengthening financial systems of PHA networks
- To build and strengthen partnerships with PHA networks and other stakeholders in the national response
- To strengthen the performing capacity of NAFOFHANU to respond to its evolving needs and those of its members

PLHIV constituency is also represented on the different Partnerships and Committees, such as HPAC, CCM, CSF, and PC,
Others include; the PEPFAR meetings, GFATBM, NUSAF, NACAES, GLIA, the TB/HIV Collaboration (NAFOPHANU 2006), etc.

Uganda has also developed policies and guidelines aimed at improving coordination and harmonizing responses to HIV and AIDS There is the over arching HIV/AIDS policy under the Uganda AIDS Commission and other sector specific policies. In addition to the above main policies, there are several initiatives and interventions put in place in the same regard.
One of the Presidential selected commissioners on the UAC Board is a PLHIV encapsulating the political goodwill and commitment to greater involvement of PLHIVs at the national level.

Other initiatives include the setting up of a Parliamentary Committee on HIV/AIDS representing the national level commitment to legislation and guidance of HIV/AIDS programmes; capacity development for

service providers in a comprehensive package on HIV/AIDS care and management, which includes quality assurance of service providers within the health sector in the context of HIV/AIDS.

The national AIDS response demands that all stakeholders are involved in planning, programming, monitoring and assessment of all prevention, care, treatments and social support responses. People living with HIV, communities affected by the epidemic, and marginalized groups particularly vulnerable to HIV infection all have special roles to play by bringing their experiences into the process of developing national priorities and policies, and actively participating in the provision of services. To accommodate and coordinate all partners working in the area of HIV/AIDS the Uganda HIV/AIDS Partnership was established as an innovative coordination mechanism at national level bringing together constituencies of the national response (UAC, 2004).
The UAC guidelines for district HIV/AIDS coordination provide for a partnership forum which has PLHIV networks as a component, in addition to government, private sector, cultural institutions, INGOs/ NGOs and CBOs and Faith Based organizations (UAC, 2002).
The District AIDS Committees are required as stipulated in the guidelines to have at least one PLHIV representative.

The Revised National Strategic Framework provided basic national guidelines for the multi-sectoral HIV/AIDS interventions and laid emphasis on collaboration and coordination among all stakeholders focusing on HIV/AIDS prevention, care, treatment and social support. The NSF focused on three main goals in the areas of reducing prevalence, mitigating the effects of the epidemic and strengthening the national capacity to respond to the epidemic.

The main reason for GIPA/MIPA is to dramatically improve the response to the HIV/AIDS epidemic. These benefits should be translated into the overall functioning of the country HIV/AIDS response activities, services and the quality of life of the beneficiaries, at individual (PLHIV) and at their households, communities and at country level.
However, there are country specific challenges in the implementation of the GIPA with many countries, reporting very tokenistic representation of positive people (NAP+, 2004). Many expert meetings did not

want PLHIV present at meetings as they felt that PLHIV were not experienced enough to take a seat at the same table (GNP+, 1998).

Due to the complex and dynamic nature of the AIDS epidemic, new challenges are constantly being faced by the PLHIV and the PLHIV networks in their effort to contribute to scaling up the universal access.
New roles and responsibilities are emerging and these roles and responsibilities call for new strategies which ought to be reflected in the country response in order strengthen the impact of the different PLHIV networks and organizations at different levels.

PLHIV involvement in Policy and Decision Making Process

Legislative Framework and Policy Environment

The government of Uganda has over the years put in place a conducive policy and legislative environment to foster GIPA which includes; the Constitution of the Republic of Uganda (1995), The draft/overarching HIV/AIDS Policy (1999), The HIV/AIDS Testing and Counseling policy (2003), ART Policy (2004),
Home Based Care Policy (2003), The National Gender Policy, Prevention of Mother to Child Transmission Policy, Condom Policy, and Youth Policy. Recently, an HIV Control and Prevention Bill came into the picture desipite its controversies.
Through these relevant policies and guidelines the government of Uganda, development partners and CSOs recognize and emphasize the contribution of the PLHIV in the response to the HIV/AIDS epidemic.

One of the presidential appointed commissioners on the board of UAC (the national coordinating arm of HIV/AIDS interventions) is a PLHIV, encapsulating the political goodwill and commitment to greater involvement of PLHIV at the national level. This reflects a high level of involvement in decision making at the national and international level.

The UAC has established the HIV/AIDS Partnership as an innovative coordination mechanism at national level. This UAC Partnership Committee5 brings together different constituencies (Self Coordinating Entities) of the national HIV/AIDS response. The PLHIV constituency is one of the 12 self-coordinating entities.
The PLHIV have been represented on the National Taskforce and on all Technical Working Groups in the preparation of the National Strategic Plan (2007/08-2011/12). PLHIV were represented in the development of the NSF and the mid-term and final review of the NSF 2000/2001.

The crafting of the NSF was based on the realization that AIDS epidemic constitutes a national and global health crisis of unprecedented magnitude, that impact on economic and social development worldwide and poses a security threat to nations. The framework viewed the involvement and participation of PLHIV in the fight against AIDS as a strategy for reducing stigma and promoting PLHIV rights. To specifically foster involvement of PLHIV in the national response, the revised NSF had the following objectives, strategies and activities shown below.
NSP Goals, Objectives, Strategies and Activities for PLHIV Involvement 2007/8-2011/12

Objectives of NSP 2007/08-2011/12

- To accelerate the prevention of sexual transmission of HIV through established as well as new and innovative strategies.
- To reduce the HIV transmission from mother-to-child by 50% by 2012
- To maintain 100% blood transfusion safety, ensure 100% adherence to universal precautions and promote 100% access to PEP at ART centres by 2012.
- To control sexually transmitted infections, increasing appropriate uptake

5 The Partnership Committee is composed of 12 SCEs namely; Youth, Parliament, Ministries of Government, UN and Bilaterals, National NGOs, International NGOs, Private Sector, Faith Based Organisations, PHA Networks, Decentralised Response, Research Academia and Science and Media Arts and Culture.

to 70% by 2012

- To promote use of new HIV prevention technologies and approaches proven to be effective.
- To increase equitable access to ART by those in need to reach 240,000 by 2012
- To increase access to prevention and treatment of opportunistic infections, including TB
- To scale up HIV counselling and testing to facilitate universal access.
- To integrate prevention into all care and treatment services by 2012.
- To support and expand the provision of home based care and stregthen referral systems to other health facilities and complementary services.
- To provide complementary support, including nutrition, to PHAs.
- To increase provision of quality psychosocial support to PHAs, OVCs and other disadvantaged groups affected by HIV and AIDS by 2012
- To promote and support sustained formal and informall education, vocational and life skills development for OVC, PHAs, IDPs, PWDs and other disadvantaged groups affected by HIV and AIDS.
- To enhance economic empowerment and livelihood of HIV/AIDS affected communities and households
- Increase access to basic entitlements for PHAs and OVCs.
- To ensure legal and appropriate social and community safety nets for PHAs, OVCs and other persons made vulnerable by HIV and AIDS.

Anticipated outcomes of the Plan

The National Strategic Plan for the next 5 years (2007/8-2011/12) takes cognisance of the challenges that lie ahead to reduce new infections, prevent mother-to-child transmissions, and facilitate universal access to enssential services.
The critical emphasis is to integrate the continuum of HIV prevention, care and treatment, and social support services; and to reserve the trend in the number of people living with HIV.
In addition, the plan aims to consolidate and scale up access to ART, while providng much improved social support to reduce the socio-economic impacts of the epidemic and reduce vulnerability to HIV infection.

The cornerstone of the NSP is the aim to reduce the incidence levels of new HIV infections by 40% by 2012; this is the basis for prioritising resource allocations to fully fund the most cost-effective HIV prevention measures. Achieving this cornerstone is projected to have the following impacts on the AIDS epidemic:

- **Prevention** - Increased funds and commitment to prevention-related interventions could decrease the annual number of new infections from 135,000 to just over 100,000 by 2012. This would imply that as many as 150,000 to 160,000 new infections could be averted over the period of the NSP, thereby saving lives and decreasing future expenditures on treatment. One key intervention will be including male circumcision within the broader framework of male reproductive and sexual health.

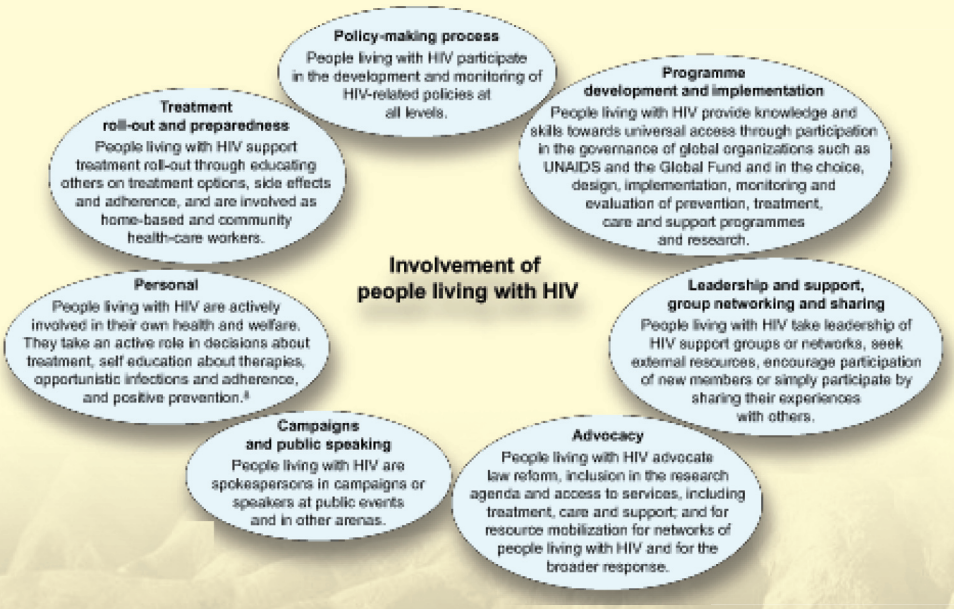
- **Care and Treatment** - The allocation for care and treatment could support an increase in the number of people receiving ART from 80,000 in 2005 to 216,000 by 2012. This level of scaling up would substantially address the support needs for those already on treatment as well as starting treatment for those newly needing it. Indeed, the proportion of those needing ART who do receive it would increase, reaching about 80% in 2011/12. This increase in coverage would extend life for many

people and avert an additional 60,000 - 90,000 AIDS-related deaths during the NSP period.

- **Social Support** - Support for OVCs would increase significantly during the NSP, improving the proportion of OVCs receiving public support to 54%. In the long term, prioritising prevention would also reduce the incidence of OVCs and other associated socio-economic effects since far fewer people would be getting infected with HIV, thereby reducing the numbers of persons getting sick and dying from AIDS.

UAC and development partners through the Partnership Forum has supported the process for scaling up involvement of PLHIV networks and groups in facilitating access to HIV/AIDS prevention, care and treatment services, provided funding and technical assistance to PLHIV networks and forums for increased advocacy, positive living and positive prevention.

Meaningful and Greater involvement of PLHIV in a response



Source: UNAIDS

UNAIDS adopted GIPA as a principle and explains the term greater involvement by the use of a pyramid of involvement. This assessment was interested in the level of contribution made by the PLHIV in the national response. The assessment considered the levels of involvement noted by UNAIDS and summarized in table 1 below.

PLHIV can be involved as; target audiences, contributors, speakers, implementers, experts, or decision makers. UNAIDS notes that GIPA can be applied at all levels with the upper most level of decision-making representing the highest level of application of and satisfying the GIPA principle requirements (UNAIDS, 1999).

Table 1: The UNAIDS six-level Pyramid of PLHIV involvement

Decision makers: PLHIV participate in decision making or policymaking bodies and their inputs are valued equally with all other members of these bodies.
Experts: PLHIV 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.
Implementers: PLHIV carry out real and instrumental roles in interventions (e.g. as caregivers, peer educators or outreach workers). However, PLHIV do not design the intervention or have much say in how it is run.
Speakers: PLHIV are used as spokespersons in campaigns to change behaviours 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 organisers are conscious of the need to be seen as involving PLHIV but do not give them any real power or responsibility.)

Contributors: Activities involve PLHIV only marginally, generally when the PLHIV 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.

Target audiences: Activities are aimed at PLHIV or address them as a group rather than as individuals. However, PLHIV should be recognised as more than (a) anonymous images on leaflets, posters, or in information, education and communication 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.

According to the study by the Population Council (Horizons Project) and International HIV/AIDS Alliance, the term involvement means giving a general typology of PLHIV involvement.This typology considers involvement as referring to a specific way in which PLHIV take part in the activities of NGOs, and identifies four ways that embrace a wide range of roles- *access to services, inclusion, participation and greater involvement6* (Horizons Project 2003). The Horizons study agreed on criteria of examining how the PLHIV was involved in the NGOs summarized in the table below.

Table 2: Categories of PLHIV involvement

Greater involvement: the most advanced stage of PLHIV involvement. PLHIV work in management and as significant policy and strategic organisational actors within the NGO and may represent it externally. PLHIV may also sit on the Management Board of the NGO (usually unpaid).

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6 See Horizons Project and International AIDS Alliance., (2003) Multi-Country Diagnostic Study report on The Involvement of PHA in Community-based prevention, care and support programs in Developing countries,,(pp 74-92)

Participation: PLHIV deliver HIV/AIDS-related services on a formal, regular basis, as employees or volunteers; may be involved in planning or consultation. PLHIV expertise is recognised and, generally, work is financially rewarded.

Inclusion: NGOs include PLHIV in non-HIV/AIDS activities or as occasional volunteers in HIV/AIDS service delivery. PLHIV involvement is not formally supported by structured training or wage remuneration but greater access to peer support and interaction with other PLHIV are important incentives.

Access to services: This level of involvement is defined as PLHIV taking part in NGO activities as beneficiaries of services. Access was the most common form of involvement observed among the 17 NGOs.

The Horizons Projects study notes that Meaningful involvement was associated with increasing levels of "vocality":

- No voice - most commonly as a service user
- Individual voice, based on one's own experience
- Collective voice, able to express the experience of other PLHIV
- Social voice - being able to advocate on behalf of all PLHIV.

The Horizons Project study also noted that higher levels of involvement were more common in rights-based organisations and/or self-help groups. These were NGOs which PLHIV had set up (with other affected people or health or social workers). Lower levels of involvement were more common in service delivery NGOs where specific professional qualifications or technical skills were required.

However, accessing certain services could provide an entry point to empower PLHIV and foster further involvement within the NGO through such activities as positive living and life skills courses, counselling and support groups7. However, this rarely led to greater

7 P77-80 Alliance (2003) multi-country study. The characteristics of the NGOs and their service users are listed on pages 61-67. Out of the 17 NGOs, only two Zambian

involvement unless there was a clear policy within the organisation to facilitate this.

There is a corollary between the Horizons Project study and the UNAIDS pyramid of involvement in that at lower levels of involvement PLHIV are mainly service users and greater involvement is achieved when PLHIV are involved in shaping policies and programs in the response. This includes designing and planning programs, managing organisations and acting as experts by playing an advocacy role. In this assessment meaningful PLHIV involvement is seen as empowering PLHIV to participate and to be able to influence HIV related policy, programming, design, implementation and monitoring and evaluation of the national response.

The terms "involvement" and "participation" are synonymous in social sciences. Participation means to sensitise people and thus to increase their receptivity and ability to respond to development programmes as well as encourage local initiatives (Umalele, 1979). It implies that people have the right and duty to participate actively in decisions concerned with identifying solutions to their problems and that they have greater responsibilities in assessing their needs, mobilising resources, and suggesting new solutions as well as creating and maintaining local organizations (Oakley and Marsden, 1986:19). Participation is a technique that is treasured because it is effective in bringing on board different stakeholders or participants (Nsibambi 1994:4). This study uses the term "involvement" rather than "participation" which is commonly used in social sciences because it was the term "involvement" that was used at the Paris AIDS Summit in 1994 where the Final Declaration of Greater Involvement of PLHIV was signed and it is also a globally accepted term used by UN agencies, AIDS activists and other development partners.

UNAIDS has outlined seven potential areas of involvement of PLHIV8. These areas are:

- **Personal**: Active involvement in own health and welfare

NGOs were listed as offering course in Positive Living (p63, p78)

8 UNAIDS, The Greater Involvement of People Living With HIV (GIPA) Policy Brief draft paper (November 2006)

e.g. self education about therapies, positive prevention9

- **Treatment roll-out and preparedness**: Support of treatments roll-out through educating other people living with HIV on treatment options
- **Policy making process:** Participation in the development of HIV-related policies at all levels
- **Programme development and implementation:** Provision of knowledge and skills and participation in the choice, design, implementation, monitoring and evaluation of projects
- ***Leadership and support, group networking and sharing:*** Leadership of HIV support groups, resource seeking, encouragement of participation of new members
- **Advocacy**: Work towards law reform and promotion of access to services
- ***Campaigns and public speaking:*** Involvement as spokespersons in campaigns or at public events.

GIPA is also recognized and outlined in the Code of Good Practice for NGOs Responding to HIV/AIDS (2004)10. The initiative a joint collaboration between NGOs, including HIV/AIDS organisations, and hosted by the International Federation of Red Cross and Red Crescent Societies put GIPA at the centre of the Code; organisations committed to the implementation of the Code and all its principles, including GIPA. Among other principles the NGO Code of Good Practice spells out how GIPA forms a prominent organisational principle and how it applies to individuals and collectively to PLHIV networks11.

9 Positive Prevention is the term used to describe the important role of PHA in prevention of HIV transmission. Prevention interventions have often been considered more appropriate for HIV-negative people, however the relevance and importance of positive prevention has increasingly been recognised.

10 NGO HIV/AIDS Code of Practice Project (2004) Renewing our voice: Code of good practice for NGOs responding to HIV/AIDS. The complete text and list of signatory organisations is available at www.ifrc.org/what/health/hivaids/code/.

11 NGO HIV/AIDS Code of Practice Project (2004) Renewing our voice: Code of good practice for NGOs responding to HIV/AIDS. (section 3.2 Involvement of PLHA and affected communities p41-42). The complete text and list of signatory organisations is available at www.ifrc.org/what/health/hivaids/code/.

The Code specifies as follows: *"We foster active and meaningful involvement of PLHIV and affected communities in our work. We need to:*

- Create an organisational environment that fosters non-discrimination and values the contribution of PLHIV and affected communities
- Recognise and foster involvement of the diverse range of PLHIV and affected communities
- Ensure involvement of PLHIV in a variety of roles at different levels within our organisations
- Define PLHIV roles and their associated responsibilities; assess what a particular role requires, and the capacity of individuals to fulfill the role; and provide the necessary organisational support, including financial
- Ensure practice and policies provide timely access to information to enable participation, preparation and input, before programmatic and policy decisions are made
- Ensure workplace policies and practices recognise the health and related needs of PLHIV and affected communities and create an enabling environment that supports their involvement
- Ensure when seeking PLHIV and affected community representatives, that PLHIV and affected community organisations and networks have strategies for accountability to their members
- Resource and support capacity-building within PLHIV and affected community organisations and networks and
- Fund and/or advocate for funding of PLHIV and affected community organisations to ensure they have the resources to build capacity and empower others within their own networks."

Barriers of GIPA

There are many barriers that prevent and deter meaningful involvement of PLHIV in the national response and universal access to prevention, care and treatment and social support in Uganda. The barriers are social, institutional and personal and they include:

- Individual egoism and selfishness among the individual PLHIV networks leaders which was contributing to the divisions and affecting the cohesion of the PLHIV constituency. Some networks such a NGEN+ do not subscribe to the concept of an umbrella forum that should champion the activities of the PLHIV constituency thus creating 'pseudo' competition that is unhealthy within the PLHIV organisations. Although the concept of the forum should not be used to stifle the dynamism of individual forums and networks, consensus on PLHIV issues needs to be reached and have GIPA demand driven.

- Some of the leaders in the PLHIV networks are not willing to resign their positions in the mother networks when they take on new responsibilities on the National Forum Board or the District PLHIV forums. This leads to conflicts of interest in decision making in national activities.

There is also a tendency for founder members of the networks wanting to hold onto positions of leadership and not allowing new members to take leadership positions. Mentoring and developing of other PLHIV is not well fostered in the PLHIV networks. This stifles dynamism and enthusiasm among the other PLHIV and the organization

- Difficulty of acknowledging HIV status publicly
- lack of organizations prepared to involve PLHIV
- Lack of skills and preparation for PLHIV
- Lack of proper conditions for HIV-positive people within organizations

Others include;

- Stigma and discrimination which is reinforced by conceptual frameworks that promote powerlessness or blame;
- Lack of perceived direct motivation for involvement especially for PLHIV professionals.
- Limited networking, conflict and competition among PLHIV networks
- Limited or inadequate capacity of PLHIV,

- Dysfunctional coordination mechanisms within the National PLHIV forum leading to limited linkages with grass roots and other communication barriers,
- Limited access to training,
- Poor remuneration and over emphasis on volunteerism,
- Unhealthy competition among service providers/PLHIV Networks/Individuals.
- Poverty and the challenges of post conflict situations especially in Northern Uganda, and
- Limited involvement of youth, men and professional PLHIV.

Recommendations for GIPA implementation

1. Facilitate the consultation and feedback mechanisms and process of district, regional and national PLHIV representatives.

2. Provide technical support to PLHIV forum and networks to streamline the governance, leadership and management structures and financial management systems. Support and scale up technical support to strengthen capacity of PLHIV networks and associations in areas such as policy analysis, research and development, resource mobilization and management, and AIDS Competence, PLHIV rights and responsibilities etc.

3. Support PLHIV networks and National PLHIV Forum to design concrete empowerment frameworks for the local level PLHIV forums and associations. These frameworks should promote hope, breakthrough and collective responsibility in the fight against HIV/AIDS. This will provide motivation for further involvement and propel GIPA in the national HIV/AIDS response.

4. Support interventions that promote involvement of PLHIV professionals such as development of a database and formation of professional PLHIV associations which should provided

skills and consultancy services to the National PLHIV forum and other PLHIV networks through a consultancy and training unit.

5. Support efforts to use the experience of PLHIV forums and networks in the implementation of GIPA through disseminating best practices for cross learning at national, district and community level. This should be done through think tanks, conferences, symposia, exchange visits and workshops to share experiences at national regional and international levels.

6. USAID, other donors, and organizations that implement HIV/AIDS activities should work together to develop operational guidelines on how to implement GIPA principles at both the organizational and project activity levels.

Strengthen the capacity of PLHIV and PLHA organizations

- Provide more support to national positive people's networks by identifying and nurturing more leaders, particularly women, who can be effective advocates and be part of planning, programs, and activities
- Encourage networking to have a united voice among PLHIV
- Provide capacity building of PLHIV in program management and sustainability
- Assess PLHA capabilities, provide appropriate training, and place PLHIV in appropriate positions after training
- Use a human rights-based approach to involving PLHIV
- Provide income-generating skills, link PLHIV to various financial schemes, and establish vocational centers for PLHIV
- Strengthen PLHA support associations
- Ensure GIPA in decision-making processes related to

programs directly affecting them

- Increase knowledge about HIV/AIDS and strengthen understanding of the need for GIPA
- Increase understanding about transmission and non-transmission, promotion of compassion both
- Among the PLHIV and communities
- Sensitize policymakers to GIPA, including understanding how they and their organizations can benefit from implementing it and showing successful stories of PLHA involvement; PLHIV at higher levels should be involved in these sensitization activities
- Encourage PLHA volunteers to participate in education programs and social marketing campaigns to enhance HIV prevention
- Ensure that PLHIV are not left vulnerable due to laws and policies
- Enforce existing laws and policies related to human rights and PLHIV
- Involve PLHIV in review and revision of unfriendly or tokenistic policies

NGO Strategies for Overcoming Challenges to GIPA

Improving skills of PLHIV

- Providing training to improve PLHIV' knowledge and skills; facilitate 'learning by doing'
- Linking PLHIV with capacity building and leadership training
- Working with support groups to help build skills in managing group activities
- Identifying talented members of PLHA networks and training them as second and third level leaders to take the place of leaders who become sick
- Building capacity of PLHIV to be research partners

Conducting advocacy and policy dialogue to generate support for GIPA

- Conducting a GIPA forum at the state level
- Using a workshop setting to sensitize program and policy managers to the needs of PLHIV and the benefits of involving PLHIV at all levels
- Conducting activities to reduce stigma and discrimination
- Addressing resistance through advocacy and gentle pressure
- Fostering advocacy by PLHIV to help create an enabling environment
- Working collaboratively with a range of government and NGO and international organizations to create a platform for GIPA-related activities
- Facilitating links between country and regional networks for PLHIV
- Working closely with relevant stakeholders in government and among nongovernmental and international organizations

Expanding PLHIV networks and fostering collaboration among the groups

- Increasing PLHA networks to encourage people to come forward with group support
- Focusing on creating more safe space for people to 'come out' about their status
- Nurturing the new generation of PLHA leaders
- Holding collective, sometimes informal, meetings of all groups to learn the meaning of solidarity and to learn about relevant topics, such as nutrition, etc.
- Collaborating with NGOs that work with PLHIV to provide job opportunities and capacity building training

Focusing on recruitment strategies

- Recruiting people who are willing to participate in the program

- Providing incentives to encourage PLHIV to participate
- Attempting to ensure participation of at-risk individuals or groups in the absence of known PLHIV

Addressing poor health

- Supporting links to ART and other health services
- Referring PLHA volunteers for health care provided at subsidized or no cost to offset small honoraria they receive

Fostering GIPA in project decision making

- Including PLHIV in decision-making bodies of the projects

Methodologies in improving GIPA initiatives

1. Documentation existing experiences and build on lessons learned
   - TASO/NACWOLA/NAFOPHANU Esxperiences
   - APN+ Experience
   - UNV Project in Malawi and Zambia
2. Create a more enabling and supportive environment Political, traditional and religious leaders have a major role to bring about these social changes. Parliamentarians can draw up antidiscrimination laws and national policies on AIDS and the workplace.
3. Understand the needs and worries of the private sector Business leaders must understand that AIDS among employees and the general public can affect productivity and profitability and therefore it is ideal for companies to plan for comprehensive prevention, care and support interventions.
4. Training and ongoing support for individuals
   Capacity building to promote the GIPA Initiative is much needed some of the skills needed among PLHIV are personal empowerment ; communication and presentation skills ; HIV/AIDS Knowledge; legal aspects of HIV/AIDS and skills for organizing and conducting policy dialogue.

CONCLUSION

The "State of GIPA" can be best summarized by the observation contained in the UN's 2002 report on progress toward implementation of the Declaration of Commitment on HIV/AIDS.

Organizations and networks of people living with HIV/AIDS are increasingly visible and influential at the global level and in many countries, but remain the world's most underutilized resource in the response.

In spite of all issues above, a clear methodology should be put in place to ensure that GIPA/MIPA is operationalized in Uganda and globally.

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