MIPA

MAINSTREAMING THE PRINCIPLE OF MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH OR AFFECTED BY HIV/AIDS (MIPA) INTO HIV/AIDS PROGRAMMING

1. BACKGROUND

Both the spread and impact of HIV/AIDS are influenced by social, cultural, economic and political factors. The epidemic is not just a 'health' problem. Rather, it has affected all facets of human livelihood. As such, responses need to be broadened to accommodate all sectors. In the first decade following the discovery of the epidemic globally, most responses were primarily designed, implemented and reviewed without the active involvement and inclusion of people infected or affected by HIV/AIDS. This exclusion has been driven by HIV and AIDS related stigma and discrimination, violation of human rights and erroneous beliefs that HIV and AIDS affected or infected persons cease being productive contributors to society.

1.1 The Buildup to GIPA/MIPA

The early approaches to HIV and AIDS viewed the problem as 'medical,' requiring response from 'experts.' At the same time, persons living with HIV/AIDS were seen as 'patients' and 'victims' who did not have anything valuable to contribute to the response. As HIV activists challenged this view, a set of principles was put forward towards a new standard of human rights and self-empowerment of people living with HIV/AIDS (PLWHA). The *Denver Principles* were born out of a national AIDS conference held in 1983 in Denver, Colorado, USA. It was at this conference the idea that personal experiences of HIV positive individuals could - and should - help shape a response to the epidemic that was first voiced.

However, in the following decade, the involvement of PLWHA was advocated almost entirely by themselves, with little formal response and support from governments. This changed in 1994 at the Paris AIDS Summit, where 42 national governments declared that the principle of *Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)* is critical to ethical and effective national responses to the epidemic.

The Paris AIDS Summit Declaration (1994) committed 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 organisations."

It also committed them to "Strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organisations" and added that "by ensuring their full involvement in our common response to the pandemic, at national, regional and global levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments."

In 2001, the United Nations Declaration of Commitment on HIV/AIDS proceeded to endorse the GIPA principle. Since GIPA's inception, UNAIDS has promoted the involvement of people living with HIV/AIDS on its Programme Coordinating Board. Likewise, other United Nations agencies have followed suit by mainstreaming GIPA principles into a variety of their structures.

1.2 From GIPA to MIPA

Regardless of these efforts by the United Nations, other key players have done little to integrate GIPA principles into regional and national responses. GIPA is primarily promoted by few individuals living with or affected by HIV/AIDS. This is often done by 'going public' about their serostatus or experiences with the epidemic in the hope of giving it a human face and voice, and directing the public's attitude towards the plight and needs of PLWHA. Prevailing gaps in the greater and meaningful involvement of PLWHA (MIPA) in HIV/AIDS related responses in the region have been recognised by SAfAIDS and, thus, prompted the development of this brochure.

Promoting the greater and meaningful involvement of people with HIV/AIDS in the decisions that affect their lives and the lives of their communities is, likewise, one of the goals of the Global Network of People Living with HIV/AIDS.

The Denver Principles (1983)

We recommend that all people:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalise about our lifestyles.

We recommend that people with AIDS:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.

2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organisations.

3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

4. Substitute low-risk sexual behaviours for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

People with AIDS have the right to…

1. Full and satisfying sexual and emotional lives, like anyone else.

2. Quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status or race.

3. Full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardising their treatment and to make informed decisions about their lives.

4. Privacy to confidentiality of medical records, to human respect and to choose who their significant others are.

5. LIVE and Die in dignity.

An important feature of the social and organizational response to the HIV epidemic has been that many people living with HIV/AIDS have demanded to have a say in the development of policies and the delivery of services. Today, it is internationally recognised that a crucial goal and hallmark of HIV/AIDS advocacy is the meaningful involvement of People Living with HIV/AIDS (PLWHA) in all aspects of programmatic and policy related responses. During the early phase of the HIV epidemic, PLWHA helped each other and drew support from friends, family and sympathetic community members. However, the medical, public health and research establishments took time to get acculturated to bringing PLWHA into decision-making and planning processes.

Experiences from around the world make it clear that no community or country can tackle the negative fall-out of HIV/AIDS without building on the strengths and the first hand knowledge of those living with the infection. In countries where PLWHA have taken the initiative to mount constructive responses, such as Brazil, Thailand and Uganda, there has been a slow-down in new infections and a more sensitive approach to care has emerged.

The strategic change from top-down to more participatory approaches not only meant the inclusion of PLWHA, but also youth, women and especially vulnerable populations in the design and implementation of responses to HIV/AIDS. Although this approach has still to become the norm in all efforts to contain the HIV epidemic and provide care and support to those infected and affected by HIV/AIDS, there has been a clear movement towards adopting it.

1.3   The Objectives of this Brochure
The purpose of this brochure is to:
- Increase understanding and appreciation of GIPA and meaningful involvement of PLWHA, and what necessitated development of these.
- Highlight the importance and relevance of MIPA to effectively respond to HIV and AIDS in all sectors.
- Share methods of ensuring that MIPA is mainstreamed into HIV and AIDS programming to bring about meaningful involvement of PLWHA.
- Explore successful mainstreaming of MIPA into regional HIV and AIDS related initiatives.

SAfAIDS has produced two other brochures addressing gender and human rights mainstreaming into HIV and AIDS programming. These earlier brochures add value to the purpose of this brochure, complementing the process of mainstreaming MIPA into HIV and AIDS programming. This information is targeted at various stakeholders responding to HIV and AIDS, including policy makers, AIDS service organisations, community based, non-governmental and faith-based organisations, national HIV and AIDS coordination structures, as well as people infected and affected by HIV/AIDS.

2.   WHAT IS MIPA?
MIPA essentially embodies two principles:
- Recognition of the important contributions people affected or infected by HIV/AIDS can make in the response to the epidemic.
- The creation of space within society and existing structures for the meaningful involvement and active participation of people infected or affected by HIV and AIDS in all aspects of HIV and AIDS related responses.

PLWHA can contribute to HIV and AIDS related responses in the community: at individual, organisational and national levels. Their involvement can be further harnessed in various facets of human livelihood, including socio-cultural, political and economic environments.

What does the term "People Living With or Affected by HIV/AIDS" (PLWHA) mean?
The original term, which only included HIV positive persons, has now been expanded to include all those persons who are affected by the epidemic, even when not HIV positive. It is important to note that PLWHA is not a single category of persons, but it is a continuum. This continuum runs from people living with symptoms of AIDS to HIV negative partners, family members and close friends of HIV positive persons.

3.   WHY IS MIPA IMPORTANT FOR EFFECTIVE HIV/AIDS PROGRAMING?
MIPA is imperative to the response to HIV and AIDS as it creates an impact at multiple levels, including:
A. Individual level
- MIPA has important benefits for PLWHA as individuals because their meaningful and productive involvement motivates them and enhances their self-esteem. This is especially effective where feelings of hopelessness and depression exist.

- PLWHA, like everyone, need to feel valued and must be offered opportunities to contribute to development in their environments. Yet many environments do not provide this support and, as a result, many PLWHA self-stigmatise, face human rights violations and struggle to live positively.

- MIPA gives them the platform and empowerment to offer sustainable and effective support, care and advocacy for their HIV positive relatives or friends.

B. Social Level
Through publicly acknowledging their meaningful involvement in HIV and AIDS related responses, people affected or infected by HIV/AIDS:
- Reduce stigma and discrimination around the epidemic, informing societies of the facts around the epidemic and enhancing public acceptance of PLWHA.
- Create recognition that being infected with HIV or affected by the epidemic does not mean inability to be productive members of society.
- Encourage other HIV positive people- or people affected by HIV/AIDS - to be proactive and meaningfully involved in responses through role modelling.
- Bring a sense of urgency to respond to the epidemic socially, culturally, economically and politically.

C. Organisational Level
- Organisations are made up of individuals, and those who are neither infected nor affected by the epidemic often carry preconceived misconceptions, reservations and fears related to HIV/AIDS and PLWHA. Therefore, MIPA presents a:
- Powerful tool for breaking down barriers - both subjective and objective - to effective HIV and AIDS related programming.
- Corrective tool in view of organisational perceptions and practices towards people affected or infected by HIV/AIDS, thus reducing stigma and discrimination related to working with PLWHA.
- Significant influence in directing organisational practice, policy and programming towards a PLWHA - friendly status, which draws upon PLWHA experiences.

In addition to reducing organisational bias and prejudice, providing a basis for partnership, mutual respect and understanding, MIPA reinforces organisational activity by:
- Exposing it to unique perspectives and experiences of people infected and affected by the epidemic.
- Reinforcing a level of general morale and team building among organisational programmers - who may be disillusioned that their designed responses are futile.
- Offering a boost of confidence to workers, reassuring them of the value of their contribution and giving them the benefit of their knowledge. This could include providing emotional and practical support to workers in their HIV and AIDS related activities, particularly geared efforts towards prevention.

- It gives HIV positive persons support and empowers them in ways that increase the value of their contribution to the organisations or activities.

MIPA has also important benefits for people affected by HIV and AIDS. Although those affected by HIV and AIDS may not be HIV positive themselves:
- They may be faced with HIV and AIDS related stigma and human rights violations because they are related to or close to an HIV positive person.

D. National, Regional and Global Levels
- These levels are accumulative of MIPA integration at social and organisational levels and can have important effects, including:
- Lobbying and advocacy for human rights and gender sensitive policy and law reform, which influence prevention, care, support, treatment and impact mitigation efforts of HIV and AIDS.
- Countering HIV and AIDS related stigma and discrimination, and creating politically, economically, culturally and socially conducive environments for people living with HIV to expand their roles and contributions to their communities.

4. CHALLENGES TO IMPLEMENTING MIPA
Whilst MIPA promises a notable number of benefits, it brings with it certain challenges, which have contributed to its delayed application in many southern African communities. These challenges have been noted at all levels of organisational structures and systems. Some of these challenges include:

- *Difficulty Acknowledging HIV Status Publicly*
  Due to prevailing HIV and AIDS related stigma and discrimination, many people may be reluctant to reveal their HIV status to their families, friends, work-mates or the general public. Where provisions towards protection of the human rights of PLWHA are lacking, the reluctance to get HIV tested and subsequently disclose a positive status has been known to increase. This inadequacy in social security for PLWHA is common in the majority of southern African communities and has created serious negative consequences regarding the livelihoods of PLWHA.

- *Inadequate Reflection in National Structures - Policy and Programmes*
  MIPA has been inadequately reflected in the majority of southern African national policies and programmes. Where reflected, MIPA remains either not concerted or small-scale in its application. There is an almost total absence of mechanisms which encourage and facilitate the meaningful involvement of PLWHA, either through sharing their experiences, perceptions or utilising their skills in policy making and programming processes. Coupled with this is the general absence of any regional or national campaigns that raise awareness and understanding around MIPA.

- *Absence of Conducive Environment*
  The social, cultural and political environment of most southern African countries are often characterised by high levels of HIV/AIDS related denial, fear and stigma. Speaking openly about sexuality or death, both strongly connected to the epidemic, are viewed as inappropriate in the majority of southern African communities. This is not conducive for meaningful involvement of PLWHA in national policy making and programming efforts.

- *Lack of Organisational Preparedness to Involve PLWHA*
  The majority of HIV and AIDS programme managers and staff lack the relevant skills, knowledge and empowerment necessary for MIPA implementation to have its optimal impact. Few organisations involve or collaborate with PLWHA in their day-to-day work; this may be due to active discrimination or unconscious prejudice. Lack of adequate information or awareness contributes to the failure of organisational management and staff to understand the potential benefits of involving PLWHA at all levels of their organisational activities.

- *Lack of Skills and Preparation for PLWHA*
  Often PLWHA are in difficult situations, both economically and socially, with few regional or national structures established towards enhancing their status and permitting them to contribute to policy, legal and programmatic changes.

Additionally, lack of skills can create obstacles to a meaningful involvement of PLWHA. Reasons include:
- Not all PLWHA are naturally capable of speaking out about sexuality and health issues, thus, these skills need to be learned.
- Facing a possibly hostile environment in the organisation or community can lead PLWHA to burn out.
- Hiring PLWHA should be based on their skills as well as their experience-based expertise; otherwise PLWHA may fail to meet the technical and skills needs of their job.

- *Lack of Proper Conditions for HIV Positive Persons Within Organisations*
  Organisations may not have satisfactory policies for the employment or involvement of PLWHA. Additionally, they may lack a suitable environment and the necessary facilities - including healthcare, medical insurance and psychosocial counselling for HIV positive persons.

- *Sustainability Queries*
  It has been recognised that HIV positive persons may fall sick with opportunistic infections, and some eventually die of AIDS related illnesses. This poses an obstacle, particularly in the private sector where employers feel threatened with loss of work hours and skilled manpower due to premature death.

5. HOW TO MAKE MIPA A REALITY: RESPONDING TO CHALLENGES
There are various ways through which MIPA can become a reality in HIV and AIDS related responses in the region. Some of these include:
- Developing HIV and AIDS workplace policies and programmes.
- Reducing stigma and discrimination and application of human rights at public, organisational and state levels.
- Advocating for political will and commitment, coupled with policy and legal reform from MIPA and human rights perspectives.
- Publishing and disseminating existing experiences and building on lessons learnt around the application of MIPA.
- Capacity building and empowerment efforts for PLWHA and related networks and groups towards their effective and meaningful involvement.
- Mainstreaming the principle of MIPA into state, sectoral and organisational programming.

6. MAINSTREAMING MIPA INTO HIV AND AIDS PROGRAMMING
Mainstreaming MIPA into HIV and AIDS programming involves:
- Including people affected by or infected with HIV/AIDS at each step of HIV/AIDS related responses.
- Creating a conducive, social, cultural, economic and political environments and simultaneous empowerment of PLWHA towards meaningful involvement in HIV/AIDS efforts.
- Taking steps to ensure that organisations are equipped with adequate funding, resources, knowledge and skills to facilitate and sustain meaningful involvement of PLWHA in day-to-day activities.
- Enabling the meaningful involvement of PLWHA in a wide range of roles and at all levels of HIV/AIDS responses.

6.1 IDENTIFYING HIV AND AIDS PROGRAMMING GAPS REQUIRING MIPA INTEGRATION

PLWHA Involvement Audit
This tool can be modified according to organisational mandates. However, in general, it should involve the collection of information on the extent and type of involvement of PLWHA in organisational activity and programming.

Involvement
- Time spent on activities.
- Regularity of activities.
- Remuneration: financial, material, technical or psychological.
- Skills used.
- Skills development provided by the organisation.
- Scope and autonomy.
- Level of visibility: internal and external to the organisation.

Identification of Methods Used for PLWHA Selection for Involvement
- Selected on the basis of their skills versus 'tokenism'.
- Members of support groups or PLWHA organisations in area.
- Of varied backgrounds: professional, racial, socio-economic, educational or other.
- Willing to adopt new skills.

- Communication, presentation, collaboration and management skills.
- Knowledge level of MIPA and appreciation of meaningful involvement of PLWHA.

Identification of Organisational Environment for PLWHA Involvement
- Availability and accessibility of health care and emotional support.
- Ability to cultivate new skills and knowledge for effective PLWHA involvement.
- Level of knowledge and understanding of MIPA and benefits of facilitating meaningful involvement of PLWHA in organisational activity, at all levels.
- Built in training, performance evaluation and skills/performance remuneration systems.
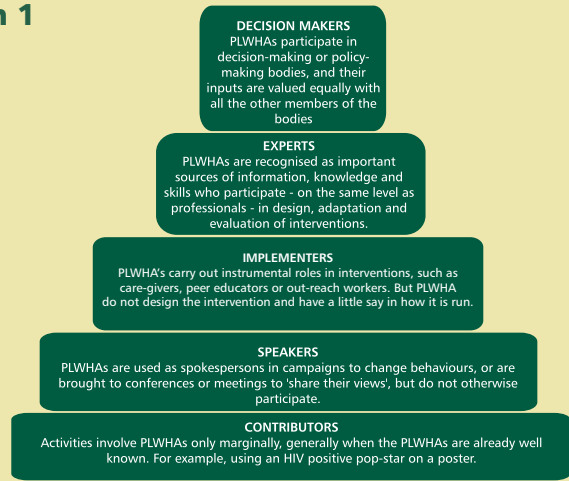- Positive environment established, including the ability to handle key issues, such as medical insurance, financial loans, education and others.
- Developed HIV/AIDS organisational policy and programme

6.2 STRATEGIES TOWARDS CLOSING IDENTIFIED GAPS IN MIPA INTEGRATION IN HIV AND AIDS PROGRAMMING

Strategies towards enhancing the meaningful involvement of PLWHA at all levels of organisational development should involve the following:

- **Sensitisation** of organisational management and staff on the benefits of involving PLWHA in their day-to-day activities, drawing on PLWHA unique and valuable experiences. Sensitisation of policy makers and governance to offer political commitment to organisational activities around relevance of MIPA to HIV and AIDS policy formulation and programme/project development. This can be accomplished through capacity building workshops and appropriate material dissemination advocating the benefits of involving PLWHA.

- **Ongoing research** that examines PLWHA involvement in the delivery of prevention, care, support, treatment and impact mitigation services and its effects on PLWHA and others affected by the epidemic.

- **Offer special orientation or job-specific training** necessary to compensate for lack of particular technical skills or knowledge. Communication, especially around sexuality and health, and personal empowerment counselling should be part of a generic training package for people participating in MIPA initiatives. Training must be reinforced by ongoing support for PLWHA if their effectiveness is to remain high and their motivation strong.

Diagram 1

DECISION MAKERS
PLWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of the bodies

EXPERTS
PLWHAs are recognised as important sources of information, knowledge and skills who participate - on the same level as professionals - in design, adaptation and evaluation of interventions.

IMPLEMENTERS
PLWHA's carry out instrumental roles in interventions, such as care-givers, peer educators or out-reach workers. But PLWHA do not design the intervention and have a little say in how it is run.

SPEAKERS
PLWHAs are used as spokespersons in campaigns to change behaviours, or are brought to conferences or meetings to 'share their views', but do not otherwise participate.

CONTRIBUTORS
Activities involve PLWHAs only marginally, generally when the PLWHAs are already well known. For example, using an HIV positive pop-star on a poster.

SOURCE - Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) - UNAIDS (1999)

The above pyramid depicts the increasing levels of involvement of PLWHA in organisational activity, advocated by MIPA, with the highest level representing complete application of the principle of MIPA. Ideally, MIPA should be mainstreamed at all levels of the organisation. This pyramid offers a model through which people living with or affected by HIV/AIDS can play a much wider range of roles.

- During hiring processes, employers should strike a balance between not being 'tokenistic' (hiring solely because of HIV positive status) and hiring upon recognition of the value of PLWHA' experience. Training must be reinforced by ongoing support for PLWHA if their effectiveness is to remain high and their motivation strong. During hiring processes, employers should strike a balance between not being 'tokenistic' (hiring solely because of HIV positive status) and hiring upon recognition of the value of PLWHA' experience.

- **Accessibility of the Declaration of the Paris AIDS Summit** and other similar international and regional treaties and instruments related to HIV/AIDS, human rights and the elimination of various types of stigma and discrimination, to leadership at state, sectoral and organisational levels.

- **Development and dissemination of training/support materials on MIPA** to assist policy makers and implementers to mainstream and promote MIPA in all their HIV/AIDS related responses.

- **HIV/AIDS related projects and programmes d**esigning, implementing, monitoring and evaluating from the perspective of MIPA.

- **Reduction of HIV and AIDS related stigma and discrimination** and human rights violations through various methods including:

  - Use of mass media, traditional and educational platforms.
  - Making HIV voluntary counselling and testing VCT), treatment and
  - STI services accessible and affordable.

- **Intensify documentation of MIPA mainstreaming efforts** made in the region and elsewhere. To enhance effectiveness, there is need to extensively disseminate products of this documentation to a wider population, especially through media and similar publicly accessed media. Elaborating on the concept and benefits of MIPA, while sharing concrete examples of how MIPA can be implemented, is a critical component of this process. Such information will not only increase knowledge around MIPA, but will also act as a significant tool to motivate people towards action, including people affected by HIV/AIDS, policy makers, opinion leaders and other stakeholders in the HIV/AIDS field.

7. BEST PRACTICES
Successes in Integrating the Principle of MIPA into HIV and AIDS Response
7.1 MIPA Workplace Model in South Africa
In 1997, UNAIDS, UNDP/UNV, the Department of Health and National Association of People Living with HIV/AIDS (NAPWA) in South Africa held initial meetings that led to the development of a pilot programme in 1998 - the GIPA Workplace Model. The aim of this model was to help different sectors to become involved in the partnership against AIDS and, in the process, to apply the GIPA principle. The objective of the GIPA Workplace Model was to select, train and place field workers (who are living openly with HIV) in partner organisations, in order to create or enrich workplace policies and programmes on HIV/AIDS.

The proposed outcomes of the model were to:
- Use the experiences of PLWHA to give a face to HIV and normalise HIV infection.
- Contribute towards a less stressed and more productive workforce.
- Create a supportive work environment for PLWHA within workforces.
- Contribute towards reducing health care costs.
- Utilise the special skills and expertise of the GIPA fieldworkers.

For PLWHA the Model provided the opportunity for 11 fieldworkers to become publicly involved in specific workplace response. These men and women, between the ages of 30- 45, and with varied life experiences and education levels, shared a willingness to speak about their HIV status. They took jobs as GIPA field workers in different environments, but their collective experiences have shown that PLWHA can add value to workplace HIV/AIDS programmes in a way that is relevant, effective, efficient, sustainable and ethical. Since 2000 many more GIPA field workers have been trained.

Involving people living with HIV in national AIDS response has proven extremely valuable. However, to accomplish this a range of needs must be recognised, including:

- Adequate support for HIV positive people (whose courage and commitment many programmes depend on) and their ongoing work as activists.
- Financial security to enable PLWHA access anti-retroviral drugs and other essential care to ensure their continued meaningful participation is not hindered.
- Consideration of the special needs of African HIV positive women who have faced enormous challenges as they took on the role of activism.
- Making organisational procedures more accessible to empower HIV positive women and young people, who have been traditionally excluded from decision-making processes, with the aim of making them participate meaningfully.

Strengthening and sustaining involvement of people living with HIV in a meaningful way requires:

- *That people know their HIV status* - this requires access to VCT facilities
- *Keeping people alive* with anti-retroviral treatment so they can remain active in their chosen field of work.
- *Creating the practical and political space for people living with HIV to expand their roles and contributions* by addressing HIV related stigma and discrimination, promoting appropriate legal and policy environments, and supporting participation with resources.
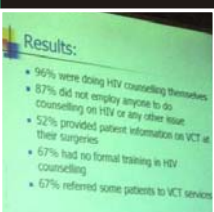
The following checklist can be useful in mainstreaming the principle of MIPA into various stages of HIV and AIDS related programmes and projects. It may be modified according to your organisational needs and focus.

Diagram 2

Checklist for Mainstreaming MIPA into HIV and AIDS Related Programme and Project Development

PHASE	QUESTION TO ADDRESS
BASELINE	✔ Will this benefit PLWHA? How empowering is the project/programme envisaged to be for PLWHA? ✔ Will it reduce stigma and discrimination and improve impact mitigation? ✔ Have PLWHA been consulted regarding relevance, need, urgency or feasibility of the project/programme? ✔ Have PLWHA personal experiences been drawn on in deciding whether to develop the project/programme? ✔ Can the initiative allow involvement of PLWHA? How? ✔ Have a pool of PLWHA been identified for involvement in the various stages of the project/programme? ✔ Are measures in place to ensure the PLWHA receive necessary training and support to be meaningfully involved in each phase, after the baseline? ✔ If any policies, legal frameworks or instruments are supporting this initiative, have PLWHA been involved in their development? Are PLWHA cognisant of these frameworks or instruments?
SITUATIONAL ANALYSIS	✔ What existing initiatives are in place? ✔ Do project/programme beneficiaries require MIPA sensitisation? ✔ Do the intended planners and implementers have sound knowledge and appreciation of MIPA and how to integrate it into the initiative? ✔ Has the organisation obtained the necessary facilities and environment for the integration of MIPA into the intended initiative? ✔ What potential obstacles are there to MIPA's integration into this initiative? ✔ What MIPA related lessons have been learnt from earlier similar projects/programmes? ✔ Are PLWHA and their networks consulted in this phase? Are PLWHA included in the data collection and analysis required for this Phase?
PLANNING	✔ Are PLWHA involved in development of project/programme aim, goals, objectives and benchmarks? ✔ Are the contributions and ideas of PLWHA recognised as equal to other members of the planning team? ✔ Are PLWHA part of the voting and decision-making processes? ✔ Have PLWHA been included in financial budgeting? Will they receive remuneration - legal, educational, financial, medical and psychosocial - for their efforts? ✔ Have donors and partner organisations been sensitised on the importance of MIPA? ✔ Do project implementers and stakeholders require MIPA training? Is this sensitisation available? ✔ To what extent are the planned activities adhering to the principle of MIPA? Are they inclusive of meaningful involvement of people living with or affected by HIV/AIDS? ✔ Will project/programme outcomes facilitate policy and legal reform in view of increasing meaningful involvement of people living with or affected by HIV/AIDS?
PILOTING AND IMPLEMENTING	✔ Is priority given to PLWHA in this phase? ✔ Have support structures been established to avoid burnout of PLWHA? ✔ Are PLWHA offered the platform necessary to make decisions in possible crisis situations? ✔ Do PLWHA have a voice in how, when and where the project/programme should be conducted? ✔ Are PLWHA trained and offered the skills to adopt management or directing positions during this phase?
MONITORING	✔ Have PLWHA been involved in development of monitoring tools and indicators? Are they trained in this? ✔ Are PLWHA involved in the monitoring process and decision-making?
EVALUATION	✔ Are the evaluation systems and tools MIPA - sensitive? Have PLWHA been involved in this process? ✔ Has the meaningful involvement of PLWHA increased organisational effectiveness through the project/programme? Has it added value to the project/programme?
DOCUMENT DISSEMINATION	✔ Have measures been taken to satisfactorily document and disseminate results, lessons learnt and the integration of MIPA in the project/programme? ✔ Are PLWHA involved in the dissemination process at all levels, including sharing feedback at government and regional/global levels, if necessary? ✔ Are PLWHA networks and organisations given feedback? Will they be involved in the process of modification of the project/programme if it continues? ✔ Will outcomes of the project/programme be used for lobbying and advocating for increased meaningful involvement of PLWHA?

Through their presence and commitment, the GIPA field workers have made companies and communities more aware of the intense need for HIV/AIDS policies, and encouraged open contact with those infected and affected by HIV/AIDS.

GIPA field workers have specifically:
- Provided role models to de-stigmatise the disease.
- Helped develop workplace HIV/AIDS policies and enriched existing policies.
- Communicated policies to employees.
- Helped implement a workplace programme by improving the effectiveness of peer education, providing informal phone-in/drop-in counselling services, providing formal pre- and post-test counselling, and extending the process to surrounding communities.
- As a result, important lessons have been learnt on how to best recruit, train and employ PLWHA in order to promote individual strengths and to protect their health.

These lessons highlight, among others, the need to:
- Select candidates according to their skills, and cultivate additional skills.
- Select candidates from within a partner organisation, or from support groups in the area, and from any background.
- Demand management collaboration.
- Build in performance appraisal and skill/performance based remuneration.
- Clarify job descriptions.
- Develop the GIPA message.
- Provide health care and emotional support, set up a positive environment and methods of redress.

Studies suggest that HIV/AIDS could reduce South African gross domestic product (GDP) growth rates by 0.3-0.4% per annum over the next 15 years. The heaviest costs will come from absenteeism, lost skills, training and recruitment costs, reduced work performance and lower productivity. The GIPA Workplace Model makes an impact on these issues and there is an obvious need for the model to be applied more widely. There is potential to build on its successes with refined recruitment, training and support mechanisms.

7.2 MIPA in the Religious Sector: The ANERELA+ Initiative

We need to bear in mind that the concepts surrounding MIPA have been developed for all sectors in our communities, and not only NGO and government-led organisations. Until MIPA is appreciated widely, HIV/AIDS related stigma and discrimination will continue to thrive. One such important area that requires to embrace MIPA, is the religious sector.

The African Network of Religious Leaders Living with or personally affected by HIV and AIDS (ANERELA+) was formed after a meeting held in Mukono, Uganda in November 2002. It was an event to mark the 10th anniversary of Canon Gideon Byamugisha living openly with HIV. Its membership includes religious leaders, ordained or lay, who are either HIV positive or personally affected by the disease. Having experienced stigma and discrimination first-hand, members seek to find ways of breaking stigma, silence, indifference and discrimination around HIV and AIDS.

Their comparative advantage is that they are religious leaders living with or personally affected by the epidemic, and that they believe by living openly with their HIV status, they can do much to overcome the negative connotations and taboos surrounding the disease.

They recognise their unique position of being able to lend support to others who find themselves in their position. They help others to accept their HIV positive status, also help them through the process of disclosure and open living. ANERELA's ultimate vision is to have an African region where religious leaders living positively and affected by HIV/AIDS are powered to live openly as witnesses to hope and be forces for change in their congregations and communities.

MIPA IN ACTION: UNAIDS APPLAUDS BOTSWANA'S LEADERSHIP IN THE FIGHT AGAINST AIDS, DECEMBER 2003

"Botswana's growing AIDS movement is the result of President Mogae's leadership and openness on AIDS coupled with the active involvement of people living with HIV," said **Dr. Peter Piot, UNAIDS Executive Director.**

7.3 Malawi and Zambia - NUNV Two-Year Pilot Project

Two countries - Malawi and Zambia - were selected to implement a two-year pilot project. The main purpose was to test the use of the National United Nations Volunteer (NUNV) modality as a possible mechanism for enhancing the greater involvement of individuals living with or affected by HIV and AIDS in the national response.

This pilot project was launched in 1997 and implemented with technical and financial support from UNAIDS and the UNDP Regional Project on HIV and Development for sub-Saharan Africa.

Long-term objectives of the project include:
- Ensuring that the knowledge and expertise of people infected and affected by the epidemic contribute to decision-making at all levels and in all relevant institutions, and that their needs and insights are reflected in policy and programme development.
- Strengthening the capacity of networks and organisations of those living with HIV and AIDS for strategic planning and programme management.
- Encouraging recognition of the potential role of volunteers in the national response to the HIV epidemic.

To achieve these objectives, the project adopted the following key strategic approaches:
- Placement of NUNVs in carefully selected local institutions - both public and private - that are involved in HIV and AIDS prevention, care and support activities.
- Capacity building for NUNVs to increase their knowledge and skills in areas such as policy analysis and development, project development and project/business management.

Example of NUNV Placement in Malawi: Chrissie Milembe

The impact of Chrissie's testimony could be seen in the reaction of her audiences. People were quite attentive as she would talk about her life, how she felt and the way people would react when they learned of her HIV positive status. "People used to tell me that I am a walking corpse, but let me ask you how would you feel if somebody told you that?"

Chrissie, a NUNV, was placed at the Lilongwe AIDS Counselling and Education Centre as a counsellor. She assisted in HIV/AIDS awareness outreach activities and provided support to HIV -positive clients. She also coordinated the activities of people living with HIV/AIDS in the centre.

It was not unusual to find a room completely silent following a testimony by Chrissie. This silence would only last a few minutes before there would be countless questions and a subsequent discussion. Chrissie would say, "You see, AIDS affected you and me, and it is you and me who should do something about it."

SOURCE - Enhancing the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) in sub-Saharan Africa, UNAIDS (2000)