

Initial GIPA Expansion Strategy Development Meeting

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Presentation by:
Victor Kamanga
Programmes Manager
MANET+ Secretariat

Overview

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Background of GIPA

- GIPA is an abbreviation for “Greater Involvement of People Living with or Affected by HIV/AIDS”
- HIV/AIDS activists advocated for the GIPA principle in 1994 at the Paris AIDS Summit for Heads of State where 42 governments called for increased support for PLWHA through their resolve of GIPA to be an appropriate, ethical and effective national response to the epidemic
- GIPA recognizes the important role PLWHA can contribute in fighting HIV/AIDS at all levels; in advocacy, policy formulation, programme planning, implementation, monitoring and evaluation
- GIPA creates opportunities for active involvement and participation of PLWHA in fighting HIV/AIDS as opposed to viewing PLWHA as recipients of charity or objects of pity, shame or blame
- GIPA recognizes PLWHA to be at the centre of the HIV/AIDS epidemic and affords the fight with a human face and voice of HIV/AIDS to the grim statistics
- GIPA is a strategy that helps to break the silence about the epidemic to ensure the prevention of HIV transmission and the impact of AIDS
- The 42 governments at the Paris AIDS Summit in 1994 agreed to support GIPA through an initiative to strengthen the capacity and coordination of networks of PLWHA and community-based organizations.

Why the GIPA principle?

- GIPA principle recognizes that PLWHA can provide important insights on how to address problems from experience
- GIPA principle recognizes that PLWHA are among the most powerful agents of change and ambassadors of hope
- GIPA principle recognizes that PLWHA have shown the world how to strive with “Positive Living with HIV and/or AIDS”
- GIPA principle shows how PLWHA can demonstrate how people can be empowered to cope with the trauma of the HIV/AIDS epidemic
- GIPA principle recognizes the need to ensure that PLWHA perceptions, experiences and capacities are ably expressed, valued, understood and acted upon.

GIPA – in the Malawi Context

- **Historical Overview of PLWHA Involvement**
 - o In 1993, a charismatic group of persons infected by HIV/AIDS formed NAPHAM and openly gave testimonies of their HIV positive sero status like pioneers Philly Lutaaya and TASO in Uganda, and Magic Johnson in the USA
 - o NAPHAM members had inspiration from a leading founder, Ms. Winnie Chikafumbwa, who had been encouraged by her participation at an overseas HIV/AIDS conference
 - o NAPHAM slowly won the recognition of both Malawi Government and the donor community
- **Piloting GIPA – Malawi & Zambia**
 - o In 1996, following a consultative process in 1995 to employ HIV-infected individuals in the insurance sector, a final outcome was a project document entitled “UNV project to support people living with HIV and AIDS” was approved with funding from the Special Voluntary Fund (SVF) and UNDP
 - o Two countries, Malawi and Zambia, were selected to implement a two-year pilot project to test the national United Nations Volunteer (NUNV) modality as a possible mechanism for enhancing GIPA in the national response
 - o The Project was launched in the 2nd quarter of 1997 with technical and financial support from UNAIDS and UNDP Regional Project on HIV and Development for sub-Saharan Africa which is based in Pretoria, South Africa.

GIPA – in the Malawi Context (continued ...)

- UNV pilot project to support people living with HIV and AIDS
 - o Long-term Objectives (through the involvement of people affected by the epidemic):
 - ✓ Deepen the understanding of the nature of the HIV epidemic
 - ✓ Strengthen the national capacity to respond effectively
 - o Specific Key Objectives:
 - ✓ Ensuring that the knowledge and experience of PLWHA 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 organizations of those living with HIV and AIDS for strategic planning and programme management
 - ✓ Encourage recognition of the potential role of volunteers and volunteerism in the national response to the HIV epidemic.

GIPA – in the Malawi Context (continued ...)

- Strategic Approaches

- o Placement of NUNVs in carefully selected local institutions, both public and private, that are involved in HIV and AIDS prevention, care and support activities, e.g. Kamuzu Central Hospital, MACRO, etc.
- o Capacity-building for NUNVs through training to increase their knowledge and skills base in areas such as policy analysis and development, project development, and project/business management
- o Capacity-building for representatives of the national network and of organizations or support groups of PLWHA through training to increase their knowledge and skills base in areas such as policy analysis and development, project development, and project/business management
- o Establishment of micro-grants facility to promote and support community-based initiatives that will arise from the work of the NUNVs, and to develop and strengthen organizations of PLWHA and their networks, e.g. IGAs of community gardens, acquisition of property (buildings), etc.

GIPA Implementation in Malawi

- Sustainability
 - o Ownership placed on Host Institutions (HIs), NAP+ and government
 - o Elaborate process of consultation at institutional level; a governance structure put in place at global and country levels (such mechanisms ensured participation of all key stakeholders in the development, implementation and monitoring of the project)
- Consultation Processes
 - o Phase 1 – Selecting Pilot Countries (with a mature epidemic and mature response – Malawi and Zambia satisfied the selection criteria and recruitment of CPC for the two countries; Confer CPC Job Description attached)
 - o Phase 2 – In the spirit of consultation, the launching of the pilot initiatives in the two countries involved planning workshops to ensure inclusiveness; reach consensus and common understanding on the aims and principles of the pilot project; identify mechanisms for project implementation, including selection and recruitment criteria of NUNVs, placements in HIs, training needs and methodologies, support and supervision; discuss aspects of M&E; and agree on an action plan and way forward lead by the UNV Project Manager with the assistance of a Project Advisory Group (PAG)

GIPA Implementation in Malawi (continued)

- o Phase 3 – Designing an M&E Framework (conducted through participatory approach between a mission and key stakeholders)
- o Phase 4 – Selecting candidates for NUNV posts and identifying future training needs (selection process used a Self-reflection and Selection workshop modality that created “safe spaces” for potential NUNVs and HIs to reflect upon their expected roles and responsibilities in the project to facilitate informed decisions about participation.) Confer attached Profile and Duties of NUNVs
- o Phase 5 – Capacity building (training of NUNVs, counterparts in HIs, and representatives of various support groups and networks of PLWHA. Needs identified included HIV and Development – a broader understanding of the epidemic; public speaking and media approaches; communication skills – including interpersonal and team work skills; peer counseling skills; writing skills – including reports, project proposals, record keeping; micro-project financing – including formation, monitoring and evaluation; and setting up and sustaining support groups
- o Phase 6 – Translation of the monitoring and evaluation framework into an operational tool for day-to-day management.

Achievements of GIPA

- What did the pilot GIPA project achieve?
 - o A number of persons living with HIV volunteered to participate in the project
 - o Ten HIs offered to participate in the project by hosting NUNVs to participate in the activities of the HIs and also bring a human face and voice of HIV/AIDS
 - o Stakeholders – government, networks, associations and support groups of PLWHA, HIs, the United Nations system – collaborated to conceptualize, promote, implement and monitor and evaluate the pilot project
 - o NUNVs participated in the formulation of the Malawi National Strategic Framework for HIV/AIDS for 2000 – 2004
 - o NUNVs helped to strengthen the Malawi Network of People Living with HIV/AIDS and helped establishment of new support groups of PLWHA
 - o NUNVs helped in mobilizing individuals, communities and organizations to recognize the need and value of voluntary counseling and testing for HIV
 - o NUNVs helped break the silence on HIV/AIDS by promoting dialogue, that resulted in increased understanding of the HIV/AIDS epidemic
 - o NUNVs helped individuals families and communities better understand HIV/AIDS, reduce misconceptions, stigma and discrimination
 - o NUNVs participated in advocating for the Human Rights and Freedoms of people living with and/or affected by HIV/AIDS
 - o The GIPA project has helped organizations to internalize HIV/AIDS and include it in their strategic plans.

Lessons Learnt

- What are the major lessons learnt?
 - o GIPA breaks down simplistic concepts of “service giver,” i.e. person who is HIV-negative, and “service recipient,” i.e. person who is HIV-positive.
 - o Publicly acknowledged involvement of persons living with HIV and AIDS helps reduce stigma and discrimination
 - o Publicly acknowledged involvement of persons living with HIV and AIDS helps to improve the recognition and acceptance of the important role PLWHA can play in fighting HIV/AIDS
 - o Stigma and discrimination against PLWHA, often subtle or hidden, is seldom recognized consciously by those who stigmatize and discriminate others
 - o Involvement of PLWHA is a powerful tool for breaking down barriers, changing mindsets or preconceptions, and correcting misinformation about PLWHA

Lessons Learnt (continued ...)

- o Involvement and participation with PLWHA helps people overcome their fears and biases
- o GIPA can reinforce an organization or activity by exposing it to the unique perspectives that the direct experiences of PLWHA can ably bring to light
- o Involvement of PLWHA, especially if it comes after a period of hopelessness and depression, can help build back a person's self-esteem and motivate them to continue carrying on with life
- o GIPA helped PLWHA (who are like everyone else) feel valued for what they can offer and who they are and not what they could be
- o GIPA has helped improve the welfare and self-esteem of people living with HIV/AIDS.

Challenges in implementing GIPA

- While GIPA is generally accepted by many countries, there are still very few successful initiatives underway partly because of the absence of demonstrated mechanisms for implementing the GIPA mandate
- From experiences of implementing pilot GIPA projects in Malawi and Zambia, restricting participation to those who are HIV sero positive eliminates critical parties who have experienced HIV and are committed to making a difference (e.g. the experience of a parent(s) who have provided care for their HIV-positive children could facilitate an understanding of how families cope with HIV/AIDS.)
- Recruited and selected persons living with HIV/AIDS sometimes decide to no longer be open about their HIV-positive sero status, which defeats the essence of giving HIV/AIDS a human face and voice
- Lack of adequate common understanding of the concept of GIPA by prospective NUNVs, government, networks and support groups of PLWHA, HIs, and other stakeholders, including donors and communities

Challenges in implementing GIPA (continued...)

- Lack of adequate resources in the HIs to accommodate a known HIV-positive individual
- Lack of preparedness and capacity by the HIs to come to terms with a person known to be HIV-positive
- Lack of basic knowledge and skills about facts of HIV/AIDS
- Stigma and discrimination against HIV/AIDS
- Lack of capacity at both individual and organizational levels to deal with denial related to HIV/AIDS
- Lack of awareness about the seriousness and consequences of the HIV/AIDS epidemic in the country by stakeholders
- Lack of clarity about the roles and responsibilities of project stakeholders

Challenges in implementing GIPA (continued...)

- The utilized selection criteria for NUNVs can prevent the selection of potentially good candidates from being recruited on the basis of, for example, their literacy level or their ability to communicate in the official language (e.g. English)
- The assumption that stakeholders should have a working knowledge of the broader developmental dimension of HIV is not valid and can lead to rejection of potentially good stakeholders (e.g. HIs) from participating in the project where establishing a shared understanding of HIV and development would reasonably suffice
- Failure to align the Job Descriptions of NUNVs with the major function of the volunteer as that of “giving a human face and voice to the HIV and AIDS epidemic.”
- There was no baseline survey conducted before the commencement of the pilot GIPA project against which to comprehensively measure progress of the stakeholders in the project

Challenges in implementing GIPA (continued...)

- Self-reflection and Selection workshop can be stressful to candidates as they reflect on what it would mean to talk publicly about their HIV-positive sero status
- Expectations that GIPA would bring about a sense of togetherness and support from PLWHA groups from where candidates originated to become NUNVs did not work out positively, as competition and resentment often arose
- There was inadequate ability from the project to access and utilize funding in the micro-grants facility
- Timely planning and conducting the HIV and Development workshop much earlier in the consultative process to provide in-depth understanding of the epidemic as foundation for subsequent stages of the process
- Provision of skills practice by NUNVs and supervision by managers to allow mastering of the knowledge and skills learnt

Challenges in implementing GIPA (continued...)

- Limited understanding that to “give a human face and voice to HIV and AIDS” is the overall aim of placing volunteers in HIs and that this can be demonstrated within the workplace, and through the services offered by the HIs to its target group(s)
- Tendency to viewing the NUNVs as merely just additional employees, but RATHER as employees that add value by virtue of their experiences of living with or being affected by HIV/AIDS
- The project’s inability to attract cadres of volunteers from super scale to better influence policy formulation, programme design, implementation, monitoring and evaluation
- Interpretation by NUNVs in the project that expecting them to share personal testimonies in the course of their work was a violation of their human rights (quite a delicate issue but the Self-reflection and Selection workshop was designed to help candidates make informed choices about whether or not to join the GIPA project)
- Lack of adequate assertiveness by the Networks of PLWHA to formulate mechanisms that would ensure NUNVs adherence to “be open” about their HIV-positive sero status.

Why Expand GIPA in Malawi?

- GIPA project recorded successes that would benefit more people living with and affected by HIV and AIDS
- Lessons from the pilot GIPA implementation will help in enhanced delivery of the project outputs to benefit not only more people living with and affected by HIV and AIDS but the country as a whole
- GIPA can enhance the prevention of HIV transmission efforts and the mitigation of the various impacts of AIDS through individual, family, community/organization mobilization
- GIPA employed the NUNV placement modality and tested its feasibility and effective in spite of the identified gaps and challenges
- There is growing willingness in stakeholders to try to explore modalities beyond the NUNV modality at an expanded scale mindful of further improving the quality of services and the desired quantity

Establishing Clarification of Key Concepts

- What does the concept PLWHA mean and encompass?
- What does the concept PLWHA involvement mean and entail?
- What does “giving HIV a human face and voice” mean?
- What do we understand “coming out in the open” to mean?
- What does the statement “individuals living with and affected by HIV/AIDS” connote in GIPA?
- What modality of GIPA expansion would Malawi consider?
- How would we interpret the right to privacy with respect to Human Rights of individuals that have joined in a fully informed manner the GIPA project?
- What would management do if contracted NUNVs should choose not to “give HIV a human face and voice” while in the GIPA project?
- What would the project do if a HIs viewed NUNVs merely just as additional employees to their organization?
- Do HIs seriously consider possibilities of absorbing NUNVs beyond the GIPA contribution in meeting the core costs of the NUNVs?

HIV/AIDS Landscape in Malawi

- HIV/AIDS is high on the political agenda, as exemplified by the leadership – Head of State, members of parliament, government, non-governmental organizations (NGOs) and private sector
- HIV/AIDS has been recognized as a socioeconomic crisis that is reversing the country's earned past development strides
- Malawi has formulated policies, strategies and programmes to prevent HIV transmission and mitigate the impact of AIDS
- Malawi has mobilized and solicited for technical and financial support from within and outside the country to build capacity to fight the HIV/AIDS epidemic, e.g. from GFATM, etc.
- Malawi is implementing its programmes in no “business as usual” manner as previously described in the World Bank report of 1996
- The health infrastructure is overwhelmed by the demands caused by the HIV/AIDS epidemic.

Strategizing for the Future

- What strategies can stakeholders formulate to bring about the expansion of GIPA beyond the national UNV modality?
- What other forms of GIPA modality would we examine to gain further insights?
- What can the stakeholder do to... etc. etc.?

Appreciation

- MANET+ strongly believes GIPA expansion is feasible and cordially invites your support and involvement
- Distinguished ladies and gentlemen, on behalf of MANET+ and, indeed, on my own behalf, I wish to thank you for your active attention and participation
- Thank you all!