Enhancing the Greater Involvement of People Living with or affected by HIV/AIDS (GIPA) in sub-Saharan Africa

A UN response: how far have we gone?

Joint United Nations Programme on HIV/AIDS

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Table of Contents

Historical context

By June 2000, the number of people living with HIV worldwide had grown to 34.3 million, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO). Of this total, over two-thirds resided in sub-Saharan Africa—a region with only a tenth of the world's population. Nearly 14 million adults and children have already died of AIDS since the beginning of the epidemic in the late 1970s. Moreover, during 1998, it is estimated that 11 individuals around the world became infected every minute.

The worldwide response of individuals and communities to the epidemic has been encouraging. With courage and compassion, they have mobilized resources to care for and support those affected and to assist others in remaining uninfected. Particularly striking has been the role of people living with HIV and AIDS (PWHA) who, within a short period of time, have given a human face to the grim statistics. (See Box 1 for definitions of terms used in the pilot projects.)

Although only a small percentage of persons living with or affected by HIV/AIDS have come out in the open, declaring their serostatus or the fact that they have been personally affected, those who have done so have been powerful catalysts in the subcontinent. The musician Philly Lutaaya is a good example of an individual who has made an impact and his message of behavioural change and hope reverberates across the continent in his song, Alone and Frightened. At the regional level, the voice of PWHA has been heard during the International Conferences on AIDS and STD in Africa (ICASA), held in 1995 in Kampala, and in 1997 in Abidjan. PWHA can provide important insights into how to address problems, how to strive for positive living and how people can be empowered through the trauma and tragedy of the epidemic.

However, in many sub-Saharan African countries, an environment characterized by high levels of denial, fear, and stigmatization has undermined the involvement of those living with or affected by HIV and AIDS. Even when the political, legal and social environments are conducive, the participation of those living with or affected by HIV and AIDS is seldom reflected in the formulation of national policies and programmes. Although the reasons for this vary from country to country, a certain pattern emerges. First, there is an absence of appropriate mechanisms to ensure that the experiences, perceptions and capacities of those living with or affected by HIV and AIDS are expressed, valued, understood and taken into consideration in the development of policies and programmes. Second, even when an appropriate forum is provided, individuals living with or affected by HIV and AIDS often lack the skills required to engage institutions and governments in policy dialogue. Third, many individuals living with or affected by HIV and AIDS are not in gainful employment, and are therefore too economically weak to engage in any serious discourse. Fourth, even when they are employed, the kinds of institutions they work for are unlikely to generate and initiate policy changes.

These issues were reflected in one of the major outcomes of the Paris AIDS Summit for Heads of State, held on 1 December 1994, where governments

from over 50 countries called for increased support for PWHA. Participants resolved that the principle of greater involvement of people living with HIV and AIDS (GIPA) was critical to an appropriate, ethical and effective national response to the epidemic. They agreed to: "Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations."

Box 1: Definitions and concepts as derived from the pilot projects

Individuals living with and affected by HIV/AIDS

The experience of implementing pilot projects in two countries—Zambia and Malawi—suggests that restricting participation to those who are seropositive eliminates critical parties who have experienced HIV and are committed to making a difference. For example, the experience of the many HIV-negative parents who have provided care to their HIV-positive children could facilitate an understanding of how households cope. The experience of the increasing number of discordant couples presents a unique opportunity for people to see that HIV affects ordinary people and, therefore, to encourage the acceptance of the problem within communities. During the recruitment process in Zambia and Malawi, it was also noted that there are many people outside the current networks of people living with HIV/AIDS who are prepared to use their experience without revealing their serostatus. Based on the understanding derived from such examples, an 'individual living with and affected by HIV/AIDS' can be defined as any person who is either HIV+ or has direct personal experience with HIV/AIDS and is committed to sharing their experience with others, to ensure an appropriate national response. An appropriate national response is one that includes policies, strategies and interventions that respect the rights and dignity of persons living with or affected by HIV/AIDS.

Giving HIV a 'human face'

In the mid-1980s, as developing countries engaged in aggressive economic austerity measures, UNICEF raised concern that these economic measures were hurting people in several ways. In their recommendations to the World Bank and International Monetary Fund, they spoke of structural adjustment with a human face. In this context, the human face was meant to reflect the fact that, at the end of the day, these policies must *improve* rather than hinder the welfare of the people. This led to the emergence within the international

community of various projects intended to ameliorate the effects of the austere programmes. In the context of HIV, the issue of 'human face' goes beyond welfare to include the experience of those affected—their joys, sorrows, sense of identity and their need to be accepted as part of the community. Giving HIV a human face therefore includes the individuals affected showing the rest of the world that, beyond the grim statistics, are humans—mothers, sons, daughters, nieces, nephews, grandmothers and grandfathers who aspire to living a full life.

Although the GIPA mandate has been generally accepted by all countries, there are still very few successful initiatives under way. Part of the reason for this has been the absence of demonstrated mechanisms for implementing the GIPA mandate. In an effort to address this gap, a collaboration was established among United Nations Volunteers Programme (UNV), United Nations Development Programme (UNDP), The Network of African people living with HIV/AIDS (NAP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to pilot a GIPA initiative in selected African countries.

Why the initiative?

The initiative was deemed necessary for the following reasons: first, to provide the required social setting for dialogue on issues related to HIV/AIDS with those who are affected; second, to allow for the expansion of the national response by involving individuals whose representation has, until now, not been fully recognized (such as parents who are HIV-negative but have nursed an adult child who is HIV-positive, or families wherein one of the partners is HIV-negative); third, to give a human face and voice to the current statistics of HIV/AIDS; fourth, to facilitate the acceptance of the presence of HIV/AIDS in the community; and fifth, to improve the economic status of those living with and affected by HIV/AIDS.

Using a participatory approach to design the project, a consultative process was initiated early in 1995 and preparatory studies were carried out to examine the impact of employing HIV-infected individuals in the insurance sector. The final outcome of this process was a project document entitled, "UNV project to support people living with HIV and AIDS". The project was approved in September 1996 with funding from the Special Voluntary Fund (SVF) and UNDP. Two countries—Malawi and Zambia—were selected to implement a two-year pilot project whose 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. The project was launched during the second quarter of 1997 and it is being implemented with technical and financial support from UNAIDS and the UNDP Regional Project on HIV and Development for sub-Saharan Africa, which is based in Pretoria, South-Africa.

The UNV pilot project to support people living with HIV and AIDS

Objectives

The long-term objectives of the project are to deepen understanding of the nature of the HIV epidemic and to strengthen the national capacity to respond effectively, through the involvement of people affected by the epidemic. Specific key objectives 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 organizations of those living with HIV and AIDS for strategic planning and programme management;

- encouraging recognition of the potential role of volunteers and volunteerism in the national response to the HIV epidemic.

Strategic approaches

To achieve these objectives, the project is adopting the following key strategic approaches:

a) Placement of NUNVs in carefully selected local institutions—both public and private—that are involved in HIV and AIDS prevention, care and support activities (see Box 2 for examples).

Box 2: Examples of NUNV placement in Malawi

Heatherwich CHISENDERA

Three times a week, Heterwich shares his experience of living with HIV/AIDS with patients and their escorts at the outpatient waiting room of the 1000-bed Lilongwe Central hospital. He is one of the volunteers placed at the hospital as a counsellor. His primary role is to add value to the HIV/AIDS efforts, activities and programmes of this hospital by giving a human face and a voice to HIV/AIDS for the staff, inpatients, outpatients and caregivers. He normally concludes the sharing of his testimony by saying, "If you have any questions you need to ask, or some issues you want to discuss with me, please come to the counselling room any time." Since his placement, there has been a steady increase in the number of people seeking help and support. The number of clients counselled and tested increased from 36 per month in March 1998, to 87 per month in October 1998. Because of the increasing number of people seeking support, the hospital has now designated every Tuesday as HIV/AIDS clinic day.

Chrissie MILEMBE (RIP)

The impact of Chrissie's testimony can be seen in the reaction of her audience. People were quite attentive as she talked about her life, how she felt and the way people reacted when they learned of her HIV 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 National United Nations Volunteer, had been placed at the Lilongwe AIDS Counselling and Education Centre as a counsellor. She assisted in HIV/AIDS awareness outreach activities and provision of 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 the room completely

silent following Chrissie's testimony. This silence lasted a few minutes and then there would be countless questions and consequent discussion. Chrissie would say, "You see, AIDS affects you and me, and it's you and me who should do something about it."

b) 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.

c) Capacity-building for representatives of the national network and of organizations or support groups of PWHA through training to increase their knowledge and skills base in areas such as policy analysis and development, project development, and project/business management.

d) Establishment of a 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 PWHA and their networks (see Box 3 for an example).

Box 3: Facilitating the establishment of income-generating activities in Zambia

Martin CHISULO

As a NUNV placed with the Copperbelt Health Education Project (CHEP), Martin has facilitated the establishment of support groups and is helping those that were already in existence but were not progressing well. He is a member of one of the groups. Through him, this group acquired a building that has been renovated with support from the Catholic Church, and a plot of land where members are growing vegetables for their own consumption and for income generation.

Implementation, monitoring and evaluation processes

To ensure long-term sustainability, emphasis is being placed on ownership by host institutions, the Network of African People Living with HIV and AIDS (NAP+) and government. A key feature of the project is the elaborate process of consultation at every major step of its design, implementation and monitoring. To reflect the consultative process at an institutional level, a governance structure at global and country level has been put in place. These mechanisms are required to ensure the participation of all key stakeholders in the development, implementation and monitoring of the project. The processes defined below highlight how the consultation has taken place on the ground.

Phase 1 – Selecting pilot countries

It was considered important to test the feasibility of using the UNV mechanism to promote GIPA in countries with a mature epidemic and relatively mature response. A preliminary review of documents and discussions resulted in a shortlist of four countries, agreed upon during a joint UNAIDS/UNDP/UNV meeting, which took place in Geneva, 24-25 October 1996. Thereafter, an assessment mission supported by UNAIDS was carried out in the four short-listed countries (26 October-30 November 1996). A combination of key informant interviews and group discussions with potential stakeholders was the *modus operandi* for the assessment mission. Although there was variation between countries, in general the following potential stakeholders were consulted: national support groups and networks of PWHA; National AIDS Control Programmes; AIDS service organizations; nongovernmental organizations (NGOs); UN Theme Groups on HIV and AIDS; and donors. Each of these groups was given the opportunity to participate in the initiative. Two English-speaking countries were selected, based on pre-set criteria. Using the pre-set criteria, the meeting held in Geneva, 5-6 December 1998, agreed that the piloting would be carried out in Malawi and Zambia. With the country selection process completed, two Country Project Coordinators (CPC) were recruited and placed in Lilongwe and Lusaka (see Box 4 for the job description).

Box 4: Job description for Country Project Coordinators

- To manage the day-to-day operation of the project in the country of assignment.
- To assist in the negotiations, selection and placement of the NUNVs in institutions/organizations.
- To support training of the national UNVs (NUNVs)—both formal and on the job—and provision of other forms of support for skills development.
- To work closely with and coordinate all necessary activities among the responsible national bodies/mechanisms, UNDP, UNV, nongovernmental organzations (NGOs), community-based organizations (CBOs), and NAP+.
- To ensure the access of NUNVs to appropriate peer support, counselling and supportive services.
- To provide appropriate guidance and support to the UNVs.
- To assist in developing policies and strategies relating to disclosure, confidentiality, and public profile of the NUNVs.

- To appraise the performance of the NUNVs and provide feedback and of the NUNVs and performance appraisal of the NAP+.
- To administer the small grants component of the project.
- To carry out on-going assessment and refinement of the pilot project and drawing-up/sharing of lessons.
- To work closely with all parties involved in the project formulation, implementation, monitoring and evaluation.

Phase 2 – Launching the project in the two selected countries

In the spirit of consultation, the launching of the pilot initiatives in the two countries involved planning workshops (see Box 5 for the aims and objectives of the workshops).

Box 5: Aims and objectives of the consultative and planning workshops

The workshops were intended to provide an appropriate launch for the project by bringing together a large number of stakeholders in each country, thereby making the process as inclusive as possible. The specific objectives of the workshops were as follows:

(a) to reach consensus and common understanding on the aims and principles of the pilot project;

(b) to identify mechanisms for project implementation, including selection and recruitment criteria of the national UNVs, their placements within institutions such as CBOs, NGOs, and ministries, training needs and methodologies, and support and supervision;

(c) to discuss aspects of project monitoring and evaluation;

(d) to agree on an action plan for the way forward.

The Malawi workshop was held in Lilongwe, 27-29 May 1997, and the Zambia one in Lusaka, 2-4 June 1997. Participants included representatives from support groups and national networks of PWHA, AIDS service organizations, NGOs, NGO umbrella organizations, government ministries and cosponsors of UNAIDS, as well as resource persons from such organizations as the Faces Project from South Africa, the Philly Lutaaya Initiative from Uganda and NAP+. The

results of both workshops were similar. A consensus was reached on the purpose and basic principles of the pilot project and on the selection criteria for NUNVs. Mechanisms were identified for implementation, including placement within host institutions and supervision methods. Training needs were also identified, along with potential resources for training in and outside the country. Finally, participants at each workshop came up with a three-month action plan to be carried out by the UNV Project Manager, with the assistance of a Project Advisory Group (PAG).

Phase 3 – Designing a monitoring and evaluation framework

The uniqueness of the design of this pilot initiative was the participatory development of a monitoring and evaluation framework. A technical mission visited both countries and worked with the project's main stakeholders to develop three major elements of the initiative: i) a monitoring and evaluation framework; ii) a process that will enable those involved to identify and meet the training and support needs of the Project; and iii) a decision-making process for the use and monitoring of the project's micro-grants facility.

Using the process facilitation approach as outlined in the UNDP manual, the facilitators worked with key players to achieve the following outcomes:

i) a Monitoring and Evaluation Framework for each country;

ii) Guidelines for the Management and Operations of the Micro-Grants Facility;

iii) a document on Training and Support Strategies, including checklists for follow-up activities.

Phase 4 – Selecting candidates for NUNV posts and identifying future training needs

To facilitate the selection of NUNVS, a joint UNAIDS/UNDP mission was carried out in Malawi, 25–31 January 1998, and in Zambia, 31 January–8 February 1998. This mission was a follow-up to a meeting of the International Technical Advisory Group (ITAG) held in Abidjan, Côte d'Ivoire, 11 December 1997. The terms of reference for the mission are detailed in Box 6. The selection process used a workshop modality to provide 'safe spaces' for potential NUNVs and host institutions to reflect upon their expected roles and responsibilities within the project, to better facilitate their informed decisions about their participation in the project and to define an objective framework for selection of the first group of volunteers to be recruited by the project. Specific objectives of the workshops were for the participants to: i) share their understanding of the project mission and proposed strategy, as well as their roles and responsibilities; ii) express their vision, hopes and fears regarding their roles and the concept of volunteerism; iii) clarify myths and misinformation about the project; iv) discuss and reflect upon the implications of being open about their serostatus (on self, family and community); and v) understand the minimum criteria for selection of the first group of volunteers and define areas where the other candidates could contribute to the project.

Box 6: profile and duties of the NUNVs

Although their job titles vary, their primary function at these institutions is to give HIV/AIDS a human face and voice by sharing their experience of Living with HIV/AIDS, providing peer education or counselling and where possible by initiating discussion/support groups for PLWA. It is expected that the activities of the NUNVs would encourage the development/ enhancement of HIV/AIDS activities, programmes and policies. The volunteers' activities have been categorised into four areas:

i) Sharing of experience with various staff and management within the host institution;

ii) Individual discussions/counselling within the host institutions. These are the one-to-one sessions which Volunteers have at the work place with staff;

iii) Out-reach activities: This refers to Sharing experiences qand performing HIV/AIDS awareness activities outside the host institutions e.g residential quarters, churches and at community events.

iv) Other activities. These activities are not related to sharing experience but are carried out by the NUNVs as in the case of Volunteers with additional responsibilities.

In both countries, the main outcomes were: i) a greater understanding of the project's vision, mission, and proposed strategies, of the roles and responsibilities of each partner, of the concept of 'coming out in the open', and of the selection criteria for NUNVs; ii) a strengthened commitment to the objectives of the project; and iii) the completion of the selection process for NUNVS and host institutions. (See Box 7 for an example of the experience of a host institution with the placement of an NUNV.)

Phase 5 – Capacity building

The fifth phase of the project's implementation involved training for the NUNVs, their counterparts in host institutions and representatives of various support groups and networks of PWHA. Following the Self-reflection and Selection Workshops, the following training needs were identified: a) HIV and development (broader understanding of the epidemic); b) public speaking and media approaches; c) communication skills (including interpersonal skills and team work); d) peer counselling skills; e) writing skills (including reports, project proposals, record keeping); f) micro-project financing (including formulation, monitoring and evaluation); and g) setting up and sustaining support groups.

Box 7: Experience of a host institution with the placement of an NUNV

The Copperbelt Health Education Project (CHEP)

CHEP is an NGO that is involved in the provision of Information, Education and Communication (IEC). Its target audience is the general public and, in particular, the vulnerable groups within society. It provides training to improve services, create a supportive environment, improve counselling services for PWHA and promote appropriate low-risk sexual behaviour.

Before its involvement with the GIPA pilot project, CHEP had both positive and negative experiences while working with PWHA, and the decision to have a PWHA working as an NUNV was informed by these experiences. The first thing CHEP management did was to appoint the new NUNV as Coordinator of PALS programmes, in order to give him greater responsibility and to broaden its own perception of the involvement of PWHA in HIV/AIDS activities.

CHEP was responsible for providing orientation for the NUNV in its ten districts to help him familiarize himself with the province and to understand the problems facing those living with HIV/AIDS. CHEP has helped the NUNV to form five support groups, which have regular meetings, and to participate in Radio Ichengelo—a community station and television. CHEP has also funded three workshops in which the NUNV has been a resource person. Finally, as an organization, CHEP has taken its own initiative to give four support groups an amount of K250,000 (Zambian kwacha) to boost income-generating activities.

In spite of this, CHEP continues to face some challenges in promoting the greater involvement of PWHA in the fight against HIV/AIDS. These are: (a) the failure to provide adequate medical assistance for support group members; and (b) the increasing number of deaths among support group members, which has a negative effect on other members and on the project (e.g. greater contributions expected from the project in terms of funeral arrangements).

In response to this, successful HIV and Development Workshops and a Skills Training Workshop have been held (Zambia, in April and October 1998; Malawi, in September 1998). The Skills Training Workshop included sessions on the basic facts about HIV and AIDS, peer counselling, basic nursing care, nutritional care, advocacy for ethics and human rights, communication skills, group formation, report writing and record keeping, project proposal writing and stress management.

Phase 6 – Translation of the monitoring and evaluation framework into an operational tool for day-to-day management

The framework for monitoring and evaluation which was developed requires further operationalization. Terms of reference have since been developed, especially for the special studies, and both countries are at the stage of implementing the evaluation framework.

Lessons learnt

In order to inculcate a systematic process of learning at global and country level, a joint UNAIDS/UNDP/UNV meeting was held in Bonn, 6-7 April 1998, to go over the experiences gained during the 18 months of the pilot initiative design and implementation.

On the selection of countries

The following were the key lessons that emerged in Phase 1 of the implementation of the pilot initiative in Zambia and Malawi:

(a) Consensus-building around key concepts and operational modalities is critical to the success of the initiative.

(b) It is necessary to establish a shared understanding of HIV and development. The assumption that stakeholders have a working knowledge of the broader developmental dimension of HIV is not valid. During the consultative and planning workshops, some of the stakeholders were not even convinced of the seriousness of the HIV epidemic in their countries. In future, consultative and planning workshops should aim to give all the project's stakeholders the opportunity to reach a shared understanding of the HIV epidemic and its consequences. This would facilitate discussions on selection criteria for the recruitment of NUNVs, and on the roles and responsibilities of host institutions and NUNVs. The use of tools such as the HIV and development workshop before the consultative and planning process would address this problem.

(c) The facilitators should challenge selection criteria proposed during these workshops which may prevent potentially good candidates from being recruited as NUNVs on the basis of, for example, their literacy level or their ability to communicate in the official language (e.g. English). In one country, such criteria have prevented good candidates (especially women) from being selected.

On developing a monitoring and evaluation framework

The monitoring and evaluation frameworks for both countries were derived directly from the project document and are therefore a good reflection of the project's goals and objectives. As indicated above, they were developed with the participation of many stakeholders, but before the selection and placement of the NUNVs. However, the job descriptions of the NUNVs seldom reflect the monitoring and evaluation framework. Moreover, in one country, none of the job descriptions outlined the major function of the volunteer as that of "giving a human face and voice to the HIV and AIDS epidemic."

In addition, the effective use of the monitoring and evaluation framework has been hampered by the fact that in neither country was a baseline assessment conducted at the start of the project. Finally, the framework for each country does not include simple monitoring targets, indicators and tools, which now need to be developed.

On the selection of candidates

The Self-reflection and Selection Workshop, whose main objective was to give an opportunity to candidates to reflect on what it means to talk publicly about their HIV status and their personal experience, was quite stressful for participants. Nonetheless, it was felt that this process was necessary, since future NUNVs would be required to be fully 'open' about their own HIV status, or about how they and their family have been affected by HIV and AIDS.

There had also been an assumption that there would be a strong feeling of 'togetherness' among the members of a particular support group. It was expected that the group would take pride in, and support, the recruitment of one or two of its members and that the NUNVs would be regarded as ambassadors of the group in whatever role they were placed. However, this did not prove to be the case and the problem of competition arose several times.

Methods should be found to minimize the stress induced by the exercise. Possible methods include shortening the selection process, and emphasizing the fact that the recruitment of ten (or more) NUNVs is only one aspect of the strategy/activities implemented by the project in the country. For those not selected during the first round, the project will provide the following opportunities: i) access to a micro-grants facility (for capacity building, income generating or networking activities initiated by their support group); ii) participation in 'generic' training workshops; and iii) the possibility of being recruited during the second (or third) year.

On the micro-grants facility

The micro-grants facility was established in order to help achieve the project's objectives. In accordance with these objectives, funding made available under the micro-grants facility can be accessed for the purpose of: a) promoting and supporting community-based initiatives that have arisen from the work of the

NUNVs; or b) developing and strengthening PWHA organizations and their networks. Eligible activities may fall into any of the following categories: community group and workplace discussions; capacity-building activities for the volunteers' own support groups; networking; legal assistance; training for members of community-based groups and PWHA organizations (e.g. public speaking, communication skills, skills training, counselling, psychosocial support, home- and community-based care, programme development, monitoring and evaluation, proposal and report writing); income-generating activities (including for survivors); psychosocial support (e.g. counselling, care for support group members and their families).

Although funds were put in place at the beginning of the project, more than 18 months passed before a few proposals submitted by PWHA support groups and NUNVs were finally screened and approved in Zambia. This experience has demonstrated the need for technical input from the project's management team and advisory group. It is felt that skills training on project and proposal writing should have taken place at an earlier stage in the implementation of the project.

On training

The HIV and development workshop proved to be a very powerful tool for bridging the knowledge and attitudinal gaps identified among the various stakeholders of the projects. As already mentioned, however, this workshop should have been conducted much earlier in the consultative process in order to provide an in-depth understanding of the epidemic as a foundation for all subsequent stages of the process. There is also a need to modify some of the content and exercises used in the workshop to improve their tone and make them more user-friendly.

The skills training programme that was organized as a one-week workshop has now been developed into a draft curriculum. This draft will be further refined in the expansion of the project to French-speaking Africa. A week of discussions was held between two of the experts who had conducted the training in both pilot countries. These discussions were aimed at assembling the different components into one draft. It was decided that the curriculum should be packaged in two portions: the workshop portion and the 'on the job' support and supervision of the development of specific skills (e.g. peer counselling, communication and public speaking, report writing, and support group formation). Most of these skills require practice and close supervision if they are to be mastered.

On the concept behind the pilot project

The overall aim of placing volunteers with host institutions is to give a human face and voice to HIV and AIDS. This human face and voice can be demonstrated within the workplace, and through the services offered by the host institution to its target group(s). Importantly, the volunteer must not merely be seen as just an additional employee, but as one who adds value by virtue of his experience of living with or being affected by HIV/AIDS.

However, 18 months after launching the project, it seems that some host institutions, despite all the consultation processes put in place, still consider the volunteers as just an additional pair of hands. Moreover, it has been reported in some instances that some volunteers regard it as a violation of their human rights for the project to expect them to share their personal testimonies in the course of their work.

This is a delicate issue since it is true that no one has the right to require another person to disclose their serostatus if they do not wish to do so. However the requirement to 'be open' was explicitly included in the selection criteria and a very elaborate process was instituted to ensure that those who were selected as volunteers understood that they would need to use their experience as PWHA in doing their work. This creates an awkward situation, resulting in frustration and resentment among those who were not selected among the first round of volunteers and may consider themselves better qualified because of their openness about their HIV status.

The networks of PWHA, both at national and regional level, who are full partners of this pilot initiative, are in the best position to legitimately resolve this dilemma. In the future, appropriate mechanisms should be put in place to give their representatives more influence in the selection process.

UN support to GIPA in South Africa

Context

South Africa has one of the fastest-growing epidemics in the world. Over three million people are currently infected with HIV, yet the epidemic remains almost silent and faceless. The levels of discrimination and social stigma are unacceptably high and people continue to live under a conspiracy of silence. The National AIDS Review of 1997 recommended that greater involvement of PWHA was crucial for effective HIV prevention and management. On the basis of this, the National AIDS Plan identifies GIPA as one of the key components for managing the epidemic in South Africa. The need for capacity building to enable PWHA to fulfil this role efficiently has been identified and training programmes, such as those included in GIPA, are crucial in addressing this.

Project development

Rapid Assessment

In January 1997, the UNAIDS Inter-country Team, together with UNV South Africa, convened a meeting with partners from the Department of Health and the National Association of People Living with HIV/AIDS (NAPWA) to explore the scope of developing a National UNV project similar to the pilot projects in Zambia and Malawi. Following this meeting, it was agreed that, in order to get a

better and deeper understanding of the issues around GIPA and to avoid replicating existing efforts, a rapid assessment should be undertaken. Two independent consultants (one a PWHA) participated in the National AIDS Review in July 1997. They also visited and interviewed representatives from a range of public and private sector organizations to assess the need for such a project and inform the design and modality of the project management. As a strategy for expanding the response, the consultants were required to actively explore the role and interest of private sector organizations to participate in such a project.

The rapid assessment confirmed that while some progress has been made in the involvement of PWHA, the epidemic remains largely invisible in South Africa. The environment is not conducive to people disclosing their HIV status because of the fear of rejection. NGOs that do work with PWHA find that their contributions are not sustained because of a high 'burn-out' factor. Workplace HIV/AIDS programmes have not always been effective because people do not see the epidemic as real if they have never seen an infected person.

Planning/consultative meeting

Following the three-month rapid assessment, the UN hosted a one-day planning/consultative meeting. The purpose of the meeting was to flesh out issues pertaining to roles and responsibilities of the project partners, criteria for recruitment and selection of GIPA Field Workers (GFWs), and operational and management issues. The meeting was attended by representatives from government (Department of Health), NGOs (AIDS Consortium, NAPWA, Wolanani, NACOSA), partner organizations (Lifeline, South African National Defence Force (SANDF), Religious AIDS Project) and UNAIDS (WHO, UNDP, United Nations Population Fund, UNV).

Project purpose

Following the planning/consultative meeting, a project document was drafted for funding and approval. The purpose of the project was then defined as being that of: (1) mobilizing the private sector to put in place effective, non-discriminatory HIV/AIDS workplace programmes and policies; and (2) strengthening existing national programmes that involve PWHA.

To fulfil this purpose, the project is placing people living openly and positively with HIV/AIDS in partner organizations to assist with work-based HIV/AIDS policies and programmes.

Project management

Implementation arrangements

A National Project Manager was recruited in March 1998 and a Steering Committee and Advisory Board were established.

Recruitment and selection of GFWs

One of the essential criteria for the GFWs agreed to by the Advisory Board was the need and importance of all candidates to be HIV-positive and willing to be open about their status. Other requirements included having good organizational, verbal and non-verbal communication skills, willingness to be trained, minimum educational qualification of Standard 10 and ability to work as a member of a team. The advertisement for the recruitment of the GFWs was placed in two national newspapers and circulated widely to partners. Following the receipt of approximately 100 application forms, 20 candidates were invited to an intensive two-day Selection Workshop.

The workshop was structured to determine whether the individuals fulfilled the stated requirements, as well as to promote self-growth and personal development. A highly participatory and experiential methodology was selected instead of straight interviews, since a workshop provides more time for assessing applicants' strengths and weaknesses. It also provides a better insight into how applicants handle themselves in different situations. The various activities were selected with the aim of being informative, educational and personally empowering.

At the end of the weekend, a total of 12 candidates were selected as GFWs. In addition to the selection process for GFWs, the workshop was attended by guest participants from Mozambique and Swaziland who used the opportunity to become sensitized to the GIPA principle and to get motivated to kick-start similar processes in their own countries.

Achievements

Placement of GFWs in partner organizations

Since the selection workshop, GFWs have been placed in partner organizations. These include our government partner the Ministry of Health, private organizations (Eskom Electricity Commission, Super Group Pty Ltd, Imperial Transport Holdings, Sowetan Newspaper, Lonrho Platinum Mines and Transnet), and NGOs (Lifeline and A.M.E. Church) (see Box 8 for an example of GFW placement in a partner organization).

Box 8: Example of placement of a GFW in a partner organization

Martin VOFLOO (Eskom South Africa)

Liz THEBE, Manager, AIDS Programme, Eskom, said:

"I have been working with Martin since October 1998. We have held presentations and given talks to more than 700 Eskom employees.

What I have experienced with him is that he does not blame anybody for being HIV-positive except himself, and that is why most people are listening to him and they invite him to come back again. Most of the people have reported seriously considering taking responsibility for their behaviour and health after listening to him. He has an ability to read his audience and is a powerful and straight-to-the-point speaker.

To have Martin as a white person living openly with HIV has made a big impact on many of the people in our company. Most of the whites were thinking of it as a 'black' thing. Some of the whites were surprised to see him, and now they support our AIDS programmes.

Some of the construction camps, where they did not believe that AIDS existed, have changed because of Martin. Most of the blacks were asking, "Why don't you bring a white person who is HIV-positive?" Our training programme has gained credibility and we seem to be reaching more HIV-negative people with prevention messages, as well as HIV-positive ones with messages of hope and health. Thanks to the GIPA Project for bringing Martin to Eskom; it has boosted our AIDS programme and made a tremendous impact so far."

Training and development

In order for the GFWs to perform their duties effectively and professionally, a comprehensive training and development programme has been formulated. The goal is to ensure that, with support and encouragement, each GFW can develop his or her own potential, on a personal and professional level. The GFWs have so far received the following training: basic computer skills; personal empowerment and guidelines to living positively with HIV, modelled on the field of psycho-neuroimmunology; communication and presentation skills; HIV and development; and HIV/AIDS policy and programme development. Further training in counselling and advanced computer skills is planned to follow soon.

GFWs also participate in various HIV/AIDS projects aimed at raising visibility and championing the cause of current issues affecting PWHA in South Africa. They have been involved in the UNDP Human Development Report for South Africa, the Ster Kinekor movie project, Stepping Stones Gender and HIV/AIDS training, UNV workshops, and activities with the South African Broadcasting Cooperation (SABC). GFWs have also assisted with regional workshops organized by UNAIDS to help kick-start GIPA activities in the region.

Media exposure

Many of the GFWs have been interviewed by local and international print and electronic media. Examples of situations where GFWs have spoken publicly about their HIV status include: World AIDS Day press conference with Dr Peter Piot; South African Business Council dinner attended by the then Deputy President, Thabo Mbeki; SABC prime-time slots including the news; and interviews with various newspapers including the *New York Times, Los Angeles Times*, and *The Sunday Independent*. Participation in radio programmes has been extensive, with most national radios having had interviews with GFWs.

Future challenges

The main challenge is to sustain the project by continuing to provide on-going training as well as support for the GFWs in order for them to fulfil their expected roles. This depends largely on availability of resources.

The South African Business Council is currently being established and it is hoped that the links with the GIPA project will go from strength to strength. The training and development programme for 1999 included: on-going skills building; development of a support system for the GFWs; electronic connectivity; an advocacy programme; developing participatory monitoring tools; and extending international opportunities to the GFWs (e.g. the International Conference on AIDS and STD in Africa, ICASA, and the Global Network of People Living with HIV/AIDS and International Community of Women Living with HIV/AIDS (GNP+/ ICW+) Conference in Poland.

Lessons learnt

Selection of partner organizations

The rapid assessment process was important as it determined the direction of the project. One of the difficult aspects of the process was the selection of partner organizations. In hindsight, more time should have been devoted to screening the suitability of the organizations identified and interviewed. At least four-out-of-six original organizations have been considered unprepared or unsuitable to host a GFW. The intention of expanding the response was not fully realized and the choice of organizations was very limited in scope. These setbacks have delayed the implementation and the placement process of the GFWs. More effort had to be spent finding new partner organizations—a process that is both very slow and labour-intensive.

Selection of GFWs

A much more intensive reference check is probably necessary to ensure that the selected GFWs have acceptable records with the communities in which they have to serve. This might have to be backed up with preparing the community

for the GFW and for talking about HIV/AIDS openly. This should help prevent the sort of unnecessary hostilities experienced in the past.

Motivation of the GFWs

It is important to find strategies that can sustain the interest of the GFWs and provide a certain financial security at the same time. On-going training and support are crucial for the GFWs to continue operating at the energy levels required.

Following a visit of the UNAIDS Executive Director to UNV Headquarters in Bonn in September 1997, and a discussion that took place in New York, in July 1998, with the Director of the UNDP Regional Bureau for Africa, agreement was reached on a number of follow-up actions on future collaborative activities. One of the follow-up actions was the possible expansion of the pilot project to other countries in Africa and to other regions. During the Joint UNAIDS/UNDP/UNV Meeting that took place in Bonn, in April 1998, participants agreed to expand the project, particularly to French-speaking African countries, using a similar approach and building on the lessons learnt.

As a result, a new project was designed to further develop appropriate approaches and mechanisms for enhancing the involvement of individuals living with or affected by HIV and AIDS in the response to the HIV epidemic. The proposal outlines an approach based on two separate but related strategies. The first strategy aims at ensuring, through an appropriate volunteer modality, the meaningful representation of individuals living with or affected by HIV and AIDS in key organizations and institutions engaged in the response to the HIV epidemic at community, district and national levels. The other strategy aims to strengthen the capacity of organizations and networks to participate at all levels in the formulation and implementation of policies and programmes that will create a supportive ethical, legal and social environment for an expanded response to the epidemic.

The NUNV modality, as currently being developed and implemented in Malawi and Zambia, provides an appropriate delivery mechanism for GIPA. Through this expansion, the NUNV modality and any other appropriate volunteer modalities will be further tested—this time in countries that are characterized by a lower HIV prevalence and poorly functioning national organizations and networks of PWHA. These various volunteer modalities will be considered in terms of the following questions: a) As currently developed, can they provide the appropriate space for individuals living with or affected by HIV and AIDS to influence policy and programming in host institutions, and at national level? b) Are these different volunteer modalities an appropriate delivery mechanism for economically empowering individuals living with or affected by HIV and AIDS, and for strengthening their organizations and networks? c) Is the NUNV modality, or any other volunteer modality, a feasible delivery mechanism for promoting GIPA?

Activities to initiate the expansion in two French-speaking countries were started in February-March 1999. UNAIDS and the UNDP HIV and Development Regional Project will be involved in the implementation of this expansion, to an even greater extent than for the pilot phase in Malawi and Zambia.

The formal 'project' approach of placing individuals living with or affected by HIV and AIDS is only one approach to GIPA. The projects currently implemented in Malawi, South Africa and Zambia should provide an opportunity to review different approaches for enhancing GIPA. To that end, a round table discussion was held during the XIth ICASA in Zambia, in September 1999, with the following theme: "Promoting GIPA in sub-Saharan Africa: what does it mean? What are the alternatives? Lessons learnt from Malawi, South Africa and Zambia".

This round table was to create space for the sharing of experiences and lessons learnt from the different approaches to enhancing GIPA, particularly in sub-Saharan Africa. It was also intended to provide a venue for examining the following prioritization issues: a) Given the current trends of the HIV epidemic, should GIPA be considered a key element in the national response to HIV in sub-Saharan Africa? b) Which mechanism is the most appropriate for promoting GIPA, given the different political, economic, cultural and social contexts?

UNAIDS has made the GIPA principles a part of its policy because it has now been demonstrated that GIPA is a key strategy in the response at all levels. A technical consultation on GIPA has taken place and key areas for action have been determined.

Sources: Project document RAF/96/VO1, UNV, Sept. 96; Monitoring & Evaluation Mission Report, UNDP, Oct. 97; Self-reflection and Selection Workshops Trip Report, UNAIDS/ UNDP/UNV, Feb. 98; Trip Report on Joint UNAIDS/UNDP/ UNV Meeting, Apr. 98; UNV SVF and SIDA Project Proposals, UNDP, Jun. 98 and Aug. 98; Malawi-Zambia Travel Report, UNAIDS, Sept. 98.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

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