

The Greater Involvement of People Infected and Affected by HIV/AIDS GIPA

NGO PCB Delegation

1. Background

In December 1994, forty-two governments gathered in Paris to sign the Paris Declaration,¹ which dealt with a variety of matters including the greater involvement of people living with HIV/AIDS. Article 4 of the text states:

We, the heads of government or representatives of the 42 states assembled in Paris on 1 December 1994 are resolved to step up the international co-operation through the following measures. We shall do so by providing our commitment and support to the development of the joint and co-sponsored United Nations programme on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and world-wide leadership in the fight against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and co-sponsored programme and other appropriate fora: support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and co-ordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all -national, regional and global- levels, this initiative will, in particular stimulate the creation of supportive political, legal and social environments.

No country has signed the Paris Declaration since 1 December 1994.² Perhaps this reflects the fact that many governments still do not understand the significance of the HIV pandemic.

We must recognize that there is no such thing as the typical person living with the virus. In some countries, the prevalence of the virus in certain groups - identified as high-risk groups which have been targeted by prevention strategies - has resulted in the development of recognizable means of access to some of those living with the virus. At the other end of the spectrum, other groups may be entirely invisible - ultimately because individuals do not themselves know that they are living with the virus until it strikes as illness.

In operationalizing GIPA and ensuring wider representation of PLWHA, the answer lies in generating community involvement and not just focusing upon individuals. Ultimately, having the virus is not a sufficient reason to identify oneself with the community of those living with the virus. All other differences between people remain. The successful application of the principles of the Paris Declaration will depend on sensitivity to this fact.

¹ 1st December 1994

² The list of signatory countries is contained in **Annex I**.

The ideal of the Paris Declaration must be matched most of all by realism. By no means every person living with the virus will wish to have a public voice: it is nevertheless in the spirit of the Paris Declaration for as many people as possible to be given, and to find, a voice. All will have needs, and those needs must be perceived as including the capacity to be heard insofar as they wish to be heard.

2. Definition and Vision

At the recent consultation on the Greater Involvement of People Living with HIV/AIDS February 28 – March 1, Nairobi, Kenya, at which one of us participated, it was agreed that the operational definition of GIPA should focus primarily on infected persons but should not exclude the affected. All participants agreed there is a need for specific focus on infected persons in order to avoid dilution of the GIPA principle, which would result from attempting to include everybody. This definition was arrived at in light of the following factors:

- Having the virus in one's body is something which cannot be shared even with one's close family
- The numbers of infected persons who are visibly involved is still very small.
- Affected persons (e.g. spouse, children, parents or close relatives) also share the stigma.
- While affected people share stigma and social discrimination with the infected person they do not share legal discrimination (e.g. immigration laws which prohibit HIV+ persons from traveling to certain countries).
- The infected person needs acceptance and support of family and close relatives to become meaningfully involved.
- Specific operational definitions of GIPA shall be made in accordance with national, environmental, political and community contextual factors.

GIPA means that PLWHA are consulted and incorporated in all areas of HIV work, whether it is decision making processes, strategic discussions, policy making or implementation of programmes. Their views should be incorporated at various programmatic levels and where possible translated into activities that benefit other PLWHA. Moreover, the involvement of PLWHA both on their own behalf and through government encouragement, if given the means to be properly, can be useful in reducing stigma, prevention campaigns and in providing care and support for other PLWHA.

For us GIPA means engaging PLWHA not only in dialogue and implementation of HIV/AIDS activities but also consulting them on issues touching upon their lives and well being. Their input provides a reality check for HIV- and untested people because there is much about their lives that cannot be fathomed if they do not say it. We need to both understand and accept that PLWHA are experts in their own right, irrespective of their level of skills. They have direct knowledge of how and what the virus does to their bodies, and hence the need to consult them on matters which touch upon their bodies. Those in power, who make decisions, must be sensitive and committed to the issue of meaningful inclusion of PLWHA. Through this strategy, of a top down approach, GIPA can become part of the national response to HIV.

3. What appears to be working to prove the advantages of GIPA?

We agree that in our experience in the field, we do not see much evidence of GIPA in operation in our regions. This view is most strongly held by people from Asia and the Pacific, Latin America and the Caribbean, and to a lesser degree North America.

Many governments do not take the HIV pandemic seriously; some do not even have a national AIDS programme. When this is the situation, how can we expect PLWHA to be involved?

4. What are the gaps in the current operationalization of GIPA? What are the obstacles to GIPA? How to address these?

4.1 Involvement

The central aim of the GIPA initiative was the greater involvement of PLWHA. However, in practice this has led to problems of “involvement in what?” and how to achieve this involvement. Clearly, there is a need to move beyond GIPA as discreet initiatives towards a situation where people with HIV/AIDS are consistently involved at all levels. However, this can only be achieved if those with power acknowledge and accept that the involvement of PLWHA is a useful strategy to follow.

Many people have reported a general lack of appreciation by both governments and organizations of the value of involving PLWHA. As the following example illustrates the creation of such an understanding is time consuming, may result in wasted opportunities and produce negative experiences for those involved.

One organization realized the multidimensional nature of PLWHA needs, and saw that hospitals and clinics were not meeting many of these. A project was established, however, the first year was a struggle. It was realized that to succeed, PLWHA must be involved in the design of the project at all levels and phases, and that, the project should not simply be 'for' them but must be 'with' them. When PLWHA were asked how the situation could be rectified, people gave the answers they felt they should give. Later staff realized that they had subconsciously viewed those with HIV as 'clients' - the charity syndrome- and that had been picked up the PLWHA and they had responded accordingly. The solution lay in creating a space in which those with HIV felt encouraged and stimulated to fully participate.

Obviously this is not an easy situation, however it is a common occurrence. If projects and programmes begin with an understanding that PLWHA have something to offer and a commitment to the involvement of PLWHA at all stages, such a situation as that described above can be avoided.

GIPA, in theory, is a fine principle, one that deserves more support and resources. Many community organizations, government committees and regional networks ensure greater involvement of PLWHA in planning and implementing policies and/or programmes. However GIPA has often degenerated into 'lip-service' or tokenism. Of particular concern to the NGO Delegates is the situation of HIV infected drug users (IDUs). GIPA is not working for IDUs largely due to the illegality of their behaviour. They are afraid to be identified. In addition to the legal issues, injecting drug use is still very much a stigmatized behaviour. IDUs lack money, resources and support, and in addition there are few drug user organizations. When drug users are appointed to government and other committees it is almost always ex-users or methadone users. As such the voice of IDUs is not heard.

A correlation of this is that people should have the personal capacity to fulfill the role that they accept. Therefore qualifications may be required. A PLWHA is an expert in many matters pertaining to HIV/AIDS. However this needs to be distinguished from the situation where a person is given a position simply on the basis of his or her HIV status. For those positions requiring

qualified personnel, people holding the requisite qualifications must fill them. Our problem is, and has been, to find these people.

We all must actively search for those PLWHA who have appropriate skills and can assist us in trying to ameliorate the effects of the HIV pandemic. In 2000, with more than 33 million people infected with HIV, the PLWHA community does have within its ranks a wide diversity of skills. It is true that this pandemic disproportionately affects the poor and uneducated; however, these people are not the only constituency. There are HIV+ doctors, accountants, lawyers, managers, teachers, technocrats, bureaucrats etc. These people exist and it is our task to identify them and convince them to become involved, that they will make a difference. A positive example is that recently, in Colombia a PLWHA was appointed to be the head of the National AIDS Program.

PLWHA must not necessarily be publicly identifiable as HIV+ as part of their involvement. It would be better if they were, but it is not a prerequisite. We need them for their skills as well as for their particular insight into the epidemic and what it means to be HIV+. Their involvement must be incorporated into national AIDS programmes as well as into local PLWHA organizations. Their inclusion is an essential part of capacity building, since these people already have capacity.

Many PLWHA, who join PLWHA organizations are socially disadvantaged, are untrained to work productively within organizations and lack the skills required to be meaningfully involved. This creates a difficult situation. The inclusion of PLWHA also means providing PLWHA with the tools for them to be efficient and effective partners - to be able to fulfill the positions to which they have been appointed. This means providing capacity building for PLWHA to be better advocates and technical assistance where required, both of which is often neither simple nor easy. Our position is further frustrated by the fact that most governments and international organizations have neither the resources nor the time to train people in the numbers required to confront the size of the current pandemic – let alone the future one. However, we must not set people up for failure.

Another obstacle to PLWHA involvement is that many PLWHA want to only deal with daily issues and not be involved in policy formation or writing issue based papers for advocacy. This is related to the fact that PLWHA and workers in organizations providing services often perceive policies or guidelines as unusable or irrelevant. This is most acute where PLWHA are invited to be part of a formal consultation process, or to sit on management bodies. The most readily available solution to this is to find PLWHA, who are trained in such areas to take on the responsibility of bringing the PLWHA voice to the table.

We need to acknowledge that we are all human both people who are HIV+ and those that are HIV-. Many PLWHA do have problems that they are coping with often related to diagnosis of HIV or related to pre-existing underlying problems. This is the basis upon which many PLWA organizations began to provide a space for people to discuss their HIV diagnosis. In public health mental health is often neglected and it needs to be built into the response to HIV through programme and project design.

One measure to ensure the greater involvement of PLWHA is the provision of quotas - affirmative action. For example, In the USA the federal government must assure the greater inclusion of PLWHA by mandating that any recipient of funds in its local planning bodies includes a minimum of 40% of PLWHA. Similarly, in New York City, the local planning body has

mandated that any program recipient of such federal funds must have an advisory body to their program including PLWHA representatives. Another example is the AIDS Support Organization in Uganda, which has two positions on its Board of Trustees exclusively reserved for an HIV + man and woman. The PLWHA who are elected by the clients councils are offered training in governance and policy issues to enhance their capacity to participate meaningfully at that policy level. Likewise the Uganda AIDS commission has one reserved position for a PLWHA who is a fully fledged commissioner at the minister of state level.

One positive step to prevent tokenism is the development of operating codes or guidelines, which provide a minimum framework for the inclusion of PLWHA. Such guidelines should not be for too long, turgid, or expressed in jargon, which excludes people. Such guidelines should be a simple way to ensure that the inclusion of PLWHA is meaningful rather than including a PLWHA for political expediency.

4.2 Visibility of PLWHA

GIPA should make PLWHA visible through engaging them in decision-making positions. To date we have witnessed appointments of PLWHA to some National AIDS Programmes and some UNAIDS Theme Group. PLWHA are employed in key positions within some National AIDS Programme in positions such as coordinator of CBOs/NGOs activities or supervisor within counseling and outreach projects. In many countries PLWHA take part in meetings with the Ministry of Health to consider strategies against HIV/AIDS. However, it is too little and *ad hoc*. The visible PLWHA in National AIDS Programmes and UNAIDS Theme Group is the exception rather than the rule.

Visibility of PLWHA in many societies is frustrated by concerns about confidentiality and privacy. This situation creates a climate where it is difficult for people to be open about their HIV status whether as a result of real or perceived fear. In many countries the emergence of HIV in marginalized populations set the stage for the development of prejudice and stigma that has characterized the social response to the pandemic. As with other oppressed populations, some PLWHA have embraced their stigmatized identity and made it a source of energy as well as using self-disclosure as a powerful tool. However, again this is the exception rather than the rule.

GIPA is part of an ongoing struggle for respect for the human rights of PLWHA. To address legal and ethical issues at the international level, such as travel and migration restrictions, and vaccine trials, as well as at the national level anti-discrimination legislation to provide security of employment, housing and access to medical services. For example, such legislation should be introduced to ensure that PLWHA are not excluded from work because of their HIV status. This should be implemented at all levels: community, national, regional and global.

The practical effect of such anti-discrimination legislation on the visibility of PLWHA is to remove one of the structural impediments to PLWHA being employed. The South African GIPA project, a partnership between business, labor, civil society, government and the United Nations, which does not follow the United Nations Volunteer model though is partly funded by the United Nations, has to date placed eleven people, who are employed by companies such as Eskom, Transnet, Sowetan Newspaper, Lonmin Platinum Mines and Imperial Transport Holdings. The nature of the initial contracts with most of the PLWHA made it difficult to provide them with the health insurance of the companies. Instead money was given to them directly to purchase their

own health insurance on the private market, even though access to such insurance for PLWHA is extremely limited in South Africa. Some of them subsequently spent the money earmarked for health insurance on other things, making it financially difficult for them to access health care in time if, and when, they fall ill. In fact, two of the eleven PLWHA have fallen ill and died. Irrespective of the individuals involved, in many countries in institutionalized settings bordering on the semi-governmental, the employees are covered by the employer's collective health insurance policy. When insurance companies exclude people from even basic health insurance cover for a pre-existing medical condition, this strikes at each person's right to health – and discriminates. Anti-discrimination legislation covering employment and the provision of insurance is capable of avoiding such incidents.

In the case of Latin America, political activism and human rights based cases brought by PLWHA has proved to be a useful strategy for the creation, modification and passing of laws guaranteeing access to treatment based on the right to health and/or the right to life. Countries including Mexico, Venezuela, Costa Rica and Columbia have seen their response to PLWHA altered through the courts through reliance on provisions in national constitutions.

Taking an HIV test may be the beginning of momentous changes in a person's life. Confidentiality of a HIV/AIDS diagnosis is necessary for both the well being of the person concerned due to stigma and discrimination as well as for public confidence in the testing programme. Intentional or unintentional disclosure of a person's status is a threat to their well being. People who are HIV+ need the space to be able to come to terms with their diagnosis and to make decisions as to whether to inform others. While on the one hand protecting the confidentiality of those who are HIV+, we must on the other encourage PLWHA organizations to work with PLWHA on disclosure of their status to family, friends, colleagues and finally the world at large. This is particularly important since the invisibility of those who are HIV+ reinforces the prejudice and stigma associated with HIV/AIDS.

An example of PLWHA attempting to put a human face to the epidemic is the Network of African People Living with HIV/AIDS's Ambassador of Hope Programme, which involves PLWHA within the region being trained and sent out to countries as role models. When on mission they assume the role of an ambassador and seek audiences with policy makers and government representatives. Their other roles are to lobby for an expanded response to the epidemic and ensure care and support programmes are put in place for PLWHA and to work with PLWHA within the country, through supporting them in forming networks and support groups. The Ambassador of Hope programme has helped to enhance the profile of PLWHA in many countries in Africa.

4.3. Care and Support

There is a critical need for the urgent development of care and support services, and this need will be accentuated as time passes. The need for care and support of PLWHA already does, and will, place pressure upon GIPA projects for assistance in this sector as it is here that the immediate area of most felt need exists, both for service delivery and as the issue most affecting participating PLWHA. This has broad implications for the implementation of GIPA.

Of great concern to us is the under reporting of HIV infections by some governments, when compared to WHO statistics. Such under reporting can have serious implications for government

planning. For example when a government states that there are some 1 000 people infected within its territory and WHO believes that the number is closer to 6 000, the provision of services on the basis of 1 000 infected is not proportionate to the response required, particularly for patients' needs. In such situations governments fail in their duty to provide care and support services through denial of the epidemic.

The issues of illegality and stigma exacerbate the care and support situation for HIV positive IDUs. Furthermore, many physicians refuse to give such users HIV therapy because of the assumption that they will not adhere to therapy regimes, despite fact that there is little evidence of this. In relation to pain control for HIV+ drug users the situation is particularly problematic, since it is assumed that they are seeking drugs. Such issues were the subjects of the Ottawa Charter for Health Promotion, 1986, at which some 150 governments agreed:

Health promotion is the process of enabling people to increase control over, and to improve their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to wellbeing.

We recognize that health promotion, particularly for vulnerable populations, including PLWHA, is an essential part of the care of and support for PLWHA.

Self-help groups are often by their nature the preserve of activists and enthusiasts, and thus exclude others. However, such groups often - indeed, inevitably - live with great internal pressures such as key members dying. Thus PLWHA organizations can be unstable, and find it hard to find a consistent collective voice. GIPA has been implemented to reduce the social vulnerability of PLWHA but in doing so the economic vulnerability of PLWHA is also addressed. We live with the uneasy truth that if those people in whom governments invest die, their expertise dies with them. We need to confront the issue of whether to provide anti-retroviral therapies to these experts.

4.4. The United Nations: Operationalizing GIPA

The United Nations Volunteers Programme (UNV) in conjunction with UNAIDS and UNDP has instigated a number of pilot projects, initially in Africa (Malawi, Zambia) and currently being finalized now for Asia (Cambodia and India) as well as Francophone Africa (Burundi and Côte d'Ivoire). It could be said that the origins of GIPA lie in an analysis of the gaps in the community and national responses to the HIV epidemic. These gaps are both at the human and social level, where silence and shame surrounds the epidemic, and at the program and policy level where those affected most by the epidemic have little influence. The UN system, notably UNDP, has been able to expand upon the value of GIPA through an analysis that locates it clearly within the Development framework. We must avoid the mistake of viewing these GIPA initiatives as an extension of existing approaches or strategies, rather than as something that is rectifying the gaps in those very same approaches.

Given the size of the epidemic, and the internationally recognized value of peer support and advocacy, there is scope for a much greater level of support and development, hence the need for

GIPA. Conversations with PLWHA activists indicate a degree of tension between them and governments based on disappointment at the level of governmental support. One of the major concerns in the two projects in Africa was the effect of the GIPA upon existing PLWHA groups. This was based on the impact upon other members when some members of the group were recruited as UN volunteers with entitlements to a volunteer's living allowance and medical benefits during the period of service. This was of major concern in the design and planning of the project and some attempts were made to offset this by the provision of skills training and access to micro-finance for support group members, but it still proved to be a major source of conflict.

The GIPA projects are complex, there are many actors and there is massive scope for activities. It is however grounded in giving those affected by the epidemic the chance to be formally involved. Thus it should be centered on providing them with the capacity to become involved in a successful and productive manner. Many of the potential participants for this project have low levels of education and work experience. In order for them to gain competency a large amount of preparation and training needs to occur and at many levels. This was one of the lessons learnt from the African projects.

The lessons from the African projects were that in being unable to effectively overcome these considerations the projects were negatively impacted upon. These lessons can be of value in future projects, but they must first become a central part of the understanding of those responsible for project implementation.

India

In a larger project on creating a supportive enabling environment in India, UNDP has inserted components specific to GIPA in relation to sex workers and PLWHA. This has resulted in an unusual project document. The GIPA aspects have a detailed analysis of the specific issues when involving marginalized people in project development. They draw upon the lessons learnt from the African experiences. However, the sections of the document regarding strategies for involving sex workers do not have a comparable level of specific analysis and strategies. This distinction could be significant when implementing the project. It may reflect that UNDP and the government do not have a highly developed understanding of the complexities inherent in this project. This suggests the need to further work with them to assist with the creation of a fuller understanding and appreciation of the nature of the project. It should be noted that in the project documents, there is an intention to commence the project's implementation with further familiarization for those responsible; however, this is at the project implementation stage rather than at the project development/design one.

Cambodia

HIV has affected all levels of Cambodian society; however, it is only the poor who are open about their status because they access public health facilities for HIV care as well as support for other problems. Those from other classes are secretive about being infected. Therefore the candidates for the UNV project may be from the less educated and skilled populations.

5. We request

i. Government representatives on the PCB to:

- Relay the request to their government, if it did not sign the Paris Declaration on 1 December 1994, to do so as an affirmation of the government's understanding of the importance of involving PLWHA.
- Promote GIPA within their own countries by sensitizing various groups to the advantages and need for GIPA.
- Be a voice for advocacy and increased support for GIPA, which must by necessity include awareness raising among people working for governments in the field of HIV/AIDS. At present the GIPA principle is unknown to many of these people.
- Provide more resources to ensure the GIPA principle is taken up by UNAIDS and its cosponsors, particularly for a GIPA Focal Point to be appointed in all seven Co-sponsors.
- Allocate funds in order to assure the participation of PLWHA.
- Identify PLWHA with appropriate skills and try to convince them to become involved.
- Mandate and ensure the representation of PLWHA. This can be achieved by mandating a percentage representation of PLWHA in all processes - a quota.
- Ensure adequate programme monitoring and evaluation.
- Provide accountability to the GIPA principle among governments and other bodies working in HIV/AIDS.
- Invite NGOs to the discussion table with the understanding that PLWHA come as equals.
- Measure their practical application of GIPA at the PCB in as much as UNAIDS supports its NGOPCB PLWHA Delegates.

ii. UNAIDS and Co-sponsors to:

- Retain the position of UNAIDS GIPA Focal Point, which was created in 1999, and that each of the seven Co-sponsors appoint a GIPA Focal Point.
- Mandate and ensure the representation of PLWHA. This can be achieved by mandating a percentage representation of PLWHA in all processes - a quota.
- Identify PLWHA with appropriate skills and try to convince them to become involved.
- Include PLWHA input in their programs as advisors and implementers.

6. We can:

- Be a voice for advocacy and increased support for GIPA and at each PCB meeting report to the PCB on progress in the implementation of GIPA.
- Help to identify PLWHA with appropriate skills and try to convince them to become involved.
- Offer advice on how to ensure that the GIPA principle is actually put into practice since we work on a daily basis with boards and organizations, which is where GIPA is implemented.
- Provide input on policy, legal and ethical issues. Of particular concern to us are HIV infected drug users, who are multiply marginalized. The PCB must address the need to ensure that harm reduction policies and programs are put into place around the world. Far too little attention is paid by governments and UNAIDS to drug-related HIV as well as hepatitis C.

7. Conclusion: Does this mean that we have not made progress?

We do not pretend to have all the answers. However, meaningful GIPA will not happen overnight. We must see the involvement of PLWHA as an on going process. We all, and in particular PLWHA, have a responsibility to make GIPA work, which in the end means moving GIPA from theory in to practice. We must operationalize GIPA. However, we must acknowledge that until some governments take the HIV pandemic seriously, there can be no understanding by them of why PLWHA should be involved or support for their involvement.

Annex I

Signatory Countries to the Paris Declaration

Argentina
Australia
Bahamas
Belgium
Brazil
Burundi
Cambodia
Cameroon
Canada
China
Côte d'Ivoire
Denmark
Djibouti
Finland
France
Germany
India
Indonesia
Italy
Japan
Mexico
Morocco
Mozambique
Netherlands
Norway
Philippines
Portugal
Romania
Russia
Senegal
Spain
Switzerland
Tanzania
Thailand
Tunisia
Uganda
United Kingdom
Vietnam
Zambia
Zimbabwe