

# ECONOMIC COMMISSION FOR AFRICA

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African Development Forum 2000

“AIDS The Greatest Leadership Challenge”

## LEADERSHIP ROLE AND APPROACHES FOR AN EFFECTIVE HIV/AIDS RESPONSE

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*Everything that needs to be said has been said. It has been said loudly and clearly across this continent and beyond.*

*The main questions today are : Have we been listening carefully and actively to each other?*

*Do we have the will and the necessary compassion to overcome this epidemic in our countries and this continent?*

*We have a vision for how we work together in our countries and on this continent. We know that we must change the direction of our collective efforts at national level and within this continent.*

*There is an urgent need to make a significant move to address priorities defined by communities and support us in our efforts to empower and accompany them in their development and response to HIV/AIDS. Such a support should be guided by trust, mutual respect, inclusion and find its illustration in clear commitment by our governments and partners.*

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The most startling feature of the epidemic throughout the world, and especially in Africa the most hit continent, has been the way individuals and communities have responded. With courage and compassion, they have mobilized to care for and support those affected and to assist others to remain uninfected.

Particularly striking has been the role of PLWHA who, within a short period of time, have given a human face to the grim statistics. Though less than 1% of those who are HIV positive have come out in the open declaring their serostatus, they have become powerful change agents in the sub-saharan continent. As evidenced by the impact of individuals such as Jeanne Gapiya, Milly Katana, Tita Isaac, Martine Somda, Lynde Francis, Winston Zulu (just to name a few) whose message of behavior change and hope re-vibrates across the continent.

At the regional level, the voice of PLWHA has been heard during various foras including the International Conferences on AIDS and STD in Africa (ICASA) held in 1995 in Kampala, in 1997 in Abidjan and in Lusaka 1999. PLWHA have ben instrumental in convincing the international community to increase their financial support to our countries. These individuals can provide important insights into how to address problems from experience, how to strive towards positive living and how people can be empowered through the trauma and the tragedy of the epidemic.

#### **GREATER INVOLVEMENT OF PEOPLE LEAVING WITH HIV/AIDS(GIPA)**

On December 1st, 1994, over fifty countries attended the Paris Summit on AIDS, where Governments called for increased support for people living with HIV and AIDS (PLWHA). Participants resolved that the 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 greater involvement of people living with HIV and AIDS through initiatives to strengthen the capacity and co-ordination of networks of people living with HIV and AIDS and, by ensuring their full involvement in our common response to the epidemic at national, regional and global levels and to stimulate and support the creation of supportive political, legal and social environments".*

However, in many sub-Saharan African countries, the involvement of those living with or affected by HIV and AIDS has been undermined by an environment characterized by high levels of denial, fear, rejection, stigmatization and so many unnecessary early deaths. And even when the political, legal and social environment is more conducive, the participation of those living with or affected by HIV and AIDS is seldom reflected into the formulation of national policies and programmes.

Although the reasons why this is the case vary from country to country, a certain pattern emerges.

**Firstly**, the 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.

**Secondly**, 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.

**Thirdly**, many individuals living with or affected by HIV and AIDS are not in gainful employment, and are therefore economically weak to engage in any serious discourse.

**Fourthly**, even when they are employed, the kind of institutions they work for are unlikely to generate and initiate policy changes.

Although the GIPA mandate has been accepted generally by all countries, there are still very few successful initiatives in this regard. Part of the reason for this failure has been the absence of tried out mechanisms for implementing this mandate. Two main strategy have emerged so far :

**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;**

and the other strategy at strengthening the capacity of their organizations and networks to participate at all levels in the formulation and implementation of policies and programmes that will support the creation of a supportive ethical, legal and social environment for an expanded response to the epidemic.

To be able to make difference and stimulate positive changes these strategies must address the following questions:

- a) - How 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) - How can a volunteer modality be an appropriate delivery mechanism for economically empowering individuals living with or affected by HIV and AIDS, and for strengthening their organizations or network?
- c) How can a volunteer modality be a feasible delivery mechanisms for enhancing GIPA?

### **EXEMPLE OF A VOLUNTEER MODALITY(VM)**

#### **1 – What can we achieve with a VM**

In the long term a VM will contribute to the establishment of a political, ethical, legal and social environment more conducive to an effective national response to the HIV epidemic, by enhancing the involvement and role of individuals living with or affected by HIV and AIDS and of their organizations or network.

In a medium or immediate term a VM will:

- \* increase the self esteem and well being of individuals living with or affected by HIV and AIDS by creating opportunities for them to contribute meaningfully to their societies.
- \* increase the role of individuals living with or affected by HIV and AIDS and of their organizations and networks in the national response by strengthening their capacity to develop and implement effective prevention, care and support activities.
- \* facilitate the incorporation (mainstreaming) of an HIV and AIDS component in the programmes of various public and private institutions that focus on specific development issues (such as education, environment, subsistence farming, small-scale industry, etc.) at community, district or national level.

\* increase the relevance and effectiveness of national AIDS programmes by ensuring that the expertise and knowledge of those living with or affected by HIV and AIDS contribute to national development, including HIV policy and programme development.

\* help document the advantages and constraints of using volunteer modalities for enhancing the GIPA mandate in sub-Saharan Africa.

## **2 – How can a VM achieve the above mentioned objectives?**

a) Placement of volunteers in carefully selected local institutions, both public and private, that are involved in HIV and AIDS prevention, care and support activities.

b) Capacity building for volunteers through personal empowerment, and training to increase their knowledge and skills base in areas such as policy analysis and development, project development, project management and business management.

c) Capacity building for representatives of the national network and of organizations or support groups of individuals living with or affected by HIV and AIDS through training, to increase their knowledge and skills base in areas such as policy analysis and development, project development, project management and business management.

d) Establishment of a micro-grants facility to promote and support community-based initiatives which will arise from the work of volunteers, and to develop and strengthen their organizations or network.

## **3 – What are the expected outputs of a VM?**

- Greater inclusion of the knowledge and expertise of individuals living with or affected by HIV and AIDS in relevant institutions, both public and private, and in all aspects of the analysis, development, implementation, monitoring and evaluation of their HIV related policies and programmes.

- Inclusion of an HIV and AIDS component in the development programmes of various institutions at community, district and national levels.

- Establishment of HIV and AIDS workplace programmes in institutions hosting volunteers.

- Increased capacity of the volunteers to contribute meaningfully to the national response as well as to their respective organizations or network.

- Increased capacity of members of organizations and national networks of individuals living with or affected by HIV and AIDS to contribute meaningfully to the national response.
- With the resources made available through the micro-grants facility, increased economic empowerment of individuals living with or affected by HIV and AIDS who have had training in business management, and strengthened role of their organizations and their national network in the national response.
- Review document assessing to which extent the volunteer modalities as a whole contributes to enhance the GIPA mandate.

### Conclusion

The Greater Involvement of People living with HIV/AIDS must be concrete. The concept has to move beyond rhetoric and be translated into the real life of people, institutions and communities.