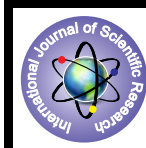


## Network of HIV Positives - A Real Mentor



HEALTHCARE

KEYWORDS :

**M. CHELLAMUTHU**

Research Scholar, Faculty of Rural Health and Sanitation, Gandhi Gram Rural Institute, Gandhi Gram, Dindigul District, Tamilnadu.

**Dr. G. DHANASEKARAN**

Associate Professor, Faculty of Rural Health and Sanitation, Gandhi Gram Rural Institute, Gandhi Gram, Dindigul District, Tamilnadu.

**INTRODUCTION:**

In a new millennium, the world witnessed a lot of spectacular events celebrated, with magnanimous enthusiasm and joy. But for the families of a few million people, there were no celebrations at all because they had lost their dear ones to AIDS (Acquired Immune Deficiency Syndrome). Unfortunately, even today AIDS is still continuing to take its toll of human lives rather very harshly necessitating the setting up of the millennium achievement goal to halt and reverse the epidemic by 2015. HIV is today the single largest infectious killer and the fourth leading cause of death in the world; it is a global crisis demanding action that cuts across all nations, all sectors, and all strata of the society.

**A FEW LINES ABOUT THE KILLER DISEASE:**

HIV/AIDS have a peculiar character of affecting the immune system of the body and make body susceptible to a number of infections leading to AIDS a fatal stage of the body. Unlike other epidermis there is no vaccine for prevention and no medicine for the cure of the diseases. It affects the entire demographic and economic structure of the society by increasing mortality rate among the youth and children who are considered as the back bone of the development of any nation. For AIDS, the transmission routes are clear and it is closely associated with individual behaviour. Therefore, it is hundred per cent preventable if the behaviour of individual is very much in line with societal expectations.

**PSYCHO-SOCIAL FEATURES OF THE KILLER DISEASE:**

Certain behaviours like sex outside matrimonial life, homosexuality, drug addiction, prostitution are in approved behaviours and these are stigmatized in the society. The spread of HIV has its route in these stigmatized behaviours. Therefore, those who got AIDS/HIV are socially neglected, economically isolated and psychologically deprived by the society in general and by their family members in particular. As a result social discrimination many infected people are generally out of the mainstream of social life. The social stigma makes them to develop mental strain and stress and unbearable fear about their future. At this juncture the positive network organizations really plays a vital role in mentoring the HIV affected from the psychological strain and other related problems they face.

**IDENTITY OF HIV POSITIVES:**

Normally the HIV infected develops a negative attitude against the society that if they reveal the fact about their infection there will be a definite discrimination that leads to hiding their infection even to their spouse and family members.

- They have higher death anxiety and lower self esteem
- Social, occupational and sexual rejection,
- Loneliness,
- Fear about future
- The possible loss of privacy of confidentiality etc,
- HIV suspects show a significantly high prevalence of anxiety and depression.

**NEED OF THE HOUR:**

Recently, a number of strong, effective support and advocacy groups and networks have been established among people living with HIV. Their involvement in the response to the HIV epidemic has challenged stigma and discrimination and made communi-

ties more knowledgeable about access to treatment resources and the need for policy change. Despite this, the involvement of HIV positive people in the struggle against the epidemic and its consequences remains largely tokenistic. Governments, bilateral and multilateral agencies and NGOs have struggled to implement the Greater Involvement of People Living with HIV Principles and to work in genuine partnership with HIV positive people. Yet the engagement, support and active participation of affected people are vital to any effective, humane response to the epidemic.

Since, it is now widely recognized in development circles that local ownership and the participation of beneficiaries are indispensable if one wishes to secure sustainable results from any initiative. It is similarly accepted that meaningful participation in programme and policy initiatives by people living with HIV is indispensable to any effective HIV/AIDS response. Unfortunately, the inclusion and participation of positive people so far tended to be marginal.

So, what can be done? The author would like to bring in the concept of GIPA Principle.

GIPA stands for Greater Involvement of People with HIV/AIDS, and derives from a principle embedded in the Paris AIDS Summit Declaration of 1994. At this summit, the leaders of 42 nations met together to determine how they could respond effectively to the AIDS crisis.

The Declaration, signed by all nations attending the meeting, acknowledged the central role of people living with HIV (positive people) in AIDS education and care, and in the design and implementation of national and international policies and programmes, to tackle HIV and AIDS more effectively. It also acknowledged that for positive people to take on a greater role in the response, they need increased support.

Article 1 of the Declaration resolved to facilitate this greater involvement of positive people. It states that:

The success of our national, regional and global programmes to confront HIV/AIDS effectively requires the 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... By ensuring their full involvement in our common response to HIV/AIDS at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.

The Declaration committed governments to develop and support structures, policies and programmes that would facilitate the greater involvement of positive people. This has since been adopted by UNAIDS as the GIPA Principle, which was reaffirmed in 2001 at the United Nations General Assembly Special Session on HIV/AIDS.

**HOW THE NETWORK TRANSFORMS PARTICIPATION TO EMPOWERMENT?**

When positive people become partners in the response to the HIV/AIDS epidemic, they are required to play new and important roles, both as individuals and as members of groups and networks. These roles are critical to the overall containment

and reversal of the epidemic. As individuals, positive people must cope with changes in lifestyle, livelihood and income, as well as in their social and family relationships. When they join HIV positive groups and networks, they must learn to work effectively alongside other people from different backgrounds. As network members, they must set to work on issues such as stigma and discrimination, care and medical treatment, and national and

International policy and programme implementation. This work calls for courage and determination. It also demands a variety of resources, both internal and external. The help and ongoing support of able and sensitive collaborators and partners is essential if they are to play their vital part in the response to the epidemic. Organisations and individuals who support positive people and their networks need to keep this context in mind.

#### **SPECIFIC CHALLENGES FACED BY SUCH NETWORK:**

- Financial Support Of Networks And
- Individual Members
- Capacity And Skills Development
- Lack Of Care And Support
- Differences In Network Operations
- Membership Diversity
- Network Constitution, Structure And
- Processes

#### **WHAT NETWORK CAN OFFER?**

In spite of the challenges faced by these networking organisations it can play a vital role in the society. The functioning of HIV positives network in India and other countries in the present day helps to support the HIV affected to overcome social exclusion and self discrimination in many ways.

Positive groups and networks are able to provide the most accurate information on the impact, both positive and negative, of policies and programmes that are part of the response. They are in a good position to identify gaps in the response and point to where new or different policy intervention and Programmes are needed. The experiences of PLHIV help them provide detailed information on the vulnerability of different sections of the population, as well as on stigma, discrimination and human rights violations.

PLHIV networks can provide human resources for conducting research and for monitoring and evaluating programmes. Such initiatives also provide capacity-building opportunities with respect to network members. Programme feedback and contributions to learning in the form of members' first-hand experience.

The most important is that the Role models are for good practice.

#### **WHAT PLHIV NETWORKS NEED?**

Positive people will need updated information in their own language on national and international policies and programmes, their rights and entitlements, and potential sources of funding.

Positive people need the opportunities and

- Highly anxious.
- "Networking of people living with HIV/AIDS".
- Results in counselling approach to anxiety
- Emphasis on getting accurate information,
- Protective Techniques,
- Gathering peers support,
- Addressing related to behavioural and emotional issues.
- Problems are adjustment reaction, psychogenic paranoid psychosis, obsessive compulsive neurosis, panic disorders and anxiety state.

A study on functioning of networking of people living with HIV/AIDS the Indian Context" revealed that the prevalence figures of around 0.81% among the low risk group like pregnant woman has been reported to be 1.5% and they found that majority of the victims are in productive age group of 20-40.

According to her most of the HIV infected people doesn't like to disclose the matter of infection to the family because of guilt, shame, fear of losing family and social stigma. She talks about the various factors like impediments in sexual relation, conception, pregnancy and delivery, launching children into marriage in the context of HIV/AIDS.

#### **TECHNICAL SUPPORT**

Technical support should be planned and implemented in equal partnership and through collaboration with the positive network or group concerned. It should cover two broad areas. First comes identification and a clarification of issues; this is followed by creation of the appropriate capacity-building packages, including training programmes, mentoring support and the development of resource materials. Issues need to be identified and understood in relation to the local cultural, language, socio-economic, geographical and political environment. This deeper understanding is vital to the communication processes too. The experience of EI has highlighted several challenges in the area of capacity-building and shown that more resources must be invested in this area over the long term in order to ensure the growth and sustainability of networks. Technical support can be provided to help positive networks to:

Identify issues where technical support is needed and can be provided Develop situation-specific perspectives and clarity Design appropriate communications strategies Identify areas of technical support in response to diverse needs Develop capacity-building plans and programme designs for providing training, follow-up support, the production of resource materials and handouts, and mentoring.

#### **PLANNING, MONITORING & EVALUATION:**

Planning and review entail the assessment of needs, both internal and external, and the mapping of resources. Internal needs are those related to capacitybuilding for organisational growth and development. The starting premise is that networks should be sufficiently empowered to run themselves. Internal needs are therefore organisational, administrative and financial. They relate to human resources, accounting and teamwork – including necessary interpersonal skills and the management of group dynamics. Some of these 'internal' needs have an external component. These are related to communications with other groups and networks and with the general public through the media, as well as to advocacy and lobbying, network facilitation and linkage development. External needs assessment is somewhat different. Essentially, what is assessed is the socio-cultural context in which the group or network must operate, since this determines its operational scope within the overall programme scenario. In specific terms, it means mapping the available external resources – human, financial, organisational, and social – and the possibilities for training and documentation. Following GIPA, all these assessments should be participatory – planned and implemented with the active involvement of positive people.

In the case of monitoring and evaluation, simple, easy-to-use systems to track institutional growth and programme impacts should be developed in partnership with positive networks. Their involvement will help ensure user-friendliness and ownership.

#### **GOVERNANCE AND COORDINATION:**

Effective and transparent governance mechanisms are critical to the success of any partnership.

The first step in setting them up is to identify all stakeholders and consider the potential support role each could play in the proposed project. Having identified all stakeholders and their potentials, a common understanding of the roles, strengths, capacities and responsibilities of the positive networks, the support organisation and the supporting partners will have to be established. There should be regular information transfer and feedback among key stakeholders during this process. It will be necessary from the outset to ensure that all stakeholders have a common understanding of GIPA in principle and prac-

tice. The next step is to draw up and agree upon a clear plan of work (including systems for monitoring and evaluation) before project or programme implementation commences. The planning process should, of course, be participatory. The partners should also set up systems for regular joint reviews, problem solving and periodic assessments of the policy environment. In doing all of this, care should be taken to ensure that: The chosen approach is one that builds on existing systems; Systems that might polarize groups are avoided; and Resources are prioritised and their optimum use pursued.

#### CONCLUSION:

It is clear that no community or organisation can tackle the consequences of this epidemic without building the strengths and the first hand experiences of the people with AIDS. Cambodia and Thailand have shown decline rate infections owing to constructive responses to such network.

Positive Network will certainly bring about positive results. Let us hope that it will encourage all stakeholders and the positive groups in joining hands and ensure working together towards the improved wellbeing of the millions of PLHIV in our region.

## REFERENCE

- Mary Ireland (2000), "Death anxiety and self- esteem on healthy understand of AIDS diagnosed children". Volume 37, Supplement 2, October 1. | | David Miller (2004) "Living with AIDS and HIV", Acquire Immune Deficiency, Syndrome. Volume 43, Supplement 4. | | Cazzullo C. C et al (2008), "Anxiety and Depression in AIDS patients", SAGE publications. | | | Lins Mathew (2009), "A study on functioning of networking of people living with HIV/AIDS". The Journal of Social Welfare. 38:9-10. December & January. | | | Krieger Irwin (2007): AIDS Guide for Community Work, Published by Unesco. | | Dr.Reence Danizger (1999), "Functioning of networking of AIDS", The Lancet 1999. | | | John Todd (2009). HIV infection in Nairobi prostitutes: spread of the epidemic to East Africa, New England Journal of Medicine, 314:414-18. | | Prof. Margarent et al (2008), UNAIDS prevention of HIV Transmission from Mother to Child. | | Dr. Shivalal et al (1995), "A study on functioning of networking of people living with HIV/AIDS the Indian Context", The Journal of Social Welfare. 38:9-10. December & January. | | S.Kalindi Muzundar (1995), "Ethical issues functioning of networking of the AIDS patients the family in the Indian context", UNAIDS Opening Up the AIDS Epidemic Geneva. |