Snapshots of GIPA: the Greater Involvement of People Living with HIV/AIDS in South Asia

An Interim Report

UNDP HIV and Development Project,
South and Southwest Asia

Foreword

The best advocates for HIV prevention and the design of care and support responses are people living with HIV and AIDS. In South Asia, the involvement of people living with HIV and AIDS (PLWHA) has been weak both in prevention and in care and support related to HIV. A major reason for this is that the voices of HIV positive people are rarely heard and their faces seldom seen in pubic. People living with HIV/AIDS cannot come out and live positive lives without fear of having their future shattered in light of the pervasive climate of denial, stigma and discrimination that exists. This lack of an enabling environment seriously jeopardises the efforts to bring a halt to the epidemic and mitigate its human, social and economic costs.

For PLWHA to come forward and take their natural position in the forefront of fighting the epidemic they need extensive support. Few PLWHA in South Asia have formed groups, networks and organisations. The capacity of PLWHA to influence decision making and participate in programmes that affect their lives is severely limited. It must therefore be a first priority in programmes addressing HIV to support existing as well as potential PLWHA networks, groups and organisations, by strengthening their capacity and voices to fight HIV/AIDS.

The UNDP supported Project for Greater Involvement of People Living with HIV/AIDS (GIPA), led by Sahara an NGO based in Delhi, is addressing these issues. Through a participatory process an initial stocktaking/situation analysis of the experience of people living with HIV/AIDS was undertaken which provided baseline information for the GIPA Project. Subsequently PLWHA, their groups, organisations and networks have identified capacity building needs and developed strategies and proposals aimed to create a more supportive environment by raising awareness of the situation of PLWHA among the general public and establishing new PLWHA support groups. The intended outcome is more and stronger PLWHA groups capable of impacting the decision making on responses to the HIV epidemic.

The GIPA initiative works to give space for those closest to the epidemic, listen to their voices and include them in the solutions of the enormous challenges posed by HIV/AIDS in South Asia.

Neville Selhore,
Director,
SAHARA

Sonam Yangchen Rana,
Project Co-ordinator,
UNDP HIV and Development Project
South and Southwest Asia

TABLE OF CONTENTS

Page

Introduction……………………………………………………………………..7

Background to the Report..……………………………………………………..8

Results of the stocktaking ………………………………………………………9

Stigma and Discrimination……………………………………………………...9

The availability and accessibility of services……………………………………..10

Human Rights…………………………………………………………………....11

Level of involvement of PLWHA…………………………………………………12

Joining PLWHA networks…………………………………………………………12

Country-wise findings:

Bangladesh………………………………………………………………………14

India……………………………………………………………………………...16

Nepal……………………………………………………………………………..18

Pakistan…………………………………………………………………………20

Sri Lanka………………………………………………………………………...21

PLWHA Networks and NGOs Working with PLWHAs

Bangladesh………………………………………………………………………22

India……………………………………………………………………………...23

Nepal……………………………………………………………………………..25

Pakistan…………………………………………………………………………..26

Sri Lanka………………………………………………………………………...27

Introduction

HIV infection has taken root in South Asia, and poses a threat to development and poverty alleviation efforts in the region. As the numbers of people infected with HIV rise, social and economic vulnerabilities are heightened. Population movements (cross-border/rural-urban migration and trafficking), unprotected sexual activities and injecting drug use are among the factors that highlight the need to act quickly and effectively. Unless action is taken to scale up the response to curb the spread of HIV/AIDS the economic and social consequences will be significant. Because HIV/AIDS is not solely a health issue, an effective response requires a multisectoral partnership. Responding to HIV/AIDS now would cost only a fraction of what would be required at a later stage when the disease becomes widespread.

Of the world's 36.1 million people living with HIV/AIDS, South Asia has about 5 million HIV-infected people. While overall prevalence rates are relatively low, a minor increase in the figures has a huge impact, as populations in this region are large. Thus, a rise of a mere 0.1 percent in the prevalence rate in India for example would increase the national total of adults living with HIV by a million persons.

After nearly a decade and a half of the epidemic, facilities for care and support remain inadequate. Stigma and discrimination confront people living with HIV/AIDS (PLWHA). Lack of awareness and understanding have been obstacles standing in the way of prevention efforts, and inappropriate overtones - condemnation and judgement of infected people - have led to discrimination and even violence against them.

Common issues of concern in South Asia[1]

- Poverty and the negative impact of globalisation
- Conflict within countries and cross border
- Political instability
- Governance issues
- Inadequate commitment to issues related to HIV
- Insufficient resources
- The tenacity of patriarchal attitudes and practices as well as discriminatory laws and policies

[1] *Progress of South Asian Women, 2000,*UNIFEM

Background to the Report

The UNDP HIV and Development in South and Southwest Asia works in partnership with Governments, bilateral and multilateral agencies and organisations of civil society to support national and regional initiatives addressing the development causes and consequences of the HIV/AIDS epidemic in nine participating countries: Afghanistan, Bangladesh, Bhutan, India, Iran, Maldives, Nepal, Pakistan and Sri Lanka.

The UNDP HIV-SSWA Project has initiated a Small Grants Project, which aims to *enable meaningful participation and* ***Greater Involvement of People living with HIV/AIDS (GIPA)*** *in response to HIV/AIDS in South Asia*. The GIPA Project is being implemented by Sahara, New Delhi, which has been working towards improving the quality of lives of drug users for over 22 years and those of HIV positive people from the initial phase of the epidemic in India. The first phase of the GIPA project consisted of carrying out a stocktaking exercise on the existing situations and experiences of the PLWHA groups and networks in India, Bangladesh, Nepal, Pakistan and Sri Lanka, to determine the extent to which GIPA principles are applied.

GIPA Principles[2]

- To support the greater involvement of people living with HIV and AIDS through initiatives to strengthen the capacity of and coordination of networks of PLWHA and CBOs stimulating the creation of a supportive political, legal and social environment;
- To involve PLWHAs fully in decision making, formulation and implementation of public policies;
- To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments;
- To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalised populations;
- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS.

The content of this interim report summarises the outcomes of this rapid stocktaking exercise, carried out during summer 2001.[3] This report gives snapshots of the status of GIPA in this region based on the real experience of HIV positive people. Leading networks and frontline organisations working with PLWHA were identified through this study and invited to participate in the second part of the project. Where such organisations or networks were not present, the most active individual PLWHA and activists were identified and invited.

[2] Taken from *Declaration of the Paris AIDS Summit,* 1 December, 1994

[3] The project commenced in April, 2001

The results of the Stocktaking

India was found to have the maximum number of active networks, distributed in almost every region of the country and had also the most success in bringing positive people into the open[5]. Nepal has one established network[6] and another group at an early stage of formation[7]. Pakistan has one network[8] in the country. Neither Bangladesh nor Sri Lanka has any registered networks or organised groups of PLWHA. Therefore, the organisations and individuals undertaking the stocktaking exercises in India, Nepal and Pakistan concentrated on the existing networks of PLWHA vis-à-vis GIPA, while in Bangladesh and Sri Lanka the same data were sought from individual PLWHA.

Common Issues of the Region

(A) Stigma and discrimination

Stigma and discrimination is widespread over the region. Bangladesh and Sri Lanka. lack PLWHA networks, and still have to overcome a deep-rooted stigma before PLWHA feel secure enough to step forward. In Bangladesh there are examples of HIV positive people being thrown into jail or isolated lockups. Eight positive people have got together in Dhaka and are trying to form a network of PLWHA. In Sri Lanka, while stigma and discrimination have not been seen to manifest in physical punishment or captivity they have serious psychological implications for PLWHA. With the exception of one HIV positive person who has come out into the open, the entire community of positive people in Sri Lanka is totally invisible.

Sri Lanka reports a trend towards higher discrimination by the more educated strata of society. Lower echelons of society in Sri Lanka, in terms of economy and literacy, are reported to be far more open and sympathetic towards the PLWHA, while the stocktaking report cites several incidents of public humiliation and rejection of an HIV positive colleague by many doctors. Noting this trend can be useful in conducting awareness and information dissemination campaigns designed as an antidote to stigma and discrimination.

There are numerous incidents across the region of rejection of PLWHA by doctors and paramedical staff and refusal to requests for treatment. This can be attributed to the fear of contracting the infection from PLWHA, especially in places that do not have the facilities to enable the doctors to practice universal precautions. The stocktakers noted a difference between these incidents and the rejection by doctors in social situations, which are indicative of discrimination not based on fear for oneself, but seemingly on prejudices towards the PLWHA. This illustrates that just getting rid of irrational fears of infection by the dissemination of information is not going to reduce discrimination and stigma, if

---

[5] See Annexe for a List of some of the organisations approached for information
[6] Prerana, Kathmandu
[7] The group in Makwanpur
[8] New Light AIDS Control and Awareness Group, Lahore
[9] Dr. (Mrs.) Kamalika Abeyratne

these originate from reasons other than lack of information, as is the situation in Sri Lanka.

This judgemental basis of the discriminatory attitudes persists in the entire region. Remarks such as "These people deserve it", "If such people die, there is no loss to anyone", "Why waste money on them?" are audible all over the sub-continent. The stocktakers[10] in India especially, felt strongly that since this attitude has already been tackled with reasonable success in several parts of the world, our region can learn from these experiences. These lessons need to be adapted to the South Asian environment and implemented as an integral part of all awareness packages on HIV.

(2) Availability and accessibility of services

Issues related to care cannot be dealt with in isolation. Some of the issues touched upon here are as much a part of Stigma & Discrimination or Human Rights. In theory no government in the region has denied that people living with HIV/AIDS also deserve health care – and that their need for this is often more acute than that of others. But the reality is that PLWHA are often denied access to necessary health services, all over the region. In some countries, there is such complete denial that there is no expectation from PLWHA of receiving any medial support.

Nepal reports a mere three to four clinics or hospitals that have undertaken to treat PLWHAs for opportunistic infections. There are counselling centers run by GOs (Government Organizations), NGOs and individual activists, but these are also far fewer than the required number. Estimated prevalence in Nepal is 50,000. Sri Lanka, has a list of four organisations doing care work, with 366 known and documented PLWHA, and an estimated prevalence of 7,500.

In India the National AIDS Control Organisation has decentralised operations into separate State AIDS Control Societies with the idea of responding more effectively to the needs in each state. However, the efficiency with which these societies respond to the needs of HIV positive people varies greatly. The Indian Government also partnered with a Delhi based NGO and initiated its first (pilot) Care Home project. Following its success, several more Care Homes have been initiated in partnership with different NGOs. The attempt to increase the number of testing centres and ensure that each of these centres has qualified counsellors attached to them to provide pre-test and post-test counselling is already underway. But these steps, though essential and commendable, are small in comparison to the vast extent of need.

Overall these findings indicate a dearth of health care services for PLWHA in the region. Also, many of the available services are unfriendly, some even openly hostile to the PLWHA who come for treatment, rendering them inaccessible.

---

[10] Mr.Cedric Fernandes of Sahara carried out the Stocktaking for India. He is also the Project Officer for this GIPA project.

On the other hand, the region is full of organisations working in the area of HIV awareness and information dissemination. But as the above section on 'Stigma & Discrimination' shows, their impact has not yet been felt by many PLWHA.

(3) Human Rights

In Bangladesh the situation of human rights in relation to PLWHA seem critical. In Sri Lanka, the confidentiality of PLWHA is absolute, to the extent of being secretive. As PLWHA are not visible, the reality of the human right situation is difficult to estimate. In Pakistan, Nepal and India, incidents of human right violations have been reported. In Nepal the stocktaker did not identify organisation(s) or individual(s) who would support the PLWHA to seek legal redress. Pakistan does have one known organisation working from the province of Sindh in this field[11].

In India NGOs and many individual activists and lawyers are working towards securing social justice for PLWHA and taking legal action against offenders. Some agencies have exclusive departments working for HIV positive people seeking legal redress. The problem remains devastating for the illiterate and poor. This group is so intimidated by people in authority that they mostly accept whatever treatment is dealt out to them and do not believe in their right to equality or defence. Most offences suffered by individuals of this group go unreported by year after year, reinforcing the sense of impunity of offenders. Each neglected incident and each passing year makes matters worse.

There are many examples in India of public interest litigation on behalf of PLWHAs. When a PLWHA was refused surgical treatment in a premier government hospital in Delhi, Public Interest Litigation (PIL) was filed in the Supreme Court of India with the help of an NGO. The hospital admitted the patient and performed the surgery before hearings commenced in court. When the Supreme Court came out with a ruling that the right of positive people to marry was suspended, another PIL was filed in the premier court by an HIV positive person and his fiancée with the help of the same NGO, challenging the ruling.

When the practice of identifying PLWHA at government hospitals in Delhi with a label that proclaimed, "AIDS case" was challenged, this practice was discontinued: the label was replaced by one proclaiming "Bio-Hazard"! The body bags containing casualties of AIDS are often labelled, ensuring total neglect of these bodies or treatment like trash. There is a report of an HIV positive woman who died under suspicious circumstances in Bangladesh. No doctor was willing to perform an autopsy and so she was buried without this. Even if the cause of her death was murder, there was no official interest in pursuing the case or the perpetrator. These incidents provide proof of the societal PLWHA are subjected to and the stigma of being HIV positive, even after death.

[11] Secretariat of Network of NGOs, Sindh

(4) Level of Involvement of PLWHA

Similar reports have been received by the stocktakers in different countries on this issue. It has been found that there is an absence of effective involvement of PLWHA at every level of the initiatives against HIV/AIDS throughout the region. For GIPA to be effective and successful, PLWHA have to be included at all levels of programme planning and implementation. Their views have to be solicited from the initial stages of the dialogue and they have to be included in the team that plans the objectives and activities. Including them in the monitoring and evaluation is also essential.

PLWHA are unique in possessing a special insight in and commitment to the success of the programmes. Moreover, since there are a number of organisations, especially NGOs, which have PLWHA working for them, there is a pool of PLWHA who possess the know-how of planning, implementation, monitoring and evaluation, and others with the potential to learn the same. The stocktakers agreed that it was worth making the effort to train this group as nobody was in a better position to assess their needs, as well as the socio-economic and other causes of vulnerability to HIV infection. Secondly, it has been demonstrated by smaller efforts such as Counselling Centres, Care Homes, etc that clients respond best to fellow PLWHA, thereby increasing the chances of the programme's success.

Another way of involving the PLWHA and building their capacity is for all organisations working in this field to employ PLWHA and include them in all their activities. Until all stakeholder organisations match the recommendations with action, GIPA, intended to be a ‘living document’, will remain an idea on paper.

Joining PLWHA Networks

At the time of the stocktaking Bangladesh and Sri Lanka did not have any registered PLWHA networks, while India had several. One established network existed in Nepal and one in Pakistan. Faced with vicious discrimination, eight positive people started trying to set up the first Network of PLWHA in Bangladesh. Their biggest obstacle was to get other positive people out in the open to face the intense stigma.

In Sri Lanka, confidentiality is practised strictly by the Ministry of Health, which keeps the records of all known HIV positive people in the country. This is considered an exemplary principle, to be followed by all counsellors in the country and also to protect the PLWHA from the psychological impact of discrimination and possible loss of employment. This strategy has worked so well that since the beginning of the pandemic, only one person has lost a job because of HIV positive status. However, the health care system has not actively tried to facilitate networking among PLWHAs for peer support though it is the only institution capable of doing so assuring the anonymity of the people testing positive. When the stocktakers placed an advertisement in newspapers for PLWHA to come for a meeting in the strictest confidence, there was no response. This situation is, however, not unique and exists even in countries with active networks.

All the countries in the region, including India with its dozens of registered networks and informal groups, need more networks to cover even 1 % of the estimated numbers of PLWHA. The reasons that stop PLWHA from coming forward and joining forces are similar across the region. The threat of severe stigma, which could be the result of revealing positive status, is a major issue. The fear of losing jobs and livelihoods while getting nothing in return from having revealed positive status is acute. All PLWWA want concrete returns from joining a group. They do not have the feeling that much will change because they join.

There is an apprehension that today GIPA heads the list of popular issues but tomorrow something else will take its place. As far as PLWHA are concerned, many feel that they have to carry their own crosses as nobody is going to help them. They may have seen that even when other PLWHA came out into the open and spoke out, nothing improved either in their lives or in those of other PLWHA. People coming out have been objects of morbid curiosity for which the clients of the mass media crave. At best, they have received handouts and at worst, their sensationalised stories have been splashed all over the newspapers / TV screens with no regard to them or their families. Those who decide to stay quiet believe that they are avoiding trouble while losing nothing.

Disclosing one's HIV status or becoming a member of a PLWHA network has been likened to a gambit in chess. One has to sacrifice several things as an immediate consequence, in the hope of later returns. A network or support group has little to offer to counter-balance these problems. In the initial months and even years, a network needs all the input its members can give to nourish it and help it grow, like a baby. Later, when it is mature, the network can take care of its members in several ways, just as when the baby grows to adulthood, the parents will be looked after. One has to measure these losses against the gains that may be anticipated in the not-too-near future – gains for oneself and for fellow victims of the pandemic. Also, visions of future gains are often not enough to offset the prospect of losing one’s job and income and the serious practical problems that are bound to follow. All the above sentiments were expressed by the PLWHA interviewed during the stocktaking process in India. All the other stocktakers also reported similar reactions from the PLWHA of their respective countries.

If GIPA were made a tangible reality, even in small ways, and PLWHA could see the implementation through the effective involvement of other PLWHA, then they might be more encouraged to join groups and become activists.

Country-wise findings

Bangladesh:

PLWHA in Bangladesh, as in many countries of the world, face manifold socio-economic and cultural problems in society. In the absence of a friendly environment, most of the identified PLWHA and their family members have to confront stigma, discrimination, and violation of human rights. This situation has also increased the number of invisible PLWHA, resulting into their non-accessibility to care, counselling and support. Most of these PLWHA prefer to live without disclosing their status because of fear and shame, or they simply are not aware of the available facilities for care and support. This situation has, however, led a handful of PLWHA to build contacts among themselves to form their own organisations and network.

The total number of PLWHA who are known to have disclosed their status is not more than 10 (6 men and 4 women). Of them one positive woman committed suicide recently. 7 of these known PLWHA live in Dhaka and 2 in Sylhet.

The PLWHAs have no registered organisation in Bangladesh. Nevertheless there is an initiative to form a self help group of people living with HIV/AIDS under the name of *Ashar Alo (Light of Hope*). The group wants to get their organisation registered with the appropriate government ministry.

With support from a group of NGOs another initiative has been taken by positive people who formed a *National Network of PLWHA in Bangladesh* on 20 January 2001 Taking stock of their situation, they have developed objectives for their network, as below.

Objectives of the National Network of PLWHA in Bangladesh

- To protect the rights of PLWHA
- To establish and enhance contact with support organisations and national, regional and international networks
- To ensure participation in policy making and implementation of the HIV/AIDS programmme at national level
- To co-operate with the government and non governmental organisations in their HIV/AIDS prevention programmmes
- To provide necessary information, counselling and services to HIV positive people

The PLWHA and their organisation/network were not, at the time of the stocktaking, aware of the GIPA principles. Most of them had never heard of the Paris Declaration. Nevertheless, their activities aimed at reaching the goal of "greater involvement" in response to the HIV/AIDS situation in the country with the effective assistance of the NGO Support Network. It was felt that through the strengthening of knowledge and understanding of GIPA principles through various strategies and activities of the

PLWHA Network and supportive NGOS would be a first step in increasing the influence of PLWHA.

The PLWHA expressed the need for skills to advocate for their concerns at various local, national and regional fora. All agreed that to respond to the HIV/AIDS epidemic in Bangladesh, it would be necessary to involve PLWHA and other marginalised communities in policy and programme development, implementation and evaluation, management and administration. The PLWHA organisations and individuals would also have critical contributions to make in the creation of a supportive environment for all HIV positive people in society.

India:

The networks for PLWHA in India are extensive and well organised. The Indian Network of Positive People INP+ has been instrumental in initiating the formation and development of positive networks.

The Activities and mandate of the networks:

- Care & Support, including palliative care, counselling, home based care
- Referral
- Advocacy
- Research
- Capacity building
- Training
- Income generation and fund mobilisation

Fledging groups are involved in:

- Emotional support
- Moral support
- Material support
- Information dissemination
- Awareness and prevention
- Personal harm minimisation

Many groups are not exclusively for PLWHA and often include affected members though sometimes their participation in discussion with regards to issues of PLWH/A is restricted.

The specific needs identified by PLWHA are:

- Access to testing and counselling
- Treatment
- Support in changing health-seeking behaviour
- Sensitising of the medical fraternity
- More clinically empowered doctors in reference to HIV/AIDS related treatment
- Support for the formation of more self-help groups
- Sensitising of families of PLWH/A
- Support of children of PLWH/A
- Overcoming excessive dependence on NGOs
- Access to accurate and sensitive information
- Fora to address human rights abuse
- Legal options to address human rights abuse
- Increasing awareness of human rights
- Ending dissemination of fear-based messages about HIV/AIDS
- Correcting discriminatory practices in the work place

The capacity building requirements of PLWHA to achieve these objectives and effectively advocate for their needs were identified as training in areas of accounting, administration, documentation, computers etc. There was also a general need expressed of equipped office space including communication facilities such as email and telephone and sustainable funds to carry out the work. Most of these groups have faced ostracism and marginalisation in the form of social rejection from landlords etc – especially in the initial stages.

Most of these groups are democratically managed and involve members in the decision-making processes through consensus or voting. A few of the groups were aware of the GIPA principles before the stocktaking and were using them as an advocacy tool.

Stigma seems to be deep seated and requiring a nation wide awareness campaigning. Even then it was estimated by the stakeholders that it would be a process which would take years before the stigma is actually reduced. Women particularly are affected by stigma. In North Indian states especially, there have been numerous incidents of monogamous women getting blamed for the infection coming into the house. The women in such situations were blamed for bringing bad luck and disease into the families, when they had, in fact, got the infection from their respective husbands who had multiple partners. On the death of the husband, such women are often turned out of the house of their in-laws. The taboo on a woman who has ‘failed in her marriage’ is so prevalent that they can not return to the homes of their parents. These women are often forced to live out their lives on the streets, at the mercy of charity. The number of such women and their children (who may also be infected) who seek the help of networks and NGOs is high. The networks feel frustrated and powerless since most do not have the resources to support such women and children who need a place to live, medical care and the means to earn their own livelihood.

Nepal

Prerana, a support group of PLWHA in Kathmandu, was formed in 1997 as a result of efforts by three NGOs, LALS, WICOM and B.P. Memorial Foundation, who were coming across a number of infected persons in the course of their work and realised the need for a self help group for PLWHA. The activities carried out included peer education, home visits, classes on alternative therapy and meditation, networking with other NGOs, INGOs, media interaction, food funding programme, treatment, facilitating access to test, drop-in-centre etc. For various reasons, including the lack of sustainable funding, Prerana could not work effectively for a long time and they are now in a process of restarting the network.

Only one member of the network expressed awareness of GIPA Principles. However, on brainstorming they did feel that it was necessary for them to be involved in decision making. One of their biggest resentments with the past management of Prerana was that they were never involved in decision making. The involvement of three separate NGOs also sometimes resulted in confusion and lack of clarity.

Another support group based in Makwanpur is just trying to start. At the stocktaking there were a total of 9 members in this network of both infected and affected people. The group was facing stigma and discrimination at all levels including family and community as well as lack of health facilities. The process of formation has just begun and the members were not aware of GIPA before the stocktaking. Until then the members met informally only once in awhile.

The obstacles for implementing GIPA in Nepal has been widespread discrimination and stigmatisation. One of the causes of discrimination seems to have been negative IEC campaigns which have had discriminatory and fear based messages and led to the belief that PLWHA are themselves to blame. The stigma has been further increased since most of the PLWHA are from the marginalised communities such as sex workers, IDUs or migrant labourers.

A majority of the PLWHA who have disclosed their status are from the economically disadvantaged sections of the society. Their immediate needs have been identified as food, shelter, medicines, home (in case of returning sex workers) or the next dose of drugs (in case of IDUs). These needs often take precedence over the cause of advocacy or involvement.

The majority of the initiatives aiming at PLWHA have been donor driven and were not seen as needs based by the PLWHA. Organisations have been criticised for adopting a directive rather than facilitative role in their approach. This has made it very difficult for PLWHAs to internalise and own the cause. There is also an expressed view that some NGOs are benefitting from working with the issue of HIV/AIDS. Further, lack of efforts of NGOs to involve PLWHA beyond the fulfilling of immediate needs also obstructs the

involvement of PLWHA. The approach has been largely welfare based and has not addressed issues of long-term sustainability.

Although in principle many organisations agree that PLWHA should be involved in the decision making, in practice they have limited themselves only to provision of services. The reasons for limited involvement of PLWHA as given by the organisations included doubts regarding the capacities of the PLWHA and lack of ways to achieve greater involvement of PLWHA.

Pakistan

The only PLWHA group identified by the stocktaking was the New Light AIDS Control Awareness Group. The network is based in Lahore and has 9 PLWHA members. The main activities have included peer group support, training and capacity building activities .The members of this group were not aware of GIPA principles.

During the stocktaking process several reasons came up explaining why PLWHA groups had not been formed elsewhere in Pakistan.

Reasons for PLWHA not forming groups in Pakistan

- People are very much attached to their families
- The number of HIV reported cases all over the country is very low (Pakistan is among the high risk but low prevalence countries)
- Geographically this small number of HIV positive people are widely scattered all over the country with different educational, cultural, ethical and economical backgrounds
- HIV infected people are not still aware of the significance and benefits of such associations
- Needs of individual HIV infected cases vary too widely
- Fear of breaching confidentiality
- Fear of discrimination / rejection
- Fear of government or law and order agencies
- No advantage visible from disclosure even at the level of support and services

A problems faced by PLWHA in the country has been social isolation. The issue of access of treatment and difficulty in getting general health care at public outlets has also been a major concern. The employment situation has been critical and the non-disclosure of HIV status is often based on fear of discrimination in finding a job or dismissal on the grounds of HIV/status. Also the absence of social benefits/life insurance has been seen as a problem.

PLWHA in Pakistan have identified needs such as treatment for opportunistic infections and access to affordable retroviral drugs. Also they want to be valued and treated at par with others getting social acceptance and family and community support. Two factors identified as necessary to strengthen advocacy on these issues are the creation of a conducive environment to form representative support groups of PLWHA to discuss and resolve their problems and personal empowerment and training.

Sri Lanka

The stocktaking exercise was not able to identify any PLWHA network despite innovative efforts to track individuals to form networks. The view expressed was that PLWHAs are not ready to come out because of the high stigma and discrimination. Intense secrecy is exercised by the Sri Lanka National AIDS Control Program over PLWHA. The few PLWHA identified were not aware of GIPA principles

Promoting awareness to address risky behavior and protect vulnerable populations has been identified as a priority. Denial, as well as the stigma attached both to HIV and to groups that are at high risk, hamper prevention efforts. Initiatives to increase knowledge and awareness, and promote positive attitudes and norms among the general population, particularly youth, about safe sexual behaviors are critical. Strategies are needed to promote the involvement of at-risk communities in the design, implementation, and monitoring of prevention programmes.

PLWHA networks in Bangladesh	
National Network of PLWHA Bangladesh	**Ashar Alo,** **C/o CCDB** (Christian commission for Development in Bangladesh), 88, Senpara Parbatta, Mirpur-10, Dhaka-1216.
NGOs working with PLWHA	
CARE Bangladesh, House No. 66, Road 7/A, Dhanmondi, Dhaka-1209, GPO Box-226 Contact person: Mr. Parul Bala Modal, Activities- personal and telephonic counselling, medical assistance and legal aid to PLWHA	**CAAP** (Confidential Approach to AIDS Prevention), House no 63, Block-D, Road 15, Banai, Dhaka-1213. Contact person: Dr. Halida Hanum khondakar (Director), Activties: counselling, care and support to PLWHA.
CCDB (Christian commission for Development in Bangladesh), 88, Senpara Parbatta, Mirpur-10, Dhaka-1216, Contact person: Ms.Dilruba Karim, Activities: Counselling	**HASAB** (HIV/AIDS&STD Alliance Bangladesh), 4/1, Iqbal Road,Mohammedpur,Dhaka-1207, Contact Person: Ms. Habiba Tasneem, Activities:capacity building, advocacy and awareness raising, treatment and management of STDs, counselling on sexual health and STD management.
SHISHUK(Shishuk Shastha Unnayan Karzkaram), 7/1,Block-A, Lalmatia, Dhaka-1207, Contact Person : Mr.S.M.Morshed., Activities: care, counselling and support programme.	**IDHRB** (Institutional Development of Human Rights in Bangladesh), House No. 500/h, Road 8, Dhanmondi R/A, Dhaka-1205, Contact Person : Mr.K.M.Huque, Activities: Awareness programme on HIV/AIDS, promotion of human rights of PLWHA.
Rotary Club Dhaka , 168/C, Green Road, Dhanmondi, Dhaka-1205, Contact person: Mr. Ahmed Faooque, Activites: Advocacy programme for media and lawyers to promote and protect the human rights of PLWHA.	

PLWHA Networks in India	
INP+(Indian Network of positive people) Flat No. 6/93 Kash Towers, South west Mambalam, T Nagar, Tel 4329580 4329582	**MNP+** (**Maharashtra Network of positive people).** 3rd floor, BMC eye hospital, Malan Shoukat Ali Marg, Don Taki, Mumbai. Tel 3011005
MNP+(Manipur Network of positive people). Post bag 145 Yasaikul police lane, Imphal-795001 Manipur. Tele-224186	**PWN+(Positive women Network of South India)**, No.23, Brindavan street, West Mambalam, Chennai.33 Tele 3711176
DNP+ (**Delhi Network of positive people).**	**GCP+(Goan Community for Positive people),** B.J.B Shetty , G.Store Gurudwara Road, Mangor Hill, Vasco-da- Gama, Goa-403802 Ph-0832-501495
Positive life. 301/3, Kirti Appartments, Mayurvihar Phase –1, New Delhi –92, Tele-6915321,2719666	**TNP+ Tamilnadu Network of Positive people** Room No 41, Hayroon Mansion, No 51, Tahyar Sahib Street, Chennai-600002 Ph 8516482(O), FAX-044-8549479,

People Plus Society (PPS) Andhra Pradesh Drop in Centre Door no.15-1-133, Bhavana Enclave Naoroji Road, Maharani Peta, Vishakpatnam - 230002 Tel: 0891-567267	**CPK+ , Council of People Living with HIV/AIDS in Kerala** 3rd Floor, Noor Mansion, St Alberts High School Lane, Cochin 68 20 35 Telephone: 0484 36 76 85
CNP+, Calcutta Network of Positive people 8/1 Bhavani Dutta Lane, Kolkata-700073, Ph-(91-33) 241-6200	

<table>
<tr><td>PLWHA Networks in Nepal</td><td></td></tr>
<tr><td>Prerana

P.O Box:20126
Kathmandu.
Ph-425901
Fax-485861</td><td>Support group in Makwanpur</td></tr>
<tr><td>NGOs working with PLWHAs in Nepal</td><td></td></tr>
<tr><td>ABC Nepal,
P.O Box 5135,Kathmandu,Nepal
Ph- 977.1.413934
FAX: 977.1.227623
Contact person: Ms. Durga Ghimire</td><td>MAITI Nepal,
Gowshala, Kathandu, Nepal
Ph-977.1.492904/494816
FAX:977.1.492055;481848
Contact person:Ms.Anuradha Koirala
Activities: Rescue and repatriation, rehabilitation centre for rescued victims of trafficking and PLWHA</td></tr>
<tr><td>Freedom Centre
Activties: Drug detoxification& rehabilitation centre,group counselling</td><td>WOREC-Women’s Rehabilitation Centre
Gaurighat, GPO BOX 13233
Kathmandu, Nepal
Ph-977.1.494815
FAX:977.1.471104
Contact person:Dr.Renu Rajbhandari
Activites: Awareness on HIV/AIDS and prevention of trafficking.</td></tr>
<tr><td></td><td>Karuna Bhawan,
Activites: Home for HIV infected women</td></tr>
</table>

PLWHA networks In Pakistan	
New Light AIDS control Awareness Group (NLACAG) 766/5-D1, Green Town, Lahore, Pakistan Ph-842893, 5113084 (o) No FAX	
NGOs working with PLWHA	
Pakistan AIDS Prevention Society(PAPS), 1st floor , Delhi Muslim Hotel, Arambgh Road, Karachi, Pakistan Ph-922.1.2626142/922.72139751® FAX:922.1.2626224 Chair person Mr. Shouket Ali. Activities HIV counselling, awareness raising programme for women/youth, workplace based interventions, human rights and HIV/AIDS	**Orphan Refugees and Aid International(ORA),** F-27, Khusgal Khan Khattak Road, University Town, Peshawer NWFP, Ph-92-91-841280, Fax: 92-91-841089 Contact Person Mr. Andrian McGee Activities: Awareness programme for students, male sex workers, truck drivers and eunuchs.
Dares Society for Health Care, F-23, Wahdat Colony, Quetta Baluchistan, Ph-92-81-838222, Fax: 92-81-838222 Contact person: Mr. Syed Qamar Uddin Activities: NGO capacity building , telephone hotline and counselling.	**All Women Advancement and Resource Development (AWARD),** 17(40-B) , Railway road, University Town, Peshawar, ph- 92-91-844206, Fax: 92-91-844209 contact person: Night Kamdar Activities: Health education, income generation, reproductive health, PLWHA involvement.
Pakistan Society for Allergy, Asthma, AIDS and Immunology, 275 , Gomal Road ,Sector E-7, Islammabad. Ph-92-51-827077, Fax:92-51-273669 Contact person: Dr. Mohammed Osman Yusuf Activites: specialised training, capacity building programme for PLWHA	**Physicians Forum for Family Planning,** House No. 16, street 13, K-3 Phase 3, Hyatabad, Peshawar, NWFP Ph- 92-21-814176 Contact person:Dr. Mohammed Tufail Activities: AIDS awareness through heath care providers, training programmes.

AIDS information and Diagnosis Services (AIDS), House No A-20 Block, North Nazimabad Karachi 74700, Sindh Ph-92-21-6678818,Fax: 92-21-6678819 Contact person: Mr. Ali Akthar Khan Activities: AIDS hotline , counselling for women	

PLWHA Networks in Sri Lanka	
Lanka+	
NGOs working with PLWHAs	
ACCESS (AIDS Coalition for Care, Education and Support Services), 91A Fifth Lane Colombo-3,Sri Lanka, ph- 00941573320 Contact person Dr. Kamalika Abeyratne Activites: AIDSLINE, in contact with 22 PLWHA	**The Salvation Army,** Hope House Union Place, Colombo-2, Sri Lanka, ph-544842 Contact person: Ms. Swarna de Silva. Activites: Care and Support for PLWHA and their families.
Community Development Services, 35/5 Horton Place , Colombo-7, Sri Lanka ph-00741 688183, Contact person:Ms. Kamanee Hapugalle Activities: Reproductive and sexual health, empowerment of women.	**Companions on a Journey,** 413 Havelock Road , Colombo-5,Sri Lanka ph-586000, Contact person; Mr. Sherman de Rose Activties: Care and support of gay men
Centre for Policy Alternatives, 32/3 Flower Road, Colombo-3, Sri Lanka ph-00941565304, Contact person:Mr. Rohan Edirisinghe Activities: Legislation to preserve human rights of PLWHA, advocacy	**NEST,** Kare House, 241 Beach Road, Pallyawatte Hendala, Sri Lanka,ph-009415376201/2 Contact person: Ms.Sally Hulugalle Activities:Country network of care and support services for mental health and PLWHA