

From Involvement to Empowerment

People Living with HIV/AIDS in Asia Pacific

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Glossary

| | |
|---------------|--|
| AIDS | Acquired Immuno Deficiency Syndrome |
| APN+ | Asia Pacific Network of PLWHA |
| APPC | Asia Pacific PLWHA Coalition |
| APPRC | Asia Pacific PLWHA Resource Centre |
| ART | Anti Retroviral Therapy |
| CCDB | Christian Commission for Development in Bangladesh |
| CD4 | A quantitative laboratory marker of immune function |
| CPK+ | Council of People Living with HIV/AIDS, Kerala, India |
| FJN+ | Fiji Network of People Living with HIV/AIDS, Suva, Fiji |
| GIPA | Greater Involvement of People Living with HIV/AIDS |
| GNP+ | Global Network of PLWHA |
| HA | HIV Anonymous |
| HIV | Human Immunodeficiency Virus |
| HPPWS | HIV Positive People's Welfare Society, Tamil Nadu, India |
| ICHAP | India Canada Collaborative HIV/AIDS Project |
| ICT | Information and Communication Technologies |
| ICW | International Community of Women with HIV/AIDS |
| IDU | Injecting Drug Use(r) |
| IEC | Information Education Communication |
| INP+ | Indian Network for PLWHA, India |
| KANOS | Korea HIV/AIDS Network of Solidarity, Seoul, Republic of Korea |
| KNP+ | Karnataka Network of PLWHA, India |
| MNP+ | Manipur Network of People Living with HIV/AIDS, India |
| MSI | Marie Stopes International, China |
| MSM | Men who have Sex with Men |
| NACO | National AIDS Control Organisation, India |
| NAF | National AIDS Foundation, Mongolia |
| NAPWA | National Association of People Living with HIV/AIDS, Australia |
| NGO | Non-Governmental Organization |
| NLACAG | The New Light AIDS Control Awareness Group, Lahore, Pakistan |
| NMP+ | Network of Maharashtra by PLWHA, Pune, India |
| NNP+ | Network of Naga PLWHA, India |
| PLWHA | People Living with HIV/AIDS |
| PWN+ | Positive Women's Network, Chennai, India |
| SACS | State AIDS Control Society, India |
| STD | Sexually Transmitted Disease |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNDP | United Nations Development Programme |
| UNGASS | United Nations General Assembly Special Session on HIV/AIDS |
| VCTC | Voluntary Counselling and Testing Centre |

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Foreword

The complex challenges posed by the HIV/AIDS epidemic calls for an extraordinary set of responses. Years of engagement with the epidemic have brought home a fundamental realisation that the active participation and support of People Living with HIV/AIDS (PLWHA) are critical for an effective, humane response to HIV/AIDS. It has been reiterated in several countries where the reversal of the epidemic has an indisputable link with the conscious efforts to respect the fundamental rights of PLWHA. It has also been convincingly expressed in international treaties and commitments.

However, the meaningful involvement of PLWHA in the response to HIV/AIDS is yet to gain momentum in the Asia Pacific region. On the one hand, decision makers do not seem to fully appreciate the potential demonstrated by PLWHA, while on the other there are limitations - some inherent and some imposed - on the capacities of PLWHA.

Since 2001, UNDP has developed and supported a number of initiatives in partnership with a range of PLWHA groups and organisations, bi and multilateral and civil society organisations to support the needs for capacity building and empowerment articulated by PLWHA. These initiatives originated from a philosophy of inclusiveness that helped people listen, learn and respond to one another and forge partnerships. These initiatives utilised a wide range of tools: policy dialogues, networking, advocacy, and capacity and

leadership development. The efforts have contributed to the gradual emergence of empowered PLWHA leaders and groups in the region, who have shown immense potential to positively influence their future as well as the course of the epidemic.

This report documents the efforts by UNDP to support the empowerment of PLWHA and their groups in the Asia Pacific from 2001 to 2004 and the lessons learnt in the process.

I wish to thank all the PLWHA in the region, their groups and networks; especially Sahara, the Asia Pacific Network of People Living with HIV/AIDS (APN+), the Indian Network for People Living with HIV/AIDS (INP+) and UNDP country offices without whose participation and leadership the initiatives described in this document would not have been possible.

I hope this report will inspire all the stakeholders and the PLWHA groups in the region to join hands and ensure the wellbeing of millions of people living with HIV/AIDS in the region and their empowered involvement in all aspects of the response to the epidemic.



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The Context

PLWHA in Asia Pacific - the Realities

THE SCALE OF THE PROBLEM

As the HIV/AIDS epidemic continues to grow rapidly across the world, the 25 million plus adults and children living with HIV/AIDS in the Sub-Saharan African region¹ continue to be at the centre of global attention. While the scale of the epidemic in Sub Saharan Africa is indeed disturbing, the region that is yet to receive equal attention is Asia Pacific, where the spread of HIV/AIDS over the last ten years is equally alarming.

Until the late eighties no country in the Asia Pacific region, which now shelters more than 60 percent of the world's population, had experienced any major HIV epidemic. Yet, only a decade later, 7.4 million people from across the region were living with HIV. In 2003 alone, one million people in the region were newly infected with HIV, an increase of 10 percent over the previous year. The Asia Pacific region now has more People Living with HIV/AIDS (PLWHA) than any other region in the world with the exception of Sub-Saharan Africa.

THE HUMAN FACE OF THE EPIDEMIC

Undoubtedly, the figures mentioned above show the scale and trends in the spread of the HIV/AIDS epidemic. However, on its own, these numbers prove to be woefully inadequate in describing the depth and intensity of the experiences of individuals and communities affected by HIV. At the centre of the epidemic in the Asia Pacific region are more than 7.4 million

PLWHA. In attempting to grasp the baffling scale of the epidemic through numbers alone, one often tends to overlook the fact that each figure conceals a man, a woman or a child, a family, a community and therein, a story, a challenge and an opportunity.

The limited control that most PLWHA have over making choices that impact their lives is one of the main causes for the spread of the HIV/AIDS epidemic in the Asia Pacific region. It is closely intertwined with the endemic socio-political and economic deprivation that majority of PLWHA face. Factors such as unequal distribution of resources, lack of access to information, gender inequality, and socio-cultural taboos surrounding sex and sexuality also play a significant role in making a large part of the population vulnerable to HIV infection.

Despite the fact that knowledge on prevention of HIV transmission has been available for almost 20 years, the rapid increase in the number of PLWHA in the region also underscores the criticality of several larger socio-political and economic factors that contribute to the spread of the infection. Some of these factors are:

- The low status of women and other marginalised sections of the population
- Absence of dependable social support systems
- Political instability that is often triggered by conflicts and larger governance challenges
- Endemic poverty and deprivation and
- Poor human rights standards and legal environments

According to UNAIDS, the window of opportunity for bringing the HIV/AIDS epidemic under control in the Asia Pacific region is closing fast. New infections are reportedly emerging at the rate of one person

¹ UNAIDS 2004 Report on the Global AIDS Epidemic (July 2004)

every minute. Each new infection has further detrimental consequences for the individual as well as his or her family and the community that the infected person resides in. This is largely on account of the fact that severe stigma and discrimination accompanies the infection.

With the exception of Cambodia, Myanmar and Thailand, the number of PLWHA as a proportion of the general population is comparatively low in most of the countries in the Asia Pacific region. However, the low national prevalence rates mask serious, localised epidemics that have large numbers of PLWHA.² China and India are examples of two densely populated countries in the region whose low HIV sero-prevalence rates do not reflect the true picture. In China (total population: greater than 1.2 billion), for instance, an estimated one million people were living with HIV/AIDS in mid-2002.

In India, the HIV prevalence rate is a low 0.8% of the adult population (total population: over 1 billion). Estimates released by the National AIDS Control Organisation (NACO) in July 2004 shows that some 5.1 million people in the country are HIV positive. This count brings home the startling reality that India now has the second largest number of PLWHA living in a single country after South Africa. The figure also marks an increase of nearly 600,000 new infections compared to the previous year. Six states within India - Tamil Nadu, Maharashtra, Karnataka, Andhra Pradesh, Manipur, and Nagaland - fall under the category of 'high prevalence' states, where HIV prevalence among ante-natal clinic attendees has crossed the one percent mark. The disturbing fact is that a vast majority of PLWHA are unaware of their sero-status.

AREAS OF CONCERN

Stigma & discrimination

AIDS-related stigma and discrimination directly hamper the effectiveness of AIDS responses. Stigma and concerns about discrimination constitute a major barrier to people opting for voluntary testing and directly affect the likelihood of protective behavior. Though there are about 7.4 million PLWHA in the

region, there is only a handful that has come out. This makes the epidemic invisible or as experts say, forces it underground.

The lack of social conditions to come out deters the opportunity to unify cohesive gathering of PLWHA as a group. Thus, their voice is still limited or unheard. Strong public perception on the association of HIV/AIDS with socially marginalised people such as sex workers and injecting drug users (IDUs) still prevails in several countries, making the stigma stronger and persistent. Several countries perceive these groups as socially deviant and illegal, which deserve punishment. The less privileged background of PLWHA deludes an impression that they are not capable of making a significant change.

The research study by the Asia-Pacific Network of People Living with HIV/AIDS (APN+)³ among HIV-positive people in India, Indonesia, Philippines and Thailand brings to fore the widespread existence and severe challenge of AIDS-related discrimination in the region. Based upon structured interviews of 764 people living with HIV/AIDS in the above countries, the study found that 80 percent of them experienced discriminatory practices in vari-

"Some people with AIDS are denied basic rights such as food or shelter and dismissed from jobs they are fit to perform. The fear of stigma leads to silence and when it comes to fighting AIDS, silence is death."

- Kofi Annan, Secretary-General, United Nations

ous settings. In particular, various forms of discrimination were experienced in the health sector (54 percent), in the community (31 percent), within the family (18 percent), and at the workplace (18 percent). The study also revealed that the extent of discrimination in the community and within the family was significantly greater for women living with HIV/AIDS than that for male PLWHA. Discriminatory practices for women included physical assault and forced relocation of residence. The study demonstrated with evidence that discrimination against PLWHA, particularly women, is present in all walks of life.

2 Fact sheet 2004, UNAIDS/Asia

3 AIDS Discrimination in Asia, APN+ (2004)

Violation of human rights

Stigma and discrimination has a direct bearing on human rights, safeguarding of which is an essential part of responding effectively to the AIDS epidemic at individual, national, regional and global levels. HIV strikes the hardest where human rights are the least protected, particularly among people and communities on the margins of society, including sex workers, injecting drug users and Men who have Sex with Men (MSM). Conversely, safeguarding people's fundamental rights improves their ability to protect themselves and others at risk of HIV infection and assists them in dealing with the impact of the epidemic.

"In the last ten years of my life as a person with HIV/AIDS, the most disturbing instances that are uppermost in my mind are images of discrimination rather than those of death - people mercilessly beaten, people thrown out of jobs, people abandoned midway on surgery tables, people denied access to property, people denied shelter, people pushed to destitution..."

- K. K. Abraham, President, Indian Network for People Living with HIV/AIDS (INP+)

Studies^{4,5} revealed that widespread human rights violations against PLWHA exist in various forms in the region. Examples include refusal of treatment or admission in the hospital, HIV testing without consent or proper counseling, breach of confidentiality, denial of social services, discriminatory practices in the workplace, community ostracism, and, above all, denial of a dignified life. Studies found that these human rights abuses are ascribed to lack of understanding on HIV and the modes of transmission and, in some cases, the presence of inappropriate or discriminatory legislations.

It has also been shown that PLWHA in marginalised groups such as women, migrant workers, injecting drug users, sex workers, and men having sex with men are particularly subjected to serious and frequent human rights abuse, which drive them further underground

and leave these rights violations unnoticed and sustained. For instance, in some South East Asian countries, coerced HIV test is performed on migrant workers, or people who work elsewhere in the region. In some Middle Eastern countries, the few million migrant workers from countries like India, Bangladesh, Pakistan and Sri Lanka are required to have HIV test every time they renew their contract. Those found positive get deported immediately without proper counseling, medical insurance coverage or any specific welfare security.

Access to treatment

Knowledge of HIV status is the gateway to HIV/AIDS treatment and other services and has documented prevention benefits; however, the current reach of HIV testing services is severely limited and uptake is often low, largely because of the fear of stigma and discrimination. Not only do healthcare providers lack experience in treating positive people, negative attitudes of most health workers, as evidenced by the APN+ study mentioned above, often deter PLWHA from receiving treatment. Moreover, what compounds matters is the fact that many PLWHA have no or little knowledge about antiretroviral (ARV) treatment for HIV and treatment for opportunistic infections.

"Lack of access to antiretroviral treatment is a global health emergency...To deliver antiretroviral treatment to the millions who need it, we must change the way we think and change the way we act."

- LEE Jong-wook, Director General, WHO

Benefits of ARV treatment have been well demonstrated. They include prolonged life expectancy, improved quality of life with reduced risk of morbidity, reduced risk of vertical transmission, reduced/deferred number of orphans, and sustenance of productive labour force, among others. Furthermore, studies⁶ have shown that increased access to ARV treatment leads to reduction in stigma and discrimination against PLWHA.

Not only does ARV treatment improve the physical

4 Law, Ethics and HIV/AIDS in South Asia, UNDP (2004)

5 Baseline needs assessment of PLWHA groups and GIPA in the Asia Pacific region (unpublished document), APPRC (2004)

6 A Public Health Approach for Scaling Up Antiretroviral (ARV) Treatment, WHO (2003).

and mental health of positive people, it also contributes to the health of a national economy. Brazil, which introduced universal access to ARV therapy in 1996, for instance, observed 60-80 percent reduction in the morbidity rate of most common opportunistic infections such as TB and Kaposi's sarcoma between 1995 and 1999⁷. The Brazilian Ministry of Health estimated that the introduction of universal ARV treatment programme saved the country US\$ 472 million between 1997 and 1999 from significantly reduced incidence of hospitalisation and treatment of opportunistic infections among PLWHA.

Despite such tremendous and demonstrated benefits from the other side of the globe, access to antiretroviral treatment and treatment for other HIV-related diseases remains abysmally low in the Asia Pacific region. Five to six million people in low and middle-income countries need antiretroviral treatment immediately. However, the World Health Organization (WHO) estimates that only 400,000 people worldwide at the end of 2003 had access to it. This means that nine out of ten people who urgently need HIV treatment are not being reached.

Though many countries in the Asia Pacific region have begun to establish systems for ARV therapy, particularly following the WHO's 3 by 5 Initiative, lack of political commitment and resources, disempowering social values and norms, fear of stigma and discrimination and lack of rights-based approaches severely hamper its reach to PLWHA. Treatment discourse is still considered a troublesome task, particularly when seen in the context of resources. Countries in the region such as India and Thailand produce cheaper generic versions of many of the ARV drugs, but more than 90 per cent of the PLWHA in Asia Pacific either do not have access to them or find them unaffordable while the same drugs benefit several countries in Africa.

The solution in transferring the financial merits of generic drugs lies in bulk-purchases and ensuring treatment preparedness universally across the region. Reports indicate that the drug companies would be able to reduce the prices further for large-scale

orders. At present, the basic first-line ARV cocktails are available for roughly US \$30 a month⁸ to PLWHA in the region, which is higher than the price of drugs (about US \$11 a month)⁹, sourced for Africa from India by Clinton Foundation. In addition, bringing ARV into the public health system by the national governments in the region would also help reduce prices. Despite the clear evidence of treatment aiding prevention, most countries in the region have not included it as part of a comprehensive prevention strategy as has been demanded by PLWHA groups and networks in the region.

Women living with HIV/AIDS

Another disturbing trend in the Asia Pacific region in the recent years is the increasing feminisation of the epidemic. Of about 7.4 million people living with HIV/AIDS in the region, about a quarter, or 2 million, are women at the end of 2003¹⁰. The number of women living with HIV/AIDS grew by 13 percent in two years between the end of 2001 and the end of 2003. This is slightly higher than the corresponding figure for men, which shows a rise of 12 percent, suggesting the potential onset of more rapid feminisation of the epidemic as observed in Africa.

Studies show that the severe gender inequality in political, social, educational, and economic areas and absence of informed choices in the region render women extremely vulnerable to HIV and subject them to intense stigma and discrimination¹¹. Women often have no control over their sexual lives and have extremely limited access to prevention information and services. However, even the best knowledge of prevention does not guarantee safety for women because of the overpowering dominance of patriarchy.

HIV infection brings in disproportionately heavy burdens on women. Reports from women living with

7 The Brazilian Ministry of Health, www.aids.gov.br/assistencia/aids_drugs_policy.htm, accessed on July 27, 2004.

8 "Expanded availability of HIV/AIDS Drugs in Asia creates urgent need for trained doctors": TREAT Asia, <http://web.amfar.org/treatment/specialreport/Appendix1.asp>, accessed on September 16, 2004.

9 "Clinton brokers AIDS drugs deal": CNN.com, dated October 24, 2003, <http://www.cnn.com/2003/ALLPOLITICS/10/23/clinton/>, accessed on September 16, 2004.

10 2004 Report on the Global AIDS Epidemic, UNAIDS (2004)

11 "Oh! This one is infected!": Women, HIV & Human Rights in the Asia-Pacific Region. Paper commissioned by the UN Office of the High Commissioner for Human Rights, from ICW 2004

HIV/AIDS in the region show that most of the time, they are morally judged, blamed for the infection of their spouses and are burdened with the care of the latter. When the women themselves fall sick with HIV-related illnesses, they are thrown out of families and denied legal rights to properties and children.

In the region, the vulnerability of women also arises from unsafe mobility and trafficking. In several parts of the region, women are compelled to move within their countries and across national borders in unsafe conditions and without informed choices. Such situations, in many cases, lead to their being trafficked. Reports by civil society organizations in the region show that the oppressive and exploitative conditions in which the trafficked women are forced to live make them soft targets of HIV, a fact corroborated by several HIV positive trafficked survivors¹². Efforts are afoot to forge a network of trafficked survivors for peer-support and also for advocacy in South Asia.

The prevailing gender inequality exacerbates the conditions of women when they are burdened with HIV. Several members of PWN+ (Positive Women Network of South India)¹³ say that they have been denied their legal rights over their own properties and that of their spouses who died of HIV-related illnesses. Therefore, improvement of overall gender situation in the region is essential for a more empowered and dignified existence of women living with HIV. Concerted efforts are needed to address both the issues simultaneously.

Participation of PLWHA

The active involvement of people living with HIV in decision-making is still far from universal. The reality is particularly grim in the Asia Pacific region. According to the recent UNAIDS publication¹⁴, for example, Asia finds itself at second position from the bottom among all the regions of the world for PLWHA representation in the national HIV/AIDS policy discussion forums. One may argue that this is largely the result of the limited capacity of PLWHA groups in the region. However, there has been a lack of understanding on GIPA among decision makers and lack of sup-

portive environment conducive to empowerment of PLWHA and their groups.

This frustrating situation is reflected in the "Bangkok Declaration" by people living with HIV/AIDS in Asia Pacific¹⁵: "A decade has passed since world leaders ratified the principle of GIPA (Greater Involvement of People Living with HIV/AIDS) at the Paris AIDS Summit in 1994, but its practice in the Asia Pacific region has been woefully feeble. We, the people living with HIV/AIDS in the region, painfully realise the disempowering presence of stigma and discrimination; lack of access to treatment and support services; lack of capacity; poor knowledge on GIPA among governments, other stakeholders and PLWHA networks prevent hundreds of thousands of experienced PLWHA from actively participating in the response to the epidemic. Our categorical learning in dealing with HIV/AIDS over the last two decades has been that without well-being and empowerment of PLWHA, GIPA can only be a pipe dream," says the Declaration.

In the second decade into the full-fledged epidemic in Asia and the Pacific, a cluster of empowered PLWHA leaders and their groups are now beginning to surface across the region. The PLWHA movement is expanding from one country to another and slowly intensifying its influence, like a quiet storm. They represent a source of inspiration, hope, support, and voice to the 7.4 million people living with HIV/AIDS in the region. At the same time, they also provide the region with a viable, promising strategy and vehicle against the epidemic- the meaningful participation of empowered PLWHA in all aspects of the response at every level of society. Their potential contributions for the wellbeing of PLWHA, the response to the HIV/AIDS epidemic, and the future of the region legitimise appropriate allocation of priority, commitment, and sustainable resources to the processes of their empowerment.

Studies and evaluation of programmes in the region clearly indicates that mere involvement does not denote participation. Participation in the true sense denotes capacity, resources, access to services

¹² Testimonials by HIV positive trafficked survivors, South Asia Court of Women on the Violence of Trafficking and HIV/AIDS. Dhaka

¹³ Interview with Kausalya, President, PWN+, for this report

¹⁴ Ibid. 10

¹⁵ The Declaration, which was released during the International AIDS Conference in Bangkok, 2004, represents the voice and pressing needs of 7.4 million PLWHA in the region.

and healthcare and an empowering and enabling environment. It is heartening that the limited understanding of involvement among PLWHA groups, Governments and other stakeholders is now gradual-

ly transforming into one that reflects participation and empowerment. However, to be effective, this emerging learning has to be translated into action, that too in an expeditious, scaled-up way.

From Involvement to Empowerment

Greater Involvement of People Living with HIV (GIPA) in all aspects of the response to the epidemic is a principle that is gaining strength since the early 1990s. What began as a rightful demand from a small group of PLWHA in Denver¹⁶ in the early 1980s has gone through a long and arduous journey, but the results are still far from satisfactory. Though the essence of GIPA is the acknowledgement of the inalienable relevance of PLWHA in the response to HIV and to involve them in every stage of planning and implementation, it is still observed more as a principle than in practice.

Revisiting the involvement of PLWHA in HIV/AIDS responses over the years will be useful in understanding why the practice of GIPA is still very weak in the region. This chapter recaps the past and argues for a "third generation response" the core of which is empowerment, capacity development and true participation of PLWHA.

THE FIRST GENERATION RESPONSE - INTERVENTIONIST APPROACHES

During the early phase of the epidemic in the United States, PLWHA helped each other and drew support from friends, family and sympathetic community members. In the popular and programmatic discourse those days, PLWHA were "victims" of disease, "targets of intervention" or "subjects of research". The medical, public health and research establishments took time to get acculturated to bringing them into areas such as clinical decision-making and planning. These early top-down

interventionist approaches constituted the '*first generation response*' to HIV/AIDS. Shades of this approach have found reflection across the world. For most countries in the Asia Pacific region where the HIV epidemic is still emerging, these first generation responses still dominate efforts to stem the spread of HIV or care for those infected and affected by HIV.

The Denver Principles

The idea that the personal experiences of PLWHA could and should shape the response to the epidemic first found a public voice in 1983 at a national medical conference on AIDS held in Denver, Colorado (United States). A small band of PLWHA gathered at this conference protesting their exclusion from the planning process of workshops related to AIDS. The group took over the plenary session of the conference to read out a series of declarations to thunderous ovation from an audience of social workers, doctors, nurses and MSM activists. These declarations are now widely known as *The Denver Principles* (See Box 1.1), and they constitute the original manifesto of the PLWHA self-empowerment movement.

THE SECOND GENERATION RESPONSE - EMERGENCE OF GIPA PRINCIPLES

The acronym GIPA was publicly vocalised for the first time during the preparatory meetings to the Paris AIDS Summit held in 1994. At this Summit, a declaration that was signed by representatives of 42 countries undertook to "fully involve people living with HIV/AIDS in the formulation and implementation of public policies..." and to "...support the greater involve-

¹⁶ More details under "The First Generation Response".

Box 1.1

The Denver Principles - Recommendations for All People

We recommend that all people:

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us, or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact. (1*)
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

We recommend that people with AIDS:

3. Form caucuses to choose their own representatives to deal with the media, to choose their own agenda and plan their own strategies.
4. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
5. Be involved in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
6. Substitute low-risk sexual behaviours for those that could endanger themselves or their partners. We feel that people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status. (2*)

People with AIDS have the right:

1. To as full and satisfying sexual and emotional lives as anyone else's.
2. To quality medical treatment and quality social service provision without discrimination of any form based on sexual orientation, gender, diagnosis, economic status, or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decisions about their lives.
4. To privacy, confidentiality of medical records, to human respect, and to choose who their significant others are.
5. To die and to LIVE in dignity.

1 HIV and the first proof that AIDS was an infectious disease was only discovered in 1985*

2 In 1983 it had not yet been scientifically proven that condoms effectively protect against HIV transmission*

Box 1.2

GIPA PRINCIPLES

- To support the greater involvement of people living with HIV and AIDS (PLWHA) 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 PLWHA 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.

Declaration of the Paris AIDS Summit, 1 December 1994.

ment of people living with HIV/AIDS (GIPA)." (see Box 1.2). The UNGASS¹⁷ Declaration of 2001, signed by almost all members of the United Nations, later reinforced the principles of GIPA. These principles were subsequently adopted by UNAIDS and since then GIPA became an integral and indispensable part of all major international declarations pertaining to the epidemic.

The strategic change from top-down to more bottom-up participatory approaches not only meant the inclusion of PLWHA but also the youths and the communities, especially vulnerable populations in the design and implementation of responses to HIV/AIDS. Although this approach is yet to become the norm in all the efforts to contain the HIV epidemic and provide care and support to those infected and affected by HIV/AIDS, there has been a clear movement towards its acceptance. Policies, projects and initiatives of this kind make the 'second generation response'.

GIPA in the Asia Pacific Region

Today, it is internationally recognised that a crucial component of HIV/AIDS advocacy is the meaningful involvement of PLWHA in all aspects of programmatic and policy related responses.

In the Asia Pacific region where a majority of PLWHA live in constant fear, battling stigma and discrimination in their daily lives, the criticality of GIPA as a strategy to alleviate their condition cannot be overstated. Public visibility of the active involvement of PLWHA at all levels was useful in challenging existing HIV-related myths and derogatory stereotyping. It has also helped in reducing the stigma and discrimination to some extent. GIPA played an important role in promoting a positive shift in the way society perceives PLWHA and laid the foundation for an enabling environment wherein PLWHA, their families and communities could live with self-respect and dignity.

Using GIPA as the guiding principle while designing responses to the HIV/AIDS epidemic in the Asia Pacific region has helped, to some extent, in qualitatively improving the effectiveness of the responses. It

¹⁷ United Nations General Assembly Special Session on HIV/AIDS, held from 25 to 27 June, 2001 in New York, resulted in a "Declaration of Commitment on HIV/AIDS" by world leaders to enhance coordination and intensification of national, regional and international efforts to fight the epidemic and mobilize resources in a more comprehensive manner.

"Despite government support, positive people are still stigmatised in Korea. They are thrown out of jobs, refused treatment and school admission and are badly discriminated. Things have to change."

- Hyun Lee, PLWHA, Republic of Korea

has also brought about a greater awareness of the GIPA Principles in the region. Unfortunately, the conditions in which PLWHA live have shown little change. Given this situation, a feeling of frustration seems to have set in amongst many of the PLWHA in the region. They feel that although GIPA has been an integral part of international declarations relating to HIV/AIDS and also in national policies, the intent of the principles, namely, to improve responses to HIV/AIDS and better the situation of PLWHA, has not been fully realised. PLWHA are still not fully included in prevention or care responses and all too often, their inclusion is tokenistic.

It is evident that the PLWHA in the region had hoped that their increased involvement in the responses to HIV through the implementation of the GIPA principles would also bring about a more meaningful empowerment across all levels. This empowerment would then enable them to address their basic needs. PLWHA groups, in partnership with UNDP and other agencies, have identified some of these needs as:

- Access to
 - information on HIV-related issues
 - testing facilities where confidentiality is respected
 - counselling services
 - quality treatment
 - community care; and
- Skills to:
 - live positive lives
 - capitalise on opportunities that could ensure sustainable livelihoods for PLWHA and their families
 - carry out advocacy and make an impact on the epidemic
 - reduce stigma and discrimination in an atmosphere where people can work together for a better future, regardless of their HIV-status.

The lack of initiative on the part of NGOs, governments and other stakeholders, to effectively implement GIPA is also a matter of concern to PLWHA. Many PLWHA have expressed anxiety that non-gov-

"To me, GIPA used to mean Greater Involvement of People Living with HIV/AIDS to ensure a better quality of life for us. But now I know that the way it is practised has flaws that need to be addressed."

- Aruna, PLWHA, Sri Lanka

ernment organisations (NGOs) neither understand the need for independent and strong PLWHA groups, nor believe that PLWHA have the potential to become an equal partner, given their limited capacities. On the other hand, Governments in many countries of the region have adopted sensitive policies but face serious difficulties in implementing them. PLWHA groups have also realised that they urgently need to strengthen their organisational capacities and build capacities of their members in order to breathe life into the GIPA principles.

THE THIRD GENERATION RESPONSE - EMPOWERMENT OF PLWHA

While the global acceptance of the GIPA principles is unquestionable, in attempting to translate these principles into practice, it becomes increasingly clear to the PLWHA and other stakeholders that even when implemented, GIPA by itself would not stimulate a change in the living condition of PLWHA. Often, PLWHA express apprehension that they were being 'used' by civil society organisations and that their representation in official committees did not necessarily translate into a truly significant manifestation of their rights or influence.

When implementing the GIPA principles, the stakeholders had implicitly assumed that it would automatically result in the emergence of an enabling environment for PLWHA. But this assumption inadvertently took away the focus from the actual needs of PLWHA. The unanticipated fallout was that a disproportionate emphasis was laid on strengthening those PLWHA who could, potentially, become part of the HIV/AIDS responses, while the vast majority of the PLWHA remained neglected and outside the reach of these efforts at involvement.

The learning from the last two decades of the epidemic, particularly in the practice of GIPA over the last decade, has been that meaningful involvement of PLWHA requires their true participation, which in turn cannot be achieved without their complete empowerment - in terms of their wellbeing and

access to information and services for a healthy life; ability to conquer fear, shame and stigma and discrimination through quality counselling and peer-support; a rights sensitive legal and ethical environment, leadership, access to sustainable livelihoods and the capacity to contribute.

This reality calls for an organic, rights-based response that is centred round the empowerment of PLWHA. This new approach views empowerment as a right of the PLWHA. Logically, this approach can also be extended to other vulnerable populations such as sex workers, trafficked girls and women, drug users, men who have sex with men and migrant workers. Efforts aimed at the empowerment of these socially marginalised populations through strengthening their self-support organisations and capacity development can be termed as "The Third Generation Response" or a response of the 21st century. While improving the quality of the lives of people infected with and affected by HIV/AIDS, this approach could also have a direct impact on HIV prevention, as empowered people would have greater capacity to make informed choices to reduce their risk of getting infected or infecting others.

The need for empowerment is strongly articulated by the PLWHA groups in Asia Pacific in the historic "Bangkok Declaration"¹⁸. The Declaration explicitly urged all stakeholders, including governments, to take expeditious steps for empowering PLWHA so that their participation in the responses can be meaningful and significant.

Strategically, the new approach has two primary objectives. One, to strengthen the knowledge base of the emerging groups of PLWHA on policy issues, upgrade their skills to navigate in political spaces, and enhance their strategies for networking. And two, to begin a process aimed at improving the quality of life of PLWHA through peer support and access to care and treatment for group members. This second objective is largely an effort to maintain organisational health and integrity of the PLWHA groups. At the same time, efforts made towards meeting the second

18 Ibid. 15

objective will also go a long way in offering peer support to those PLWHA, who often have no one to turn to in their community and, therefore, tend to or are forced to isolate themselves.

Experience has shown that PLWHA and people indirectly affected by the epidemic have proven to be among the best peer educators for supporting change - both among marginalised populations and the general public - towards safer practices, positive living, reducing stigma and discrimination and bringing about an enabling environment. They also help themselves and other peers to withstand the many difficul-

ties that they face and lead positive lives. The empowerment of PLWHA will enable their equal partnership with NGOs and the government at many levels and will strengthen HIV prevention, treatment, care and support responses. Finally, a rights-based approach can help in mitigating the adverse impacts of the HIV/AIDS epidemic on the Millennium Development Goals (MDGs) and human development in general. Empowerment can also increase the social capital of communities, facilitating new and innovative responses to the crises faced by individuals, their families and society at large.

"There needs to be a fully concerted effort on behalf of all partners to play a more participatory role in the response to HIV/AIDS. The problems and, therefore, the solutions need to be addressed by every sector of society. Stigma and discrimination issues facing PLWHA need to be further addressed and access to treatment, care and support for PLWHA should be made available to all. This can be achieved by further strengthening the meaningful involvement with PLWHA to create an enabling environment, one that involves promoting human rights, empowering PLWHA and encouraging the widespread participation in policy and program development as equal partners and without relying on tokenistic representation."

- Greg Gray, Regional Coordinator, APN+

The Process

Facilitating Transformation

Along with other bi- and multilateral agencies and civil society organisations, United Nations Development Programme (UNDP) has been involved in designing and implementing responses to the HIV/AIDS epidemic since the early eighties. The cornerstone of UNDP's efforts has been the empowerment of PLWHA and their active participation in the response. Therefore, strengthening networks, developing capacity and creating new leadership among PLWHA form the first few tiers of UNDP's long-term response to HIV/AIDS in the Asia Pacific region. This chapter documents the processes facilitated by UNDP along with PLWHA groups and other stakeholders in the region in three key areas: fostering networks among PLWHA, helping build their capacities and strengthening leadership qualities among them.

THE SOUTH ASIA GIPA INITIATIVE

The UNDP Regional HIV and Development Programme began working with the PLWHA in the Asia Pacific region since the late nineties. Given that a vast majority of countries in the region were in the early stages of the epidemic, it was evident that it would be difficult to attempt an immediate and large-scale replication of the lessons learned elsewhere in the world such as Sub Saharan Africa. The visibility of PLWHA in the region was extremely poor; groups were either absent or nascent and capacities quite weak. Therefore, as a start-up exercise, a pilot project focusing on the five South Asian countries - Bangladesh, India, Nepal, Pakistan and Sri Lanka - was initiated in 2001. Titled the Greater Involvement of People Living with HIV/AIDS (GIPA) Project, it aimed at meaningful

participation of PLWHA in the response to HIV/AIDS in South Asia and was implemented jointly by UNDP and Sahara - a New Delhi based NGO - through close partnerships with 12 PLWHA groups in the sub-region.

STOCKTAKING & MAPPING

The first step under this initiative was a stocktaking exercise coordinated by Sahara. It involved a baseline mapping of existing PLWHA organisations, groups and networks, the conditions in which PLWHA existed and the extent to which the GIPA Principles were being applied in the participating countries of South Asia.

The mapping exercise revealed that the understanding of GIPA in the region was extremely poor, including in countries where PLWHA support groups existed. It also revealed that India had the maximum number of active PLWHA groups in South Asia, spread over almost every part of the country, and it had achieved the greatest success in persuading positive people to 'come out'. Nepal had one established network and a group on the verge of being formed while Pakistan had a lone network. Neither Bangladesh nor Sri Lanka had any registered groups of PLWHA although an informal support group existed in Dhaka, Bangladesh.

PARTICIPATORY PROBLEM ANALYSIS

The stocktaking exercise was followed by a start-up workshop in New Delhi that brought together PLWHA and NGO resource specialists from the five participating countries to discuss a range of challenges faced by PLWHA in South Asia. In countries where PLWHA had very low capacity, they teamed up with NGOs that had

taken part in the mapping exercise. Some of the PLWHA and NGO members formed a Steering Committee to support the implementation of small-scale capacity development activities by PLWHA networks. A total of 17 proposals for capacity development -- in the areas of organisational development, awareness building and sensitisation, care and support activities and employment -- came under the purview of this initiative. These were issues that PLWHA felt were crucial for enhancing their capacity to gain influence.

The South Asia GIPA Initiative was the first project aimed at gaining visibility for GIPA principles in the region. The project provided a unique opportunity for PLWHA to network and implement small-scale activities together. It also signaled the beginning of extensive networking between PLWHA across the Asia Pacific region. But, by the close of this pilot project in the spring of 2002, while the process of learning about GIPA had been complete, the difficulties of implementing these principles had begun. The hopes and aspirations of the PLWHA in the region vis-à-vis the implementation of the GIPA principles are succinctly

the concerned stakeholders had realized the need for developing a new GIPA initiative, with a sharper focus. The new initiative would necessarily need to shift the focus from the limited understanding of GIPA as "genuine involvement"- to an expansive vision aimed at the overall empowerment and subsequent meaningful involvement of all PLWHA, their groups and networks.

The pilot phase made it apparent that PLWHA did not view GIPA as an end in itself. They viewed it as a tool to achieve the objectives they had set for themselves and their networks. This distinction was crucial in formulating the next phase of the project, which symbolised the "third generation response". Named the Asia Pacific Initiative for the Empowerment of PLWHA (Box 2.1), the second phase of the South Asia GIPA Initiative was conceived as a three-year long involvement aimed at the empowerment of PLWHA in the region. The preparatory phase of this project was initiated in the summer of 2002.

This new approach supported the overall aim of UNDP: human development. For decades, UNDP has

Box 2.1

The Asia Pacific Initiative for the Empowerment of PLWHA

The Asia Pacific Initiative for the Empowerment of PLWHA focuses on the empowerment of PLWHA and their groups through national and regional networking for mutual support, experience sharing and advocacy and capacity development so as to:

- establish and strengthen PLWHA organisations;
- facilitate care and support for group members; and
- enhance advocacy and leadership skills.

The Initiative is implemented in partnership with Asia Pacific Network of PLWHA (APN+) and Indian Network for PLWHA (INP+). Direct support is being provided to 17 groups in 12 countries across Asia Pacific for capacity development. A virtual Asia Pacific PLWHA Resource Centre has been established to take forward regional advocacy, facilitate capacity transfer among PLWHA groups and to disseminate information; provide space for all Asia Pacific PLWHA groups to put up their own websites and facilitate networking among these 17 groups as well as among a coalition of PLWHA individuals and groups from 23 countries of the region.

captured in a vision statement that was formulated by all the PLWHA from South Asia who participated in the pilot phase of the GIPA Project in South Asia¹⁹.

At the end of the pilot phase of the GIPA-Project,

worked towards the goal of human development in partnership with governments and civil society. Therefore, it brought to the partnership with PLWHA a wealth of experience, assisting PLWHA groups to develop capacity to tackle poverty, gender inequity and exploitation.

The new initiative rests upon this development

¹⁹ The participants were from Bangladesh, India, Nepal, Pakistan and Sri Lanka.

strategy and involves the application of new technologies including the Internet. It includes the development of their own responses in the areas of care, support and prevention and aims to stimulate the transformation of individual behaviour, attitudes, collective norms and structures in society at large.

Through this new approach, UNDP and its PLWHA partners primarily focused their attention on the lives of HIV positive people as a starting point. The aim was to support PLWHA to reach out and empower each other, expand their choices and to ensure dignity by strengthening the networks to evolve into strong community-based organisations and movements. UNDP intended to provide this support through a rights-based approach, which stressed the legitimate importance of a societal space for PLWHA and also emphasised the value of facilitating the access of PLWHA to sustainable livelihoods and treatment. Above all, PLWHA needed to carve out a political platform for themselves to gain a meaningful, powerful role in the response to the epidemic. Implicit was the acknowledgement that GIPA principles must be adapted to the realities faced by positive people in their specific contexts through emphasising the rights of PLWHA to individual and collective empowerment.

SHARING EXPERIENCES

The GIPA pilot project ended in December 2001 with a workshop that coincided with the Fifth International Conference on Home and Community Care for Persons Living with HIV/AIDS in Chiang Mai, Thailand. The workshop was facilitated by PLWHA who were GIPA experts from South Africa and Australia. The meeting provided an exciting opportunity to share experiences, analyse the lessons learned and come up with suggestions to take forward the key elements in putting GIPA in operation in South Asia.

A major part of the process was UNDP's support to organisational development and networking with PLWHA groups. In 2002, support was provided to build PLWHA networks across the Asia and the Pacific. In the first phase, UNDP helped to set up five PLWHA groups in South Asia. This included Bangladesh, India, Nepal, Pakistan and Sri Lanka.

The next wave saw PLWHA networks being

forged in North East and West Asia, i.e. in China, Mongolia and Iran. These PLWHA groups were identified and formed with the help of the local governments, UNDP country offices and other partner organisations.

LAUNCHING THE SECOND PHASE

Based on the GIPA pilot project, UNDP, in collaboration with APN+ (the Asia Pacific Network of People Living with HIV/AIDS) and INP+ decided to come together to develop a regional GIPA Initiative. The initiative was aimed at strengthening the capacity of PLWHA groups in South and North East Asia, in order to facilitate more holistic and enabling HIV/AIDS responses with a rights-based and gender sensitive approach.

A strategic planning start-up workshop in Marawila, Sri Lanka, in October 2002 set in motion the planning process for this initiative. It focused on PLWHA empowerment and brought together a number of participants from South, South West and North East Asia. The workshop presented the first opportunity for several PLWHA, particularly those from China, Mongolia, South Korea and Iran, to meet and exchange thoughts and experiences with their peers from other countries in the region.

The Marawila workshop served as a catalyst for networking among PLWHA in the region. The networking was followed up through a common e-group that was developed for the implementation and coordination of the South Asia GIPA Initiative and began to attract new and emerging PLWHA groups into the

"The Marawila workshop was a great experience for me, personally, to be with other positive people. There was a unique energy around us all the time and I felt I was surrounded by people who cared and understood me after a long time of feeling isolated and lonely. It was good to see some very active PLWHA and hear what they had accomplished in their countries in response to HIV/AIDS. I have also had supportive e-mail correspondence and received clues on writing proposals and work plans."

- Maana, Coordinator, Persia+, Tehran, Iran

loop. It was also a defining moment for PLWHA as they identified and prioritised areas they felt were crucial to their empowerment.

In 2003, the framework for a new initiative was developed, which was unanimously endorsed by the Annual General Meeting of APN+ and the Board of INP+. Simultaneously, another strategic planning workshop was organised in Bangkok, Thailand, in March 2003 to expand the initiative to include South East Asia and the Pacific region, thereby mak-

ing the Initiative for the Empowerment of PLWHA truly Asia-Pacific. PLWHA from Cambodia, Indonesia, Papua New Guinea, Thailand and Vietnam met at the Bangkok workshop and joined forces with the emerging regional coalition of PLWHA groups in the Asia and Pacific. The coalition paved the way to support the development of a small PLWHA support group in Hanoi, Vietnam and to establish a PLWHA group in Papua New Guinea, called Igat Hope.

Taking the Lead

Globally, leadership is the cornerstone of UNDP's response to HIV/AIDS. Recognising the increasing need for leadership from all sectors and levels of society and reflecting the essence of UNGASS Declaration of Commitment²⁰ and MDGs²¹, UNDP has developed a comprehensive programme titled "Leadership for Results" (L4R) that is offered to key constituencies such as Governments and Civil Society; Arts and Media; Development Planners and PLWHA. This programme is being rolled out in more than 20 countries in the world.

As part of the strategy to develop leadership among PLWHA, the L4R Programme was launched in India in partnership with the Indian Network of PLWHA (INP+), National AIDS Control Organisation (NACO) and the Indian Institute of Planning and Management (IIPM). The programme included three leadership training workshops over a period of nine months. The workshops had a gap of three months between each of them during which the participants undertook several "breakthrough initiatives."

The first PLWHA Leadership for Results workshop was held in May 2003 in Kapashera, near New Delhi, India. It was followed by two more leadership workshops, one in Kochi, India (December 2003) and the last one in Kolkata, India (March 2004). These workshops will be discussed in detail in the Leadership chapter.

20 Ibid. 17

21 The UN General Assembly adopted the Millennium Development Goals (MDG) at the Millennium Summit held in September 2000. MDG set the global objectives for attaining peace and security, human rights and sustainable development. All 191 U.N. member states have pledged to meet the MDG by the year 2015. Of the eight goals, one is to halt and begin to reverse the spread of HIV/AIDS.

In May 2003, UNDP launched its leadership programme for Arts and Media in Goa, western India, in which more than 120 arts and media leaders from India and Nepal participated. Several PLWHA representatives shared their experiences and perspectives to sensitise arts and media practitioners. The key aim of the programme was to shift society-wide perceptions and conversations to create new images, icons and metaphors to take a stand and seize the opportunities to create an enabling environment for PLWHA.

At the regional level, the Asia Pacific Leadership for Results Programme was launched in Pattaya, Thailand. Attended by over 120 PLWHA leaders from 21 Asian countries, the programme envisaged the strengthening of leadership and capacities of PLWHA as individual members of a regional PLWHA movement. The aim was to gain strength from each other so as to influence regional and global processes. Like the Indian programme, it drew on some of the most advanced approaches from management and leadership practices, including transformational leadership, conversations, appreciative enquiry, emotional intelligence, transforming organisations and generating new ways of working together.

The Leadership Programme also coincided with the first working group seminar aimed at developing the capacity of the 17 PLWHA groups receiving direct financial support from UNDP. The twin efforts marked the start of the Initiative for the Empowerment of PLWHA. It provided the first opportunity for all the PLWHA groups - who had been brought on board as part of a three year long process - to network face to face and work collectively for their self-empowerment.

The events enabled PLWHA groups in Lao PDR to co-opt existing groups into a national network called Lao Network of PLWHA (LNP+), and helped Fiji to establish the country's first PLWHA group known as the Fiji Network of PLWHA (FJN+).

Building on the efforts aimed at networking, capacity building and leadership, the next step in the Empowerment Initiative was to establish the Asia-Pacific PLWHA Resource Centre (APPRC) in 2003²² to enable PLWHA to take active lead in advocacy decision making and implementation of activities. Located in New Delhi, India, and established through the joint efforts of INP+, APN+ and UNDP, the Centre coordinates a wide spectrum of PLWHA-related activities. An exciting aspect of the centre is its internet-based connectivity component (www.plwha.org), an exclusive, web-based and automated networking platform for PLWHA groups in the region, which includes e-groups, on-line chat forums and an electronic workspace called the 'PLWHA Community of Practice.'

Among the leading initiatives of APPRC was the First Asia Pacific PLWHA Congress in Bangkok in January, 2004. This was organised by the APPRC together with APN+, INP+ and UNDP as part of the Asia Pacific PLWHA Coalition for Advocacy and Capacity Transfer. The Congress focussed on developing Asia Pacific regional advocacy agendas and strategic action plans based on the issues identified by the Asia Pacific PLWHA Coalition (APPC). The other areas the Congress stressed were advocacy for GIPA; access to treatment, care and support; and stigma and discrimination. The APN+ general body meeting had identified these issues in 2003 as priority areas. About 50 PLWHA leaders from 19 Asia Pacific countries - Australia, Bangladesh, Cambodia, China, India, Indonesia, Iran, Lao, Nepal, Malaysia, the Philippines, Pakistan, Papua New Guinea, Singapore, Sri Lanka, South Korea, Thailand, East Timor and Vietnam -

attended the Congress.

The Second Asia Pacific PLWHA Congress was held on July 10, 2004 in Bangkok, prior to the XVth International AIDS Conference. It was attended by more than 100 leaders of PLWHA groups from 25 countries in the Asia Pacific region. The Second Congress focussed on strategies and specific action plans to be carried out by APPRC and the adaptation of a charter of demands and resolutions, the "Bangkok Declaration" that reflected the determination and collective voice of PLWHA in the region. Prior to the Congress, APPRC had undertaken consultations with PLWHA in Asia Pacific to facilitate the formulation of the declaration. The main objectives of the Second Congress were as follows:

- To discuss and obtain consensus with regard to the draft regional advocacy strategic action plans and agenda prepared by APPRC with APN+ and INP+ based on the results of the first PLWHA Congress.

- To adopt the "Bangkok Declaration" addressing the issues of GIPA, empowerment, treatment, and stigma and discrimination

- To discuss functions of APPRC in coordinating regional advocacy activities and providing support to PLWHA and their groups in the region.

The "Bangkok Declaration," was unveiled at a press conference during the 15th International AIDS Conference in Bangkok on July 13. Dr. Peter Piot, Executive Director, UNAIDS; Mr. Zepherin Diabre, Associate Administrator, UNDP; Dr. Jack C. Chow, Assistant Director-General, WHO; Mr. Greg Gray, Regional Coordinator, APN+; Mr. K.K. Abraham, President, INP+; Mr. Shiba Phurailatpam, APPRC Coordinator; Mr. Stuart Flavell, Coordinator, GNP+ and; Ms. Dy Many, Member CPN+ were present on the occasion. This was also an example of providing an interface between PLWHA leaders and key policy makers. The Declaration, for the first time in the region, urged all governments, bi- and multilateral agencies, civil society organisations and others to take specific steps for the well-being and empowerment of PLWHA so that their involvement in the response to the epidemic is total and meaningful. (See Box 2.2)

The following chapters will describe the results, including areas where goals have been achieved and where there is business left to be done.

22 The Asia Pacific PLWHA Resource Centre in New Delhi, India, is hosts the PLWHA Community of Practice. This is an electronic work group and message forum to provide a platform for PLWHA in the region to share information between groups, to identify gaps in treatment, to produce training and implementation materials, and to provide ongoing support for implementation of activities. The overarching purpose of the Resource Centre is to increase the quality and effectiveness of the response to HIV in prevention, treatment, care and support through the empowerment of PLWHA.

BANGKOK DECLARATION

by
**People Living with HIV/AIDS
in Asia Pacific**

July 11, 2004



A decade has passed since world leaders ratified the principle of GIPA (Greater Involvement of People Living with HIV/AIDS) at the Paris AIDS Summit in 1994, but its practice in the Asia Pacific region has been woefully feeble. We, the people living with HIV/AIDS in the region, painfully realise that the disempowering presence of stigma and discrimination; lack of access to treatment and support services; lack of capacity; and poor knowledge on GIPA among governments, other stakeholders and PLWHA networks prevent hundreds of thousands of experienced PLWHA from actively participating in the responses to the epidemic. Our categorical learning in dealing with HIV/AIDS over the last two decades has been that without the well-being and empowerment of PLWHA, GIPA can only be a pipe dream.

T rue practice of GIPA requires total empowerment of People Living with HIV/AIDS - power that is both generated from within and imparted from outside. This empowerment relates to a healthy and dignified life; a rights and gender sensitive environment that is free of stigma and discrimination; availability of livelihood options, political and decision making capacity; and access to affordable treatment including ARV.

W e, representatives of PLWHA networks in Asia Pacific region, therefore, urge all Governments, political parties, civil society organisations, UN, bi- and multilateral agencies, corporates, public and private sectors and the media in the region to create an empowering environment for PLWHA and people affected by HIV through the following measures:

Policy and Decision Making

1. PLWHA representatives should be given direct access to relevant ministries dealing with HIV/AIDS issues
2. PLWHA representatives should be part of decision making bodies related to HIV/AIDS in every country, both in the Government and Non-Government sectors
3. GIPA should be incorporated into national policies as a prevention strategy
4. Legal reforms should be undertaken expeditiously in every country to protect the rights of PLWHA
5. A budget-line dedicated to supporting PLWHA groups should be included in the budget of every country

Access to Treatment and Support Services

1. Universal and free ARV, laboratory tests and OI treatment should be made available in all the countries
2. Every company should have a comprehensive workplace policy, conforming to global guidelines, that protects the rights of infected employees
3. Quality, confidential counselling services should be made available up to the primary health care delivery points

Social and Economic Empowerment

1. National AIDS Committees should be made multisectoral
2. Governments, corporates, public and private sectors should help PLWHA groups, particularly women's groups, with income generation activities, micro credits, grants and revolving funds
3. HIV should be mainstreamed into existing poverty alleviation programmes
4. Social security measures must be initiated for poor PLWHA
5. Large scale leadership and capacity building efforts should be initiated for PLWHA
6. Governments should earmark special programmes and budgets for people affected by HIV, widows and children

The Results

Nurturing Networks

The existence of HIV/AIDS as a reality in the communities is best illustrated wherever and whenever PLWHA speak out in public. They are a living testimony to the manner in which the epidemic impacts individuals, families and communities. Most importantly, they demonstrate that empowered PLWHA can and do lead affirmative, productive lives.

Whenever PLWHA share the experiences that led to their decision to go public or discuss what it means to live with HIV, they influence the course of the response to the epidemic, reduce stigma, misunderstanding and inspire so many other PLWHA. By sharing their coping strategies and the lessons learnt in tackling the biological and societal challenges posed by infection and illness, they also enhance the quality of life for other PLWHA. Indeed, the participation of PLWHA is critical to eliciting and promoting effective prevention, care and support responses from community members and policy makers. All too often, however, the fear of discrimination and rejection discourages PLWHA from coming out. Isolation, marginalisation and self-stigmatisation threaten the quality of life for PLWHA as much, if not more, than living with the infection. These prevailing realities led to the strengthening of self-help groups of PLWHA in the Asia and Pacific, and help create new groups and networks.

The UNDP-PLWHA partnership has shared significant stakes in bringing PLWHA together. In countries where PLWHA are relatively better organised, support from the partnership has facilitated interaction with other PLWHA networks in the region. For many PLWHA, the face-to-face meetings and Internet-based discussions in real time provided excellent opportunities to share experiences and learn from each other.

PLWHA from various countries in Asia and Pacific were encouraged to participate in conferences and workshops on issues that involved and interested them. For PLWHA, it was also a splendid opportunity to interact with policy makers and civil society organisations. In essence, these networking events and opportunities provided a platform for PLWHA to come together, set their own agenda and communicate directly with key stakeholders.

Box 3.1

Nepal+, Kathmandu, Nepal

Nepal+ is a nascent PLWHA group whose members include drug users and survivors of human trafficking. The former has a relatively higher degree of technical skills and was instrumental in setting up the group. Their vulnerability to relapse and the stiff challenges of surviving a hostile environment pose a daily challenge to their determination. The trafficked women in the group have been forced into a life of untold misery and are yet able to display immense inner strength. They today encourage and support IDU members, building self confidence and self-esteem among them. These two 'sub-groups' of PLWHA have united to share coping strategies and work together, living out an empowering synergy for change.

Positive Beginnings

Three years of work in the region have registered significant progress: in many countries such as Iran, Mongolia, and Fiji, where PLWHA used to be nearly

invisible, a few determined individuals - sometimes with support from others - have initiated efforts to create safer societal spaces for other PLWHA. New PLWHA networks have appeared in countries with low HIV prevalence and high stigma such as Sri Lanka and South Korea. In China and Laos, informal PLWHA groups are emerging and in South Asia, new as well as existing networks are expanding their outreach.

In 2002, support was provided to the development of five PLWHA groups in the region, a process that in turn led to the formation of three more. In the 'first wave' of the five new groups that were formed in South Asia, two women's groups of wives and widows of migrant workers, IDUs and trafficked survivors came into being in India and Nepal. The Indian group is located in Manipur; a North-eastern State significantly affected by HIV and has named itself the Affected and Infected Women's Association in Churachandpur (AIWAC). The Nepali group, namely, the Makwanpur Women's Group, is located in Makwanpur, where HIV disproportionately affects migrants. Another Nepali group has also emerged in Kathmandu and largely comprises HIV positive drug users and trafficked survivors. PLWHA from all walks of life came together in Pakistan and Sri Lanka to form the Positive Action Society (PAS) in Karachi and Lanka+ in Colombo respectively. Similar strategies also worked in the case of Ashar Alo Society, a

PLWHA group in Dhaka, Bangladesh. In India, Humsafar Trust, a community-based organization of MSM, established one of the country's first support groups for HIV positive MSM in Mumbai.

Next, three groups were established in North East Asia and West Asia. With the support of the UNDP Country Office in China and Marie Stopes International (MSI), a Beijing based organisation - the Mangrove Support Group (MSG) - was identified. The aspirations of the group to develop a country-wide PLWHA network were encouraged and supported leading to the establishment of firm linkages with unorganised PLWHA in Guangdong. This step also marked the start of another PLWHA group called AIDS Care. The process helped the group to establish four provincial level PLWHA groups in the country including AIDS Care with technical and economic support provided by both MSI and UNDP.

The creation of AIDS Care is an example among many where partnerships between PLWHA, UNDP and country offices of international NGOs like MSI have resulted in the expansion of national and regional PLWHA networks. MSI has been working on HIV related issues and PLWHA for a few years.

In many of the countries, NGO partners worked jointly with UNDP to help identify PLWHA groups. In Sri Lanka, Iran and South Korea, for example, the UNDP country offices played a key role in identifying PLWHA groups and providing them with constant support. In this, they were helped by the respective national governments and civil society partners.

Box 3.2

Support women in Cambodia

Cambodia is one of the three countries in Asia with a generalised epidemic. The country also has one of the largest networks of people living with HIV/AIDS in the region- Cambodian People Living with HIV/AIDS Network (CPN+) with membership of more than 9,000. Nearly two-third of the CPN+ members are women. To facilitate the network to take up issues and activities specific to women living with HIV/AIDS, UNDP is assisting the formation of a Women's Wing within CPN+. The Women's Wing will allow women members to make financial and programmatic decisions to advance their unique issues, needs and interests.

Positive Beginnings

"I met several PLWHA from outside China through the networking opportunities that UNDP provided. These occasions have helped me make contact with government officials and NGOs. But more needs to be done at the grassroots level, for those who are unable to access the internet or those living in complete isolation."

- Thomas, Coordinator, AIDS Care China, Gaungzhou, China

In Mongolia, UNDP was able to reach out to PLWHA with help from the Mongolian National AIDS Foundation (NAF), a government supported organisation. At the time, the NAF had three members and

only one PLWHA in the country, a woman living with HIV. Since then, she has formed NAF+1, which is working towards the establishment of a PLWHA group in the country. In the process, two more PLWHA have been identified.

In the Islamic Republic of Iran, the UNDP country office was able to contact a PLWHA through a doctor at the Teheran University Hospital. UNDP also worked to win governmental and societal acceptance for the formation of a PLWHA group, Persia+. In South Korea, the partners were identified with assistance from the country office in Seoul and the Salvation Army, an NGO working on HIV/AIDS issues and with PLWHA. Two formal groups and two informal support groups were identified; however none was involved in carrying out substantial activities on the ground. UNDP and the Salvation Army helped one of the support groups get organised into a formal group called Korea HIV/AIDS Network of Solidarity (KANOS), which proved exceptionally committed to working for PLWHA empowerment.

VIRTUAL NETWORKS FOR REAL SUPPORT

The setting up of the Asia-Pacific PLWHA Resource Centre in 2003 in New Delhi has been a very important move towards building and fostering PLWHA networks in the region. The connectivity component - www.plwha.org - has provided 17 core groups of the Initiative with online training in Information Technology (IT) and logistical support to enable PLWHA to share experiences and work cohesively on related issues.

The APPRC also provides technical assistance to

"What makes www.plwha.org unique is that any PLWHA group or network will be able to make its web presence felt within this structure. It is easy and simple to operate. One needs to have basic knowledge of English and Computers. One does not need designers or web developers."

- Shibbananda Phurailatpam, Coordinator, Asia Pacific PLWHA Resource Centre

PLWHA groups to create their own websites and private electronic space for communication, and to upload content. This enables the groups to become part of the global electronic network and gain visibility. It also facilitates PLWHA with Internet access to identify groups that have the potential to become strategic partners in reaching out and recruiting new members. Several PLWHA groups have created their electronic networks and uploaded their websites and more are to follow. Facilitated by Mahiti, an Indian NGO based in Bangalore and supported by UNDP, the portal was created using open source software and aimed at bridging the digital divide among PLWHA.

The First Asia Pacific PLWHA Congress in Bangkok in 2004 gave an opportunity to identify and focus on advocacy issues - GIPA, care and support and stigma and discrimination -- among PLWHA leaders from 19 Asia Pacific countries to help build a common plat-

Box 3.3

The Journey So Far...

- Emergence of 12 new groups
- 11 nascent groups strengthened
- Emergence of a virtual PLWHA community by creation of APPRC
- Creation of a new website (www.livingwithhiv.net) by Bangalore-based Karnataka Network of Positive People (KNP+)
- Digital divide narrowed due to connectivity
- Heightened awareness about PLWHA concerns
- UNDP has facilitated partnerships between PLWHA groups and civil society, policy makers, donor agencies, NGOs and private companies
- PWN+ has begun not only organising HIV positive women in India but also reaching out to HIV positive women in the region
- Creation of supportive coalitions around each of the PLWHA groups
- Empowered PLWHA in Bangladesh have succeeded in incorporating GIPA Principles into the national programme of the country
- Strong PLWHA groups have started lobbying
- In Iran, Persia+ has won government support and succeeded in adding second-line drugs on the list of ARV drugs provided free of cost

form for PLWHA in the Asia Pacific Region by networking and learning on issues concerning them. It also gave a clear picture that access to HIV/AIDS treatment is still the biggest problem for most PLWHA in the Asia Pacific Region. It strengthened PLWHA networking and helped set the agenda for action in the region and facilitated PLWHA to prioritise strategies for future action.

The GIPA Initiative has made gratifying progress in providing PLWHA groups with technical support - at least during the start-up phase - and in facilitating partnerships between PLWHA groups and civil society. PLWHA support groups have also been encouraged to identify local civil society organisations that can mentor them. Examples of such partnerships include one between Lanka+ and Community Development Services (CDS), which has proven crucial for the survival of the PLWHA group. Another example is the partnership between AIWAC and CARE.

This networking process has also enabled women living with HIV/AIDS to meet and discuss issues of specific concern to them and has helped them to join hands to fight stigma, have dialogues with policy makers and negotiate greater access to care, support and treatment. A concrete outcome is that the PWN+ in India has begun to organise women living with HIV/AIDS in the country while also reaching out to other women living with HIV/AIDS in the region.

In Nepal, stronger PLWHA groups such as Nepal+ have made fresh contact with the government and begun lobbying for legislation to protect the rights of PLWHA. In Bangladesh, empowered PLWHA have been successful in incorporating the GIPA principles in the national programme of the country. In Iran, winning governmental support has been critical to Persia+.

Given the disparities in PLWHA capacity and skills, both at organisational and individual levels, mechanisms were employed for bringing together pairs of PLWHA groups in various stages of evolution to enable the transfer of skills between them. The "twinning strategy" has fetched rewards. For example, the twinning of the experienced Indian Network for PLWHA (INP+) with the nascent networks of PLWHA in Nepal enabled the latter to better access anti-retroviral drugs. Support groups that were earlier indifferent to each other have begun functioning in harmony for mutual advantage and created a new national-

level network called the National Network for PLWHA in Nepal (NNP+N). Another example is the twinning of the Makwanapur Women's Group with Nepal+ whose members include a large number of IDUs and trafficked survivors. Nepal+, being highly literate in English and Nepali, assists the women's group by conducting training programmes together, helps them in strategic planning and in translating English IEC material into Nepali.

LESSONS LEARNED

Networking and sharing of experiences between PLWHA groups reveals that the GIPA principles cannot stand on their own but must be adapted to fit the various capacity levels and felt needs of groups in their local settings. As far as PLWHA are concerned, their greatest worries pertain to stigma and discrimination, treatment and livelihood. The fears of loss of income and failing health fog other apparently distinct relevant issues. Many individuals and groups need to develop strength for GIPA to become meaningful. But in the absence of an enabling environment, there is no incentive for people to come forward for voluntary testing or for PLWHA to come out and lend their expertise to national, regional or global responses.

Secondly, networking opportunities and events can bring PLWHA together but the outcome is dependent on several issues. Any goal or target has to factor in the problems faced by PLWHA on the ground, notably those of resources, stigma and discrimination, failing health and the difficulties in accessing treatment. Projects for the Empowerment of PLWHA with small time-frames are unable to achieve substantive results because of time constraints to train the people who will execute projects. Networking cannot be an exclusive activity in the absence of resources. What is urgently needed are sustainable livelihood models that can improve the quality of life for people living with HIV/AIDS and support networks. An additional challenge is the lack of coordinated efforts and common understanding of GIPA and the need for empowerment among PLWHA groups and civil society organisations.

Even though networks are spawning a regional PLWHA coalition, greater effort is needed to ensure that groups that feel marginalised even within the

PLWHA community, such as MSM and sex workers, are heard. PLWHA view themselves through the same prism of the norms and values of the societies they live in. Most adopt self-exclusion as a defensive strategy. There is thus a clear need for mental or psycho-social support and healing to realise that one should not suffer guilt for getting infected with HIV, be it through sex, drug use or any other mode of transmission.

THE ROAD AHEAD

The interaction of PLWHA within and between countries in the Asia and Pacific has resulted in new, strong PLWHA groups. Daunting challenges lie ahead: they need to reach out to PLWHA who are not part of any organised interest group, particularly the poor and women, even while developing their capacities and equipping themselves to campaign for significant changes in the local, national, regional and global responses to the epidemic.

The Asia Pacific Initiative for the Empowerment of PLWHA is scheduled to end in December 2005. Through the initiative, increased focus on sizeable regional networking must take place to position PLWHA groups in the Asia Pacific region as major players in the development of a third generation global response to HIV/AIDS. The PLWHA groups and networks that emerge need to hone their regional and global outlook to carry out advocacy with governments and civil society in order to draw attention of the world to PLWHA of the region.

The use of Information and Communication Technologies (ICT) to create a regional platform needs to be strengthened further to accelerate the process of mutual empowerment and outreach. For the electronic platforms to become an effective tool, skills related to the usage of both computer and the English language must be developed further and its efforts supported. New cost effective tools that could be utilised include online discussion and tele or video conferencing that allow PLWHA to network with one another across the entire Asia and the Pacific. Large-scale Internet-based communication promises to emerge as a core strategy for effective learning and sharing at affordable costs. It would provide new opportunities for PLWHA to meet and develop stronger personal and professional ties with one another than what is now

possible through e-groups and networking events such as seminars and conferences.

UNDP is committed to helping PLWHA groups reach out to more PLWHA in the region. Through its mainstreaming efforts in the coming years, UNDP will aim at facilitating new partnerships between PLWHA groups, civil society organisations and government institutions working on broader issues of development, as well as the private sector, to strengthen the outreach and support to PLWHA. UNDP will also provide continuous support to the connectivity and networking components of the Asia Pacific Initiative for the Empowerment of PLWHA as well as the APPRC. The goal is to improve the quality of lives of PLWHA by facilitating greater interaction among PLWHA groups and their members. The APPRC seeks to achieve this goal through promoting creative Information Technology solutions and computer literacy to augment the bond among PLWHA in Asia Pacific.

Another key learning has been the efficacy of Information and Communication Technologies (ICT) in bringing together PLWHA and their groups across the region, sharing of information and experience among them, and periodic virtual consultations. The experience has been that virtual networking and consultations have been nearly as effective as meeting physically - demonstrating the immense possibility of cost-effectiveness in using ICT.

However, the use of ICT hinges heavily on the capacity of the PLWHA in using them, which includes basic skills in using computers and Internet tools. Applying the learning from best practices elsewhere that lack of knowledge of English and inexperience in using computers and related interfaces cannot deter employing ICT, the Empowerment Programme persisted with the use of ICT. The fact that PLWHA groups personally upload content to the web-based PLWHA network, www.plwha.org and meet online for consultations suggest the increasing acceptability of flexible technology tools.

The web-based network also addresses the impact of digital divide on HIV positive individuals. As one of the most marginalised communities, digital deprivation is acute among them. In this context, the network was built on an open source platform called ZOPE. Though it was for the first time in the world that an open source software was used for creating a web-based network of

PLWHA, over a period of one year, the users have gained adequate skills to be comfortable with its utilities. The level of automation of this network is so high that the PLWHA do not require high-end skills to create their own websites and upload content.

The use of ICT in effective outreach of services through the Asia Pacific HIV/AIDS Portal, www.youandaids.org and the web-based PLWHA network, www.plwha.org reinforces its utility and makes a

strong case for its widespread use by PLWHA. There is increasing demand from PLWHA that in addition to counselling and treatment support available at the portal, niche services such as treatment networks may be introduced so that the comparative advantage of some countries in the region can be harnessed in diagnostics and treatment including training of medical and paramedical staff and web-supported drug procurement and distribution to achieve economies of scale.

Capacity Enhancement

The participation of PLWHA in all aspects of HIV programme and policy development is a pre-requisite to creating programmes that will meet their needs best and thus mitigate the impact of the epidemic. But PLWHA can intervene in a meaningful way to influence public discourse on the epidemic and improve the quality of their lives only if they have sufficient capacity and they feel empowered. The capacity enhancement of PLWHA involves enabling individuals to embark upon a continuous learning process - building on existing knowledge and skills and extending these in new directions as fresh opportunities arise. In many countries in the region, this means starting from the basics, including how to conduct a meeting or even how to read and write.

"There were thousands like me who carried on with verve. I didn't want to look back. I just wanted to move forward."

- Helen, PLWHA, Port Moresby, Papua New Guinea.

For self-empowerment and capacity development, the first requirement is support and information about the implications of HIV and how to live positively with the virus. This equips PLWHA with a better understanding of their situation and strengthens them to make positive changes in their lives. The next requirement includes skills to tackle stigma and discrimination as they prepare themselves to disclose their status within their families, among their friends and perhaps in their local community. For PLWHA who wish to bring about changes in

existing conditions for other people living with HIV/AIDS, the next challenge is to develop capacity to advocate for change in the local, national and regional response to the epidemic and to push for improved access to treatment, care and support services. In order to act, PLWHA and their groups need strong technical and financial support at the grassroots, to carry out various activities such as family and peer counselling, build referral systems for treatment and make available something as basic as safe meeting spaces.

The last three years have been a period of constant learning for the PLWHA groups in the Asia Pacific region as well as for UNDP. In the pilot phase, each PLWHA group identified individual activities to enhance capacity. These inputs and experiences helped PLWHA develop a vision and strategically plan their activities in three core areas:

- Organisational development
- Care & support
- Advocacy

In practical terms, this has meant facilitating partnerships for capacity transfer among PLWHA groups in almost all countries of the region, in a wide-ranging exercise involving APN+ and INP+, NGOs working with PLWHA, and UNDP. A key strategy for developing capacity among PLWHA in the region has been creating opportunities for well-trained PLWHA to train other PLWHA in core competencies such as peer counselling and public speaking. Over time, such PLWHA emerge as "positive role models" and function as facilitators of workshops and seminars, thereby honing their strategic planning skills.

ORGANISATIONAL DEVELOPMENT

At the start of the South Asia GIPA Initiative, almost all the PLWHA groups in South Asia associated with the pilot project had limited skills and resources to run an organisation and implement activities. Many of the groups did not have office space. Many were not formally registered with the authorities concerned and, therefore, faced problems in receiving funds. At this stage, the development of organisational capacity of both nascent and emerging groups often focused on providing templates for the bylaws of the organisation - a necessary step in applying for registration with the authorities. UNDP facilitated meetings of PLWHA interested in the creation of a formal PLWHA group in order to identify potential board members and formulate constitutions for the groups to be registered. To support the groups at this critical phase, the informal PLWHA support groups teamed up with NGOs that were willing to train and equip them with skills to develop their organisations. The PLWHA groups felt it was important that the participating NGOs shared the vision of a strong independent PLWHA collective and helped in its realisation. UNDP facilitated many of these partnerships by asking the PLWHA groups to select NGOs they felt comfortable with and proceeded to work towards a triangular relationship involving all three stakeholders.

The innovation was successfully deployed in Bangladesh, Nepal and Sri Lanka. The modest seed money for upcoming PLWHA groups to carry out their activities was channelised through these NGO part-

ners, who simultaneously involved the PLWHA in accounting for the funds. This exercise helped develop the organisational capacity of PLWHA to take on the same task once they became full-fledged formal organisations. A similar strategy was adopted for unregistered PLWHA groups that joined the Asia Pacific Initiative for the Empowerment of PLWHA.

The process of formulating individual proposals, budgets and workplans that the PLWHA groups wished to carry out, was strongly supported. Here, the partner NGOs played crucial roles, helping the groups implement, monitor and report on their activities. This also aided the new and nascent PLWHA groups to enhance organisational capacity and develop the skills and confidence of their members.

A number of activities to strengthen organisational capacity were identified by the PLWHA groups in the region and were implemented with support from UNDP, Sahara and their partner organisations. Six groups conducted a series of capacity development workshops on office management, routine correspondence, coordination with other organisations and proposal writing. Needs assessment studies were undertaken by two groups to gauge the situation of PLWHA in their respective countries. Six PLWHA support groups were formed and regular support group meetings were conducted. The groups also established strong partnerships for capacity development with other PLWHA groups and organisations in the region.

Towards the end of the South Asia GIPA Initiative, the importance of adequate infrastructure for communication had been recognised as being crucial to build-

Box 3.4

Positive Beginnings

Ashar Alo Society and CCDB

The partnership between the Ashar Alo Society, a Bangladeshi PLWHA group, and the Christian Commission for Development in Bangladesh (CCDB) is a successful example of synergy between a PLWHA group and an NGO. Bangladeshi registration formalities demands that a minimum number of 21 members be required to form a society. The names and contact details of key office bearers also had to be given to the authorities. CCDB helped the organisation with these formalities. An innovative formula of including people who were not HIV-positive in the board as members, with the clause that they would have to leave the board once the group reached the required size, enabled Ashar Alo to get official registration. Members of the CCDB, friends and family showed willingness to fill the empty slots in the membership and the board. Today, the society has grown in organisational strength and has established district level groups in Chittagong and Sylhet. Ashar Alo also coordinates a national network of PLWHA support groups belonging to various NGOs.

Box 3.5

PLWHA groups and NACO

As a cooperative effort between National AIDS Control Organisation in India and UNAIDS, UNDP took the initiative of facilitating connectivity among PLWHA by providing ten PLWHA groups in India with the required equipment and software. A number of computers were given to PWN+ to help them set up a computer-training centre and provide Internet connections to all the groups, thus linking them with each other and expanding the existing e-group.

ing organisational capacity. This was given prominence in the Asia Pacific Initiative for the Empowerment of PLWHA through the connectivity component (e.g. APPRC). Provisions were made for all the participating PLWHA groups receiving funds to get trained in computer literacy and for purchasing necessary communication equipment.

At the Strategic Planning workshop in Sri Lanka in October 2002, the focus was on identifying the types of capacity building PLWHA groups and their members needed for self-empowerment. Together, the participants came up with a plan that spelt out the need for a full time coordinator, training, setting up of accounting systems, office infrastructure, developing skills to manage an organisation and building partnerships to further capacity development (Box 3.6). A principle of "learning by doing" was adopted that linked training to concrete activities. The APPRC, with the support of INP+, APN+ and UNDP, was put in charge of identifying, developing and sharing training material, and identifying experts who could provide various kinds of technical support.

The APPRC linked up with the Australian National Association of People Living with HIV/AIDS (NAPWA), a strong group with a wealth of experience in NGO management, to produce a comprehensive training manual on organisational development. The manual covered the basics of starting, managing, developing, and sustaining an NGO, using examples and issues specific to PLWHA organisations. This was accompanied by an instructor's manual, designed to

Box 3.6

Organisational Development

The five elements of the strategy for developing organisational capacity of PLWHA Groups in the Asia Pacific region include:

1) Staff: PLWHA group coordinators will be employed and trained in project management to take the projects forward. The PLWHA group co-ordinators of the Empowerment for GIPA Initiative will network with each other through the regional electronic connectivity programme, developing and using shared tools.

2) Accounting: Two people from each PLWHA group will be trained and supported to set up a financial management system for the PLWHA group accounts. The system will be developed in cooperation with other PLWHA groups under the regional project and the emphasis will be on making it user friendly and transparent. UNDP has developed a user-friendly accounting excel programme called "Empowerment Accounting," which allows groups members to keep track of accounting without much knowledge and experience of accounting. As the system will be shared by a number of PLWHA groups, regional support for implementing and maintaining the system will be made available.

3) Office infrastructure: The organisation of the PLWHA groups will be set up, including office infrastructure such as furniture, communication technology, stationery, and filing systems. The space will also function as a permanent meeting place for PLWHA group members and as the base for activities to be implemented during the project.

4) Organisational management: Training will be conducted in organisational management for the members of PLWHA group, including the Board, on issues such as fundraising, proposal writing, project implementation, report writing/documentation, monitoring and evaluation and on how to delegate responsibilities after the training.

5) Building partnerships: A national coalition will be created for technical and financial support, by networking with the government and civil society, to create a strong base for implementation and sustainability of the PLWHA groups and the organisations' activities.

enable each of the PLWHA groups to undertake the training within their countries, together with their partner organisation.

As part of strengthening, monitoring and evaluation of the Asia Pacific Initiative for the Empowerment of PLWHA, UNDP commissioned a baseline study in countries where PLWHA groups were receiving support. The team for this study consisted of a mix of PLWHA and university researchers from Asia and the Pacific who had high capacity and academic credentials and UNDP staff. These researchers were also selected for their ability as facilitators, as they were additionally tasked with introducing the organisational training manual to the PLWHA groups. The final report on the baseline study will be distributed among PLWHA groups worldwide through the APPRC.

Box 3.7

Baseline need assessment of GIPA

The baseline study provides an overview of the environment in which PLWHA groups have been operating. The information obtained from the study would be used to guide interventions as well as to provide basis for monitoring and evaluation of the Initiative. The study specifically provides information regarding the forms of discrimination (social, political, legislative and economical) experienced by individual members and PLWHA groups as a collective entity. It also provides information on the extent to which HIV prevention, care and support responses at local or national levels encourage and include PLWHA in policy formulation and implementation. It talks of regional commonalities and differences in terms of issues, problems and needs as well as the general situation in each of the countries.

CARE AND SUPPORT

When the South Asia GIPA initiative began, PLWHA in most countries of South Asia had limited access to any kind of psycho-social, legal, medical or economic support. Care and treatment issues posed serious problems for most of the ailing members. The activi-

ties that the groups proposed reflected these needs, in the form of mobilising support for medical care, for their children to continue schooling, for income generation programmes as well as for voluntary counselling and testing centres (VCTCs) run by PLWHA. However, the twin constraints of a limited time frame and uncertain sustainability rendered these proposals non-feasible and the project had to refocus on short term activities that would have an immediate impact on the lives of PLWHA group members. The magnitude of the activities was also scaled up to practical proportions in working towards long-term goals.

Various activities were defined along these lines and were eventually carried out, supported by UNDP and its partners. Five groups in the region conducted a series of awareness workshops for PLWHA, their families and communities with the aim of enhancing their knowledge of HIV/AIDS. Two groups conducted workshops on positive living, and almost all the groups trained their members on peer support and peer counselling. As part of the care and support services, a few groups also established referral systems for medical and non medical services. Women from the groups conducted a feasibility study as part of the pilot project, their main concern being the identification and development of livelihood opportunities.

By the time the Initiative for the Empowerment of PLWHA was launched in 2002, PLWHA from South Asia had gained valuable experience on how issues related to care and support could be addressed. The feedback on the utility of the Positive Development Manual - developed by the International Community of Women living with HIV/AIDS (ICW) - was incorporated into the strategy of the new Initiative. The input covered a range of issues such as positive living, peer counselling, outreach to people who test positive at VCTC, the provision of counselling services and the development of referral systems as well as the need for providing safe spaces for PLWHA members (Box 3.8). The exercise followed the principles of linking training and activities to promote capacity development.

Organisational health is directly dependent on the health of its individual members. Positive living was an important element in the capacity development workshops carried out by PLWHA groups for their members

Box 3.8

Care and Support

The five elements of the strategy for developing capacity for care and support among members of PLWHA groups in the Asia Pacific region include:

1) Positive living: This would involve the empowerment of all members of each PLWHA group for positive living through training, providing basic information about HIV/AIDS, aspects of health & nutrition and physiological wellbeing. Regionally developed training manuals will be used and the training will be conducted by various resource people from the region.

2) Peer counsellors: Selected members of the PLWHA group in peer counselling, who have followed the positive living training programme, will be trained as peer counsellors. A training manual has been developed by Australian Red Cross (ARC)/NAPWA/APN+. The regional training will be conducted by ARC for PLWHA group representatives who have attended the regional train-the-trainer programme, during the Second Working Group Seminar in October, 2004 organised by APPRC in partnership with APN+/INP+/UNDP.

3) Peer counselling services: A counselling project will be set up, which will offer counselling by PLWHA to people living with and affected by HIV/AIDS. This will include post-test counselling for those testing positive as well as family members of PLWHA. The project will include face-to-face counselling and the establishment of a hotline. Linkages will be established with voluntary counselling centres and other locations where HIV tests are conducted, to ensure referral of newly tested PLWHA from these counselling centres to PLWHA groups. Support from institutions responsible for HIV post-test counselling will be sought to sustain these and other PLWHA group activities.

4) Referrals: A referral system for the quality treatment of opportunistic infections and social services will be built up and expanded. An intrinsic part of the activity will be to identify sensitive practitioners and service providers who can provide immediate help to PLWHA. Partnering with these resource persons, NGOs and institutions, PLWHA group will sensitise a broader segment of health care and social service providers, thereby making these organisations and institutions more accessible to PLWHA.

5) Day centre: A session on day centre, its purposes and management will be provided to the PLWHA groups in the Second Working Group Seminar. This will be followed by a feasibility study will be conducted on running a drop-in/day centre for PLWHA run by PLWHA group. Focus will be on whether PLWHA feel a need for such a centre, assessing the number of prospective users and identifying the activities and facilities that such a centre should offer. Manuals on both referrals and day centres will be developed by NAPWA(Australia).

in India, Bangladesh, Nepal and Pakistan. These workshops were conducted in 2002 with support from the partner NGOs and UNDP. The workshops exposed PLWHA to basic information on HIV/AIDS and sexually transmitted diseases (STDs), treatment issues included the kinds of drugs used, their side effects, drug resistance, opportunistic infections and their management and the parallel investigations such as CD4 counts. Useful information on topics such as sex and sexuality, pregnancy and childbirth, which can assist a positive person in leading a normal life, was also integrated into the training. Additionally, the positive living workshops honed the aptitude of many PLWHA to function as peer

counsellors. As part of the Initiative, six networks in South Asia worked towards strengthening their systems of peer counselling and support.

An example of work that helped formulate a feasible strategy for peer counselling was that of a PLWHA group in Pakistan. The New Light AIDS Control Awareness Group (NLACAG) in Lahore adopted a method of counselling the people living with HIV/AIDS and their families by visiting their homes, covering issues of stigma and discrimination and providing support to the individual and family members. During the first phase of the GIPA Initiative, NLACAG developed IEC (Information, Education, Communication) materi-

als promoting the group and its peer counselling services. These were distributed at public places such as bus stops, mosques, and also at religious functions and training sessions. The information kits were also placed at hospitals, chemists, laboratories and clinics. Another example of innovation comes from the Chinese PLWHA group - AIDS Care. AIDS Care has set up an innovative model, providing web-based counselling to many people with access to the Internet. The cyber-community nurtured by AIDS Care has been quite vibrant, but the group would like to see the emergence of more grass-roots groups to take peer counselling to rural China. The web-based counselling service of AIDS Care has become popular and the group has been able to establish a hospice for PLWHA with funds contributed by people who drew on their services.

UNDP has also supported PLWHA groups in South Asia to establish referral²³ services in partnership with hospitals, counselling centres, and NGOs. There are many successful examples of such referral services from South Asia. In India, En-joy, Kolkata, has established referral services for their members and families. Nepal+ has graduated to operating a drop-in centre for pre-, post-test, couple and nutrition counselling. It has also launched the HIV Anonymous (HA) where PLWHA meet weekly to share their experiences. The HA meetings are conducted in partnership with an NGO and members of the medical fraternity. The establishment of these referral services have helped networks increase their membership.

One of the most important capacity development needs of positive people has been identified as income generation. Under the South Asia GIPA Initiative, Chennai-based PWN+ and AIWAC of Churachandpur from India carried out feasibility studies on income-generating projects. The studies have yielded useful data and spurred the process of developing a project that can generate a sustainable income for groups of HIV-positive women. The project also hopes to enable these groups to give out small grants to other HIV-positive women or groups of women, for vocational training or livelihood initiatives.

23 Referral means sending PLWHA to a health care or social service provider if they experience medical or non-medical problems that require professional assistance. It can also mean sending PLWHA from a counseling centre to a PLWHA support group, MSM support group or IDU support group

ADVOCACY

Advocacy skills were identified by PLWHA as the third critical component of capacity development. These are crucial to implementing GIPA and have the potential to improve the conditions of PLWHA at all levels. Under the South Asia GIPA Initiative, activities had mainly clustered around organisational issues and provision of care and support. Subsequently, a number of activities were carried out to enhance the capacity of PLWHA to influence their environment, mainly in the area of developing advocacy material. In order to reduce stigma and discrimination, and spread the right information on relevant issues, several groups participating in the project developed a number of brochures and leaflets. Two groups also conducted a positive speakers' programme.

At the Strategic Planning Workshop in Marawila, Sri Lanka, PLWHA groups discussed the following strategies:

- Strengthen advocacy efforts to reduce stigma and discrimination;
- Involve meaningfully in HIV/AIDS responses at all levels;
- Increase awareness about HIV/AIDS; and
- Promote positive images of PLWHA in the general population.

"The Health Minister of Bangladesh visited Ashar Alo Society (AAS) for an advocacy workshop. After AAS members spoke to the Minister, he promised to write to the Department of Health to ensure that doctors provide treatment and home care facilities."

- Nasreen, Member, Ashar Alo Society (AAS), Bangladesh

Most did not have a clear picture as to how to craft and execute advocacy efforts. They identified a strong need to understand the concept of advocacy better, develop general advocacy skills and acquire the ability to strategise and carry out advocacy activities. The experiences of PLWHA groups involved in public speaking during the South Asia GIPA Initiative showed that advocacy was a way of creating awareness and addressing stigma and discrimination at the community level. There was also a strong need felt by PLWHA groups for media sen-

sitisation and advocacy. This emanated from the fact that many PLWHA had suffered the consequences of insensitive media reporting on HIV/AIDS. The reportage frequently portrayed PLWHA in a negative light, manipulated interview content and violated confidentiality.

Whether during the start up GIPA phase or the subsequent and ongoing empowerment phase, the PLWHA programme strove to create linkages between advocacy blocks and PLWHA groups. For instance, the participation of Mangrove Support Group coordinator at a round table of senior editors of leading newspapers of the Asia Pacific region in New Delhi in May, 2002, ensured that the concerns of PLWHA were well represented at the meeting. The editors eventually issued a statement of commitment (see page 41) affirming the media's responsibility in "sensitising society to the rights of PLWHA" and giving serious attention to "human rights violations and discrimination".

The efforts of strengthening the individual skills of PLWHA have translated into strengthened capacity to make change at the policy level. For instance, as briefly mentioned above, the President of Ashar Alo Society (AAS) in Bangladesh organised a national dialogue on GIPA with key stakeholders including the national government in which she emphasised the meaningful participation of PLWHA in national programmes. This led to AAS becoming a member of the National STI/HIV/AIDS Network and the National AIDS Committee.

The APPRC was central to the capacity development of PLWHA in the area of advocacy. The APPRC, with support from APN+, INP+ and UNDP, identified resource persons to develop training manuals on general as well as media advocacy and to establish a positive speakers' bureau. The last drew from the existing manual on positive speaking; *Lifting the Burden of Secrecy*, published by APN+. Both manuals contain training modules that help PLWHA advocate for the changes necessary to improve their lives and protecting their rights.

The *Public Speakers' Bureau Manual* is a direct continuation of the *Lifting the Burden of Secrecy* manual by APN+, which is aimed at training PLWHA and preparing them to speak in public. It equips PLWHA groups with tools and frameworks for setting up public speakers' bureaux for systematic awareness creation and reduction of stigma and discrimination. It is also aimed as an activity for income generation for both PLWHA groups and individuals.

Both the manuals were introduced and reviewed by the PLWHA groups in September 2003 at the first Working Group Seminar of the 17 PLWHA networks in Pattaya, Thailand. The three-day seminar aimed to equip PLWHA with advocacy skills to deal with a variety of constituencies, and focused on three key areas: general advocacy, media advocacy and public speaking (See Box 3.9).

LESSONS LEARNED

Among the key lessons learned from the efforts to build the capacity of PLWHA networks, is the need to set realistic time-frames for accomplishing specific tasks. The capacities they require need to be broad-based, at the same specific. For a response with true participation of PLWHA, efforts are needed to strengthen their capacity in advocacy; particularly on issues like stigma and discrimination, access to treatment and livelihoods; networking; Internet and IT tools; public speaking; peer counseling, legal and rights literacy and more importantly, leadership. In the last few years, it has also been evident that sustained and systematic capacity building efforts can qualitatively transform the PLWHA movement. Although PLWHA groups need to twin with NGOs during the start up period, their growth depends on their ability to enter into and sustain a wide spectrum of partnerships at the community, national and regional levels. Potential partners for PLWHA groups include government agencies, the private sector and civil society organisations, bi-laterals and international institutions such as the SAARC, ASEAN and UN organizations.

THE ROAD AHEAD

Development of a comprehensive strategy to address the needs of PLWHA is a priority area. The strategy must provide focus, particularly in the areas of treatment, care & support, and sustainable livelihoods. This would ensure that the progress made thus far is consolidated, strengthened and sustained, and that positive changes can acquire permanence in the lives of PLWHA and their families.

The process of developing capacity for advocacy on key issues needs to accelerate. Each PLWHA group needs to be assisted in formulating advocacy strategies

Box 3.9

Advocacy

The five elements of the strategy for developing capacity for advocacy of PLWHA Groups in the Asia Pacific region include:

- 1) Advocacy skills:** PLWHA group members will be trained in advocacy with various stakeholders such as governments, NGOs, politicians, community leaders, and the media. The emphasis will be on normalising the HIV epidemic and promoting rights based approach for prevention, care and support responses and fighting stigma and discrimination. The training modules will be developed at the regional level and one member of each PLWHA group will be trained as a trainer in advocacy, and will conduct the programme together with a support person from a trusted NGO.
- 2) Public speaking:** A project on public speaking will be developed and implemented. The project will educate PLWHA who are ready to come out and speak in public, to address staff of government and civil society organisations, communities and workplaces. Emphasis will be on conducting systematic public speaking campaigns to raise awareness about HIV/AIDS and 'normalise' public perception on the epidemic. The PLWHA groups will offer these services to civil society organisations and governments on a contractual basis in order to cover the costs of the project and provide resources for their other activities. Practices and manuals already developed in the region will be applied in the development of the programme.
- 3) Media advocacy:** A capacity development project will be implemented among media representatives. A model for sustainable sensitisation of the media, including editors and journalists will be developed regionally and carried to the national level by the PLWHA groups. Strategies and tools provided will focus on basic awareness about HIV and PLWHA-sensitive prevention messages, promotion of rights-based approaches and reduction of stigma and discrimination, as well as promoting the right to access to treatment, care and support.
- 4) Policy advocacy:** Strategising exercises to influence policy makers and implementers of HIV prevention care and support responses including government, politicians, bi- and multilaterals and civil society will be carried out. Each PLWHA group will democratically identify two persons to lead this advocacy activity. These representatives will go through a regional leadership training programme together with other PLWHA to empower them to assume this role. This training will include participatory methodologies ensuring that the selected policy/advocacy leaders are taking forward the concerns and ideas of all members of PLWHA group. The goals will be to gain direct influence, e.g., getting PLWHA representation in the board of national HIV/AIDS control programmes, being heard when major HIV/AIDS campaign initiatives or activities are being planned or new policies formulated and being involved as experts in implementation of HIV/AIDS responses. PLWHA group will seek remuneration for these services, in a move to ensure quality of the involvement and sustainability of the activities.
- 5) Advocacy materials:** The PLWHA groups will together develop appropriate advocacy tools and IEC materials for wide distribution, in order to strengthen their advocacy activities. Using and adapting existing material from the region and the world will be crucial in developing quality products and avoiding duplication.

on how to use the media, influence governments and obtain increased support from civil society and the private sector. They also need to learn to influence the situation at the community level. While priorities must be defined at the national and regional level, concrete advocacy activities must be brought into a result-oriented plan of action.

Capacity development both at the individual and organisational levels needs to be continuously strengthened. As capacity is built, the focus of facilitation should shift towards promoting self/mutual support. It will also strive towards providing tools to move the empowerment processes forward from just granting seed funding and other hands-on support.

Leadership for Change

THE NEED FOR NEW PLWHA LEADERS

Around the world, strong leadership has proven to be a vital ingredient for an effective response to HIV/AIDS. Responsible leadership can inspire hope, foster transformation and generate an enabling environment for sustainable results. World leaders attending the UNGASS in June 2001²⁴ acknowledged this critical role of leadership. The UNGASS Declaration of Commitment called for a fundamental shift in our response to HIV/AIDS from being health-centric to a holistic approach - one that perceived the epidemic as a threat to global development. The UNGASS Declaration acknowledges "the particular role and significant contribution of people living with HIV/AIDS" and calls for their "full involvement and participation in design, planning, implementation and evaluation of programmes," in order to bring about an effective response to the epidemic.

The leadership qualities required to enhance the quality of HIV/AIDS responses are not defined by power and influence, but by a shared commitment to working in collaboration with others to pioneer responses to HIV/AIDS at every level. These leaders include PLWHA, media, women, policy makers, community representatives, young men and women, religious leaders and others who are distinguished by their shared vision, goals and commitment to results.

Nurturing a leadership culture that brings HIV-positive leaders into the forefront of the third generation response requires the systematic support and training of a new crop of potential PLWHA leaders.

²⁴ Ibid. 17

STRENGTHENING TRANSFORMATIONAL LEADERSHIP AMONG PLWHA GROUPS

There are two aspects to enhancing leadership among PLWHA:

- Facilitating the emergence of PLWHA as leaders; and
- Developing organisations of PLWHA that can take a lead in the responses to HIV.

At present, most countries in the region have a few strong PLWHA leaders who are ready to be involved with the HIV/AIDS responses at community, national and regional levels. Most of these leaders have developed capacity by becoming an integral part of nascent PLWHA groups. They have built their knowledge and skills by synergizing individual leadership with organisational leadership.

Within South Asia, PLWHA in India have taken the lead in providing a supportive environment for themselves. The Chennai-based INP+ pioneered a strong PLWHA movement in the country. It assisted in shaping new leaders and groups at the state and provincial levels. It also supported leadership development efforts at the regional level through the APPRC, administered by the organisation with support from APN+ and UNDP.

Founded with just 12 members in 1997, INP+ today has more than 10,000 members and a presence in a dozen states in India. As a representative of nearly five million PLWHA in the country, the vast majority of whom are not organised, INP+ has a stupendous task. One of its major mechanisms to reduce stigma and discrimination is to present the network's vision at every national and international forum. Positive speakers from INP+ and other state

level networks are in a way attempting to provide the same.

APN+, founded by 42 PLWHA from eight different countries in 1994, is another crucial player developing new regional leaders at the Asia Pacific level. The organisation has brought up a number of leaders and is at the frontline of the Asia Pacific PLWHA movement, with contacts and representatives in 23 countries of the region. It represents Asia Pacific in the Global Network of PLWHA (GNP+).

GENERATING NEW PLWHA LEADERS

Over the last three years, the PLWHA groups, networks, bi- and multilateral agencies, including UNDP, and other stakeholders have worked to strengthen PLWHA leaders and build up top PLWHA groups in the region through a series of activities:

- Helping PLWHA to develop the messages they require to convey
- Facilitating opportunities for them to speak at influential press conferences
- Help them embark on a process of learning transformative leadership techniques and core competencies.

UNDP, along with its partners, has leveraged governmental support to include PLWHA leaders in decision-making processes within national HIV/AIDS programmes, thereby creating a more responsive policy environment in which PLWHA leaders can take action. This has meant advocacy at the highest level with policy makers and implementers.

LEADERSHIP FOR RESULTS AND PLWHA

In the region, UNDP's Leadership for Results Programme involves PLWHA on a large scale. The programme, specially tailored for PLWHA, taps into the existing leadership resources in the PLWHA movement and seeks to develop comprehensive leadership skills at all levels - district, provincial and national levels. The programme was offered at the National level to the networks in India and at the regional level to the networks in Asia Pacific. In India, the programme was organised in partnership with INP+, National AIDS Control Organisation and Indian Institute of Planning and Management (IIPM), a management training institution in the private sector. At

the Asia Pacific level, the programme had as partners, APN+ and the networks of the region.

The India programme began in May 2003 at Kapashera, near New Delhi. It brought more than 130 PLWHA from different parts of India for a leadership development process over a period of nine months. After the first workshop in Kapashera, two more training workshops were conducted in Kochi, Kerala, and Kolkata, West Bengal, respectively. The occasions also doubled as advocacy events spinning off impressive civil society and governmental involvement. The workshops also created the space for additional skills for selected PLWHA who functioned as co-facilitators for different sessions in the programme and the break out sessions.

Besides hands-on training employing cutting edge transformational leadership methodologies, the first workshop provided the INP+ leadership with an invaluable opportunity to interact directly with the Project Director of NACO in India. The result: A new open door policy for PLWHA announced by the Project Director with an open letter to all State AIDS Control Societies (SACS) to involve PLWHA in more meaningful ways (see Box 3.10).

Through a process of exploring how transformational approaches can bring breakthrough results for PLWHA leaders and groups, the participants generated breakthrough initiatives that they undertook throughout the course of the programme and beyond.

PLWHA groups who participated in the first leadership programme in Delhi conducted a number of activities that contributed to the various goals they had identified in their breakthrough initiatives. The workshops led to a breakthrough in terms of a more enabling policy environment. The Table 3.1 highlights some of the major breakthrough initiatives undertaken by various PLWHA groups across the country.

The second workshop in Kochi (India) represented a breakthrough for INP+ as a leading PLWHA movement. Throughout the programme INP+ leadership organised a massive advocacy campaign including direct interaction with religious leaders, law students and the film industry providing opportunities for both formal and informal interaction. INP+ also organised the first protest march of PLWHA during the seminar - a show of strength that gathered together more than 100 PLWHA in support

of positive people who had been exploited and ruined by quacks pretending to possess a cure for HIV. This event was significant owing to the high level of media coverage it received, an outcome that boosted the self-confidence of PLWHA, both as individuals and collectives. The occasion also had the leaders of South Indian entertainment industry, religious and political leaders and youth representatives joining hands with PLWHA activists. Two film personalities, who participated in the advocacy event, are now in the process of making full-length feature films with PLWHA as central characters.

The third workshop of the series that took place in March 2004 in Kolkata, also witnessed a repeat show of strength in the form of a public procession in the streets of Kolkata. Organised by En-Joy, the local PLWHA affiliate of INP+, the rally demanded better access to treatment for PLWHA. The participants of the

workshop linked their experiences from the three workshops and shared their visions of a future in which they could play a more decisive role. INP+ has expressed enthusiasm that the leadership programme could be taken from the National to State and District levels of their organisation to train all their members in transformational leadership.

At the regional level, a significant initiative was the launch of the Asia Pacific Leadership for Results

"Transformational Leadership starts with self and leads to community.

Transformation occurs when you recognise, acknowledge and give up an automatic "way of being" in favour of making something new possible."

- Jon Love, international Transformational Leadership expert who facilitated the 'UNDP PLWHA Leadership for Results' programme in India

Box 3.10

Open letter to Project Directors of State AIDS Control Societies (SACS) in India: Excerpts

1. People living with HIV/AIDS, many of them already organised into networks, are now rapidly firming up existing affiliations. We must support these efforts and document their referral coordinates in respect of each state.
2. Many of these networks of positive people are working with you. Can you include a representative of the INP+ or from the state forum of positive persons in decision-making bodies of the State AIDS Control Society, such as the Executive Committee or the Governing Body? You could request for a panel of names from the INP+ or any equivalent affiliation, and then nominate at least one HIV-positive person from the panel. Where more than one person is chosen from a given list, there should be at least one woman representative.
3. The PLWHA representatives often complain that the nature of IEC messages has in fact led to an increase in the stigma they face. In order to ensure that the messages typically used in IEC campaigns do not add to the stigma and discrimination they encounter, kindly include a representative from the positive people's network in the IEC Committee within the SACS.
4. The recent workshop on Care and Support at Bangalore (12-14 May, 2003) jointly organised by NACO and ICHAAP, demonstrated that positive persons are not being involved even in the management of the care and support centres. A direction may be issued to all present and future NGOs setting up Community Care Centres that Persons Living with HIV/AIDS should be represented on the Governing body of each Community Centre.
5. PLWHA have reported that counsellors at the VCTCs very often did not have enough experience to empathise with and support persons who test positive for HIV/AIDS. Having HIV-positive persons as peer counsellors would sensitise our efforts and could be extremely relevant and useful. Please examine this suggestion. We look forward to early proposal in this respect, particularly in respect of those VCTCs where persons are testing positive in substantial numbers.

Project Director, National AIDS Control Organisation, 13 June 2003

Table 3.1: Breakthrough Initiatives from PLWHA groups in India

| State | PLWHA group | Breakthrough Initiatives |
|-------------|-------------|---|
| Nagaland | NNP+ | <ul style="list-style-type: none"> Documentary on reducing stigma and discrimination One-day advocacy programme on the topic |
| Manipur | MNP+ | <ul style="list-style-type: none"> Two-day workshop on capacity development for key stakeholders in Manipur Initiated formation of district level networks |
| Tamil Nadu | HPPWS | <ul style="list-style-type: none"> Sensitisation programmes for healthcare providers in select districts Registered new district level network in Tiruchi |
| Tamil Nadu | PWN+ | <ul style="list-style-type: none"> Legal literacy workshop for women living with HIV/AIDS in various states The training programme helped positive women learn about their rights and the ways to seek support for legal problems |
| Kerala | CPK+ | <ul style="list-style-type: none"> Conducted meetings in two districts in a bid to form networks |
| Karnataka | KNP+ | <ul style="list-style-type: none"> Initiated processes in registering their two district level networks Developed proposal for enhancing the capacity of the district level networks and submitted it to ICHAP |
| West Bengal | En-Joy | <ul style="list-style-type: none"> Conducted a survey on the provision of treatment to PLWHA in West Bengal |

Programme in September at Pattaya, Thailand in 2003. Attended by over 120 PLWHA leaders from 21 Asian countries, the programme envisaged strengthening the leadership and capacities of PLWHA as individual members of a regional PLWHA movement.

A number of breakthrough initiatives, which were the outcome of the earlier workshop, are already under implementation. For example, in Iran where a PLWHA self-help group has recently come into being, the PLWHA members have set themselves the target of enrolling at least 25 more people by January 2004, and 50 by July 2004. Nepal-based PLWHA has envisioned a future free of HIV-related stigma and discrimination in their country. To that end, they have committed themselves to work on advocacy for a legislation addressing anti-discrimination by January 2004. A draft legislation, which could be submitted to the Cabinet Ministry, is under preparation. They envisage a full-fledged legislation in place by July 2004.

HIV-POSITIVE WOMEN AS LEADERS

In many countries in Asia and Pacific, women living with HIV are doubly marginalised. As a result, very few HIV-positive women have come out to play a substantive role in the response to the epidemic. To change this situation, the GIPA Project and the Empowerment Initiative have sought to foster and

Box 3.11

Persia+, Tehran, Iran

Through the Marawila workshop (p.23) and other regional PLWHA gatherings, Maana became convinced of the power of a PLWHA self-help group and its significant role in helping PLWHA cope with adversities and advocate for their rights, needs and dignity. Inspired and supported by PLWHA activists from across the Asia Pacific region, Maana decided to form the first Iranian PLWHA group in 2003.

Women living with HIV/AIDS often face double stigma of being a woman and being HIV positive, particularly in societies where women do not enjoy the social status and privileges equal to those of men. Maana's case was no exception. At the beginning, it was painfully challenging for her to gain the support and understanding she needed.

With continuous support and encouragement from her peers and supporters from the region, however, Maana did not give up. Now Persia+ is recognized and supported by the Health Ministry and other stakeholders and plays an important role in upholding the interest of PLWHA in Iran.

promote HIV-positive women's groups and leaders. AIWAC in Nepal and PWN+ in India drew their strength from the South Asia GIPA Initiative.

In Sri Lanka, the GIPA-project played a crucial role in encouraging and supporting Dr. Kamalika Abeyaratne - the first female PLWHA to go public in the island nation - to form Lanka+. Interaction with PLWHA from other South Asian countries including India provided her with the much-needed emotional impetus towards empowerment and forming the group.

Yet another HIV-positive woman in the region who is playing an increasingly influential role is P. Kausalya, the backbone of Positive Women's Network (PWN+), Chennai, India.

HITTING THE BULL'S EYE

The outcomes of the leadership efforts have been the development of male and female PLWHA leaders, leadership competencies of contemporary relevance among PLWHA and discernible changes in the policy environment. Both outcomes have enabled the new PLWHA leaders to access government and key policy decision making forums. The sustained exposure and the institutional support facilitated by UNDP have contributed to the emergence of several accomplished speakers within the PLWHA movement. These speakers display conviction and confidence when faced with a range of audiences - whether of government officials, representatives of the arts and media or the corporate sector. They also facilitate training sessions for the general public.

HIV&YOU PROGRAMME: PLWHA LEAD PREVENTION AND CARE EFFORTS

Another achievement that illustrates the potential of the new leaders is "HIV&You", a prevention and care centred awareness programme spearheaded by INP+ in partnership with the private sector and UNDP. Addressing the vulnerabilities of migrants and industrial workers in Gajraula, an industrial town near Delhi, India, this programme reached more than a thousand beneficiaries. Based on demand, INP+ organised a similar programme at a similar industrial setting in Pune, Western India. This initiative offered the emerging leaders of INP+ an opportunity to sensitise both senior management

Tamir's Story from Mongolia

Being the only person in Mongolia to come out with her HIV positive status, Tamir was the target of humiliation and discrimination. Life was difficult till she met activists from around the region during an international conference. Their vitality, commitment and compassion instilled in her the courage and conviction to form a PLWHA group. She is now actively involved in providing AIDS-related information to marginalized communities.

Kousalya's Triumph

Kousalya comes from Nammakal, a small town in Tamil Nadu in South India. Widowed when she lost her husband to AIDS, Kousalya could have been at the receiving end of intense stigma, but was spared. Namakkal is the hub of the trucking industry in South India and records HIV prevalence rates that rank among the highest in India. Kousalya heads PWN operations from an office in Chennai, the state capital. She has been able to lead a movement of HIV-positive women by adopting a calibrated approach. "I began with messages in the print media, sustained it for a while, and gradually added education through TV, concealing my identity. The responses were encouraging. By the time I made my third appearance on TV, I was ready to show my face. The response was overwhelming. Even my neighbours came to know about my status after my TV appearance. Instead of discrimination, they expressed compassion. Almost everybody who spoke to me was by then aware of my HIV-positive status." Today Kausalya is perhaps the most visible face of the HIV-positive women's movement in India and speaks out frequently at national and international forums.

and vulnerable mobile populations. For INP+ trainers being openly HIV-positive proved to be a powerful platform to provide messages of both prevention and anti-discrimination. This was again an example of the third generation response in which PLWHA took a proactive and principal role.

HIV&You is also significant because of the triangular partnership among INP+, UNDP and Jubilant

Helen's Story

Helen Berem from Port Moresby in Papua New Guinea was tested HIV positive in 1998, following her husband's HIV positive test result. At first Helen was dejected and afraid but her resilient spirit led her through a transformational journey - from being a docile wife and mother of five to becoming a leader who can evoke hope in thousands of Papua New Guineans. Recently, Helen has founded and is the President of Igat Hope, the first group of people living with HIV/AIDS in Papua New Guinea.

Organosys Limited, a speciality chemical company in India, representing PLWHA, the UN and the corporate sector respectively. Jubilant, in partnership with UNDP, plans to scale up the initiative involving many small and medium sized industrial groups in India.

LESSONS LEARNED

Despite the emerging PLWHA movement in the region, the leadership role of many of the newly formed groups remains severely limited. One of the biggest obstacles in developing PLWHA leadership is the silence and stigma that envelop positive people. Those who have greater capacity within the community are often afraid to come out and take charge due to the fear of social isolation.

PLWHA also require modern leadership competen-

cies that can inspire people, transform societal attitudes, change processes and produce meaningful results. This requires a countrywide, fundamental change in leadership practice and skills. The response to the Leadership for Results programme in India, as evidenced by the breakthrough initiatives and the consistent participation of more than 120 people, despite ill-health and other constraints, reflected the growing need for leadership development. The fact that INP+ and PLWHA groups have requested expansion of the programme to state and district levels demonstrates the utility and need for transformational leadership development.

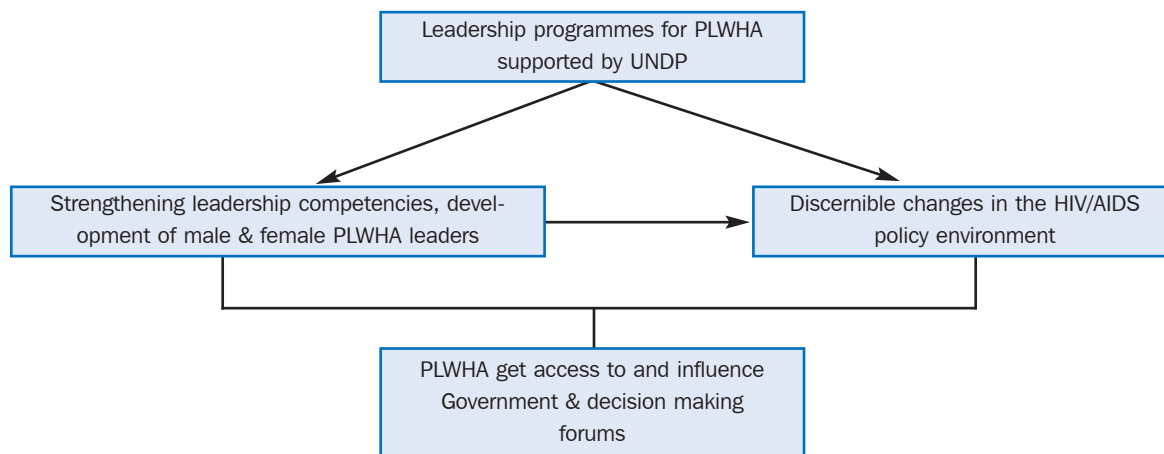
A significant learning has been the correlation between access to ARV and leadership. While leadership takes years to develop, it is tragic to see emerging PLWHA leaders fall ill before they get the opportunity to effectively apply their skills or fulfil their potential. Some of the key leaders, who have been part of the programme, are no more today because of lack of timely access to drugs.

THE ROAD AHEAD

Sustained strengthening of capacity of PLWHA groups in organisational development, care and support, networking and advocacy is indispensable to expedite the process of building new and strong PLWHA leaders.

PLWHA leaders have time and again stressed the need for continued support in developing leadership

Fig 3.1: Leadership for change



skills. This would enable them to play a more substantive role at the policy level. Every PLWHA is a potential leader within the family, the local community and society at large. Therefore, the PLWHA leaders have emphasised that more people within the groups should get opportunities to develop leadership capabilities. This would enable ordinary members to take responsibilities for strengthening the movement. It would also ensure that PLWHA become strong players in the HIV/AIDS response at all levels. It would also make the PLWHA organisations less vulnerable.

UNDP plans to continue its focus on the develop-

ment of leadership competencies of PLWHA and is exploring the possibility of offering the Programme in China. The methodology would organically evolve in response to the needs of emerging PLWHA leaders and would be reflected in the training materials developed. These materials would be made available throughout the region through the APPRC to ensure that transformative leadership tools can percolate to the grassroots level of the PLWHA movement. UNDP is also helping to establish an Asia Pacific PLWHA Support Fund, a financial mechanism designed to meet immediate needs of PLWHA and their family members with the involvement of local PLWHA groups.

Quiet Storm: Triumph of Human Spirit over HIV/AIDS

"Quiet Storm", a pictorial book on the inspiring lives of People Living with HIV/AIDS (PLWHA) in South and North East Asia, exemplifies the emerging empowerment of PLWHA in the region.

Told through evocative text and compelling images, this 60-page book is a tribute to the indomitable will of millions of people living with HIV/AIDS, who fight stigma and discrimination on their own terms and lead the campaign against the epidemic from the forefront. It features the inspiring stories and voices of 15 PLWHA leaders in the region who are part of the Asia Pacific Initiative for the Empowerment PLWHA.

As the strap-line of the book says, it celebrates the triumph of human spirit over HIV/AIDS.

Produced by UNDP Regional HIV and Development Programme in partnership with INP+ (Indian Network for People Living with HIV/AIDS), APN+ (Asia Pacific Network of People Living with HIV/AIDS) and PLWHA groups in the region, the book has also been converted into a six minute film that is available in 11 languages in the region. PLWHA in different countries of the region took an active part in translating the original English text into various languages. Both the book and the film have been used extensively by PLWHA groups, UN organisations, public and private sector companies, corporates, NGOs and Governments for advocacy and training on issues related to PLWHA.

Two language editions, Chinese and Japanese, have also been released. The Japanese version is an expanded Asia Pacific edition, which features 20 PLWHA, including three from Japan. Published in partnership with Tokyo based Pot Publishing, Solid Alliance and JaNP+ (Japanese Network of People Living with HIV/AIDS) the book will be used for advocacy and resource mobilisation for supporting the needs of PLWHA in the region.

An expanded, priced edition in English will be launched in December, 2004 with the twin objective of advocacy and resource mobilisation.

Conclusion

The Unfinished Agenda

The concerted efforts of PLWHA groups, networks and other stakeholders during the last few years have led to the emergence of an impressive PLWHA movement in the region, but their inclusion in the responses to the epidemic is far from satisfactory. Though the principle of GIPA has gained currency across the region, its practice is still feeble, and, in many instances, tokenistic.

The learning of PLWHA groups and UNDP while implementing programmes such as the GIPA Initiative and the Asia Pacific Initiative for the Empowerment of PLWHA in the last three years clearly points to the need for the well-being and empowerment of PLWHA for their meaningful participation. These are the indispensable ingredients for a third generation response that is rights based and gender sensitive.

Such a response needs deeper understanding of the issues faced by PLWHA, the principles of GIPA and commitment, all of which call for increased human, technical and financial resources and focussed attention on issues such as stigma and discrimination, access to treatment, enabling legal and ethical situation and avenues for sustainable livelihoods.

Three major areas that are integral to empowering the PLWHA groups in the region and helping their participation in the HIV/AIDS responses are networking, capacity development and leadership. As seen in the region, networking brings individuals and groups together and helps harness the collective energy of PLWHA coalitions. As the pace and face of the epidemic as well as competencies vary from

country to country in the region, networking helps them learn from each other and foster trans-border peer-support. Similarly capacity building in areas such as organisational development; advocacy on issues such as stigma and discrimination, access to treatment, livelihoods and policy changes and public speaking and communication are the other elements of a comprehensive plan to ensure the meaningful involvement of PLWHA. Leadership development organically links with networking and capacity building and lays the foundation for a strong PLWHA movement in the region.

Some concrete steps have been taken in the above-mentioned areas that have produced considerable results, but much more needs to be done with every stakeholder in HIV/AIDS responses, particularly national and local governments, making GIPA, an inalienable principle of HIV/AIDS programming. Without empowerment, the participation of PLWHA will never be complete and GIPA will never be meaningful.

The efforts and results mentioned in this document are only the beginning of an empowering process. Though the challenges are formidable, the journey ahead cannot be too long as HIV has an undue advantage in its race against time. Required are expeditious, time-bound steps that are aimed at the overall well-being of PLWHA, an enabling environment that is rights and gender based and their informed and proactive participation in the responses to the epidemic.

More than seven million PLWHA is not a mere number, but a sign of possibilities and opportunities.

PLWHA Groups and Networks in the Asia Pacific PLWHA Empowerment Initiative

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Email: msg_china@yahoo.com.cn
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Council of People Living with HIV/AIDS in Kerala (CPK+)

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Network of Maharashtra by People Living with HIV/AIDS (NMP+)

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Network of Naga PLWHA (NNP+)

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Positive Women's Network (PWN+)

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HIV Positive People's Welfare Society (TNP+)

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Delhi Network of Positive people (DNP+)

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63132884-215
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Email: icpmo@chinaids.org.cn

Marie Stopes International (MSI)

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Care Agency For All (CAFA)

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Indian Institute of Planning and Management (IIPM)

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1-A, Sector 16-A,
Institutional Area,
Noida - 201031
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Tel: 91-120-2516601-11
Fax: 91-120-2511008-9
URL: www.jubilantorganosys.com

Mahiti Infotech Pvt. Ltd.

314/1, 7th Cross,
Domlur
Bangalore - 560 071
Karnataka
India
Tel/Fax: 91-80-4150580
URL: www.mahiti.org

**National AIDS Control
Organisation**

Ministry of Health & Family
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Government of India
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36, Janpath
New Delhi - 110001
India
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MALAYSIA

Pelangi Community Foundation

No. 24 Jalan Intan 2/12,
Taman Puchong,
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Malaysia
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URL: www.pelangifoundation.org

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THAILAND

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15th Floor,
One Pacific Place,
140 Sukhumvit Road,
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