

The Involvement of People Living with HIV/AIDS

in Community-based Prevention,
Care and Support Programs
in Developing Countries

A Multi-country Diagnostic Study

Acknowledgements

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Terminology

Advocacy A process to bring about change in the attitudes, practices, policies and laws of influential individuals, groups and institutions, carried out by people proposing improvements on behalf of themselves or others.

Beneficiary In this report, beneficiary is used interchangeably with service user and refers to:

- People living with HIV/AIDS (PLHA) or people affected by HIV/AIDS who request and use the care or support services of one or several non-governmental organizations (NGOs) or community-based organizations (CBOs) on a regular or occasional basis.
- PLHA or people who are HIV negative who benefit from the prevention activities of NGOs or CBOs on a regular or occasional basis.

Care and support Efforts that aim to improve the quality of life and life expectancy of PLHA and people affected by HIV/AIDS.

Community-based organization (CBO) Group and association formed by people living within specific communities that works at the local level and mostly seeks to ensure benefits for its members. CBOs do not always require formal procedures, such as legal registration.

Community services and activities Services provided and activities undertaken by an NGO or CBO at community level, for or with the community. This study analyses community HIV/AIDS prevention, care and support services and activities.

Discrimination toward PLHA See stigma.

Empowerment In this report, empowerment refers to a process whereby PLHA, or other groups that are stigmatized or discriminated against, develop their capacity to participate in and gain control over the decision-making process that affects them. Empowerment enables them to speak, be listened to, define their perspective on the issue in question, be recognized, respected and treated as equal citizens. The purpose of empowerment, at both individual and collective level, is to allow PLHA to influence the process of social change.

HIV-negative service providers Service providers of the participating NGOs who did not identify themselves as PLHA during the study. This may mean that they do not know their HIV status or they know they are HIV positive but do not wish to disclose it.

Involvement At the Paris AIDS Summit in 1994, 42 governments signed a Final Declaration on the importance of the “Greater Involvement of PLHA” (GIPA) in the response to the HIV/AIDS epidemic. Since then, most stakeholders, such as United Nations (UN) agencies and AIDS activists, have used the word “involvement” rather than “participation”, which is commonly used in social science. For this reason, this study uses the term “involvement”.

While the Paris Summit noted that PLHA can be involved in a range of areas and at different levels,¹ this study analyzed PLHA involvement with *specific reference to prevention, care and support services of NGOs and CBOs*.

This research was based on the assumption that PLHA can take part in the activities of NGOs and CBOs in many different ways. One of the main study objectives was to develop a conceptual framework to identify these different types of involvement and their characteristics. Together with this typology of involvement, the study has developed a new terminology where the word “involvement” is used in two ways:

1. As a generic word to describe any way in which PLHA take part in NGO or CBO activities;
2. As a specific way in which PLHA take part in the activities of NGOs, or type of involvement, described by the term *greater involvement*; the other types being *access*, *inclusion* and *participation*.

Involvement is italicized in the term “*greater involvement*” when it refers to one of the four types of involvement identified by the study (2) rather than to generic involvement (1). The terms “*access*”, “*inclusion*”, “*participation*” are also italicized when they refer to particular types of involvement. Chapter 3 of this report includes detailed definitions of *access*, *inclusion*, *participation* and *greater involvement*. Adjectives such as *inclusive*, *participatory*, or verbs such as *involve(d)*, *participate* are also italicized when they refer specifically to the corresponding types of involvement.

Non-governmental organization (NGO) Formally registered not-for-profit organization that seeks to address a particular need or cause. NGOs are generally larger than CBOs and may be local, national or international.

Person affected by HIV/AIDS In this study, the term “person affected by HIV/AIDS” refers to:

- Those living with a PLHA (wife/husband/partner, children, parents, brothers/sisters).
- Those who are part of the close circle of a PLHA but not living with them, who are personally involved in the care and support of one or more PLHA.

The definition used therefore excludes people who provide care and support to PLHA in a professional capacity.

Person (or people) living with HIV/AIDS (PLHA) This study only includes as PLHA those who are HIV positive and aware of their seropositive status. Many people infected with HIV do not know that they are seropositive because they have not taken a test, or have taken a test but do not know the result. In this report, the terms “seropositive”, “positive” and “HIV positive” are used interchangeably. PLHA are sometimes referred to as PWA (people with AIDS). When the study refers to the involvement of PLHA in NGOs and CBOs, PLHA can be service users of the organizations (former, current and potential service users), as well as positive people who have never used and will never use the services provided by these organizations.

¹ Declaration of the Paris AIDS Summit, 1 December, 1994, in UNAIDS, *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*.

Prevention That which aims to prevent the transmission of HIV from people infected with the virus to non-infected people, as well as the re-infection of those who are already HIV positive.

Self-help A support system where people with a common problem meet in groups to find joint solutions. Self-help assumes that each person takes responsibility in the search for solutions to his or her problem, and that the sharing of information, experience and techniques between people facilitates finding solutions. Self-help groups are normally voluntary structures formed by peers who have come together for mutual assistance or to support each other to meet a common need.

Service provider In this study, a person employed by or working under the auspices of an NGO or CBO who provides planned services to users or beneficiaries. Those carrying out activities as a result of their own individual actions are not defined as service providers.

Stigma toward PLHA Several authors² divide stigma into *felt* or *perceived* stigma and *enacted* stigma. Felt stigma refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, disease (such as HIV) or association with a particular group. For example, an individual may deny his or her risk of HIV infection, refuse to use condoms, or refuse to disclose HIV status for fear of the possible negative reactions of family, friends and community. Felt stigma may be a survival strategy to limit the occurrence of enacted stigma. Enacted stigma refers to the real experience of discrimination. For example, the disclosure of an individual's HIV-positive status leads to loss of a job or social ostracism.

Types of involvement (Typology) Various ways for PLHA to be involved and for organizations to involve them. "Models", "forms" and "types" of involvement are used interchangeably in this study.

Visibility A PLHA is visible when he or she is open about his or her HIV status at one or several of the levels listed below:

- At home, with his or her family.
- In the community, with friends and/or other community members.
- At the workplace, with work colleagues.
- In the NGO or CBO where he or she is involved:
 - with staff and volunteers who are carers, if the PLHA is a beneficiary;
 - with staff and volunteers who are colleagues, if the PLHA is a service provider;
 - with service users of the organization, if the PLHA is a service provider or service user.
- In other NGOs and CBOs, including, for example, support groups of PLHA.
- In the media, at national and/or international levels.
- In other forums, such as workshops or conferences at national and/or international levels.

It is important to note that the person may be visible either because he or she has knowingly and intentionally disclosed his or her status, or because the person became open about his or her HIV status after others disclosed it, with or without his or her consent.

² Brown, L., Trujillo, L. Macintyre, K. (2001) *Interventions to Reduce HIV/AIDS Stigma: What Have We Learned?* Horizons and Tulane University, September, p. 4.

Abbreviations and acronyms

AAS	Association African Solidarité (Ouagadougou, Burkina Faso)
ALAVI	Association Laafi la Viim (Ouagadougou, Burkina Faso)
AMMIE	Appui Moral Matériel et Intellectuel à l'Enfant (Ouahigouya, Burkina Faso)
ARV	Antiretroviral
ASO	AIDS Service Organization
CBO	Community Based Organization
CCDT	Committed Community Development Trust (Mumbai, India)
CEPAR	Centro de Estudios de Población y Desarrollo Soical
CHEP	Copperbelt Health Education Project (Kitwe, Zambia)
CPT	Care and Prevention Team (Salvation Army Chikankata Hospital, Zambia)
DHMT	District Health Management Team
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HBC	Home-based Care
HDI	Human Development Index
ICW	International Community of Women Living with HIV/AIDS
IDU	Injecting Drug User
INP+	Indian Network for Positive People
IPC	Initiative Privée et Communautaire de lutte contre le VIH/SIDA
KAB	Knowledge, Attitudes, Behavior
MNP+	Maharashtra Network for Positive People (Mumbai, India)
MSM	Men who have Sex with Men
NGO	Non-Governmental Organization
NZP+	Network of Zambian People Living with HIV/AIDS
PLAC	Positive Living Advocacy Course
PLHA	Person (or People) Living with HIV/AIDS
PRA	Participatory Rapid Appraisal
REVS+	Association Responsabilité Espoir, Vie, Solidarité + (Bobo Dioulasso, Burkina Faso)
SBS	Sexual Behavior Survey
SOFOSH	Society of Friends of the Sassoon Hospital (Pune, India)
STI	Sexually Transmitted Infection
TISS	Tata Institute of Social Sciences
UNAIDS	Joint United Nations Program on HIV/AIDS
UNDP	United Nations Development Program
UNV	United Nations Volunteers
USAID	United States Agency for International Development
VCT	Voluntary Counseling and Testing
ZDHS	Zambia Demographic and Health Survey
ZIHP	Zambia Integrated Health Program

Executive Summary

At the conclusion of the Paris AIDS Summit in 1994, 42 governments issued a declaration supporting greater involvement of people living with HIV/AIDS (PLHA) in policy formulation and service delivery. Despite growing recognition of its importance, there has been little research that examines PLHA involvement in the delivery of prevention, care and support services in developing countries and its effects on PLHA, others affected by HIV/AIDS and non-governmental organizations (NGOs). To address this gap, the Horizons Program and the International HIV/AIDS Alliance conducted a study of PLHA involvement in NGOs in Burkina Faso, Ecuador, Zambia and Maharashtra State, India, between October 1998 and August 2001. The goal of the study was to identify the conditions that foster PLHA involvement and the strategies that organizations can use to achieve meaningful involvement of PLHA.

Seventeen NGOs participated in the study, all of whom focus on HIV/AIDS prevention, care and support. The NGOs chosen represent different types of organizations and a range of PLHA involvement, and all expressed interest in the aims of the study.

Participating NGOs

- **Burkina Faso:** Association African Solidarité (AAS); Association Laafi la Viim (ALAVI); Appui Moral Matériel et Intellectuel à l'Enfant (AMMIE); La Bergerie-Foi, Univers, Compassion; Association Responsabilité Espoir, Vie, Solidarité + (REVS+)
- **Ecuador:** Fundación Dios, Vida y Esperanza; Fundación Esperanza; Fundación Siempre Vida; Fundación Vivir
- **Maharashtra, India:** Project CHILD of Committed Communities Development Trust (CCDT); Maharashtra Network for Positive People (MNP+); Salvation Army Mumbai HIV/AIDS Community Development Program; Society of Friends of Sassoon Hospitals (SOFOSH)
- **Zambia:** Copperbelt Health Education Project (CHEP); Hope Humana People to People; Kara Counseling and Training Trust; Salvation Army Chikankata Mission Hospital

Study methods

Researchers from each of the four countries collected data via qualitative and quantitative methods, including individual and group interviews, focus-group discussions, observation, service statistics, and a questionnaire, from 745 individuals, including HIV-negative and -positive service users, NGO staff and volunteers, and such key informants as policymakers, health professionals, and community leaders. In all four countries, PLHA were involved in the participating NGOs as service providers, service users or both.

PLHA represented about half of study participants in India and Zambia, 35 per cent in Ecuador and 15 per cent in Burkina Faso. Table 1 summarizes the number of participating NGOs and research sites, and the type and number of respondents per country.

Table 1 Characteristics of study sites and populations

Country	No. NGOs	Study sites	Respondents			
			Service providers (Staff or volunteers)	Service users	Relatives of PLHA providers	Key informants
Burkina Faso	5	1 urban and semi-rural 4 urban	103	19	5	49
Ecuador	4	4 urban	* 115		5	52
India	4	1 urban and semi-rural 3 urban	48	82	2	10
Zambia	4	1 rural 1 urban and semi-rural 2 urban	101	115	7	34

*In Ecuador, the researchers did not distinguish between service providers and service users, because many HIV-positive service providers are also service users.

The research teams used a participatory approach throughout the study. The NGOs in each country were actively involved in study design, implementation, and validation and interpretation of the findings. An orientation workshop held at the start of the study in each country familiarized the NGOs with basic research concepts, discussed the study rationale, relevance and process, and adapted the methodology and tools to the national context. The teams also conducted a data analysis and interpretation workshop with the participating NGOs in each country to discuss the findings and to identify strategies to increase PLHA involvement.

Identifying the types of PLHA involvement

The research teams used the following criteria to examine how PLHA are involved in NGOs:

- **Time and regularity** spent on activities.
- **Remuneration: financial** (salary, allowance, reimbursement of travel costs), **material** (food, medicines), **technical** (training) or psychological (support and counseling).
- **Skills used.**
- **Skills development provided by the organization.**
- **Scope and autonomy of decision-making.**
- Level of **visibility: internal** (within the NGO) and **external** (outside the NGO).

Country context

HIV prevalence in the general population varies considerably among the four countries (Ecuador, less than 1 per cent; Burkina Faso, 6.5 per cent; Zambia, 20 per cent). In Maharashtra State, India, almost 2 per cent of women attending antenatal services are infected; a figure suggesting spread in the general population. In the two African countries, transmission is mainly heterosexual, whereas in Ecuador, homosexual and bisexual transmission account for about a third of AIDS cases. Transmission is also predominantly heterosexual in India, but there are important sub-epidemics among men who have sex with men (MSM) and injecting drug users. More than half of PLHA in Burkina Faso and Zambia are women, compared to about 35 per cent in Ecuador and India.

PLHA are highly stigmatized in all four countries because of the association of HIV/AIDS with certain behaviors and population groups. Fear of stigma and discrimination means that few individuals are willing to divulge their HIV status or find out their status through HIV testing. In Burkina Faso, India and Zambia, voluntary counseling and testing (VCT) services are not widely available, and access to antiretrovirals (ARVs) is limited to PLHA with money or international contacts. In Ecuador, ARVs are available to those eligible to use police and military hospitals and in one region to those with access to social security. Access to non-ARV treatment and care is particularly poor in Burkina Faso, India and rural Zambia.

There are national networks of PLHA in Ecuador, India and Zambia, but visible involvement of PLHA is low in all four countries. The organization of PLHA started in the late 1980s and early 1990s in Ecuador and Zambia, but is a relatively recent phenomenon in Burkina Faso and India. In all four countries, the main impetus for greater PLHA involvement has come from international donors, NGOs and activists who have supported the development of PLHA organizations and networks and encouraged governments to give higher priority to PLHA involvement in the response to the epidemic.

Key Findings

There are four distinct types of PLHA involvement:

Access to services for PLHA involves taking part in NGO activities as beneficiaries or users of services, such as medical care, counseling or training. *Access* was the most common type of PLHA involvement observed among the 17 NGOs participating in the study. At this first stage, PLHA learn not only about HIV/AIDS but also about how to accept their HIV status and cope with infection, which can help motivate them to help others.

Examples of services that aim to empower PLHA and thus foster further involvement in NGO activities include:

- **Positive living and life skills courses** Help PLHA come to terms with their HIV status and provide information and skills to gain control over their lives.
- **Support groups** Provide an opportunity to share problems, offer mutual support and furnish a safe space for PLHA to become visible. Support groups can empower PLHA by building their self-esteem and preparing them to be open about their HIV status.
- **Counseling** Helps PLHA accept their HIV status and prepare for possible repercussions of visibility. Counselors can refer PLHA to other activities and to training to develop their capacity for further involvement.

Inclusion is when NGOs involve PLHA as support staff and volunteers in non-HIV/AIDS activities or as occasional volunteers in HIV/AIDS service delivery (for example, providing informal peer support at support group meetings, conducting home and hospital visits or community outreach activities). Formal training at this stage is limited. Important incentives for PLHA include greater access to peer support and interaction with other PLHA. However, there are few material rewards for their efforts. Use of PLHA as volunteers may be cost-effective for NGOs but can have an adverse effect on service quality if volunteers are poorly trained.

Participation is when PLHA deliver HIV/AIDS-related services on a formal, regular basis as employees or volunteers. Their expertise is recognized by the organization and they generally receive financial remuneration for their work, although in Burkina Faso and Ecuador many regular volunteers do not receive any financial remuneration. These PLHA may be involved in planning the services they deliver and, in some organizations, are consulted about other services. At this level of involvement, PLHA have accepted their status and use their experience of living with HIV/AIDS, plus the skills and theoretical knowledge gained in formal training, to deliver services.

Greater involvement is the most advanced stage of involvement, where PLHA take part in management, policymaking and strategic planning as directors, trustees or program managers, and may represent the organization externally. This type of involvement implies a higher level of visibility that can expose PLHA to the risk of stigma and discrimination, although these PLHA are likely to be better able to cope because generally they have high levels of personal acceptance and support.

PLHA involvement in management and decision-making occurs in the rights-based organizations such as PLHA groups and networks. With one exception, PLHA who participate in management, policymaking and strategic planning have completed at least

secondary education and are from middle-income socio-economic groups. Most have been involved in the fight against the epidemic for many years and have had considerable training. Examples of this type of involvement include the following:

- At MNP+ in India and REVS+ in Burkina Faso, PLHA manage the organization and specific programs, and at CHEP in Zambia, the coordinator and assistant of the PLHA program are both HIV positive.
- At MNP+ as well as at REVS+, PLHA were volunteer members of the board of trustees. At CHEP and Kara in Zambia, PLHA program coordinators are involved in organizational strategic planning.
- PLHA who manage organizations and programs often have a significant representative role outside the NGO with which they are involved, expressing the perspectives of PLHA in different forums, and many participate in advocacy efforts in national and regional networks of PLHA.

PLHA mobilization and involvement

The data reveal that PLHA become mobilized in different ways:

- In five NGOs, PLHA set up organizations, often together with other affected people or health and social workers. These NGOs are rights-based organizations and/or self-help groups. The dominant models are *greater involvement* and *participation*, but there are also PLHA who use services. These organizations can evolve depending on the composition of the membership. In two NGOs, the HIV-positive founders died and the organizations became more service-oriented and less focused on rights.

In NGOs where there were originally no visible PLHA, such as secular or religious welfare organizations and development NGOs:

- NGOs empower their HIV-positive service users to become service providers through *inclusion* and sometimes *participation*, as was the case with six NGOs. This rarely leads to *greater involvement*, unless there is a clear policy within the organization, as in the case of one NGO in Zambia.
- Organizations recruit PLHA who are not their service users and who are already visible and have the experience and skills to be involved in formal service delivery and/or management (*participation* and *greater involvement*). This scenario was observed in one development NGO in Zambia.
- Sometimes NGO staff or volunteers find out that they are HIV positive and choose to become visible. However, this only occurred in one organization in Burkina Faso.

Involvement in NGO activities can have therapeutic effects for PLHA

Although the impact of involvement on PLHA depends on the way they are involved in NGOs, study respondents overall reported a therapeutic effect of involvement for PLHA. This includes: improved psychological health as a result of increased peer support and knowledge and decreased isolation; improved physical health due to access to information about care (including where and how to access it) and, in some cases, medical care and treatment; and increased income or access to material benefits as compensation for services. Some respondents in Zambia and Ecuador also cited less risky behavior, especially reductions in the number of sexual partners and better integration in

the family, as members realize that PLHA can be productive and inform others in the family about HIV/AIDS.

Nonetheless, respondents in all four countries reported drawbacks to PLHA involvement, depending on the activities carried out and the level of visibility. For example, when delivering care and support services, the psychological health of asymptomatic PLHA can be impaired as a result of contact with those who are very sick. In Ecuador and Zambia, some PLHA reported personal experiences of stigma and discrimination because of their visible involvement in delivering services and/or managing the NGO. A few respondents from Burkina Faso and Zambia reported that occasionally community members accuse PLHA of pretending to be HIV positive in order to obtain money from donors. NGOs need to be conscious of potential negative effects in order to take steps to minimize them.

PLHA involvement strengthens NGOs

Data from the study highlight that PLHA involvement in service delivery and management helps to improve services and strengthen organizations by:

- Improving care and support services by making them more relevant and personalized.
- Increasing effectiveness of prevention activities by improving people's perceptions of PLHA.
- Raising staff awareness of the issues from the PLHA perspective and promoting recognition by staff of the contributions PLHA can make.
- Increasing credibility of the organization and its services.
- Broadening activities to include advocacy for the rights of PLHA.

Respondents also identified several detrimental effects that PLHA involvement can have on the organization. However, with adequate planning these negative repercussions can be reduced. For example, PLHA who are poorly trained may convey inaccurate information or impose their own solutions during counseling. When PLHA become ill and die, the NGO may experience disrupted service delivery and increased costs for training replacements, which may affect the sustainability of the organization itself. In some instances, visibility can lead to a kind of "stardom" for a few PLHA, which can create tensions within an organization. There is also the potential for conflict between PLHA and HIV-negative staff if the role and contribution of either are undervalued.

The socio-economic context strongly influences PLHA involvement

Any strategies to promote the involvement of PLHA in developing countries must take into account the social context, especially conditions of poverty, limited access to health care and treatment, gender inequality and stigma and discrimination. With regard to poverty, most PLHA in the study are from low-income groups and need to use their available time to earn an income, thereby limiting their involvement on a voluntary basis. Poor health can limit involvement, although PLHA can remain involved even when they are sick, providing they are asked to do tasks that take into account their health needs and have access to treatment. PLHA, especially women and those from low-income groups, are least likely to have had access to education required for formal service delivery and program management. In some settings, illiteracy is a major barrier to involvement. Gender inequalities in access to education and services, domestic and childcare responsibilities, and financial dependence on men prevent many HIV-positive women from becoming involved in NGO activities.

Fear of stigma and discrimination inhibit many PLHA from involvement, especially in NGOs perceived to be “PLHA organizations” and in roles with high visibility. This was particularly true in Burkina Faso and India, and in rural settings where fewer PLHA are visible. Rejection by family, friends and the community due to stigma and lack of knowledge and discrimination within health service and workplace settings, reinforce fears about PLHA involvement. In Ecuador and Zambia, some PLHA informants described actual experiences of stigma and discrimination as a result of their visible involvement in NGOs.

PLHA involvement should not be equated with public disclosure and visibility

In all four countries the study documented a range of NGO activities carried out by PLHA, not all of which entail disclosure within the organization or public visibility. For example, not all PLHA disclose their status to clients they counsel or to the community while doing outreach education. However, examples of PLHA who are visibly involved in providing personal testimonies that give a “human face” to the epidemic were found in each country, although few PLHA have gone public in the media. In Zambia, outreach education is the activity in which PLHA are most likely to be involved. In contrast, in the other three countries PLHA involvement in community awareness-raising activities was limited to a few individuals. Most informants noted that some degree of visible PLHA involvement within NGOs increases awareness of PLHA perspectives and needs and contributes to better services. However, the involvement of PLHA should be matched to the degree of visibility they feel comfortable with. PLHA should not be forced to disclose their HIV status and NGOs should guarantee confidentiality of all service providers and beneficiaries.

Greater PLHA involvement requires creating a supportive NGO environment

The researchers found that lack of adequate financial and material resources for remuneration of PLHA is a serious problem for NGOs in all four countries. But many NGOs also need to examine their own operations, policies and attitudes if they want to increase PLHA involvement. Specific barriers include:

- Judgmental and paternalistic attitudes about PLHA and their involvement by professional health and social workers.
- Lack of institutional will and policies to create varied opportunities for PLHA to become involved.
- Lack of attention to gender and sexuality. The misperception that all PLHA have the same needs, regardless of gender or sexual orientation, may lead to one-size-fits-all designs for service provision that do not adequately serve women or MSM. Informants in Ecuador and India also cited the homophobic attitudes of some NGO staff, which prevent MSM from being involved and/or coming out as homosexual/bisexual men when they are involved.

The study identified five categories of institutional factors that contribute to building a supportive environment for PLHA involvement: non-discriminatory staff attitudes, policies, and procedures; capacity-building; psychological support; material support; and networking. These are further addressed in the following section.

Conclusions and Recommendations

Findings from this four-country study show that there are many ways for PLHA to take part in the activities of NGOs, and the four types of involvement – *access*, *inclusion*, *participation*, and *greater involvement* – embrace a wide range of roles. However, the most common types of involvement observed in the NGOs that participated in the study were *access* and *inclusion*. Most PLHA visibly involved in service delivery were volunteers, often working on an informal basis, and relatively few were employed as professionals by NGOs. Nevertheless, an important finding of the study is that all types of involvement can make a difference and that meaningful PLHA involvement should not be equated with public visibility and disclosure.

The study also highlights the fact that PLHA involvement in NGO activities is an organizational process, and if key steps are not taken, the positive effects tend to be limited and negative effects can increase. For example, if PLHA are involved in outreach education without receiving the necessary training and support, this can adversely affect the quality of the service and can be harmful for the PLHA themselves.

NGOs can overcome many of the factors that limit involvement by implementing the following recommendations:

Promote positive and non-discriminatory attitudes and policies toward PLHA

- Assess the attitudes of management and service providers and provide them with sensitization training where necessary.
- Review policies and procedures and overhaul those that stigmatize or discriminate against PLHA, including women and MSM.
- Ensure the confidentiality of all PLHA, both staff and clients.
- Allow PLHA to make decisions about their own disclosure and visibility.

Build the capacity of PLHA for involvement

- Provide accurate information about prevention and treatment of HIV/AIDS, as well as about services available to PLHA within the organization and from other sources.
- Use counseling services as a starting point for empowering beneficiaries.
- Orient PLHA to opportunities for involvement within the organization.
- Create capacity-building opportunities for PLHA that build their knowledge and skills.
- Ensure that PLHA receive free or affordable training relevant to their activities like any other staff member or volunteer.
- Plan individual follow-up to training to ensure that benefits are not short term.

Offer psychological support, including peer support, to PLHA

- Ensure that care and support provided by “professional” service providers is high quality and complemented by peer support.
- Provide PLHA beneficiaries with the opportunity to meet other PLHA, whether through peer counseling or support group meetings, taking into account gender and sexual orientation.

- Counsel PLHA and their families prior to giving public testimony or becoming more widely visible.
- Develop counseling strategies to help PLHA cope with perceived and actual experiences of stigma and discrimination.

Provide material support to PLHA with few resources

- Provide remuneration depending on the amount of time spent on activities and skills used. This could include financial compensation, food, drugs, medical care, travel reimbursement or childcare.
- Ensure that PLHA have free or low-cost access to health care, including treatment for opportunistic infections, by offering health insurance, access to the NGO's own care facilities, or referral to other organizations or public services.

Network with other organizations and services to foster PLHA involvement

- Encourage public- and private-sector HIV-testing services to offer information to PLHA about NGO services and to refer PLHA to NGOs as quickly as possible.
- Diversify activities and choose communication strategies carefully to avoid identification as solely a "PLHA organization".
- Work with other groups to reduce stigma and discrimination at the community level by promoting tolerance and compassion, improving community knowledge and awareness about HIV/AIDS, sensitizing community and religious leaders, and advocating for the legal and human rights of PLHA.

Forming and sustaining support groups

Support or self-help groups are an important component of psychological support to PLHA because they provide a non-discriminatory environment in which PLHA can share experiences and information. To enhance their sustainability, NGOs should:

- Help members develop common objectives and expectations.
- Focus on involving participants in a similar geographical area, thus avoiding unsustainable transportation costs.
- Clarify the roles and responsibilities of support group members and the NGO, including the decision-making process.
- Develop mechanisms to cope with death of members.
- Include opportunities for skills building.

Report contents

- **Chapter 1** introduces the study, describing the background, objectives and stakeholders.
- **Chapter 2** describes the participatory process that was used to implement the study and the rationale for developing this innovative methodology.
- **Chapter 3** summarizes the main characteristics of the HIV/AIDS epidemic and of the social context in the four countries where the study was conducted.
- **Chapter 4** describes the forms of PLHA involvement observed in the participating NGOs, and explains the typology of involvement that was developed by the study.
- **Chapter 5** provides an overview of the positive and negative effects of involvement on individual PLHA, on the NGOs with which they are involved, and on their families and communities, and analyzes the relationship between different types of involvement and positive and negative effects.
- **Chapter 6** discusses the individual, social and organizational factors that enhance or limit PLHA involvement, and describes “pathways to involvement” – the steps that PLHA and NGOs need to take to achieve meaningful involvement.
- **Chapter 7** provides a brief conclusion and makes recommendations for action by PLHA and by NGOs to increase PLHA involvement.

1. Introduction

1.1 Background

Early in the history of the HIV/AIDS epidemic, the people who were first associated with AIDS – gay men in North America and Europe – started to get involved in community-based education and support services, and challenge inadequate responses to their needs.³ In 1983 in the USA, a group called the National Association of People with AIDS released a statement known as the “Denver Principles”,⁴ in which HIV-positive people claimed the right to “*be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations*”.

The same statement rejected the terminology that labeled HIV-positive people as “*victims*” because “*it implies passivity, helplessness, and dependence upon the care of others*” and identified people who are HIV positive as “*people with AIDS*” or “*people living with HIV/AIDS*” (PLHA).⁵ A new social and/or political identity⁶ was born, stressing that people who are HIV positive or have AIDS are not dying; they are living and they are able to take care of their own lives. AIDS activists adopted this terminology with the creation of international networks such as the Global Network of People Living with HIV/AIDS (GNP+) in the late 1980s and the International Community of Women Living with HIV/AIDS (ICW) in the early 1990s. Regional networks of PLHA were also created in Africa, Asia and Latin America. In 1989, during a World AIDS Conference in Montreal, ACT-UP New York produced the “Montréal Manifesto” that advocated for the “active involvement of affected communities of people with HIV disease in decision-making that may affect them” and researchers presented PLHA as the new agents of social change.⁷

At the same time, there was increasing recognition among policymakers that greater involvement of PLHA (GIPA) in policy formulation and service delivery was a critical aspect of the response to the HIV/AIDS epidemic. At the end of the Paris AIDS Summit in 1994, 42 governments issued a declaration in which they made a commitment to support “*full involvement*” of PLHA in the “*common response to the pandemic at all – national, regional and global – levels*”.⁸

However, despite consensus about the positive impact of PLHA involvement in service delivery and decision-making, and the need for greater PLHA involvement at all levels, there has been little systematic research to explore how involvement contributes to improving the quality of life of people infected and affected by HIV/AIDS and to preventing the transmission of HIV. There has also been an assumption that the experience of PLHA involvement in the United States and Europe

³ See Roy, C.M. and Cain, R. (2001) ‘The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints’, in *AIDS Care*, Vol. 13, No. 4: 421–32.

⁴ See Annexes.

⁵ See Roy, C.M. and Cain, R. (2001) ‘The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints’, in *AIDS Care*, Vol. 13, No. 4: 421–32.

⁶ Do Valle, Carlos G. (1998) *Identities and Social Organization: An ethnographic study in the AIDS voluntary sector in Rio de Janeiro, Brazil*. Poster presentation 24102, 12th World AIDS Conference, Geneva, Switzerland.

⁷ By Daniel Defert, the French sociologist and partner of the philosopher Michel Foucault, who died of AIDS in 1984. See Cornu, C. (1996) *Les associations de personnes vivant avec le VIH/SIDA à Abidjan, Côte d’Ivoire: le malade du sida, réformateur social en Afrique sub-saharienne?* Paris: IEDES.

⁸ Declaration of the Paris AIDS Summit, 1994. See Annexes.

can be replicated in the developing world, where 95 per cent of PLHA live and die, regardless of social circumstances such as poverty and its consequences.⁹

This report summarizes the methodology, findings and recommendations of a diagnostic study of PLHA involvement in four developing countries – Burkina Faso, Ecuador, India and Zambia – which was conducted between September 1998 and August 2001. While the GIPA Declaration promotes full involvement of PLHA at all levels, the focus of this study was the involvement of PLHA in community-based prevention, care and support activities through their participation in NGOs and community-based organizations (CBOs).

The study was part of the Horizons global operations research program, funded by the United States Agency for International Development (USAID) and implemented by the Population Council in collaboration with five partner organizations, including the International HIV/AIDS Alliance, which coordinated this study.

Horizons carries out operations research to identify ways to improve prevention, care and support programs and service delivery, and is currently conducting more than 60 activities in Asia, Africa, Latin America and the Caribbean. The International HIV/AIDS Alliance is an international NGO that supports community action on HIV/AIDS in developing countries and currently has programs in 19 countries.

1.2 Objectives

The objectives of the study were:

- To describe the current ways in which PLHA are involved in NGOs and CBOs in developing countries, and to develop a conceptual framework to describe the different types of involvement and their characteristics.
- To identify the factors that limit or enhance PLHA involvement in these organizations.
- To show whether PLHA involvement in NGOs and CBOs can improve the quality of life of PLHA who are involved in the delivery of services and of those who benefit from these services.
- To understand how involvement can affect the relevance, quality and effectiveness of the services provided by NGOs and CBOs.
- To identify the types or models of involvement that can have the most beneficial effects on the relevance, quality and effectiveness of services delivered by NGOs and CBOs.

A better understanding of these issues was intended to provide answers to the following questions:

- What types of PLHA involvement have positive effects on the quality and effectiveness of activities at community level?
- What are the minimum conditions that need to be present for PLHA involvement to happen and to have a positive impact?

⁹ More literature is available on the involvement of PLHA in western countries, with a particular focus on advocacy through what is usually described as “AIDS activism”.

- What strategies could NGOs and CBOs employ to achieve PLHA involvement that contributes to an improvement in the quality and effectiveness of the services they deliver?
- Under what circumstances does PLHA involvement not have positive effects or have negative consequences for PLHA, either as service providers within NGOs or CBOs, or as beneficiaries of these services, or for their families and communities?

Although there has been little systematic research to explore how PLHA involvement contributes to improving the quality of life of people infected and affected by HIV/AIDS, the diagnostic study was able to draw on research related to: the concept of patient or service-user involvement in areas such as partnerships between professional providers of health services and the users of these services, user-centered approaches, patient rights and, more recently, “consumerism” in health;¹⁰ self-help movements; and issues such as community mobilization and participation in development.

1.3 Stakeholders

A summary of stakeholders is provided in Table 1.1. The roles of the different stakeholders are described in more detail in Chapter 2.

In order to study PLHA involvement at the community level in the developing world, 17 NGOs were invited to participate in the research in the four countries where the study was conducted. The following criteria were used to select the participating NGOs:

- They currently work or have worked both in HIV/AIDS prevention and in care and support of PLHA and/or people affected by HIV/AIDS.
- They represent between them a cross-section of NGOs that already have different forms of PLHA involvement in their activities or are open to the possibility of PLHA involvement.
- They are interested in the issue of PLHA involvement and in any lessons that could be learned from the study and used to improve their services.


More information about the characteristics of the organizations, their services and activities is included in Chapter 4.

Local research teams were recruited in each of the four countries. The International HIV/AIDS Alliance and Horizons provided the research teams with technical support and, in Ecuador and India, the research teams worked closely with local research institutions.

International HIV/AIDS Alliance-linking organizations and Horizons/Population Council regional or country offices were also involved in the study.

¹⁰ Hogg, C. (1999) *Patients, Power and Politics: From Patients to Citizens*, London: SAGE Publications.

Table 1.1 Stakeholders

<p>United Kingdom International HIV/AIDS Alliance, Horizons partner Coordinator and Principal Investigator Project Support Officer Consultant Editor</p>			
<p>United States Horizons Study Coordinator</p>			
			
Burkina Faso	Ecuador	India	Zambia
Participating NGOs			
<ul style="list-style-type: none"> • Association African Solidarité (AAS) – Ouagadougou • Association Laafi la Viim (ALAVI) – Ouagadougou • Appui Moral Matériel et Intellectuel à l'Enfant (AMMIE) – Ouahigouya • La Bergerie-Foi, Univers, Compassion – Ouagadougou • Association Responsabilité, Espoir, Vie, Solidarité + (REVS+) – Bobo Dioulasso 	<ul style="list-style-type: none"> • Fundación Dios, Vida y Esperanza – Guayaquil • Fundación Esperanza – Quito • Fundación Siempre Vida – Guayaquil • Fundación Vivir – Quito 	<ul style="list-style-type: none"> • Project Child of Committed Community Development Trust (CCDT) – Mumbai • Maharashtra Network for Positive People (MNP+) – Mumbai • Salvation Army Mumbai HIV/AIDS Community Development Program – Mumbai • Society of Friends of the Sassoon Hospital (SOFOSH) – Pune 	<ul style="list-style-type: none"> • Copperbelt Health Education Project (CHEP) – Kitwe • Hope Humana People to People – Ndola • Kara Counselling and Training Trust – Lusaka & Choma • Salvation Army Chikankata Mission Hospital – Mazabuka
Study respondents/participants			
176	172	140	257
Including 122 service providers and users from the participating NGOs.	Including 115 service providers and users from the participating NGOs.	Including 130 service providers and users from the participating NGOs.	Including 223 service providers and users from the participating NGOs.

Research teams*			
1 Research Coordinator and 3 Research Assistants	2 Research Officers, 1 Research Assistant and 2 transcribers	1 Research Coordinator, 1 National Principal Investigator, 1 Research Officer, 2 Research Assistants, 1 Office Assistant, 11 transcribers and 13 translators	1 Research Coordinator, 1 Research Officer, 4 Research Assistants, 2 transcribers and 2 translators
Main implementing partners in the four countries			
<ul style="list-style-type: none"> Initiative Privée et Communautaire de lutte contre le VIH/SIDA (IPC)** Population Council Office 	<ul style="list-style-type: none"> Kimirina** Centro de Estudios de Población y Desarrollo Social (CEPAR) 	<ul style="list-style-type: none"> Tata Institute of Social Sciences (TISS) Regional Horizons/Population Council Office in Delhi 	<ul style="list-style-type: none"> Population Council Office Zambia Integrated Health Program (ZIHP) Alliance Zambia**
Other partners in the four countries			
<ul style="list-style-type: none"> American Embassy UNAIDS 		<ul style="list-style-type: none"> Indian Network for Positive People (INP+) USAID Mission 	<ul style="list-style-type: none"> Network of Zambian People Living with HIV/AIDS (NZP+) USAID Mission

* Full-time, part-time, temporary staff and consultants employed at various stages of the implementation of the study in each country.

** Linking organization of the International HIV/AIDS Alliance

Some facts and figures

The study took place in:

- 11 research sites in 4 countries on 3 continents and involved working in 10 languages (Bemba, Dioula, English, French, Hindi, Marathi, Moore, Nyanja, Portuguese, Spanish).

The study involved:

- 17 NGOs and CBOs.
- 745 participants, including 590 service providers and users from the 17 participating organizations, of whom an estimated 55 per cent were PLHA in India, 50 per cent in Zambia, 35 per cent in Ecuador, and 15 per cent in Burkina Faso.
- 419 individual interviews, 98 group interviews or focus group discussions, and 364 questionnaires.
- 50 people in the research teams.
- 15 partner implementing agencies at country level.

25 reports and research summaries are available in 4 languages.

2. Study Methodology

This chapter explains the participatory approach used to design, adapt and implement the study in the four countries. It describes the criteria used to select the research sites and the study population, the methods used to collect, classify, analyze and validate the data, and the lessons learned about participatory research with NGOs and CBOs.

2.1 Choice of Research Sites

The study selected two countries in sub-Saharan Africa (Burkina Faso and Zambia), one country in South Asia (India) and one country in Latin America (Ecuador). Given the size of India, the study focused only on Maharashtra State, which has a high prevalence of HIV. There were 11 research sites: three in Burkina Faso, two in Ecuador, two in Maharashtra and four in Zambia. In each country, with the exception of Ecuador,¹¹ one site was rural or semi-rural and the other sites were urban. Criteria used to select the research sites included:

- **Impact of the HIV/AIDS epidemic** Africa is the region worst affected by the epidemic, with more than 28 million adults and children living with HIV/AIDS. South and South-East Asia, with more than 6 million people infected, is the region with the second highest number of PLHA. Latin America has the third highest number of PLHA: an estimated 1.4 million people.
- **Range of HIV prevalence** Prevalence rates in the study sites range from low to very high.
- **Differences in routes of HIV transmission** In the two African countries, transmission is mostly heterosexual, whereas in Ecuador, homosexual and bisexual transmission accounts for around a third of AIDS cases. In Maharashtra, transmission is mostly heterosexual, but there is also transmission among MSM.
- **Diversity in civil society and government response to the epidemic** The response to the epidemic, including community and PLHA mobilization, has a longer history in Zambia than in Burkina Faso or India, where mobilization at all levels is a more recent phenomenon.
- **Cultural diversity** The sites reflect a range of cultures, religions and languages, including an English-speaking country and a French-speaking country in sub-Saharan Africa.
- **Presence of International HIV/AIDS Alliance-linking organizations and/or Horizons/Population Council Offices** To provide logistical and technical support during study implementation and dissemination of the results and follow-up to the study at country level. In Burkina Faso, Ecuador and Zambia, some of the participating NGOs had already received technical and financial assistance from Alliance-linking organizations prior to the study.
- **Interest and agreement of national authorities and of USAID missions.**

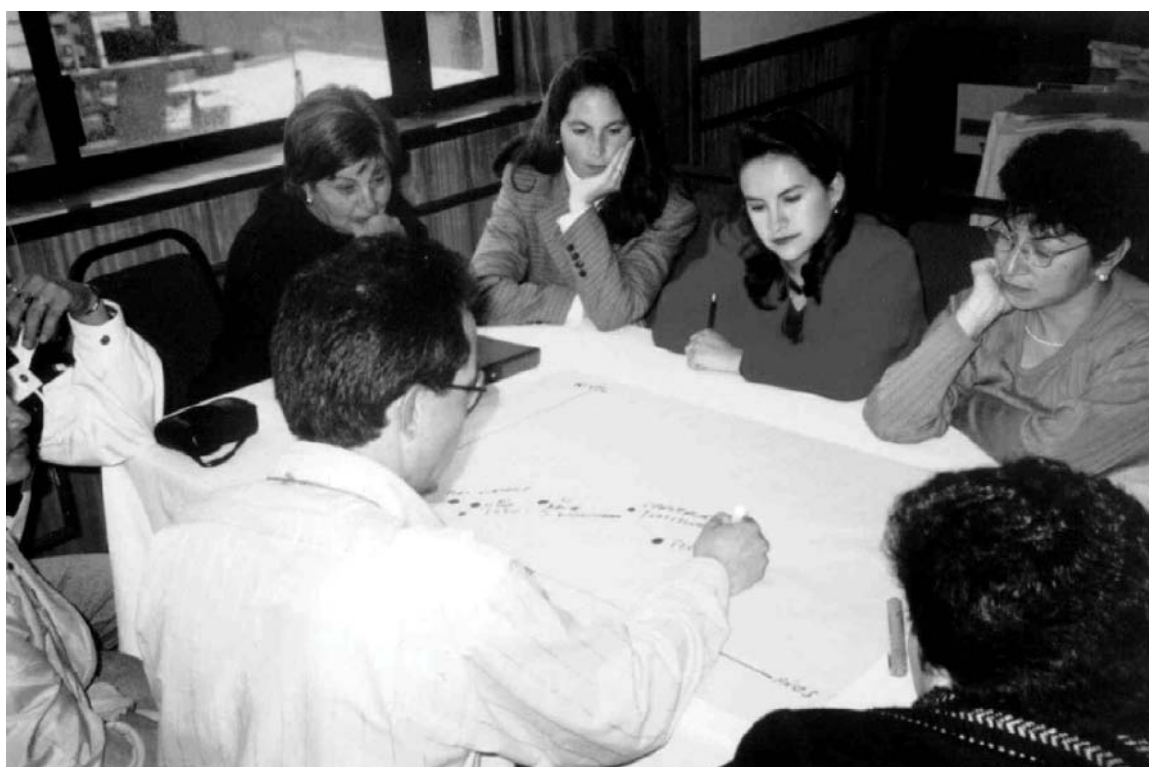
¹¹ A fifth NGO with activities in rural areas was selected but subsequently withdrew from the study.

2.2 Participatory Approach

2.2.1 Rationale for participatory methodology

The study used a participatory methodology, which emphasized the active involvement of respondents – in particular, NGO management and service providers – in the research process, for ethical, scientific and programmatic reasons.

- **Ethical rationale** The rights of participants to information about the study and the possible risks and benefits of participation, informed consent, voluntary participation, confidentiality, and withdrawal from the process at any time, were particularly important because many of the participants were PLHA or people affected by HIV/AIDS. The participating NGOs were involved in ensuring that researchers respected the rights of study participants (see Box 2.1).
- **Scientific rationale** The challenge was to collect an adequate amount of high-quality data from PLHA respondents. This was compounded by the research timeframe, which did not allow for more than one in-depth interview with each respondent. The study needed to access a reasonable number of PLHA who were willing to participate in the research. The active involvement of NGOs and visible PLHA in identifying and recruiting study participants was intended to encourage other HIV-positive service providers and users to be interviewed.
- **Programmatic rationale** The active involvement of service providers and users in the research process was intended to increase their interest in and willingness to use the findings.



Participatory methodologies in use during the orientation workshop in Ecuador



Using chapati to collect data: training during the orientation workshop in India

Box 2.1 Ethics of Research

The study involved strict respect for informed consent, voluntary participation and confidentiality. All PLHA respondents interviewed were aware that they were HIV positive and had agreed to disclose their HIV status to the research team. Consent forms were used at every stage of data collection and copies were given to respondents. The wishes of those who chose not to participate were respected. Data access was restricted to the local researchers, Alliance and Horizons teams. Names and job titles of participants are not included when they are quoted in reports.

An evaluation conducted among NGO representatives at the end of the study in each country found a very high level of satisfaction regarding the way the rights of study participants had been respected. The emphasis on ethical issues during the research had also increased awareness among NGOs of the importance of respect for the rights of PLHA, especially confidentiality, in their work in care and support.

Yes, the confidentiality was respected throughout and the PLHA felt that for the first time their consent was truly valued.
(HIV-positive service provider, MNP+, Maharashtra, India)

It is the first time a research team has valued PLHA consent and confidentiality... people who do research in the future should do the same.
(MNP+ representative, MNP+, Maharashtra, India)

2.2.2 NGO participation in the research process

The study methodology was piloted in Burkina Faso and then adapted in Ecuador, India and Zambia.¹² Adaptation resulted in some minor differences in the process in each country, but NGOs participation in the research process was similar in all four sites (see Table 2.1).

¹² The study was conducted simultaneously in India and Zambia.

Table 2.1 Summary of NGO participation in the research process

What	How
Design and preparation of the study	
Discussion on the relevance of the study for the participating NGOs	⇒ Meetings between NGOs and representatives from the international study coordination team, Alliance partner or linking organizations ¹³ and/or Horizons offices. In India, a rapid assessment was commissioned by the USAID Mission and conducted before the implementation of the study
Adaptation of the study methodology and data collection tools to the context of each country	⇒ Participation in a five-day orientation workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study coordination team), as well as representatives from Alliance linking organizations, Population Council/Horizons offices, and national PLHA networks in India and Zambia
Presentation of the study to other national stakeholders	⇒ Participation in a one-day meeting with national stakeholders ¹⁴
Appointment of “contact persons” within each organization to liaise with the research team	⇒ Meetings within each NGO
Definition of sample population for each organization (categories and numbers of respondents)	⇒ Meetings between contact persons from each NGO and the research team
Identification and recruitment of study respondents	⇒ Work carried out by contact persons within each NGO
Adaptation of informed consent forms and preparation for the use of the forms	⇒ Meetings between contact persons from each NGO and the research team. In India, participation in a one-day workshop facilitated by a local NGO specializing in the defence of PLHA rights ¹⁵

¹³ IPC in Burkina Faso, Kimirina in Ecuador, ZIHP in Zambia.

¹⁴ Stakeholders usually included representatives of: governmental bodies, bilateral donors, UN agencies, PLHA networks, major national and international NGOs, and the media.

¹⁵ Lawyers Collective is a Mumbai-based NGO that provides free legal advice and aid to PLHA and people affected by HIV/AIDS, and advocates for their rights.

Data collection	
Circulation of consent forms and monitoring of informed consent process	⇒ Work carried out by contact persons together with researchers within each NGO
Development of indicators to assess the quality and impact of one of the services of each organization	⇒ Each organization chose one service. Meetings of groups of three to five service providers of the selected service were facilitated by the researchers
Use of Photovoice ¹⁶ to collect information	⇒ Photographs taken by representatives of NGOs to illustrate PLHA involvement in their organization
Data analysis	
Validation of data	⇒ Review by contact persons and management from each NGO of reports of findings (organizational profiles) prepared by the researchers for each participating organization ⇒ Participation in a four-day data analysis workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study coordination team) as well as the program teams of Alliance Linking Organizations and/or Horizons
Interpretation and analysis of data	
Writing of reports	
Final review of the analysis	⇒ Review and editing of the organizational profiles or summaries of key findings produced by the researchers for each participating NGO

The study was different from others of this kind because of the way it was conducted. We were actively involved in the process and we were able to validate the results all along.
 (President, AAS, Burkina Faso)

2.2.3 Adaptation of the study methodology

In each country, an orientation workshop was held at the beginning of the research process. Workshop participants included representatives from the participating NGOs, national and international researchers (Horizons and International HIV/AIDS Alliance study coordination team), and representatives from Alliance linking organizations, Population Council/Horizons offices and, in India and Zambia, from national PLHA networks. The purpose of the workshop was to familiarize participants with basic research concepts and terminology, explore the study rationale and process, and ensure the relevance of the research to the participating organizations and the national context.

¹⁶ See detailed explanation of Photovoice under 1.3.

Participants discussed:

- Objectives and expected outcomes of the study.
- Research questions and data collection methods.
- Roles and expectations of different stakeholders.
- Rights of study participants and how to ensure these rights were respected by the researchers.
- Proposed dissemination and use of study findings.

Participants also explored their understanding of PLHA involvement and identified key questions to be answered. These discussions led to consensus about the methodology to be used, based on the original methodology, and lessons learned from study implementation in other countries.

We learned from the orientation workshop ... now research is a more friendly word for us.

(CCDT representative, Maharashtra, India)

When the workshop started and I heard about Ecuador and India, I was worried and thought I wouldn't be able to cope ... but now I feel that I understand the study and feel like a researcher.

(NGO representative, Zambia)

The workshop enabled NGO representatives and researchers to get to know each other in a supportive learning environment before the start of the fieldwork. It also provided an opportunity to observe the communication skills and attitudes toward PLHA of applicants for research positions, and in most countries the selection of researchers was finalized after the orientation workshop.

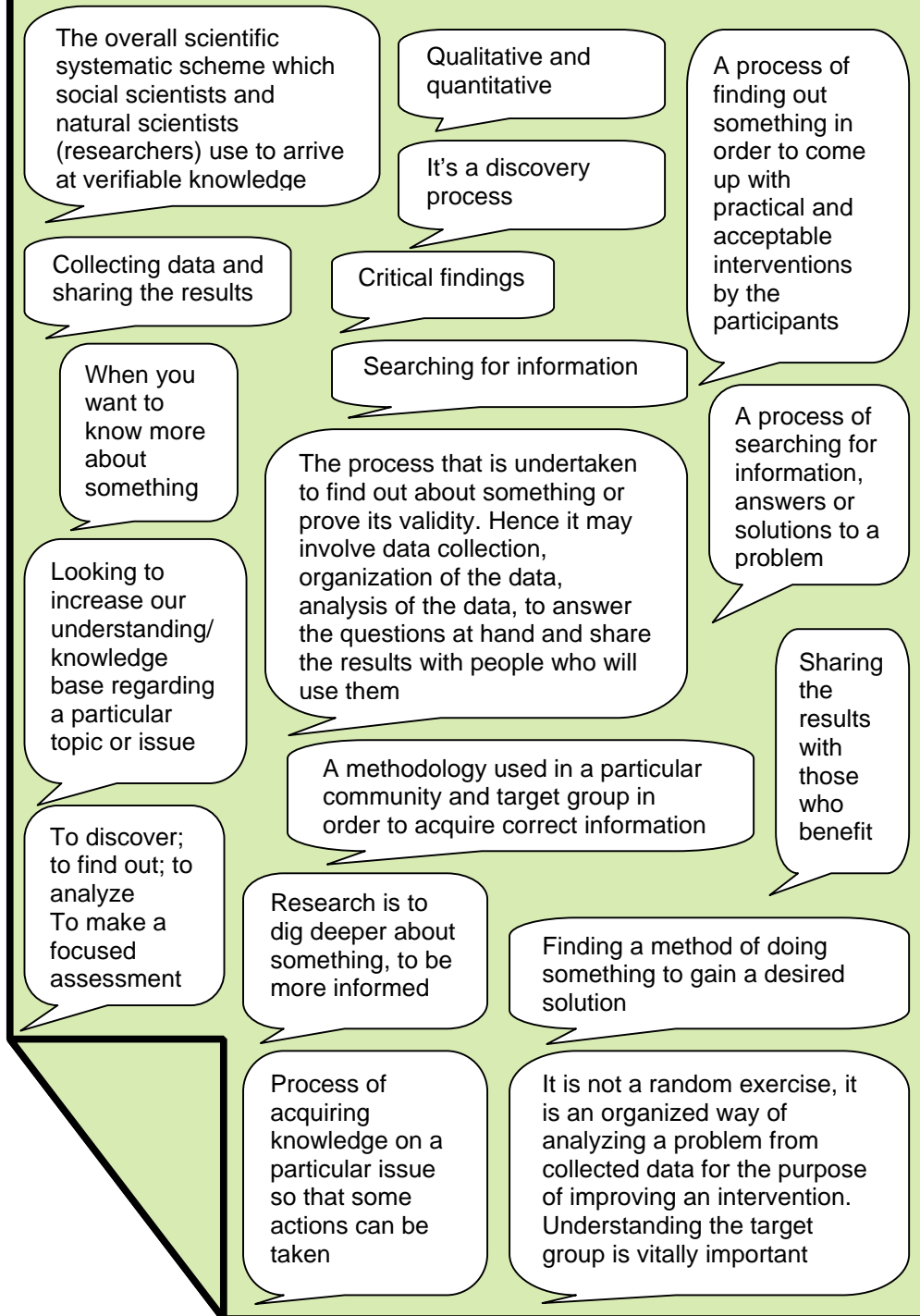
Following the orientation workshop, each participating NGO designated at least two people as “contact persons” to work with the research team. The researchers and the contact persons then met to plan and prepare for data collection, including determining sample population and reviewing data collection tools.

2.3 Research team composition and training

Researchers were not requested to disclose their HIV status – positive or negative – to their colleagues and supervisor or in public. Although HIV-positive people were encouraged to apply for research positions, none of the teams included visible PLHA. However, the international and national teams did include people affected by HIV/AIDS and with experience in delivery of counseling, care and support services at community level.

Specific training was provided for researchers with limited experience of HIV/AIDS and of working with PLHA in order to create empathy with PLHA, avoid judgmental attitudes and help them to cope with the emotional impact of working closely with PLHA. In Ecuador and Zambia, PLHA from local NGOs and networks facilitated some aspects of this training. The training helped to promote good relationships between researchers and study participants in all four countries.

Box 2.2 Results of a brainstorm “What is research?” during the orientation workshop in Zambia



2.4 Data collection methods

The study methodology included a review of the literature and collection of qualitative and quantitative data. The study mainly used qualitative methods, which included:

- In-depth one-to-one interviews.
- Shorter, one-to-one key informant interviews.
- Group interviews and focus group discussions, some involving participatory rapid appraisal (PRA) techniques such as Venn diagrams, causal flowcharts, timelines and matrix ranking. All interviews and focus group discussions were tape-recorded and transcribed verbatim.
- Observation, structured and unstructured, of service delivery and internal organizational meetings, where possible.
- “Photovoice”, a participatory research technique that consists of giving cameras to study participants so they can take photographs to collect information about their activities. Images generated by study participants format the data in a way that they can analyze through a process of “self-research”. Each NGO was given a camera and asked to take pictures that illustrated visible or non-visible PLHA involvement in the organization, having first obtained consent from the subjects. HIV-positive service providers were encouraged to take pictures of their own involvement. The process was as important as the outputs because it helped to stimulate reflection about confidentiality and PLHA visibility, which were two major themes in the study.



Photo taken as part of the photovoice technique in Zambia



Photo taken as part of the photovoice technique in India

Interviews were used more than other techniques because they provide a safer environment for discussion of sensitive issues than group settings (see Box 2.3)

The research teams were responsible for data collection, apart from Photovoice. During the orientation workshops it was agreed that NGO representatives would not conduct interviews or facilitate group discussions, for the following reasons:

- **Time** NGO service providers do not have enough time to be involved in data collection and their involvement might disrupt services.
- **Confidentiality** Interviews carried out by NGO representatives with other service providers would breach confidentiality. It would be a particular problem for those PLHA who are not visible within the organization.
- **Bias** Interviews carried out by service providers could influence responses of service users.

Qualitative data was supplemented by quantitative data about the NGOs' services and activities, and socio-demographic profiles of service providers and users collected by questionnaire.

Box 2.3 Results of discussion of data collection methods during the orientation workshop in Zambia

One-to-one in-depth interview	
<p>Advantages</p> <ul style="list-style-type: none"> • Opportunity for probing • Generates a lot of information in a short time • Confidentiality • Personal, allows for rapport to be established 	<p>Disadvantages</p> <ul style="list-style-type: none"> • Expensive • Time-consuming • Could be biased • Can be awkward (too intimate) • Can be intimidating (danger of coercion) • May limit response
Focus group discussion	
<p>Advantages</p> <ul style="list-style-type: none"> • Group dynamic can encourage exchange of views • Larger number of people reached than in one-to-one interview 	<p>Disadvantages</p> <ul style="list-style-type: none"> • Some people find it hard to open up in a group • Danger of domination by one or some participants • Some topics may be too sensitive for a group discussion • Some participants may feel intimidated by note taker (use of a tape recorder is one way to avoid this) • Findings cannot be generalized to the population

2.5 Study population

The study aimed to collect data both from those who deliver services at community level and service beneficiaries, and from stakeholders outside the participating NGOs who might influence the provision of services and the process of involvement. NGO contact persons initially identified potential respondents, explained the purpose of the study to them and the risks and benefits of participating, and recruited study participants.

Box 2.4 Criteria used to select study participants from NGOs

Criteria for the selection of service providers and sampling were:

- As many visible HIV-positive service providers as possible.
- Gender balance.
- Minimum of 20 per cent of staff or of total service providers, including volunteers;.
- Availability and willingness to participate in the study.

Criteria for the selection of service users and sampling were:

- Type of services used.
- Exposure to HIV-positive service providers.
- Gender balance.
- Availability and willingness to participate in the study.

No specific criteria, apart from availability and willingness to participate in the study were used to select the relatives of HIV-positive service providers, who were recruited by service providers themselves.

A total of 745 participants were involved in the study (see Table 2.2). Study participants included:

- Management and service providers, both staff and volunteers, of the participating NGOs.
- PLHA and people affected by HIV/AIDS who are beneficiaries of the services of the participating NGOs.
- PLHA who are both providers and beneficiaries of services of the participating NGOs.
- Other beneficiaries – for example, recipients of outreach activities.
- Relatives of PLHA who are involved in the participating NGOs.
- PLHA who are neither service providers nor beneficiaries of the NGOs.
- Other key informants, such as health care professionals, policymakers and community leaders.

Table 2.2 Summary of study participants

	Burkina Faso	Ecuador	India	Zambia	Total
<ul style="list-style-type: none"> • Service providers of participating NGOs • Service users of participating NGOs (PLHA, people affected by HIV, people who are neither infected nor affected) 	103 19	115	48 82	101 115	367 216
Total participants from NGOs	122	115	130	216	583
Relatives of HIV-positive service providers of participating NGOs	5	5	2	7	19
Key informants outside participating NGOs	49	52	8	34	143
Total other respondents	54	57	10	41	162
TOTAL	176	172	140	257	745

It was not always easy to categorize NGO participants as service providers or service users because some PLHA who are involved in service delivery also use the services of the NGO and are therefore both service providers and users, and because many NGOs do not have a clear definition of service providers, especially when volunteers are involved in service delivery.

In Burkina Faso and Ecuador, the researchers initially used the category “NGO or CBO members” but soon realized that this resulted in confusion between service providers and service users, and that being a “member” did not necessarily imply involvement in service delivery. In Ecuador, researchers decided not to make a distinction between service providers and service users (see Table 2.2), because it did not reflect reality. In Maharashtra and Zambia, NGO participants were categorized as service providers or service users, but the figures in Table 2.2 should be interpreted carefully as some PLHA service users were also involved in some way in service delivery and some PLHA service providers also used the services of the NGO with which they were involved.

The study also encountered two major limitations. First, it was not always possible to identify and recruit respondents. For example, the researchers wanted to conduct focus group discussions with people who had been reached by HIV-positive outreach educators, but some NGOs could not mobilize this category of respondents because they had no way of tracing them. As a result, the data collected to measure impact of involvement on some services, such as outreach education, is limited. Second, it was not always possible to identify PLHA who had been involved in an NGO or had used its services but were no longer involved or accessing services. NGO participants and key informants were involved in one-to-one interviews, group interviews or focus group discussions as shown in Table 2.3.

Table 2.3 Summary of data collection methods

	Burkina Faso	Ecuador	India	Zambia	Total
One-to-one interviews with service providers and users	52	79	92	64	287
One-to-one interviews with other key informants	52	47	2	31	132
Total one-to-one interviews	104	126	94	95	419
Group interviews with service providers and users	0	0	3	15	18
Total group interviews	0	0	3	15	18
Focus group discussions with service providers and users	12	13	6	11	42
Focus group discussions on quality and impact of services	10	8	7	4	29
Focus group discussions with other key informants	3	5	0	1	9
Total focus group discussions	25	26	13	16	80
Total questionnaires	67	78	NA	219	364

Despite the difficulties in categorizing study participants (and hence their involvement in service delivery), plus the limitations described above, the study was able to collect data from a large representative sample:

- With the exception of Maharashtra, which cannot represent the diversity of India, the participating NGOs represent a significant proportion of organizations providing HIV/AIDS prevention and care services (40 per cent in Ecuador and 33 per cent in Burkina Faso), and of organizations with some form of PLHA involvement. In Zambia, the four participating NGOs are good examples of organizations that provide a range of innovative HIV/AIDS services to a relatively large number of beneficiaries, and at least three of them have a high profile nationally, regionally and internationally.
- A significant proportion of staff involved in management and service delivery (between 20 per cent and 100 per cent of total service providers, depending on the NGO) participated in the study.
- Almost all of the relatively small number of PLHA involved as staff and volunteers in the participating NGOs participated in the study.
- A large number of PLHA, including service providers, service users and PLHA with no links with the participating NGOs, participated in the study. Approximately 55 per cent of study participants in India were PLHA, 50 per cent in Zambia, 35 per cent in Ecuador and 15 per cent in Burkina Faso.¹⁷

¹⁷ Estimates.

2.6 Data classification, analysis and validation

The research teams transcribed, translated and classified the data using an approach agreed with the participating NGOs. For each NGO, data collected was classified according to:

- Characteristics of involvement of PLHA in the NGO.
- Factors that limit and enhance PLHA involvement.
- Positive and negative effects of involvement.
- Gender issues, including links between gender and involvement.
- Characteristics of the NGO.
- Characteristics of services of the NGO.
- Views about prevention, care and support, and knowledge, attitudes and behaviors related to HIV/AIDS and PLHA in the country.

The researchers then compiled a profile and preliminary analysis of the data for each NGO. The profiles were shared with the respective organizations to enable them to review and validate the data and the preliminary analysis. In each country, this was followed by a data analysis workshop, attended by representatives of the participating NGOs, the researchers, the International HIV/AIDS Alliance and Horizons study coordination team and, in Burkina Faso, Ecuador and Zambia, the program teams of Alliance linking organizations.

At the data analysis workshop, one or two researchers worked with the representatives of each NGO on their respective profiles. Specific examples from each NGO were not shared during the workshop until the NGO and the researchers had agreed on the analysis. This approach enabled NGOs to focus on their own data without competing or comparing their organization with the other participating NGOs. Researchers and NGOs had the right to disagree in their analysis and, where there was a disagreement, checked which interpretation was supported by the data. In the few cases where the NGO and researchers could not agree, both interpretations of the data were kept in the organizational profiles. Based on the preliminary findings, each NGO identified strategies to improve the involvement of PLHA in the organization.

At the workshop, the researchers also presented an overview of general findings and trends, which allowed NGOs to discuss the analysis and wider implications. Participants at the data analysis workshops in India and Zambia also validated the typology of involvement (see Chapter 4).



Data analysis workshop in Zambia: researchers and a representative from the Salvation Army discuss the analysis of the findings



Representatives of the Salvation Army and researchers working together to write an organisational profile during the data analysis workshop in India

Box 2.5 Lessons learned from the methodology of the diagnostic study

Involvement of NGOs in participatory research

- Research and researchers should not be intimidating for the NGOs. Terminology, concepts and processes should be explained in a way that is accessible to non-researchers.
- NGOs should be involved in study design or adaptation.
- The respective roles of researchers and NGOs should be clear from the start.
- Researchers should be accountable to NGOs for respecting the rights of study participants.
- NGOs should have access to the data in a way that protects the confidentiality of respondents, including service providers and service users, and does not represent a threat to their work in the organization or the quality of the services they receive.
- Research should not disrupt the ongoing activities of NGOs, in particular the services they deliver.
- NGOs should benefit from the research, learning both from the results and from the process itself.
- The supporting data should determine who is right when interpretation of the data differs. If agreement is not possible, interpretation of both the NGO and the researchers should be presented in reports.

Participatory methodology

- **Advantages** The participatory approach helped to identify and recruit a significant number of PLHA in contexts where HIV/AIDS is highly stigmatized and to guarantee the rights of study participants; it allowed NGOs and PLHA to learn from and be empowered by the research process; it created a high level of interest in the study and its results among participants; and it increased NGO ownership of and willingness to use the findings.
- **Disadvantages** The participatory approach took considerable time and human resources; it created pressure for researchers and participating NGOs, especially as many partners were involved in the process and their availability was limited; it raised NGO expectations about the financial and technical follow-up that would be provided to assist organizations to translate research results into programs.

2.7 From research to action

Although designed as a diagnostic study, the research process was also designed to encourage translation of findings into action by:

- Involving participating NGOs at every stage to promote ownership of the findings and encourage their use in informing changes in policies and programs.
- Encouraging participating NGOs to use the data analysis workshop to identify strategies to increase PLHA involvement in their organizations.

In Burkina Faso, a follow-up study was conducted one year later (2000) by Horizons with Tulane University in order to determine if and how the diagnostic study resulted in changes in the activities of the participating CBOs and/or national-level policy on involvement of PLHA.

Box 2.6 summarizes objectives and findings of the follow-up study in Burkina Faso.

Box 2.6 Follow-up study in Burkina Faso

Objectives

- To assess the impact of the diagnostic study on the participating CBOs in terms of changes in organizational structure, programs, service provision and PLHA involvement.
- To identify the strategies used by the CBOs to improve PLHA involvement and service delivery based on the findings of the diagnostic study.
- To document obstacles that may have prevented implementation of recommendations emerging from the diagnostic study.
- To document national-level policy changes resulting from the diagnostic study.

Key findings

- **National level** Following the diagnostic study dissemination workshop in March 1999, the National AIDS Program (SP/CNLS) and Joint United Nations Program on HIV/AIDS (UNAIDS) have used the data to inform the development of the national HIV/AIDS strategy, which includes community care and support of PLHA. The diagnostic study served as an important reference document, as there were no other data on the needs of PLHA. Several of the CBOs that participated in the diagnostic study were involved in meetings to develop the national strategy.
- **NGO and CBO level** The diagnostic study provided an important opportunity for CBOs to reflect on their work, identify weaknesses and develop strategies to improve their services. However, one year after completion of the study, In general, CBOs were more likely to implement strategies successfully that were internal to the associations or that were under their control, while many of the activities that were dependent on outside assistance were not achieved.

Evaluation with participating NGOs in each country indicates that participation in the study had:

- Increased awareness of PLHA involvement in some NGOs.

We were not even conscious that there was involvement [of PLHA in the organization]. We came to know several areas where PLHA are already involved.

(Service provider, SOFOSH, Maharashtra, India)

- Allowed NGOs to share experiences at community and national level.

Rather than being a competition between the participating CBOs to find the best model, the study was an opportunity to share lessons and experiences with other local CBOs.

(President, AAS, Burkina Faso)¹⁸

¹⁸ In *Alliance Newsletter*, Volume 4, Number 2, September 1999, 'Enhancing the involvement of People Living with HIV/AIDS: The impact of the study on local communities, Viewpoint: Issoufou Tiendrebeogo, President, Association African Solidarité, Burkina Faso'.

- Prompted consideration of further PLHA involvement.

The most significant result for AAS is that, following the study, we have developed a plan to promote the greater involvement of PLHA within our organization ... New positions have been created within AAS and these have been filled by PLHA.

(President, AAS, Burkina Faso)

- Encouraged some NGOs to share the study results presented in their organizational profiles with other staff and management in order to improve their services.

Constructing a profile was like looking at ourselves in a mirror, seeing ourselves for how we really are, and it's a reliable portrait of what the organization is with its strengths and weaknesses. This is going to allow us to carry out our work in an organized way.

(NGO member, Guayaquil, Ecuador, during the data analysis workshop)

- Provided participating NGOs with practical tools to evaluate their services.

One worthwhile thing for our organization was the development of tools to evaluate the impact; that is to say, to measure everything we were doing and how much was being grasped in the population. Up until that point, we had only carried out an evaluation of the use of condoms, condom control and nothing else. The evaluation that was carried out as part of the investigation was important because it allowed us to realize what was being captured and what needed improving. In addition, it was important to know the opinions of each of the members of our organization, individual difficulties, positive aspects and whether or not there is an opening for participation.

(NGO director, Ecuador, during the data analysis workshop)

- Helped some NGOs to explain what they do to external partners.

We found that this was a really accurate reflection of what AAS does and are using it often as a kind of "identity card" with key partners and donors. It has made it easier to explain our work to others and has greatly enhanced our relationships with our partners.

(President, AAS, Burkina Faso)

We are still using the Venn diagram to explain [about our work and interactions] to delegates who come from other countries.

(Service provider, Salvation Army, Maharashtra, India)

- Developed capacity for research, including use of participatory tools.

We now have a technical expertise about what things should be done in research.

(MNP+ representative, Maharashtra, India)

3. Context: HIV/AIDS in Burkina Faso, Ecuador, India and Zambia

This chapter provides an overview of the context in the four countries where the study was conducted. It includes information about: the socio-economic and health context; HIV/AIDS epidemiology; knowledge, attitudes and behaviors with regard to HIV/AIDS and to PLHA; and government and civil society response to the epidemic, including the care, support and legal rights available to PLHA and the extent of PLHA mobilization.

3.1 Socio-economic context

There are significant differences between the four study countries in terms of population size and density, urbanization, religious beliefs and levels of development and poverty.

3.1.1 Demography and religion

- Zambia, Burkina Faso and Ecuador have relatively small populations, ranging from 10.1 million to 12.6 million people. In contrast, the population of Maharashtra State alone is 96.8 million.
- India is the most densely populated and Zambia the least densely populated of the four countries. Ecuador is the most urbanized and Burkina Faso the least urbanized of the four countries.
- In Ecuador, 95 per cent of the population is Christian and in India, 81 per cent is Hindu. In Burkina Faso, 50 per cent of the population is Muslim, 40 per cent follow indigenous beliefs and 10 per cent is Christian. In Zambia, 50–75 per cent of the population is Christian and 24–49 per cent Muslim or Hindu.

Table 3.1 Demographic indicators and geographic data

	Burkina Faso	Ecuador	India (Maharashtra)	Zambia
Population (millions) 1999	11.3	12.6	1,016 (96.8)	10.1
Urban population (%)	19	65	28	44
Population density (per square mile) 1999	41	46	342	14
Capital city	Ouagadougou	Quito	Delhi (Mumbai)	Lusaka
Main cities	Bobo Dioulasso Ouahigouya	Guayaquil	(Pune)	Ndola Livingstone

Source: World Development Report, World Bank, 2000-2001

3.1.2 Development

- Ecuador, with a GDP per capita four times that of Burkina Faso and three times that of Zambia, is the most developed of the four countries. It has the highest Human Development Index (HDI) ranking and the lowest proportion of the population living below the poverty line. High rates of school enrollment are reflected in the adult illiteracy rate of 9 per cent.
- India has the second highest GDP per capita and HDI ranking of the four countries, but the adult illiteracy rate in Maharashtra State is similar to that of Zambia.
- Burkina Faso and Zambia are among the poorest countries in the world. Three in five people in these two countries live on less than US\$1.00 a day, and rural and female-headed households are disproportionately poor. Of the four, Burkina Faso has the lowest HDI ranking, the lowest school enrollment rates and an adult illiteracy rate of 76 per cent.

Table 3.2 Development indicators

	Burkina Faso	Ecuador	India (Maharashtra)	Zambia
HDI (rank of 162 countries)	159	84	115	143
Population living below the poverty line (%) 1999	61.2	20.2	44.2	63.7
GDP per capita (US\$) 1999	965	2,994	2,248	756
Adult illiteracy rate (%)	76	9	43 (22.73)	22

Sources: UNDP, 1999; World Bank, World Development Report, 2000-2001; Census, India, 2001.

3.2 Health

Differences in life expectancy, infant mortality rate, maternal mortality rate and contraceptive prevalence rate in the four countries reflect differences in the level of development, as well as in health expenditure, health service coverage and health systems.

3.2.1 Health indicators, health service expenditure and coverage

- Ecuador, with the highest number of physicians per 100,000 people, has the lowest rates of infant and maternal mortality and the highest contraceptive prevalence rate and life expectancy.
- Although India has better health indicators than Zambia or Burkina Faso, infant and mortality rates are high and physician coverage per 100,000 people is lower than in Zambia. In 1996, the Maharashtra State government managed 741 hospitals and 1,423 health posts or primary health centers, and there were 143 hospital beds per 100,000 people.
- Zambia spends a higher proportion of its GDP on health than the other three countries, but health services are under-resourced and health status is poor. Of the four, Zambia has the lowest life expectancy at birth and highest infant and maternal mortality rates, reflecting the severe impact of the AIDS epidemic.
- Burkina Faso spends the lowest proportion of its GDP on health and has the worst health service coverage of the four countries.

Table 3.3 Health indicators

	Burkina Faso	Ecuador	India	Zambia
Public health expenditure (% of GDP) 1998	1.2	1.7	--	3.6
Life expectancy at birth	46.1	69.8	62.9	41
Maternal mortality rate (per 100,000) 1980-1999	--	160	410	650
Infant mortality rate (per 100,000) 1999	106	27	70	112
Physicians (per 100,000 people) 1999	3	170	4 ¹	7
Contraceptive prevalence rate (%) 1995-2000	12	66	48	25

Source: UNDP, 2000.

¹ Physician coverage in urban areas, including the city of Mumbai in Maharashtra, is significantly higher.

3.2.2 Health systems

- Compared to the other four countries, Ecuador's health system offers accessible services to most people. The majority use the public health system (60 per cent) and services covered by a social security system for employees in the formal sector (18 per cent), but there are also health institutions run by non-profit NGOs. The private profit-making sector provides 10 per cent of health services.
- In India, the public health system operates at three levels, with health centers in rural areas and health posts in urban areas at primary level, civil hospitals at district level, and teaching hospitals at state level. There is also a substantial private sector, although private hospitals and physicians are mostly located in urban areas and serve higher income groups. Religious health organizations, NGOs, charitable trusts and cooperative societies are also important providers of health services, charging more than government facilities but less than the private sector. There is also considerable use of traditional medicine.
- In Zambia, most people rely on public-sector health services. However, religious health providers – mission hospitals and clinics – NGOs and traditional healers provide a substantial proportion of health care. The small private sector caters for the wealthy elite in urban areas.
- In Burkina Faso, public, private and traditional health systems co-exist. Most people cannot afford private health care. Since public health service coverage is poor, many people seek care from traditional healers as a first option.

3.3 HIV/AIDS epidemiology

HIV prevalence rates and the number of PLHA vary considerably between the four countries. Variations in age and sex prevalence data reflect differences in the relative importance of routes of transmission and in the stage of the epidemic in each country.

3.3.1 AIDS cases and HIV prevalence

- In Zambia, the first AIDS case was reported in 1984. Burkina Faso, Ecuador and India reported their first AIDS cases in 1986.
- HIV prevalence in 1999 ranged from almost 20 per cent in Zambia to less than 1 per cent in Ecuador. Prevalence is high in Burkina Faso, at more than 6 per cent, and Burkina is the second most affected country in West Africa. Maharashtra is a high-prevalence state, with HIV prevalence in antenatal women estimated to be 1.75 per cent in 2001,¹⁹ and between 1986 and June 1999, 58,188 people were found HIV positive out of 566,708 persons tested in the state (10.26 per cent).²⁰

Table 3.4 HIV/AIDS epidemiology

	Burkina Faso	Ecuador	India (Maharashtra)	Zambia
Number of PLHA (adults and children) 1999	350,000	19,000	3,700,000 (400,000) ¹	870,000
HIV prevalence (% adults) 1999	6.44	0.29	0.70	19.95

Source: UNAIDS Epidemiological Fact Sheet, 2000.

¹ National AIDS Control Organization, India, 2000.

- In Zambia and Burkina Faso, more than 50 per cent of PLHA are women. In India, approximately 35 per cent of PLHA are women. In Ecuador, the percentage of PLHA who are women rose from an average of 22 per cent between 1984–1998 to 36 per cent in 1999. In 1999, sentinel surveillance data found HIV infection rates as high as 6 per cent in women attending clinics in slum areas of Mumbai. In Zambia, prevalence rates in antenatal clinic attendees aged under 20 years in urban areas fell from over 20 per cent to around 15 per cent between 1994 and 1998, while rates in the same age group in rural areas fell from 14 per cent to 6 per cent in the same time period. While prevalence appears to be declining, infection rates in pregnant women are still extremely high.
- In all four countries, available data suggest that rates of HIV infection are higher in some geographical areas and population groups. In Zambia, HIV prevalence rates are higher in urban centers, border areas and along major transport routes than in rural areas. In Ecuador, the coast region is most affected by the epidemic, followed by the capital city of Quito. In Maharashtra, an estimated 52.26 per cent of sex workers are infected, and sentinel surveillance data in 2001 found HIV infection rates of between 9 per cent and 20 per cent in sexually transmitted infection (STI) clinic attendees. In 1991 in the Zambian capital city of Lusaka, 60 per cent of male and 69 per cent of female STI patients tested were HIV positive.

¹⁹ High prevalence states are states where HIV prevalence in antenatal women is 1 per cent or more. NACO (2002) *HIV/AIDS Indian Scenario: HIV Estimates for Year 2001*. <http://naco.nic.in>

²⁰ *National HIV/AIDS Status in Maharashtra, Annual Progress Report, 1999–2000*.

3.3.2 HIV transmission

- In all four countries, sexual transmission is the main route of HIV transmission. Heterosexual transmission is responsible for 90 per cent of HIV infection in Zambia and Burkina Faso. Until 1998, almost 40 per cent of cases in Ecuador were attributable to homosexual or bisexual transmission, but in 1999 this fell to 20 per cent, and 60 per cent of new infections are now caused by heterosexual transmission. In Maharashtra, the epidemic is driven mainly by heterosexual transmission, but sex between men is also an important though under-reported route of transmission. In 2001, HIV prevalence among MSM was 23.60 per cent.
- Mother-to-child transmission is increasing in all four countries, as growing numbers of women are infected. In Zambia, an estimated 25,000 HIV-positive infants are born each year.
- Injecting drug use is responsible for about 5 per cent of HIV infections in India – HIV prevalence among injecting drug users (IDUs) was 41.38 per cent in Maharashtra and Mumbai in 2001 – but is not a significant route of transmission in Burkina Faso, Ecuador or Zambia. Transmission via blood or blood products accounts for about 5 per cent of HIV infections in India.

3.4 Knowledge, attitudes and behaviors (KAB)

3.4.1 KAB: HIV/AIDS

- Most people in all four countries have heard of AIDS. There is little research data on HIV/AIDS knowledge, attitudes and behaviors in Ecuador, perhaps because of the low prevalence. Levels of accurate knowledge and awareness are low in Burkina Faso, where people do not differentiate between HIV infection and AIDS, and PLHA are perceived as sick people who have AIDS and will die. This is largely as a result of prevention campaigns emphasizing death and lack of hope for those infected with the virus. Levels of knowledge and awareness are also low in India, although surveillance surveys to monitor behavior trends in population sub-groups in states such as Tamil Nadu suggest that knowledge about HIV transmission and methods of prevention and condom use have increased among groups such as truckers, factory workers and sex workers.
- In all four countries, HIV/AIDS is associated with “immoral” sexual behavior and marginalized groups such as “promiscuous” men and women, sex workers and homosexuals. There are also widespread misconceptions about HIV transmission and risk. In Zambia and Burkina Faso, many people believe that HIV is caused by witchcraft or sorcery, and in Zambia a substantial proportion believe it is transmitted by mosquitoes. In Ecuador, people still view AIDS as a “contagious” disease.
- Sex between men is common in Ecuador and India, but it is widely denied in India, where most men reporting MSM activity are married. Pre-marital and extra-marital sexual activity is disapproved of in all four countries, but the extent to which it is acknowledged varies. For example, such behavior is openly acknowledged in Zambia but not in India, despite the fact that there are an estimated 400,000 sex workers in Indian cities and studies have shown that between 8 per cent and 29 per cent of men have paid for sex.
- Levels of knowledge and awareness about how to prevent HIV transmission vary. In Burkina Faso and Zambia, where awareness is higher, condom use with non-marital and non-regular partners appears to be increasing, but this is not the case in India or Ecuador. Rates of consistent

condom use by sex workers and their clients, and of condom use within marriage remain low in all four countries.

3.4.2 KAB: PLHA

- PLHA are highly stigmatized in all four countries. In Zambia, for example, negative attitudes towards PLHA are widespread, and fear of stigma and discrimination, in addition to lack of access to information, counseling, care and support, means that few individuals are willing to find out or divulge their HIV status. There is also widespread denial of HIV/AIDS as a cause of illness and death. As a result, few people seek testing or disclose their status, and only two in five people report knowing someone living with HIV. In Burkina Faso, a national survey in 1996 found that 45 per cent of rural people and 60 per cent of urban inhabitants had discriminatory attitudes towards PLHA.
- PLHA are stigmatized because of the association of HIV/AIDS with certain behaviors and population groups. Other factors contributing to stigmatization include: prevention campaigns (for example, in Burkina Faso and India, which have helped to create the perception that AIDS is associated with promiscuity and is a shameful disease); beliefs (for example, in Burkina Faso and Zambia, that AIDS is caused by witchcraft or sorcery); and widespread ignorance and fear (for example, in India, exacerbated by inaccurate media reporting).
- Many PLHA have experienced stigma and discrimination in the home and community, and in educational, workplace and health-service settings. In India, PLHA, especially women, have reported being blamed, ill-treated, rejected and abandoned by their families. Discrimination in health care settings appears to be a particular problem, with reports of testing without informed consent, failure to maintain confidentiality, differential treatment, refusal to provide treatment and care, and disrespectful handling of AIDS patients after death. Similarly, in Burkina Faso many people are tested for HIV without their knowledge. In India, PLHA who have revealed their status reported experience of stigma and discrimination in the workplace. In Zambia, more than a third of workers surveyed in private-sector firms said they would not be willing to share cups or plates with infected employees and that PLHA should be isolated.

Despite having the HIV epidemic now for the last 15–16 years, we still have an extremely high level of stigma. In our communities, people hardly talk about HIV/AIDS. Even as a family inside the house ... if there is someone suffering from HIV/AIDS ... no one will say they are suffering from HIV/AIDS ... they will say something else because of fear of discrimination and social costs.
(Central Board of Health representative, Zambia, interviewed during the study)

3.5 National responses to the HIV/AIDS epidemic: Governments

3.5.1 Government structures and policy priorities

- All four countries have a national AIDS control program and other bodies in charge of coordinating and supervising the response to the HIV/AIDS epidemic at the national level. In Zambia, the epidemic was on the political agenda early on because of the involvement of President Kaunda. In India, the government response accelerated more recently, following initial denial that the epidemic might affect the country. Government response in Ecuador has been limited, since HIV/AIDS is not considered to be a major public health problem. In Burkina

Faso, the government response has been characterized by delays, and stronger commitment at the political level is a recent development.

- Zambia, Burkina Faso and India have shifted from an initial focus on prevention to an emphasis on a multi-sectoral response to the epidemic involving all sectors of society. Ecuador has targeted “high risk” groups.
- Policies in all four countries highlight the need to provide care and support for PLHA and to tackle stigma and discrimination.

Burkina Faso

- ⇒ The National AIDS Program was set up in 1987 but has not been operational for almost 10 years. However, the government’s contribution to the Population and AIDS Project (Projet Population et Lutte contre le SIDA) has increased.
- ⇒ The government response has been characterized by considerable delay. National AIDS policies were only formulated 13 years after notification of the first AIDS case and these have yet to be followed up with concrete action

Ecuador

- ⇒ The National AIDS Committee is responsible for coordinating an intersectoral response and the National AIDS Program is responsible for implementing policies. However, lack of financial and human resources has limited action, and many initiatives have not been sustained.
- ⇒ The government response has been relatively limited, and HIV/AIDS has not been a public health priority in Ecuador, possibly because of low prevalence and because the epidemic initially only affected so-called “high risk” groups.

India

- ⇒ India is implementing the second phase of the National AIDS Control Program, coordinated by the National AIDS Control Organization. While there is a National AIDS Control Policy, responsibility for implementation is devolved to state AIDS control societies, which are overseen by state AIDS control committees.
- ⇒ The second phase, a multi-sectoral approach involving government, NGOs and civil society, includes targeted interventions for communities at high risk, prevention of HIV transmission among the general population, strengthening institutional capacity, and increasing access to community-based and home-based care and treatment of opportunistic infections.

Zambia

- ⇒ Zambia’s National HIV/AIDS Strategic Framework (2000–2002) emphasizes a multi-sectoral approach (involving government, NGOs, CBOs and the private sector) to prevention, care and support at central, district and community levels. The National HIV/AIDS/STD/TB Council coordinates implementation, and there are HIV/AIDS focal points in each sector ministry.
- ⇒ The Framework prioritizes geographic areas, sub-populations (including PLHA) and interventions, including destigmatization of HIV/AIDS, VCT, improved hospital care, home-based care and support for PLHA, as well as preventive interventions.

3.5.2 International cooperation

- International donors and other stakeholders play a significant role in all four countries in terms of providing financial support for national programs and specific interventions implemented by governments and NGOs. Donor financial support is substantial in Zambia, Burkina Faso and India. Multilateral and bilateral agencies have been less involved in Ecuador, as it is considered to be a low-prevalence country, but external donors have provided a significant proportion of funding as well as the impetus for HIV/AIDS initiatives.

- The degree of external influence on policy varies and depends to a large extent on donor dependence. In India, policies are influenced by the international agenda but are still set by national bodies. In Burkina Faso and Zambia, which depend heavily on international aid to fund their health systems, the influence of donors is greater.
- In all four countries, the impetus for greater PLHA involvement has largely come from international donors, NGOs and activists in international networks of PLHA, which have supported local and regional PLHA mobilization and the development of national PLHA organizations and networks. UNAIDS and its co-sponsors like the United Nations Development Program (UNDP), for example, has given high priority to tackling stigma and discrimination through GIPA initiatives and locating the response to HIV/AIDS within a human rights framework. In some cases, greater involvement of PLHA in programs and decision-making bodies has been a condition of funding.

3.5.3 Legal framework and PLHA rights

- Only Ecuador has a specific AIDS law, passed in April 2000. The law aims to guarantee HIV-prevention activities, specific state medical care for PLHA and to reduce discrimination within society. However, the law does not prevent institutions carrying out compulsory testing as a prerequisite for access to services or employment, and also enables legal action to be taken against people who are aware of their HIV status and consciously and voluntarily transmit HIV to another person.
- In India, the Draft National AIDS Control Policy acknowledges the problem of stigma and discrimination, emphasizes the rights of PLHA to health care, employment and education, and states that there should be no mandatory testing and that a person's HIV status should be kept confidential and should not in any way affect their rights. However, greater efforts are required to ensure that these policies are put into practice and to establish a supportive legal framework for the rights of PLHA. Several current laws and policies violate the rights of PLHA. For example, in 1998 the Supreme Court ruled that a person with HIV does not have the right to marry and that disclosure of their HIV status is permissible to protect the health of a potential marriage partner. Also, in 1999, the Delhi Ministry of Social Welfare was reported to be proposing the introduction of mandatory HIV testing for women and children in state shelters.
- Zambia does not have HIV/AIDS-specific legislation to protect PLHA from discrimination. However, the National HIV/AIDS Strategic Framework highlights the impact of stigma and discrimination on PLHA and their families and on delaying community responses to the epidemic, and acknowledges the importance of protecting the rights of PLHA in order to promote openness, tolerance and greater community involvement. The Framework also highlights the need to focus, in collaboration with civil society and legal institutions, on the rights of vulnerable women and children to mitigate the discriminatory aspects of HIV/AIDS.

3.6 National responses to the HIV/AIDS epidemic: Civil society

3.6.1 NGO and CBO mobilization

- NGOs and CBOs have played an important role in social mobilization in all four countries, but to a greater extent in Zambia than in Burkina Faso, Ecuador or India. However, even in Zambia, there has been limited coordination between NGOs and CBOs.

- There has also been a more active community response in Zambia than in the other three countries.
- The response of the business sector has been limited in all four countries.

Burkina Faso

- ⇒ In 1998, at the time of data collection, around 100 CBOs were involved in some type of HIV/AIDS work, but only a few were carrying out regular activities. Most CBOs started with prevention work, and in the mid-1990s some expanded their remit to include care.
- ⇒ While there were many CBOs at district and village level, there were few NGOs of sufficient size to influence policy and there was little coordination between civil society organizations. However, in 1997 15 CBOs involved in the care of PLHA joined together to form a network in order to work more closely with health facilities and political and administrative structures.

Ecuador

- ⇒ In 2000, approximately 40 NGOs included HIV/AIDS in their work.
- ⇒ Networks exist, including a network of NGOs working in HIV/AIDS. However, collaboration is affected by rivalry and competition for limited funding, and differences in approaches and target groups; for example, between mainstream NGOs and groups working with MSM.

India

- ⇒ The number of NGOs and CBOs supported by NACO and state AIDS control societies increased from six in 1995–1996 to over 200 in 1998–1999. In Maharashtra, at the time of data collection, the state government was providing support for over 30 NGOs and CBOs. Most were working on preventive interventions with sex workers, truckers and MSM. Few were focusing on care and support for PLHA.
- ⇒ The Draft National AIDS Control Policy highlights cooperation with NGOs and CBOs and their role in social mobilization, counseling, condom promotion and home-based and hospice care.

Zambia

- ⇒ In Zambia, civil society organizations are identified by the government as a key partner in the national response. Many NGOs have played a significant role in prevention, care and support initiatives, including education, welfare, income-generating activities and home-based care. However, most NGOs are located in urban areas, and until recently, with the exception of Ndola, there has been very little coordination between the various organizations.
- ⇒ The private sector has played a limited role, although there is now a business coalition on AIDS and a forum for private-sector interaction with government on HIV/AIDS issues.

3.7 National responses to the HIV/AIDS epidemic: PLHA involvement

3.7.1 PLHA organizations and networks

- There are national networks of PLHA in Zambia, Ecuador and India. PLHA organization started in the late 1980s and early 1990s in Ecuador and Zambia, but is a relatively recent phenomenon in Burkina Faso and India. However, visible PLHA involvement is low in all four countries and is mostly urban, as networks and organizations have not been very successful in reaching out to PLHA in rural areas.
- In Ecuador, the first self-help groups were established in the late 1980s. These have subsequently evolved into AIDS service organizations (ASOs) and membership has expanded to include social and health workers and family members of PLHA. Subsequently, new self-

help groups have been formed, some of which are focusing on empowerment, advocacy and defence of PLHA rights, and there is a national PLHA network, although it is not very active.

- Visible involvement of PLHA started in 1990 in Zambia, and the Network of Zambian People Living with HIV/AIDS (NZP+) was established in 1996. NZP+ is active in advocating for the rights of PLHA, and aims to reduce stigma, improve quality of life, strengthen PLHA support groups and facilitate representation. UNDP initiated a project in 1998 that supported the placement of visible HIV-positive UN volunteers in various administrations, NGOs and private companies (UNV Project). Despite these initiatives, visible involvement remains low: only 1,000 PLHA in Zambia belong to NZP+ and the Network has been less successful in establishing a presence in the provinces.
- In Burkina Faso, PLHA initially became involved in a few NGOs and CBOs that were providing medical and psychosocial care and support, and some PLHA support groups have been established, either by these CBOs or by PLHA themselves.
- Although support groups for PLHA were set up in India as early as 1993, it was not until 1997 that PLHA established the Indian Network for Positive People (INP+). There are also state-level networks of PLHA; for example, the Maharashtra Network for Positive People (MNP+) was established in 1998. PLHA organizations are involved in advocacy, networking, counseling, care and support. However, there is a lack of clarity about the respective roles of national- and state-level networks, and different perspectives about whether or not PLHA networks should be involved in direct delivery of services.

3.7.2 PLHA representation

- There are PLHA representatives on national policymaking bodies in Ecuador and India. In India, this is a relatively recent development: the first PLHA representative was included on the committee that oversees NACO in 1999. However, even where there is PLHA representation, the roles of PLHA representatives and the extent to which they can influence policy decisions are not always clear.
- In Zambia, as result of the UNV PLHA pilot project, PLHA have been posted in ministries, defense forces, district health management teams (DHMTs) and NGOs. However, while NZP+ has been a partner in dialogue with the government, PLHA were not represented in national bodies at the time of data collection. NZP+ is seeking greater representation on national and district decision-making bodies.

3.7.3 PLHA involvement as a policy priority

- Only the governments of India and Zambia signed the GIPA Declaration in 1994.
- PLHA involvement is not an explicit policy priority in any of the four countries. This may reflect that fact that promotion of greater involvement of PLHA has been more of a priority for international agencies, such as UNAIDS, than for governments.
- In India, the Draft National AIDS Control Policy refers to government support for the formation of self-help groups among PLHA for group counseling and home care and support, but does not explicitly highlight PLHA involvement as a policy priority or strategy.
- Similarly, in Zambia the National HIV/AIDS Strategic Framework identifies PLHA as essential partners in the Zambian response and as partners in the design, development and implementation of policies and programs, but there is no explicit commitment to involvement.

3.8 Care and support for PLHA and affected people

3.8.1 Access to care

- Access to care reflects health service coverage and is therefore greater in Ecuador than in the other three countries. In Ecuador, 70 per cent of AIDS patients are treated in state hospitals and the remainder access care provided by private hospitals or NGOs.
- In all four countries, people in urban centers have better access to care than those in rural areas. In Burkina Faso, for example, there is virtually no access to care and treatment for PLHA outside the cities of Bobo Dioulasso and Ouagadougou. In Zambia, although HIV/AIDS services are included in a basic package of health care at district level, the 1996 Zambia Demographic Health Survey (ZDHS) at only 14 per cent of the rural population had access to health services.
- Access to care is also affected by cost. The cost of consultations and drugs is a significant barrier in Burkina Faso and Zambia.
- Demand exceeds capacity to provide treatment and care in Burkina Faso, India and Zambia. In all four countries, access to quality care is limited by a shortage of health personnel trained in treatment and care of HIV/AIDS and by discrimination on the part of many health workers.
- Zambia has the most well-developed home-based care programs, but only 20 per cent of PLHA have access to these programs. Home-based care is in its infancy in Burkina Faso and India. In Zambia, the National HIV/AIDS Strategic Framework identifies improved care and support, including home-based and hospital-based care, for PLHA among its priority areas, and in India, the Draft National AIDS Control Policy highlights the need to provide a continuum of care comprising clinical management, nursing care, counseling and socio-economic support, and to support NGOs and CBOs to provide hospice care.

3.8.2 Voluntary counseling and testing

- In Burkina Faso, India and Zambia, VCT is not widely available. In Burkina Faso, when data collection started, there was only one VCT center – in the city of Bobo Dioulasso. In India, the draft National AIDS Control Policy highlights the need to establish additional centers to expand access to VCT. In all four countries, access is mostly limited to urban centers.
- In these countries, cost and concerns about confidentiality and stigma also limit access to VCT.
- Consequently, few people in these countries have taken a test or are aware of their HIV status. In Zambia for example, the sexual behavior survey (SBS) found that only 8 per cent of respondents had taken a test and only 6 per cent knew their HIV status.

3.8.3 Treatment for opportunistic infections

- Access to treatment for opportunistic infections also reflects health service coverage, and is therefore greater in Ecuador than in the other three countries. Access to treatment is particularly poor in Burkina Faso and India, and in rural areas of Zambia.
- In Burkina Faso, PLHA rarely go to health centers because these services have little to offer them, and access to treatment for opportunistic infections at hospitals depends on ability to pay for drugs. Although drugs to treat opportunistic infections are included in the essential drugs list, doctors do not always prescribe generic drugs. This increases the cost to patients, many of whom can only afford some of the drugs prescribed or buy medicines in insufficient quantities.

- Many PLHA in India do not have access to treatment for opportunistic infections because of denial of care by health professionals or because of lack of drugs. The Draft National AIDS Control Policy proposes improving availability and access through sensitizing health workers and making more widely available free drugs for management of opportunistic infections.
- In Zambia, many health centers, especially in rural areas, do not have sufficient trained staff or drugs to manage opportunistic infections. As a result, many people seek treatment for opportunistic infections from secondary or tertiary facilities.

3.8.4 Antiretroviral drugs

- In Burkina Faso, India and Zambia, access to ARVs is limited to PLHA with sufficient money to pay for them – often in the private sector, or who have contacts with friends or institutions in high-income countries or other developing countries where ARVs are more widely accessible. In India, ARVs are produced by Indian pharmaceutical companies and sold at prices well below those in industrialized countries. But, even at these prices, only 3–5 per cent of HIV-positive people could afford such therapy.
- In Ecuador, ARVs are available only to social security users in one region of the country, and to people eligible to use police and military hospitals. Even then, treatment may be incomplete and intermittent depending on resources available. When the diagnostic study was carried out, the cost of unsubsidized monthly treatment was more than ten times the average monthly salary of a person working in the formal sector.
- In all four countries, there are insufficient trained staff to provide effective prescribing and laboratory facilities to ensure monitoring and follow-up of antiretroviral therapy. In Burkina Faso, for example, ARVs are included in the essential drugs list but, when the diagnostic study was carried out, capacity to carry out CD4 counting was only available in Bobo Dioulasso.

4. Roles of PLHA in Community-based Programs: A Typology of PLHA Involvement

Who knows most about HIV/AIDS? The doctor? The expert? The scientist? The nurse? The psychotherapist? The theological counselor? The family? The patient? It is the patients who are living the reality. It is them. Because of this, we, as professionals, as an integrated group working with them, have to start to view the patients with respect. We have to regard the patients with respect because they know more than we do about AIDS ... They know more about AIDS than any other person, and therefore are the ones qualified to guide and tell us where to go; how and which way to go.

(Representative, Evangelical church, Quito)

This chapter presents the typology of involvement that was developed during the diagnostic study, based on the different types of PLHA involvement observed in the participating NGOs and CBOs. It provides an overview of the structure, services and activities of these 17 organizations, describes the methodology used to develop the typology of involvement, and defines and summarizes the main characteristics of the four types of involvement identified, illustrating these different types of involvement with examples from the four countries.

4.1 Rationale for a typology of PLHA involvement in NGOs and CBOs

The lack of a typology has resulted in lack of a common understanding about what “PLHA involvement” really means, and this has contributed to differences in interpretation by the various stakeholders. For example, what AIDS activists understand “involvement” to mean may be completely different from what governments or NGOs understand it to mean. One important reason for developing a systematic typology of involvement is, therefore, to promote a common understanding of what is meant by involvement.

On a more practical level, a typology of involvement can be used by NGOs and CBOs: to analyze what type or types of involvement are meaningful and make a difference in the lives of PLHA who are involved in their activities, and how this involvement benefits the organizations and their services; to understand what makes different types of involvement possible or difficult to achieve; and to consider how to improve the involvement of PLHA in their organizations.

It can also be used by donors and organizations that provide NGOs and CBOs with technical assistance to evaluate how PLHA are involved in the NGOs and CBOs they support, and to decide what types of involvement they want to encourage.



In Zambia, HIV positive outreach educators at Kara Counselling working with mothers receiving antenatal care at a local clinic

4.2 Characteristics of the participating NGOs and CBOs

The study analyzed whether or not the characteristics of an NGO or CBO influence the type of PLHA involvement in community-based prevention, care and support, and the factors that limit or enhance their involvement. The following tables summarize the main characteristics of the 17 organizations that participated in the study. It should be noted that while some organizations in Burkina Faso described themselves as CBOs, all 17 organizations were NGOs, although these vary considerably in size and scope.

Table 4.1 Types of NGOs

Organization	Type of organization	Date established or activities started	Location
Burkina Faso			
AAS	Development organization, providing care services for PLHA and carrying out prevention activities	1993	Ouagadougou, urban
ALAVI	Self-help group of PLHA and affected people, rights-based organization	1995	Ouagadougou, urban
AMMIE	Secular welfare organization, providing care services to the seriously ill and elderly in the community	1993	Ouahigouya, urban and semi-urban
La Bergerie-Foi	Religious welfare organization, providing care services to the seriously ill who have no financial resources	1996	Ouagadougou, urban
REVS+	Self-help group of PLHA and affected people, rights-based organization	1998	Bobo Dioulasso, urban
Ecuador			
Dios, Vida y Esperanza	Secular welfare organization, originally a self-help group of PLHA	1987	Guayaquil, urban
Esperanza	Secular welfare organization working with sex workers and PLHA	1992	Quito, urban
Siempre Vida	Self-help group of PLHA and affected people, rights-based organization	1992	Guayaquil, urban
Vivir	Secular welfare organization, originally a self-help group of PLHA and affected people	1988	Quito, urban
India			
CCDT	Development organization working with sex workers and other marginalized communities	1990	Mumbai, urban
MNP+	PLHA organization (network) now registered as a charitable trust, rights-based organization, network	1998	Mumbai, Pune, Thane, Nagpur districts, urban and rural
Salvation Army (Mumbai HIV/AIDS Community Development Program)	Religious welfare organization	1882 in India HIV/AIDS activities 1989	Mumbai, urban
SOFOSH	Secular and hospital-based welfare organization providing social services to the patients of the Sassoon Hospital in Pune	1964 HIV/AIDS activities 1995	Pune, serves urban and rural population

Organization	Type of organization	Date established or activities started	Location
Zambia			
CHEP	Development organization established in response to HIV/AIDS	1988	Kitwe, urban and rural
Hope	Project of secular NGO Development Aid People to People, development organization working on HIV/AIDS	1996	Ndola, urban
Kara	Secular development organization, initially a counseling center	1989	Lusaka & Choma, urban
Salvation Army (Chikankata Hospital)	Religious welfare organization, runs hospital and health centers, CHDP conducts HIV/AIDS activities	Hospital 1946 HIV/AIDS activities 1988	Rural

Table 4.2 Services and activities of participating NGOs

	Burkina Faso					Ecuador		
Category of service	AAS	ALAVI	AMMIE	Bergerie	REVS+	Dios, Vida, Esperanza	Esperanza	Siempre Vida
Outreach education	✓		✓	✓	✓	✓	✓	✓
General public	✓		✓		✓	✓		✓
Youth, schools	✓					✓		✓
Workplace	✓							
Sex workers	✓						✓	
Affected families	✓	✓	✓	✓	✓	✓		✓
Testimonies of PLHA					✓	✓		✓
Health care	✓	✓	✓	✓	✓	✓	✓	✓
Consultations	✓	✓	✓	✓		✓	✓	
Medicines	✓	✓	✓	✓		✓	✓	
Home care	✓		✓	✓	✓			
Referral	✓	✓	✓	✓	✓	✓	✓	✓
HIV testing	✓							
Psychological support	✓	✓	✓	✓	✓	✓	✓	✓
Drop-in center	✓			✓				
Home visits	✓	✓	✓	✓	✓	✓	✓	✓
Counseling	✓			✓	✓	✓	✓	✓
Pre/post-test counseling	✓							✓
Peer counseling					✓			✓
Support groups	✓	✓		✓	✓			✓
Material support	✓	✓	✓	✓	✓	✓		
Financial	✓	✓	✓					
Medicines	✓	✓	✓	✓	✓			
Food	✓	✓	✓					
Shelter								
Income generation	✓							
Training				✓				✓
Positive living								
Advocacy and networking	✓	✓			✓	✓	✓	✓

Ecuador		India				Zambia			
Category of service	Vivir	CCDT	MNP +	Salvation Army	SOFOSH	CHEP	Hope	Kara	Salvation Army
Outreach education	✓	✓	✓	✓		✓	✓	✓	✓
General public	✓		✓	✓		✓	✓	✓	✓
Youth, schools	✓					✓	✓	✓	
Workplace						✓	✓	✓	
Sex workers		✓		✓			✓		
Affected families		✓	✓	✓		✓	✓		✓
Testimonies of PLHA			✓	✓		✓	✓	✓	
Health care	✓	✓	✓	✓	✓	✓	✓	✓	✓
Consultations	✓			✓			✓	✓	
Medicines	✓			✓			✓	✓	
Home care				✓		✓			
Referral	✓	✓	✓	✓	✓	✓	✓	✓	✓
HIV testing				✓			✓	✓	
Psychological support	✓	✓	✓	✓	✓	✓	✓	✓	✓
Drop-in center		✓		✓			✓		
Home visits	✓	✓		✓					✓
Counseling	✓	✓	✓	✓	✓	✓	✓	✓	
Pre/post-test counseling		✓		✓			✓	✓	
Peer counseling			✓	✓					
Support groups		✓	✓	✓		✓	✓	✓	
Material support	✓	✓		✓	✓	✓	✓	✓	
Financial	✓	✓			✓				
Medicines	✓			✓					
Food		✓			✓				✓
Shelter		✓			✓				
Income generation		✓				✓	✓	✓	
Training		✓	✓		✓	✓	✓	✓	✓
Positive living							✓	✓	
Advocacy and networking	✓	✓	✓	✓		✓	✓		

Table 4.3 Users of HIV/AIDS services of participating NGOs

Organization	Categories and numbers
<i>Burkina Faso</i>	
AAS	Care and support: 35 PLHA and families Prevention: general population, youth, sex workers, barbers
ALAVI	Care and support: 22 PLHA and families Prevention: women
AMMIE	Care and support: patients who are seriously ill, including PLHA (80 PLHA), the elderly and families. 50 per cent of PLHA are bedridden Prevention: general population, women
La Bergerie	Care and support: patients who are seriously ill, including PLHA (55 PLHA) and families Prevention: teachers, religious leaders
REVS+	Care and support: PLHA and affected people. No precise number of beneficiaries when the study was conducted as the organization only started to provide services Prevention: general population, students, health workers
<i>Ecuador</i>	
Dios, Vida y Esperanza	Care and support: 60 PLHA on average Prevention: youth, community leaders, general population
Esperanza	Care and support: sex workers, 15 PLHA and 20 affected people Prevention: sex workers
Siempre Vida	Care and support: 100 PLHA, mostly men Prevention: students, general population
Vivir	Care and support: 35 PLHA, mostly men Prevention: students, general population
<i>India</i>	
CCDT (project Child)	Care and support: 115 children and families affected by HIV/AIDS Predominantly urban, young, single or widowed PLHA mothers with children. Some are sex workers. Most have completed primary education and are from low-income groups
MNP+	Care and support: number of beneficiaries not clear, 500 PLHA joined Maharashtra Major Group (platform for network of self-help groups in Maharashtra). Predominantly urban, equal numbers of women and men. Most are married with children, have completed secondary education, are employed but from low-income groups Prevention: general population
Salvation Army (Mumbai HIV/AIDS Community Development Program)	Care and support: 1100 PLHA and affected beneficiaries in 1999 at the Byculla Centre in Mumbai. Predominantly urban, mainly young men. Most have completed secondary education and many of them are unemployed. Material support provided to children of sex workers Prevention: 7 communities in Greater Mumbai
SOFOSH	Patients of the Sassoon Hospitals, 322 infected and affected women and children in 1999. 55 per cent urban and 45 per cent rural within 100 mile radius of Pune, low-income groups

Organization	Categories and numbers
<i>Zambia</i>	
CHEP	Care and support: 125 PLHA and affected people in 12 support groups Prevention: youth, women, workers, general population
Hope	Care and support: 600 people used the services of the clinic in 2000. Approximately 120 PLHA took part in positive living advocacy courses since 1998. They are men and women aged 16–60 years, mostly unemployed, self-employed or retired, and most have completed secondary education Prevention: youth, teachers, women, workers, general public
Kara	Care and support: Clients of 5 VCT centers. The Life Skills training course targets economically disadvantaged PLHA Prevention: general public Training: health and social workers
Salvation Army (Chikankata Health Services)	Care and support: members of 45 communities, each with approximately 10 villages. 240-bed hospital and 4 rural health centers Prevention: general public in the catchment area Training: health and social workers, community leaders

Table 4.4 Service providers of participating NGOs

Organization	Categories and numbers	Characteristics *	PLHA involvement
<i>Burkina Faso</i>			
AAS	45 staff, 400 members	Members are young, have had schooling, many unemployed, 40 per cent women	Difficult to estimate as low visibility of PLHA
ALAVI	1 staff, 30 members (volunteers)	One third of members are health and social workers, middle class, 50 per cent women	One third of members are PLHA
AMMIE	40 staff, 20 community assistants, 40 members	80 per cent of members are health workers, 50 per cent women	No visible PLHA involvement
La Bergerie	1 staff, 20 members	90 per cent of members are health workers, 25 per cent women	Yes, but limited
REVS+	No staff, 50 members	67 per cent are health and social workers, 63 per cent women	One third of members are PLHA
<i>Ecuador</i>			
Dios, Vida y Esperanza	2 staff, 70 members (includes 40 active service providers)	75 per cent health and social workers. Majority of women	30 per cent of active members are HIV positive
Esperanza	2 staff, 10 members (includes 7 active service providers)	100 per cent health and social workers. Majority of women	No involvement of PLHA as service providers
Siempre Vida	3 staff, 35 members (includes 14 active service providers)	45 per cent MSM. 10 per cent of volunteers are women	90 per cent of volunteers and 67 per cent of staff member are HIV positive

Organization	Type of organization	Date established or activities started	Location
<i>India</i>			
CCDT	122 staff (CCDT) 21 staff (Project CHILD)	Majority of 21 staff are women, trained social workers and other professionals. The majority are women	Some PLHA employed as support staff. Other PLHA belong to support groups
MNP+	11 staff, 10 volunteers	Gender balance among staff members	Two thirds of staff are PLHA
Salvation Army (Mumbai HIV/AIDS Community Development Program)	9 staff, community and center-based volunteers	Staff are mostly social workers. The majority are men	Visible PLHA among service providers, support staff and volunteers
SOFOSH	65 staff, 35 volunteers	Staff are mostly social workers, teachers, nurses, child-care helpers. The vast majority are women	A few PLHA involved in activities as volunteers
<i>Zambia</i>			
CHEP	41 salaried staff, 3 types of volunteers (part-time, community-based and workplace peer educators)		2 full-time employees in the PLHA Program. 3 part-time volunteer workers are visible PLHA. Many community-based volunteers in support groups are PLHA
Hope	17 salaried staff, 2 types of volunteers (community-based and foreign volunteers), activists (PLHA, teachers, peer educators)		2 visible PLHA are employed full time as outreach educators. Many volunteers involved in outreach and advocacy are HIV positive (Positive Living Advocates). One PLHA employed as support staff
Kara	37 salaried staff, part-time counselors and PLHA outreach educators who receive allowance, 40 volunteer community mobilizers	The majority are health and social workers	6 visible PLHA, 4 men and 2 women, work as part-time outreach educators. The coordinator of the outreach program is HIV positive
Salvation Army (Chikankata Health Services)	Salvation Army has a staff of around 184. All the members of the 24 care and prevention teams (CPTs) are volunteers (between 10 and 34 members in each CPT)	Most of them are farmers.	Only 2 CPT members are visible PLHA

* As discussed in Chapter 2, in some cases beneficiaries are also service providers. In the CBOs in Burkina Faso in particular, "members" often refers to service providers (staff and volunteers) and users.

4.3 Methodology used to develop the typology of PLHA involvement

Methodological challenges included:

- The lack of previous research on PLHA involvement to use as a reference for definitions.
- The need to develop a definition of “involvement” for the research teams in each country which would be flexible enough to encompass many different forms and definitions of involvement.
- The choice of criteria to distinguish and characterize the different forms of involvement.
- The choice of terminology to describe the different forms of involvement.

To develop a definition of involvement, the research teams and participating NGOs in each country explored and discussed concepts and terminology, and the international research team ensured that these concepts and terminology were shared between countries and that a common and consistent typology emerged from the study. The bases of the terminology were set during the rapid assessment conducted with various stakeholders before the implementation of the study in India. In Zambia and India, the participating NGOs were also able to reflect on the relevance of the definitions of types and terminology and contributed to refining them during the data analysis workshops held in these two countries.²¹ The participatory process used to develop the conceptual framework, and the number and diversity of stakeholders involved in its development, give extra validity to the typology.

The typology of involvement, shown in Table 4.6, was developed based on analysis of the areas of involvement of PLHA and of the main characteristics of involvement in each area. The areas of involvement and the criteria used to define the main characteristics of involvement in each of these areas are described in the following sections.

4.3.1 Areas of involvement

Since the main focus of the research was the involvement of PLHA in service delivery, the study looked first at how PLHA take part in services and identified three broad “areas” of involvement:

- **Utilization** of services of NGOs and CBOs.
- **Implementation** of activities and/or **delivery of services** offered by NGOs and CBOs.
- **Decision-making** about the services delivered by NGOs and CBOs.

Following more detailed analysis, a further distinction was made between:

- **Implementation of HIV/AIDS activities (delivery of HIV/AIDS services)**, such as prevention, care and support and **implementation of non-HIV/AIDS-related activities**.
- **Decision-making** that affects the **design and planning of** activities and services, and **decision-making** that affects the overall **functioning of the organization** and its **policies**.

The study finally developed five categories or “**areas**” of involvement and corresponding **roles for PLHA** (see Table 4.5).

²¹ In Burkina Faso and Ecuador, the data analysis workshops were scheduled earlier and did not allow NGOs and researchers to discuss these issues.

Table 4.5 Areas of involvement of PLHA in NGOs and CBOs

Areas of involvement	Roles for PLHA
Utilization of the services of the NGO	⇒ PLHA are service users or beneficiaries
Support to services	⇒ PLHA are support staff or volunteers in non-HIV/AIDS-related activities such as administration, maintenance and other technical tasks (cooking, gardening, etc.)
Delivery of HIV/AIDS services	⇒ PLHA are service providers , either as staff members or volunteers (e.g. counselors, carers, outreach educators)
Planning and design of services	⇒ PLHA are service designers and planners (e.g. as program or project staff)
Management, policymaking and strategic planning	⇒ PLHA are managers and policy makers within the organization (e.g. as trustees, directors)

4.3.2 Criteria to describe the involvement of PLHA in each area

With the exception of utilization of services, the involvement of PLHA in an NGO or CBO can be seen as an economic relationship between the organization and individuals, whereby PLHA give their time, use their skills and make efforts in order to produce something; for example, a service. The organization in exchange can reward this by a remuneration that can be financial (for example, salary, allowance), material (for example, food, drugs), intellectual/technical (for example, training) and/or psychological (for example, support). How much time is spent, what skills are used and how this is rewarded by the organization also determine whether the exchange is formal – with a contract of employment, for example – or informal, when PLHA give their time and skills on a voluntary basis, without a remuneration defined contractually.

In order to develop the typology, the study analyzed the relative importance of each of the following criteria in the exchange between PLHA and organizations:

- The amount of **time** that PLHA spend taking part in the activities of the organizations.
- The level of **remuneration given by the organizations to PLHA** in exchange for their time, skills and efforts.

- The categories of **skills** or **expertise** used by PLHA when they take part in the activities of NGOs and CBOs:
 - from the perspective of PLHA, the skills they bring to the organizations and use when involved in the activities;
 - from the perspective of the NGOs and CBOs, the skills that the organization provides PLHA with.

In the area of involvement in the decision-making process, the study also analyzed:

- The **scope of the decisions** that PLHA make.
- The **autonomy of the decisions** that PLHA make.

Another important criteria in the development of the typology was visibility, since a unique characteristic of the involvement of PLHA is that it can be visible or non-visible. Many PLHA are not visibly involved because of stigma and fear of discrimination.

Time and remuneration

The involvement of PLHA in terms of **time** spent with an organization can be:

- **Regular** – involvement can be as **full-time** or **part-time** employees, or on a voluntary, usually part-time, basis.
- **Occasional** – involvement does not occur at fixed or prearranged times.

The types of reward or **remuneration** that PLHA receive in exchange for their involvement in the activities of an organization can be:

- **Financial** – salary, fees or allowances, reimbursement of transport expenses.
- **Material** – food, medicines.
- **Technical** – training in life skills or income generation, for example.
- **Psychological** – counseling, support.

The amount of time spent and the skills used by PLHA, and the way this is rewarded by the organization, also determine whether the exchange is:

- **Formal** – **regular** involvement, for which PLHA usually receive **financial or material remuneration**.
- **Informal** – **regular** or **occasional** involvement, for which PLHA receive **little or no financial or material remuneration**.

Formal versus informal involvement is closely linked to the concepts of “professional” versus “voluntary” involvement. While it is usually assumed that voluntary involvement is unpaid, the study found that the meaning of “voluntary” varied considerably between different organizations and countries, and this is discussed in more detail later in this chapter.

Knowledge and skills

PLHA involved in NGOs and CBOs may use different sorts of **skills** or **knowledge**, which can be categorized as follows:

- Experience of living with HIV/AIDS (for example, coping skills).
- Knowledge of basic facts on HIV/AIDS (for example, methods of HIV transmission).
- Technical skills related to the delivery of HIV/AIDS services (for example, counseling skills).
- Other technical or professional skills.
- Organizational skills (for example, management).
- Knowledge of the organization with which they are involved.

The first category is mainly empirical knowledge, since it derives from personal experience, while the other forms of knowledge can be learned from theory, observation and practice.

The study also considered **skills or knowledge provided to PLHA by the organizations** in order for them to be involved, as a criteria to distinguish types of involvement. Knowledge provided to PLHA can be categorized as follows:

- Information on HIV/AIDS (for example, epidemiology).
- Information on life with HIV/AIDS (for example, nutrition).
- Delivery of HIV/AIDS services (for example, provision of home-based care).
- Vocational (for example, income generation).
- Organizational development (for example, documentation, communication, advocacy skills).
- Information on the structure and functioning of the organization with which they are involved.

Knowledge can be transferred:

- **Formally** – planned and structured orientation and training activities, such as workshops, courses, seminars and on-the-job training within or outside the organization.
- **Informally** – not planned or structured, and usually results from interpersonal communication before, during and after activities.

Scope and autonomy in decision-making

The study identified the following categories of PLHA scope and autonomy in decision-making:

- **Direct** involvement in decision-making.
- **Indirect** involvement in decision-making (for example, consultation by the organization).
- Decisions **limited to activities in which they take part**.
- Decisions on **organization-wide activities, including activities they do not take part in**.

A document produced for the Pan London HIV/AIDS Providers Consortium provides an interesting framework to analyze the areas that may be affected by decisions of PLHA:²²

- ⇒ **Therapeutic** – the involvement of individuals in planning their own care.
- ⇒ **Operational** – the involvement of service users or PLHA in planning the day-to-day activities of their organization.
- ⇒ **Strategic** – the involvement of service users or PLHA in planning the future direction and development of their organization.
- ⇒ **Governance** – the involvement of service users or PLHA in management of their organization.

The study also explored whether PLHA had **taken the initiative** to become involved in activities or whether PLHA had been **requested** to take part in the activities by the organizations.

Visible or non-visible involvement

PLHA involvement in NGOs and CBOs can be visible or non-visible.²³ It is important to be aware that the person may be visible because he or she has intentionally disclosed his or her status or because others have disclosed it, with or without his or her consent.

A PLHA is visible when he or she is open about his or her HIV status at any of the following levels:

- At home, with the family.
- In the community, with friends or other community members.
- At the workplace, with work colleagues.
- In the NGO or CBO where he or she is involved:
 - with staff and volunteers who are carers, if the PLHA is a beneficiary;
 - with staff and volunteers who are colleagues, if the PLHA is a service provider;
 - with service users of the organization, if the PLHA is either a service user or a service provider.
- In other NGOs and CBOs, including support groups of PLHA.
- In the media, at national and/or international levels.
- In other forums, such as AIDS workshops or conferences, at national and/or international levels.

The study focused in particular on the level of visibility of PLHA within the NGO or CBO with which they were involved (**internal visibility**) versus the level of visibility of PLHA outside the NGO or CBO (**external visibility**).

²² Bell, Michael (1997) *Principles, Policy and Practice: Guidelines For Service User/People With HIV/AIDS Involvement in AIDS Service Organisations*, London: Michael Bell Associates & Pan London HIV/AIDS Providers Consortium.

²³ A definition of visibility is also included in the general terminology.

As discussed in Chapter 2 in the section on ethics of research:

- **Respondents selected as PLHA** All the respondents the researchers interviewed as PLHA, whether they were NGO service providers or users, were aware that they were HIV positive. These respondents were recruited by the participating NGOs, or in some cases health professionals outside the NGOs, and they had agreed to disclose their HIV status to the research team.
- **Other respondents** In a few cases, people disclosed that they were HIV positive during an interview with a researcher, although other people in their organization did not know their HIV status. On some occasions, the researchers came to know the seropositivity of people involved in the NGOs even though they had chosen not to disclose within or outside the organization. This information was not included in the analysis in order to maintain confidentiality.

This report describes only the levels of visibility that the researchers were able to observe within the ethical framework of the study, and therefore excludes PLHA who do not know their HIV status and PLHA who chose not to disclose their status.

4.4 The four types of involvement of PLHA

The study identified four types of involvement – *access*, *inclusion*, *participation* and *greater involvement* (see Terminology).

The term “type” is used to describe involvement, in preference to “level”, because it is more neutral, whereas describing involvement as high level or a low level implies that some levels are better than others. The term “*greater involvement*” was selected to refer to the situation where PLHA take part in all the areas of activity of an NGO, because this is what is implied by GIPA.

The definition and characteristics of each type of involvement follows Table 4.6.

Table 4.6 General typology of PLHA involvement

Types of PLHA involvement	Areas of involvement for PLHA				
	PLHA use the services of the NGO	PLHA support activities and services of the organization	PLHA deliver HIV/AIDS services	PLHA plan and design services	PLHA manage the organization, run or influence the policymaking and strategic planning process
Access	Yes	No	No	No	No
Inclusion	Yes	Yes, for non- HIV-related tasks	Yes, informally; e.g. as occasional volunteers	No	No
Participation	Yes	Yes	Yes, formally; e.g. as part-time or full-time service providers (staff or regular volunteers)	Yes, they usually plan the services they deliver, and may also be consulted on other services	No
Greater involvement	Yes	Yes	Yes, formally; e.g. as part-time or full-time service providers (staff or regular volunteers)	Yes, they plan the services they deliver. They may also contribute directly to planning of other services	Yes; e.g. as program or project coordinators, directors, trustees

4.4.1 Definition of *Access*

Table 4.7 Definition of Access: Areas of involvement of PLHA

Definition of Access: Areas of involvement of PLHA	
PLHA utilize services of the NGO	Yes
PLHA support activities and services	No
PLHA take part in the delivery of services	No
PLHA take part in the planning and design of programs	No
PLHA take part in management, policymaking and strategic planning	No

Access describes the situation where PLHA take part in NGO activities as beneficiaries of services or service users. They may be clients of counseling services, patients receiving medical care or participants in training courses.

In some NGOs and CBOs, especially where most service providers are trained health professionals or social workers, being service users is the only way for PLHA to be involved in the services of the organization. In these NGOs and CBOs, the only organizational type of involvement is therefore *access*. In this case, HIV-positive service users are not involved in the decision-making process, although they might be consulted on decisions regarding their own care (“therapeutic” level).

In other organizations, while some PLHA access services as beneficiaries, others also take part in the delivery of services and in other activities (see *inclusion*, *participation* and *greater involvement*). Therefore, while some PLHA are only *accessing* services, other types of involvement co-exist in the NGO. When NGOs or CBOs provide services aimed at empowering PLHA, such as counseling and training, *access* can be a starting point for further involvement.

4.4.2 Definition of *Inclusion*

Table 4.8 Definition of Inclusion: Areas of involvement of PLHA

Inclusion: Areas of involvement of PLHA	
PLHA utilize services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Informally Occasionally
PLHA take part in the planning and design of programs	No
PLHA take part in management, policymaking and strategic planning	No

Inclusion describes the situation where PLHA are not only beneficiaries but are also involved in the implementation of the activities of an organization in a supporting role, either as support staff or “aides” in the delivery of services – or both.

PLHA may be employed by an NGO as support staff in tasks that are not related to HIV/AIDS; for example, maintenance, administration, cooking and gardening. “Aides” are PLHA who are usually service users taking part on a voluntary and occasional basis in outreach activities at the request of the organization. They assist service providers by talking about their own experience and give a

“human face” to HIV/AIDS. PLHA are not considered formal service providers and do not receive any remuneration for their contribution. PLHA employed as support staff may also share informally their personal experience of living with HIV with other positive people who are beneficiaries of the organization they work for.

Given their limited involvement in service delivery, PLHA do not play a part in the design and planning of services, except when consulted on decisions regarding their own care (“therapeutic” level).

4.4.3 Definition of *Participation*

Table 4.9 Definition of *Participation*: Areas of involvement of PLHA

Definition of <i>Participation</i>: Areas of involvement of PLHA	
PLHA utilize services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Formally Regularly
PLHA take part in the planning and design of programs	Yes
PLHA take part in management, policymaking and strategic planning	No

Participation describes the situation where PLHA actively implement HIV/AIDS-related programs as regular service providers, usually employees or regular volunteers, of an NGO. They usually receive financial compensation for their work, since their expertise is officially recognized by the NGO. PLHA may or may not be former or current service users of the NGO.

They may be involved directly in the planning of services, especially the day-to-day implementation of activities (“operational” level), but only of the services they deliver and usually in cooperation with a supervisor. The NGO may also consult these PLHA about other services, but final decisions lie with program and NGO management.

4.4.4 Definition of *greater involvement*

Table 4.10 Definition of *Greater involvement*: Areas of involvement of PLHA

Definition of <i>greater involvement</i>: Areas of involvement of PLHA	
PLHA utilize services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Formally Regularly
PLHA take part in the planning and design of programs	Yes
PLHA take part in management, policymaking and strategic planning	Yes

Greater involvement describes the situation where PLHA take part in areas including management, policymaking and strategic planning. PLHA make decisions that affect organizational, strategic and programmatic issues (“strategic” and “governance” levels) as trustees or directors, or as program

coordinators or managers, and may represent the NGO in external forums. PLHA may also be former or current service users of the organization, or not.

Greater involvement may also refer to self-help groups, where PLHA decisions affect “therapeutic”, “operational”, “strategic” and “governance” levels.

4.5 Involvement as an individual and organizational process

The typology of involvement applies to both individuals and NGOs. Where involvement refers to the way(s) a PLHA takes part in the activities of an organization, it describes an individual process. At the individual level, a PLHA can be both a beneficiary and a service provider in the same organization. There can also be many individual types of involvement as PLHA within an NGO. For example, a PLHA can be a trustee of an organization (*greater involvement*), while another PLHA works as a counselor in the same organization (*participation*) and many other HIV-positive people come to this organization to see this counselor as clients (*access*).

The typology can also refer to how PLHA take part generally in the activities of an NGO and how the organization involves PLHA (its philosophy, policies and practices); and it then describes an organizational process. Although several types of involvement can co-exist in the same organization, one or two types may be predominant. When an NGO provides services to PLHA but, for example, does not seek to involve beneficiaries in its activities, its approach to involvement can be characterized as *access*. Another NGO might have some PLHA who are only beneficiaries and some service providers who are HIV positive, and its approach to involvement can be characterized as *participation*.

The following sections describe in more detail the roles of PLHA in NGO services and activities or “internal involvement”.

4.6 Access to services: A first step towards involvement?

In the four countries where the study was conducted, the majority of PLHA only take part in the activities and services of NGOs and CBOs as beneficiaries. While *access* was not the only type of PLHA involvement observed in most participating organizations, using services is the only way that most PLHA take part.

Access is often the predominant type of involvement in secular or religious welfare organizations, which are run by health and social work professionals. In terms of an exchange between the organization and PLHA, the major characteristic of this model is that PLHA are passive recipients of services.

However, some organizations, particularly rights-based and development NGOs, use their services to empower PLHA and to encourage them to take care of themselves, their families and communities. *Access* to services may therefore be the first step toward further involvement of PLHA, and this section describes some of the NGO services that are intended to empower PLHA.

Positive Living Courses

Two organizations in Zambia offer specific courses for PLHA that aim to help PLHA to live positively. Hope conducts Positive Living Advocacy Courses and Kara provides a Life Skills Training program. For Hope and Kara, positive living is about PLHA coming to terms with their HIV status and psychological well-being, knowing how to take care of their health and nutrition, and developing the skills to support themselves economically. These courses also aim to encourage PLHA to be open about their status in order to give HIV/AIDS a human face and to educate and mobilize the community.

The components of the positive living advocacy course include fitness, health and hygiene, nutrition and cooking, behavioral change, gardening, entrepreneurial skills and advocacy for positive living. The components of the Life Skills Training program include vocational training and development of skills for outreach work; for example, in communication and peer counseling.

This type of training provides PLHA with the opportunity to reflect on their HIV status and can also empower positive people, providing them with the information and skills to gain control and make decisions about their lives. Analysis of the impact of these courses on the participants (see Chapter 5) and of how they have enabled some of the participants to become involved in different ways in the activities of Hope, Kara and other organizations (Chapter 6) demonstrates that this kind of training can transform HIV-positive service users into service providers and advocates. For example, Hope calls the graduates of its courses “Positive Living Advocates”.

Support group meetings

Several of the organizations that participated in the study had encouraged their HIV-positive beneficiaries to meet in order to share their problems and experiences and provide each other with mutual support. These initiatives have led to support group meetings and, in some cases, to the formation of PLHA support groups.

Sometimes NGOs encourage the formation of self-help groups of PLHA and affected people that are more or less autonomous (see section 4.11).

However, in most cases, PLHA who use the services of an NGO – for example, as clients of counseling services or patients of care services – are invited to attend meetings organized by the service providers of the NGO. These meetings take place on a more or less regular basis on the premises of the NGO and are usually facilitated by health or social workers, or, in some cases, a PLHA who has some experience with the NGO. This section focuses on this type of support group.

In the four countries, the study observed that most of the groups are mixed (male and female). The support group meetings held at the Byculla center of the Salvation Army in Mumbai are open to both women and men, but most participants are men as only a small percentage of service users of the center are female. Some NGOs have set up groups for PLHA based on gender, sexual orientation or different needs. In Maharashtra, MNP+ created support group meetings called “forums”. At the time of data collection, there was a forum for women and a forum for MSM, although the latter was not active (see Chapter 6). Also in Maharashtra, CCDT initially established a support group for female PLHA clients, but it soon became clear that sex workers and other positive women had different experiences and needs, and the support group was split into two

separate groups. Subsequently, CCDT assisted with the formation of two additional support groups for affected people. In Burkina Faso, where participating NGOs had just started, or were about to start, support groups when the study was conducted, only REVS+ was planning to have a support group for women only.

In most of the groups, facilitators and participants know each other's HIV status. For example, AAS, ALAVI and REVS+ in Burkina Faso are taking an "inside visibility" approach, where most facilitators and all participants are PLHA, and all members are aware of their own serostatus and that of other group members. In contrast, La Bergerie has taken a different approach, where only the facilitators, who are HIV positive themselves, know that the participants are PLHA, but participants do not know the HIV status of the other participants and of the facilitators. This approach is intended to progressively bring about visibility within the group in a context where few PLHA know their HIV status and where it is difficult for those who do to discuss it openly. In India, MNP+ also organizes monthly support group meetings in parallel to the forums. These were originally only for HIV-positive people, but after some time MNP+ decided to open the meetings to other people, such as social workers or relatives and friends of PLHA, so that HIV-positive participants did not feel that they were identified as PLHA.

These examples show that support groups use different strategies in terms of visibility, but in general they are perceived as a way of enabling PLHA to become visible, providing a "safe space" in contexts where there is a significant level of fear about stigma and discrimination. The rationale for this is that PLHA may feel more at ease inside a group of peers, where people tend not to judge each other, and that they need to feel comfortable with their status in such an environment before they can feel at ease outside the group, both within the NGO and in wider society.

What happens during the meetings also varies considerably. In Maharashtra, MNP+ and the Salvation Army usually invite resource persons to discuss topics of interest to the participants. At CCDT in Maharashtra, and in NGOs in Burkina Faso, group members tend to talk about their lives. Members of the support group at La Bergerie also pray together, as the NGO is a church-based organization. Sometimes members are involved in recreational activities.

Support groups are usually "open", which means that new members or participants can join at any time. In most cases, PLHA belong to a support group only by attending the meetings and there are no other membership requirements.

For most PLHA, support group meetings are a service offered by an NGO that provides information and psychological support, and PLHA do not facilitate the meetings or make decisions about the agenda or how the group functions. Nevertheless, support group meetings, like positive living courses, can be empowering for PLHA, building their self-esteem and preparing them to be open about their HIV status.

Counseling

Counseling can help PLHA to accept their HIV status and to prepare for the possible repercussions of visibility. Counselors at Kara in Zambia perceived that individual and group counseling helped PLHA to be visible and to take part in the effort to fight the epidemic. Some health professionals in Ecuador explained that it was a necessary first step before involvement. PLHA at Hope in Zambia mentioned good counseling as one of the reasons for becoming involved in activities. Counselors

are also in a good position to refer PLHA to other activities as well as to courses and training programs where they can develop skills and the capacity for becoming more involved.

When they are in a terrible depression ... that nobody should know [that they are HIV positive]...when they are feeling awful, we give them the opportunity to open up, maintaining strict confidentiality. When they have taken in and got over their problem, we suggest other organizations where they can help more, where they are able to work in preventing other people contracting HIV or help other positive people.

(Service provider, Fundación Esperanza)

During the counseling ... they discover their personal value in society and the community where they come from. The things they learn during counseling, education they acquire and their own life experience tend to make them come out in the open to help the community.

(Service provider, Kara, Lusaka & Choma, Zambia)

4.7 Supporting the activities of NGOs: *Inclusion* of PLHA

In some participating organizations, some PLHA were not only beneficiaries of services but were also involved in non-HIV/AIDS-related activities, usually as support staff. For example, Hope in Zambia employs as a full-time gardener an HIV-positive man, who was recruited after completing the Positive Living Advocacy Course (PLAC) and is visible within and outside the organization. Another PLAC graduate now works as a volunteer housekeeper. In India, CCDT employs two HIV-positive women as helpers and attendants; one at a drop-in center for PLHA and one at the temporary shelter for the children of PLHA. The Salvation Army also employs one PLHA in a support staff position. *Inclusion* in this way is usually characterized by low-qualified and low-paid jobs.

In some cases – for example, in Ecuador – NGOs ask their beneficiaries to help with relatively simple administrative tasks such as sticking stamps on envelopes. Other NGOs see *inclusion* as a kind of occupational therapy for beneficiaries.

The single and deserted mothers at the shelter need to be occupied ... otherwise they will sleep all day or fight.

(Service provider, SOFOSH, Mumbai, Maharashtra, India)

However, PLHA employed as support staff in activities which have little to do with HIV/AIDS may also have the opportunity to use their experience of living with HIV in other activities directly related to HIV/AIDS, as the following section illustrates.

4.8 From service users to service providers: *Inclusion* and *participation* of PLHA in the delivery of services

In some of the participating organizations, PLHA are involved in the delivery of HIV/AIDS services. Involvement can be informal, irregular and unpaid, and in response to requests from the

NGO. With this type of involvement – *inclusion* – PLHA act as “aides” to other service providers, especially health and social workers. Alternatively, involvement can be regular and formalized, and is usually remunerated in some way. With this type of involvement – *participation* – PLHA make decisions about the services they deliver. This section includes examples of both the *inclusion* and *participation* of PLHA in the delivery of a range of services provided by the NGOs that took part in the study.

4.8.1 Involvement of PLHA in peer psychological and social support: Helping each other

The main purpose of peer support is for PLHA to help each other to come to terms with their HIV status and to live positively. The study found that PLHA provide psychological and social support to other PLHA, as well as to affected people, in a range of different ways, including through individual peer counseling, regular support group meetings and home and hospital visits.

Individual peer counseling

PLHA are formally involved in only a few organizations as individual counselors, including face-to-face pre and post-test counseling and telephone counseling. In these NGOs, HIV-positive counselors are staff or receive some remuneration for the services they deliver (*participation*). All the other organizations employ ‘professional’ counselors to conduct pre-test and post-test counselling, rather than explicitly recruiting or training PLHA to be counselors. Some of these organizations claim that their HIV-positive staff or volunteers conduct counseling, but what they do is better defined as informal peer support. For example, one of the HIV-positive support staff of the Salvation Army in Mumbai sometimes sits down with HIV-positive clients who come to the Byculla center and provides them with support while they are waiting to see the doctor or one of the counselors. Participants in the support groups of the same organization sometimes share their experience with beneficiaries when they happen to be at the center. However they are not requested to do this and are not paid for this activity (*inclusion*).

Respondents in all four countries perceive that counseling by PLHA who are open about their status has benefits for those being counseled (see Chapter 5). HIV-positive counselors explain that they emphasize with their clients that a positive test result is not a death sentence, and use their own experience to demonstrate that it is possible to live positively with the virus.

When I give my example ... I can tell what is happening in my life. So I tell to each one in counseling ... they are very happy after that and it is a great feeling in the sense of responsibility.

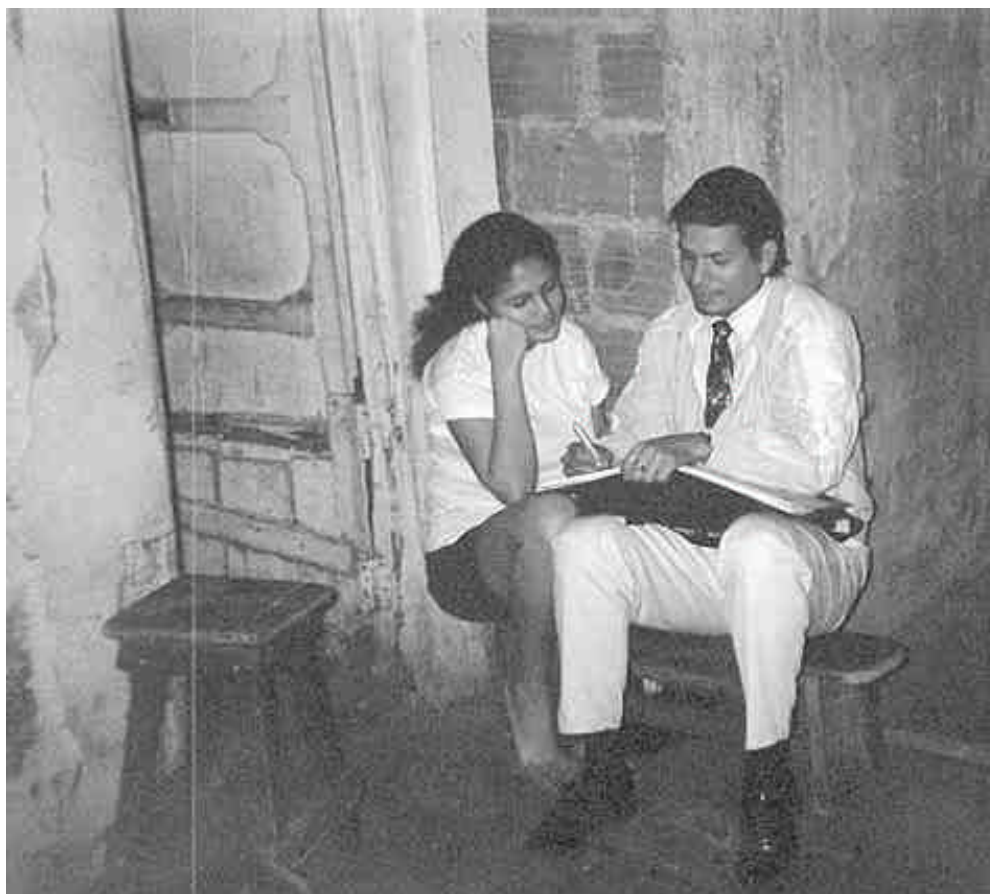
(PLHA service provider, MNP+, Mumbai, Maharashtra, India)

HIV-positive counselors from Siempre Vida in Ecuador stress that they try not to take a technical approach, although they do also give “technical” information about transmission, prevention and treatments.

Sometimes the only thing that the doctors do is to prescribe the drugs ... For example, they prescribe antiretrovirals but they don't explain that you have to drink a lot of water because of the side-effects of some drugs ... so they [PLHA]

come here and tell us: “That’s the medication they gave me. What am I supposed to do? How do I have to take the drugs? What is the -dosage? All these questions.

(HIV-positive counsellor, Siempre Vida)



A member of Siempre Vida providing peer support, Guayaquil, Ecuador

The study also found that HIV-positive counselors use different strategies to disclose their HIV status to their clients. Some do it immediately during post-test counseling when the result is positive; others prefer to wait and share the news when they feel that the need arises – for example, if a client is depressed.

While some PLHA counselors disclose their HIV-positive status to clients, others do not. In Burkina Faso, for example, the majority of seropositive voluntary counselors do not reveal their status to those they support. Where a counselor does not disclose, it is probably not accurate to describe this as peer counseling. However, in some cases in Burkina Faso, voluntary counselors reported that they say they are HIV positive even when they do not know their status, to reassure the client. This may also be a strategy used by volunteer counselors to progressively accept and reveal their own suspected status.

Support group meetings

As discussed earlier in the chapter, PLHA may attend support group meetings where they receive information, sometimes ask questions, and share their experiences (*access*). Even at MNP+, monthly support group meetings are mostly facilitated by resource persons from outside the NGO, such as medical doctors, lawyers and social workers, although an HIV-positive staff member was the main facilitator of one of the support groups.

However, PLHA involvement in support groups can also take the form of *inclusion* and *participation*, where PLHA act as facilitators and coordinators of the meetings and participants get involved in other care and support activities. At CCDT in India, for example, social workers initially designed and facilitated the support groups, but now participants take responsibility for deciding on their own agendas and facilitating the meetings. This process has empowered support group members, some of whom have become involved as volunteers, who visit group members who are too sick to attend meetings. In this NGO, support groups have encouraged a change in the type of PLHA involvement from *access* to *inclusion*.

A similar process occurred at the Salvation Army in Mumbai. Support group meetings were originally facilitated by social or health workers based at the Byculla center, but they identified one of the participants and asked him to facilitate the meetings. Later on he was hired by the NGO and became coordinator of the activity as well as a counselor (*participation*). Other participants in the meetings have progressively started to help at the Byculla center, orienting PLHA who come for the first time and assisting the coordinator of the meetings when he goes to the hospital to visit patients (*inclusion*).

NGOs like CCDT and the Salvation Army in India would like to transform support group meetings into self-help groups (see section 4.11).

We also identify leaders, then get them involved in the planning of support-group meetings ... leaders can then take these groups into a self-help group.
(Service provider, CCDT, Mumbai, Maharashtra, India)

Home and hospital visit

The role of PLHA who work as counselors is usually not limited to counseling on the premises of their organization. They also carry out home and hospital visits, sometimes to follow up counseling sessions. In Ecuador and India, HIV-positive service providers take PLHA beneficiaries to hospital, where they mediate with health professionals and facilitate access to care. Some also refer HIV-positive service users to social services and facilitate administrative paperwork.

They know me at the hospital and the doors are always open for me. I get there and make sure they attend my patients.
(HIV-positive counselor, Siempre Vida, Guayaquil, Ecuador)

At Dios, Vida y Esperanza in Ecuador, eight teams of volunteers are involved in home visits. Each team is made up of two service providers, one HIV positive and one HIV negative. Although they are not paid for the work they carry out with the NGO, they are highly committed to this activity

and visit beneficiaries weekly or every fortnight. In Zambia, CHEP community-based volunteers, most of whom are PLHA, are also involved on a regular basis in support activities, including home and hospital visits (*participation*). Some Salvation Army PLHA beneficiaries in India also occasionally carry out home, hospital and hospice visits on a voluntary basis. This is often as part of a team that includes service providers, and not all PLHA disclose their HIV status during the visits (*inclusion*).

“Informal” peer support

In all four countries, the study observed that most peer support cannot be described as a “service” that is delivered formally or informally by PLHA to other HIV-positive people. Peer support is characterized by informality. For example, HIV-positive service providers within the same organization may support each other during the day or after work hours, as many of them are friends. PLHA may also provide each other with support and share experience outside work, support-group or home-visit settings.

4.8.2 Involvement of PLHA in the provision of care

Visible PLHA involvement in provision of care was very limited in all four countries. Factors that may limit involvement include:

- Provision of care requires theoretical knowledge and technical skills that most PLHA do not have.
- PLHA who do have the knowledge and skills – for example, medical doctors, nurses, other health workers and social workers – are not willing to disclose their HIV status because of the potentially adverse impact on their social position.

There were no openly positive medical doctors involved in any of the NGOs that participated in the study. Although there were several HIV-positive health workers, notably nurses, in three NGOs in Burkina Faso, their visibility was relatively limited. Even though they used their professional skills during care and support activities, they usually did not disclose their HIV status to the patients they cared for. It is also interesting to note that many health workers in Burkina Faso, Ecuador and India had not taken an HIV test because they thought they were not at risk.

Home-based nursing care

Although PLHA are involved in home visits, they mostly provide psychological, practical and spiritual support, and very few were observed to be involved in home nursing care.

Information on treatments and nutrition

The study observed only limited PLHA involvement in disseminating information about treatments – with the exception of PLHA staff at MNP+ in India and Siempre Vida in Ecuador– since few PLHA receive the training to provide them with the up-to-date technical knowledge this requires.

Only PLHA who *participate* in organizations as staff or regular volunteers provide this kind of information because of the experience required.

HIV-positive service providers from Siempre Vida give a lot of information that doctors do not. For example, this may be about treatments such as side-effects of drugs for opportunistic infections and antiretrovirals, about cheaper generic drugs when doctors prescribe branded medicines, and about what kind of tests PLHA are supposed to take on a regular basis and where to have these tests done. Most of these service providers are themselves on combination therapy and therefore have experience of taking antiretrovirals. In India, service providers of MNP+ access up-to-date information on treatments through websites produced in the United States or the United Kingdom.

In several organizations, PLHA provide information to other PLHA about nutrition, but not in a formal or systematic way. Exceptions to this are PLHA graduates of the Hope PLAC in Zambia, which includes extensive nutrition information, who contribute to the same training course for other PLHA.

4.8.3 Involvement of PLHA in awareness-raising: Voices and faces of the epidemic

As explained in Chapter 3, in these four countries, most PLHA are ‘invisible’, except when they are sick, because of stigma and discrimination. There is also a widespread assumption that people do not want to talk about HIV/AIDS or will deny its existence in their community because PLHA are not visible.

Many of the participating NGOs and CBOs are trying to raise community awareness of HIV/AIDS and to encourage people to talk about it and other issues, which are closely linked to the epidemic but are often culturally taboo, such as sexual behavior, sex between men, prostitution and use of drugs. Visible involvement of PLHA in awareness-raising and outreach education is one of the strategies used to increase community awareness and prompt discussion. The study observed various examples of this involvement and explored questions including: what do PLHA talk about when they raise the awareness in the community? Who do they talk to? Do they carry out activities as PLHA or not? What kind of skills and knowledge do they employ? What media do they use?

The study observed that in Zambia the most common area of activity in which PLHA are involved is outreach education in schools, workplaces and the community. Relatively few PLHA in the participating NGOs in Zambia are involved in the delivery of other types of services.

In contrast, in Burkina Faso, Ecuador and India, PLHA involvement in awareness-raising activities was limited. For example, in Burkina Faso, only three of the five participating NGOs are involved in public awareness-raising on a regular basis, and only three PLHA, all members of REVS+, give testimony as part of these awareness-raising activities. In Ecuador, at the time of data collection, there were only a few PLHA involved in awareness-raising, mostly in Guayaquil. In India, some MNP+ beneficiaries are involved in awareness-raising activities on a voluntary, irregular basis. One CCDT beneficiary provides health information and condoms to sex workers, for which she receives an honorarium. At the Salvation Army, the only PLHA who is visible outside the organization is a part-time employee who coordinates support-group meetings. Like other staff, he carries out awareness-raising activities and outreach education.

Individual voices: The living examples

In many NGOs, PLHA involved in awareness-raising do so by giving public testimonies. They mostly talk about their own story, using their personal experience of living with HIV/AIDS. Based on this experience, they may describe some of the problems they have faced since they became infected with HIV and also promote solutions, such as positive living, as well as HIV testing. The main objective of these testimonies is to provide a “human face” to the epidemic, to show that HIV/AIDS is real, explain the risks and give messages of hope. However, the study observed that in Ecuador and India, PLHA involved in this kind of testimony do not provide technical information; for example, about treatments. This is usually done by other service providers, mainly health and social workers. In most NGOs, there is a clear division of tasks between PLHA who tell their story and other service providers, who offer information about epidemiology, transmission routes, prevention, opportunistic infections and care available.

In this *inclusive model* of involvement in awareness-raising, PLHA tend to be volunteers who are involved on an informal, occasional basis when requested to do so by an NGO. Activities in which they are involved are designed and planned by other service providers, and PLHA are told when and where to go. They are less likely to receive formal training to support this work. Their visibility is selective and may be limited to small audiences. In this model, they may also be support staff. In Zambia, for example, two HIV-positive support staff at Hope share their own experience of living with HIV/AIDS with participants in the PLAC.

Collective voices: The ‘experts’

In other circumstances, the study observed that PLHA involved in awareness-raising use their personal experience of living with HIV/AIDS and the experience of other PLHA, as well as theoretical knowledge of HIV/AIDS gained through training.

In these cases, PLHA are involved on a more formal basis (*participation*), and they may be paid for their contribution – as in Zambia, where full-time or part-time HIV-positive outreach educators are employed by CHEP, Hope and Kara Counselling. These PLHA have usually been trained to carry out awareness-raising. In Zambia, for example, all of the PLHA employed as outreach educators by Hope and Kara have participated in the positive living or life skills training courses. Outreach educators at Kara have also received additional training to develop their communication skills, and those at CHEP are provided with information about HIV/AIDS and training in counseling. Since their expertise on HIV/AIDS is quite extensive, they also have more control over the contents and methodology of the outreach education they conduct. In Zambia, there were PLHA in charge of coordinating outreach activities in two organizations. In many cases, PLHA facilitate meetings without the presence of other service providers, as they are able to answer questions on a wide range of issues, including technical aspects of HIV/AIDS. Also in Zambia, the level of expertise of some HIV-positive outreach educators was high enough for them to train other PLHA.

The level of visibility of these PLHA is usually higher than that of PLHA who only give personal testimonies. However, the study found various strategies in terms of visibility. Volunteers of REVS+ conduct awareness-raising as a team. They tell their audience that some of them are HIV positive and others are not. This usually has a strong impact on the public, as they realize that it is impossible to guess who is HIV positive just from appearances. It is also a way to protect to some extent the confidentiality of those who are HIV positive. The volunteers and staff of Siempre Vida

in Ecuador use a different strategy, although they go to meetings – for example, in schools – as a team. Some of the volunteers sit down and socialize with the audience. Other volunteers provide information and answer questions. At the end of the meeting they ask, “Who is HIV positive in this room?” The volunteers who were in the audience stand up and tell the truth. This approach has proved to be a useful way to demonstrate to members of the community that in everyday life they might be in contact with PLHA, talk to them, find them nice or even attractive, and cannot tell whether somebody is HIV positive or not.

We have two strategies ... in our organization ... One method is that sometimes when all the team goes to facilitate a workshop ... there are a man and a woman from the team who join the audience ... I mean, they are not with the facilitators, they are with the public who attends the workshop ... The woman starts to flirt with men and the man starts to flirt with women. When we finish the talk, we ask from the stage whether anyone knows by chance if there is somebody who is HIV positive in the room. They are all stunned: “No, nobody looks HIV positive here; we can’t see anybody who is skinny, or who looks like he is dying, short of breath”... So we tell them: “In reality there are two people who are HIV positive and you have been sharing with them”. So they stand up and the impact is like, “My God, but I was talking to her, I even wanted to sleep with her”. That’s how they see the reality, about AIDS ... Also PLHA give a talk, they discuss what HIV is, they give testimonies, their experiences and sometimes people can’t believe it: “How can they be there talking?” ... It has a very strong impact.

(HIV-positive service provider, Siempre Vida)

Few of the PLHA who participated in the study have gone public in the media, in particular on television, because of the fear of stigma and discrimination. In Maharashtra, only one PLHA had given testimony on television and in newspapers, but he does not allow his face to be seen. However, some visible PLHA in Burkina Faso and Zambia have become well-known, popular figures. Some PLHA in India and Burkina Faso have a high profile at the international level – for example, in conferences – but are not open about their HIV status in their own community.

4.9 From *participation* to *greater involvement* of PLHA: Shaping programs and policies

4.9.1 Involvement in the design and planning of programs

As described earlier, PLHA may be directly or indirectly involved in the design and planning of services that they deliver, or of other services delivered by the organization with which they are involved.

The study found that in several NGOs, the only way many PLHA influence the programs in which they are involved, as service users or service providers, is indirectly through consultation. For example, support group members at the Salvation Army and CCDT in India are consulted about topics for discussion at meetings and about frequency of meetings.

In some organizations, PLHA are also consulted about other services, but their opinions and decisions affect only the “therapeutic” level and involvement is limited to “planning their own care”. This applies to the *inclusive model* of involvement, and sometimes *access*, when the opinion of service users is taken into account by an NGO. For example, Salvation Army support-group participants in India requested, and now can obtain, homeopathic treatment at the Byculla center.

Yes, they come forward to put their views. For example, before doing our strategies, we have this support group. So we put forth to them what actually we want to do, what we are trying to do, and take their ideas and what their expectations are from us; what they want to see should happen, what they would like to see which will help people living with HIV/AIDS. I mean, we take those suggestions into consideration when we design our programs.
(Service provider, Salvation Army, Mumbai, Maharashtra, India)

At the “operational” level, the study observed that PLHA who plan day-to-day services are more likely to be those who are employed by the organization, as in Zambia and India, or are regular volunteers, as in Burkina Faso and Ecuador (*participation*). At Hope, for example, the Positive Living Advocate prepares her own schedule, raises funds and is responsible for managing her own budget. These PLHA have usually received more training and are more experienced and autonomous than PLHA whose involvement is *inclusive*. However, with exception of rights-based organizations, including those founded and run by PLHA, the direct involvement of most HIV-positive service providers in the design and planning of programs is limited to the services they deliver.

Involvement of HIV-positive service providers in the design and planning of other services generally only applies in NGOs where there is *greater involvement* and where other PLHA manage a program or the organization itself. In India, for example, MNP+ HIV-positive staff are involved in the planning and design of all activities, together with the HIV-positive trustees of the organization. In Zambia, the coordinator of the PLHA program at CHEP and his assistant, who are both HIV positive, are invited to inform the design and planning of other CHEP services, in addition to the ones they deliver themselves or supervise.

4.9.2 PLHA managing organizations

With few exceptions, visible PLHA are not involved in NGO management, policymaking and strategic planning (“strategic” and “governance” levels of decision-making). This type of involvement is most likely to be observed in rights-based organizations, mostly groups or networks of PLHA, and to a lesser extent in NGOs with a focus on empowerment and development of their beneficiaries.

Greater involvement manifests itself in two ways: when PLHA are employed by organizations and hold management positions, or when they are volunteers and belong to strategic decision-making bodies, such as boards of trustees. As noted above, the coordinator of the PLHA program at CHEP is HIV positive, and he is involved in the organization’s annual strategic planning review. At Kara, the coordinator of the outreach program is HIV positive, and he is involved in the organization’s strategic planning. Kara is also planning to institute a board of directors, which will include a PLHA representative. At MNP+, all three trustees – responsible for management, policymaking and

strategic planning – are PLHA. MNP+ was established by PLHA and has also given preference to recruitment of HIV-positive staff. In Burkina Faso, the president of REVS+ is a woman living with HIV.

Other NGOs have taken steps to develop the skills of PLHA employees, to enable them to take on additional management responsibilities and to move from *participation* towards *greater involvement*. For example, Hope has enrolled the full-time Positive Living Advocate in a six-month management course (see Chapter 6).



The PLHA programme at CHEP: an opportunity for HIV positive staff to share experiences with colleagues

4.9.3 PLHA advocates: Social voices

As described earlier, PLHA can be individual and collective voices, telling their stories as living examples and speaking on behalf of other PLHA as experts. They are also powerful social voices when they advocate for the rights of HIV-positive people, and *greater involvement* in NGOs cannot be separated from *greater involvement* in policies at national and international level. PLHA who manage programs and organizations usually have a significant representative role outside the NGO with which they are involved, expressing the position of PLHA in general in various forums. In Zambia, HIV-positive coordinators at CHEP and Kara are or have been the chair of the national network of positive people. Trustees of MNP+ also have responsibilities in the national network of PLHA (INP+), as most active HIV-positive volunteers of Siempre Vida and Dios, Vida, Esperanza do in Ecuador. The first PLHA who came out on publicly on television in Burkina Faso was a member of the executive committee of REVS+.



Greater involvement at the community level may lead to further involvement. Many PLHA with responsibilities in NGOs become involved in regional and international PLHA networks, such as GNP+ and ICW. For example, the HIV-positive coordinator of the outreach education program at Kara was one of the two African GNP+ board members who attended the 1994 Paris AIDS Summit and worked toward the final Summit Declaration to promote GIPA.

A representative of REV+ speaks to a rally calling for better access to care for PLHA, Burkina Faso

4.10 Tokenism and exclusion

The study also identified two “types” of non-involvement: tokenism and exclusion.

Tokenistic involvement is where PLHA are assigned management positions because they are HIV positive but they do not have any access to the decision-making process. They may, for example, be appointed to the board of an organization but have no influence on policy, programming or financial issues. Tokenism also includes visibility; for example, where PLHA attend meetings and conferences but only give testimony and are not allowed to speak on behalf of the organization with which they are involved. Some forms of tokenism were observed in organizations in Burkina Faso and Ecuador.

Exclusion is where a person who identifies himself or herself as HIV positive, or is identified as HIV positive by an NGO, cannot access the services provided by the organization and cannot take part in the activities of the organization in any way. None of the participating organizations demonstrated *exclusion*, as all of them had been selected because they provide services to PLHA and involve HIV-positive service providers and decision-makers. However it was observed that many other NGOs and CBOs who carry out prevention activities do exclude PLHA, at least those who are visible, because they believe that people who are already infected do not need any form of prevention and because the potential contribution of PLHA to outreach education is ignored.

4.11 Promoting “external” involvement

This section focuses on “external involvement”, describing how some NGOs support the formation of self-help groups of PLHA by providing them with technical, and sometimes financial, assistance.

Most NGOs and CBOs have limited capacity to involve PLHA, either as paid staff or as volunteers. In Zambia and India, some of the NGOs that participated in the study have promoted the creation of self-help groups of PLHA and of affected people as a strategy for “external involvement”, with a particular focus on community mobilization.

In Zambia, for example, CHEP has supported the formation of support groups at community level, and in 2000 there were 12 groups with around 125 members, 60 per cent of whom were visible PLHA. Support group leaders or coordinators are mostly CHEP community-based volunteers. The groups have developed their own objectives, which include mutual support through meetings and home and hospital visits, income-generating activities and raising awareness in the community. Hope also perceives support groups as one way to reach out to more people in the community – most members are graduates of the PLAC – and these groups have similar objectives to those of CHEP. Using a different approach, Kara has supported post-test clubs in Lusaka.

In India, MNP+ has encouraged the establishment of self-help groups of PLHA and the Maharashtra Major Group, which is intended to provide a platform for PLHA in Maharashtra to have a collective voice and to create district-level PLHA networks.

This self-help group approach has been more successful in some cases than others. While intended to be independent, it is often difficult for such groups to remain active and sustainable without ongoing support from the NGO that helped to establish them. Most are what the study defines as “assisted self-help” groups, with an inherent contradiction between the intended nature of the groups and the actual links between them and the NGOs that support them. Factors that enhance or limit the success and sustainability of support and self-help groups are discussed in Chapter 6.

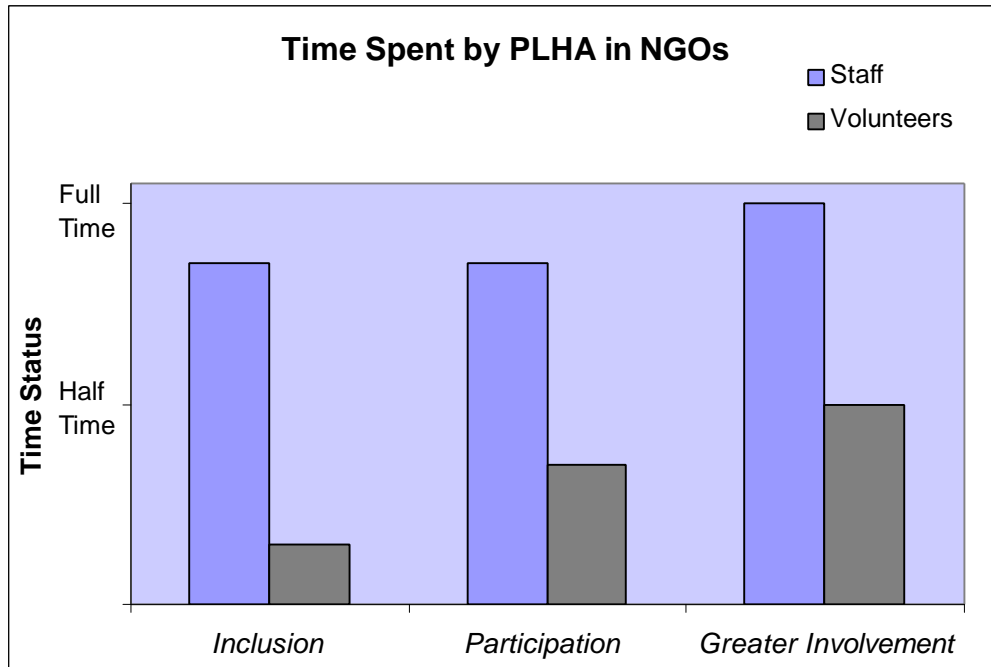
4.12 Conclusions: Many ways for PLHA to take part

The study shows there are many ways for PLHA to take part in the activities of NGOs and CBOs (internal involvement). The four types of involvement – *access*, *inclusion*, *participation* and *greater involvement* – embrace a wide range of roles. However, the most common types of involvement observed in the NGOs that participated in the study were *access* and *inclusion*. PLHA can also be involved in self-help groups supported by NGOs (external involvement). The main characteristics of the different types of involvement are summarized below.

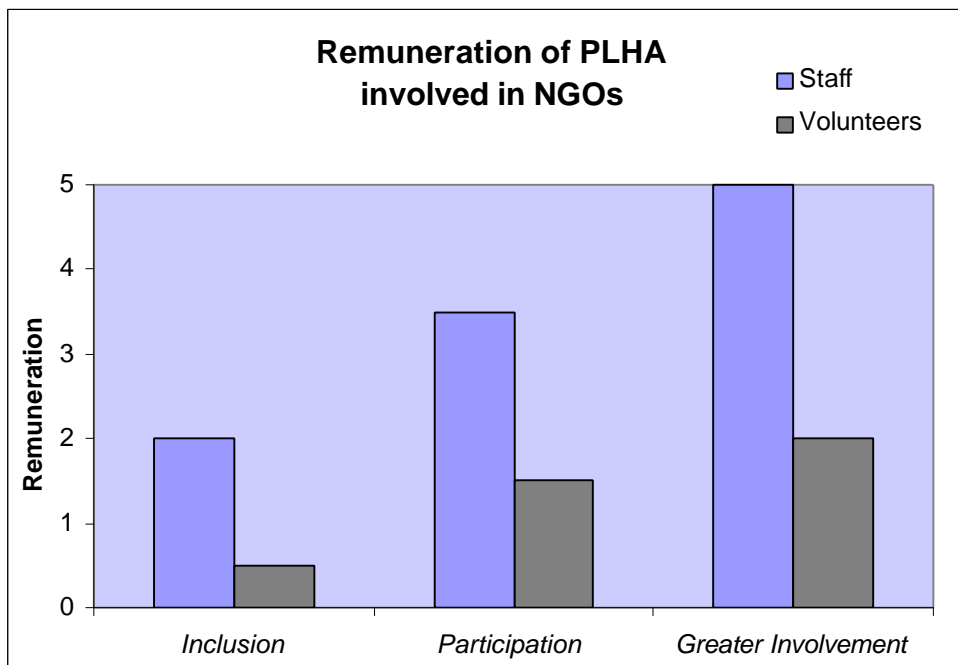
4.12.1 “Voluntary” versus “professional” involvement

- **Time** The study found that most PLHA involved in the NGOs that participated in the study were volunteers. Some PLHA involved on a voluntary basis give little time to the NGO, especially when they are involved on a very irregular basis (*inclusion*). However, HIV-positive volunteers who deliver care and support services, such as counseling or home visits, tend to be involved in these activities twice a week on average. The few who are involved in management on a voluntary basis spend a considerable amount of time working for the NGO with which they are involved, since most of them are also service providers. The small number of PLHA employed by NGOs worked full time or part time as support staff, service providers or managers. The last category was more likely to work full time.
- **Remuneration** As the graphs overleaf show, the level of remuneration received by PLHA for the work they carry out is usually linked to the time they give to the NGO and to the type of involvement, as well as to whether or not they are employed or work as volunteers. (Note: these and other graphs included in this chapter are not based on quantitative data but are intended to show trends.)

Graph 4.1



Graph 4.2



- ***Inclusion*** In the *inclusive* model, voluntary involvement of PLHA in the delivery of services is informal, occasional and poorly rewarded – financially and materially. The limited remuneration received by PLHA is also linked to the level of skills and expertise they use. In general, PLHA who contribute informally to service delivery are requested to use their own experience of living with HIV/AIDS to give testimony or share their experience with other PLHA, and they do not use technical or theoretical expertise. In Zambia, for example, community-based volunteers, who are involved in care and support activities such as home and hospital visiting, and volunteer outreach educators, who are asked to give testimony, are generally involved on an occasional basis and do not receive any financial remuneration for their work. In some NGOs, these volunteers receive meals, per diems or reimbursement of travel expenses, which provides an important incentive for involvement. The salaries of PLHA employed as support staff in non-HIV/AIDS related activities are relatively low, but provide a regular income and greater remuneration than per diems or reimbursement of expenses. Financial remuneration or lack of it can have a positive or negative on involvement (see Chapter 5).
- ***Participation*** PLHA who *participate* in NGOs as service providers are either paid staff or volunteers. HIV-positive employees may work full time or part time, but most PLHA are part-time employees and, in some cases, their contractual status is not very clear. In Zambia for example, the outreach educators of one NGO are called part-time “volunteers”, but they are more like part-time workers and receive an allowance or honorarium for their work that is much like a salary. In most cases, these “volunteers” also have access to the same benefits, such as health insurance, which are available to employed staff. In general, *participation* is more formal and regular than *inclusion*, PLHA are expected to use a wider range of skills and expertise and these are acknowledged by the organization, so *participation* therefore receives higher financial or material rewards. In Ecuador, and to some extent in Maharashtra, there were volunteers who did not receive any remuneration despite dedicating much time to the organizations they were involved with.
- ***Greater involvement*** As for *participation*, *greater involvement* of PLHA in service delivery is usually formal, regular and financially or materially rewarded. Most PLHA who are involved are full-time employees, are likely to have a clear formal contract of employment, and to receive higher remuneration than PLHA who *participate*. Higher remuneration is also related to the higher levels of responsibility and expertise required for *greater involvement*. However, the study found that there are a few PLHA involved at the management level – for example, as trustees – who do not receive any financial remuneration. Most of them attend many workshops and conferences, for which they receive per diem – and in African countries and in India, per diem may be perceived as extra income.

There was considerable variation between the four countries in understanding of the terms “volunteer” and “voluntary work”. In NGOs in Ecuador, and to a lesser extent in India, voluntary work is understood in a way that is similar to understandings in Europe and North America, but in Zambia and Burkina Faso, the understanding was often quite different. This is not surprising, since in poor countries most PLHA cannot afford to work as volunteers. Chapter 6 analyzes further the links between poverty and involvement. There were also significant differences in the way in which membership of an NGO or CBO is understood. In some CBOs in Burkina Faso, for example, members are mostly beneficiaries of services, while in others members are involved in service

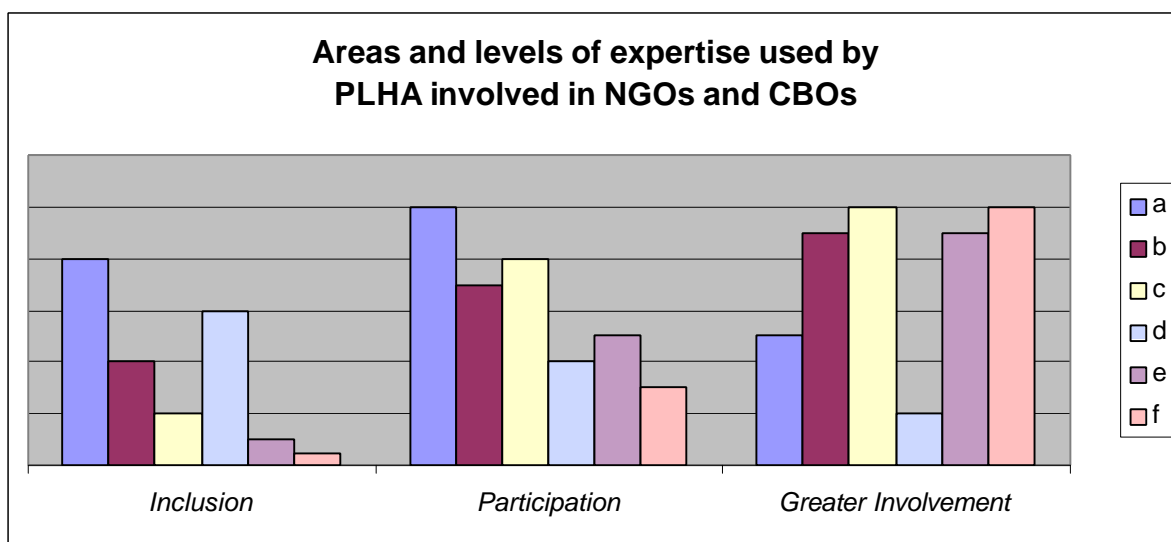
delivery. In several organizations in Ecuador, members are both service providers and service users in order to avoid stigma. In India, the MNP+ Maharashtra Major Group has 500 members, but it is not clear what membership entails in terms of rights, obligations and involvement in activities of the network, and the only condition for belonging was to be HIV positive and to complete a membership form.

There is also a link between voluntary or professional involvement and the level of skills and expertise used by PLHA (see section 4.12.2)

4.12.2 PLHA: tokens, aides or experts?²⁴

One of the criteria the study used to develop the typology of involvement is the expertise that PLHA use and the transfer of knowledge from organizations to PLHA involved in their activities. The graph below summarizes the expertise used by PLHA, depending on the type of involvement.

Graph 4.3



Legend

Empirical expertise: (a) Experience of living with HIV

Theoretical expertise: (b) HIV/AIDS facts

Technical expertise: (c) Skills related to the delivery of HIV/AIDS services (d) Other technical skills

Organizational expertise: (e) Organizational skills (f) Knowledge of the NGO and other NGOs

²⁴ Based on the title of an article by Ian Kramer and Paul McCrory published in 2001 in *Positive Nation*, the magazine of the UK Coalition of People Living with HIV/AIDS. Ian Kramer and Paul McCrory were two openly HIV-positive members of the Steering Group advising the Department of Health on the development of the English HIV and Sexual Health Strategy.

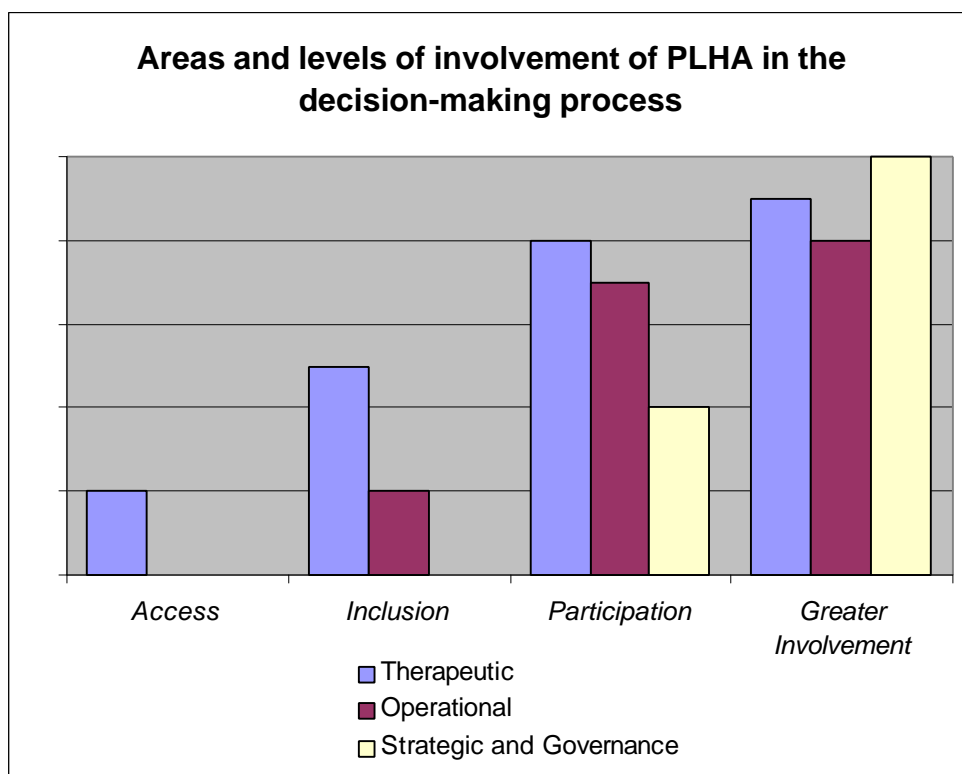
Kinds of expertise and transfer of knowledge

- **Inclusion** PLHA are “living examples” and therefore are required to use mainly their empirical experience of HIV/AIDS. PLHA may have received basic training – for example, information about HIV/AIDS, positive living and coping skills, vocational training, and skills for outreach education – but not specific training to deliver HIV/AIDS-related services. Other service providers bring technical and theoretical expertise, and PLHA act as “aides” and assist with activities. In most cases, service providers are health or social work professionals, although they can also be other PLHA who have received further training. PLHA involved in non-HIV-related activities, such as gardening or cooking, use other technical skills.
- **Participation** With the *participatory* model, PLHA involved in peer support, outreach education and awareness-raising activities use their personal experience of living with HIV/AIDS as well as theoretical knowledge of HIV and technical skills for service delivery. However, as described earlier, the study observed no visible PLHA employed in medical care. In this model, PLHA service providers have received more training from the NGO than PLHA who are volunteers or beneficiaries, and have a better knowledge of the organization and its services. They may have received, for example, training for conducting outreach education, such as in communication skills, in addition to information about HIV/AIDS and positive living.
- **Greater involvement** With this type of involvement, PLHA use a wide range of skills, including organizational and managerial skills. They also have a high level of knowledge of the organization, as well as of other HIV/AIDS organizations. PLHA have usually received formal training, inside and outside the organization, and have had considerable exposure to information and opportunities such as workshops and conferences.

Knowledge and power

- **Inclusion** PLHA are only involved in decisions affecting their own care or that have direct implications for the day-to-day delivery of services. The relationship between service providers, particularly health and social workers, and PLHA beneficiaries is vertical. Professional service providers have theoretical and technical expertise that is more valued than the empirical expertise of PLHA. However, in some cases there is also an emphasis on empowerment through transfer of knowledge, and beneficiaries are viewed as having the capacity to become independent and to help themselves and others.
- **Participation** PLHA who *participate* are more autonomous than PLHA in the *inclusive* model, planning and carrying out activities without supervision. Decision-making is limited to the services that they deliver, although they may be consulted about other services. The relationship between service providers and beneficiaries is horizontal, as service providers are more likely to consider beneficiaries as equals. The objective is to empower PLHA and meet their needs through advocacy and self-help rather than through dependence on welfare.
- **Greater involvement** PLHA have considerable decision-making power and autonomy in terms of programs, and also influence organizational, policy and strategic planning issues. The relationship between service providers and beneficiaries is horizontal and equal, and as with *participation*, emphasizes empowerment and rights of PLHA.

Graph 4.4



Tokenism is characterized by the involvement of PLHA without the appropriate skills in decision-making bodies, but without any efforts to develop their capacity, or by the involvement of PLHA with a high degree of expertise in so-called decision-making bodies, but decisions are made outside of these bodies.

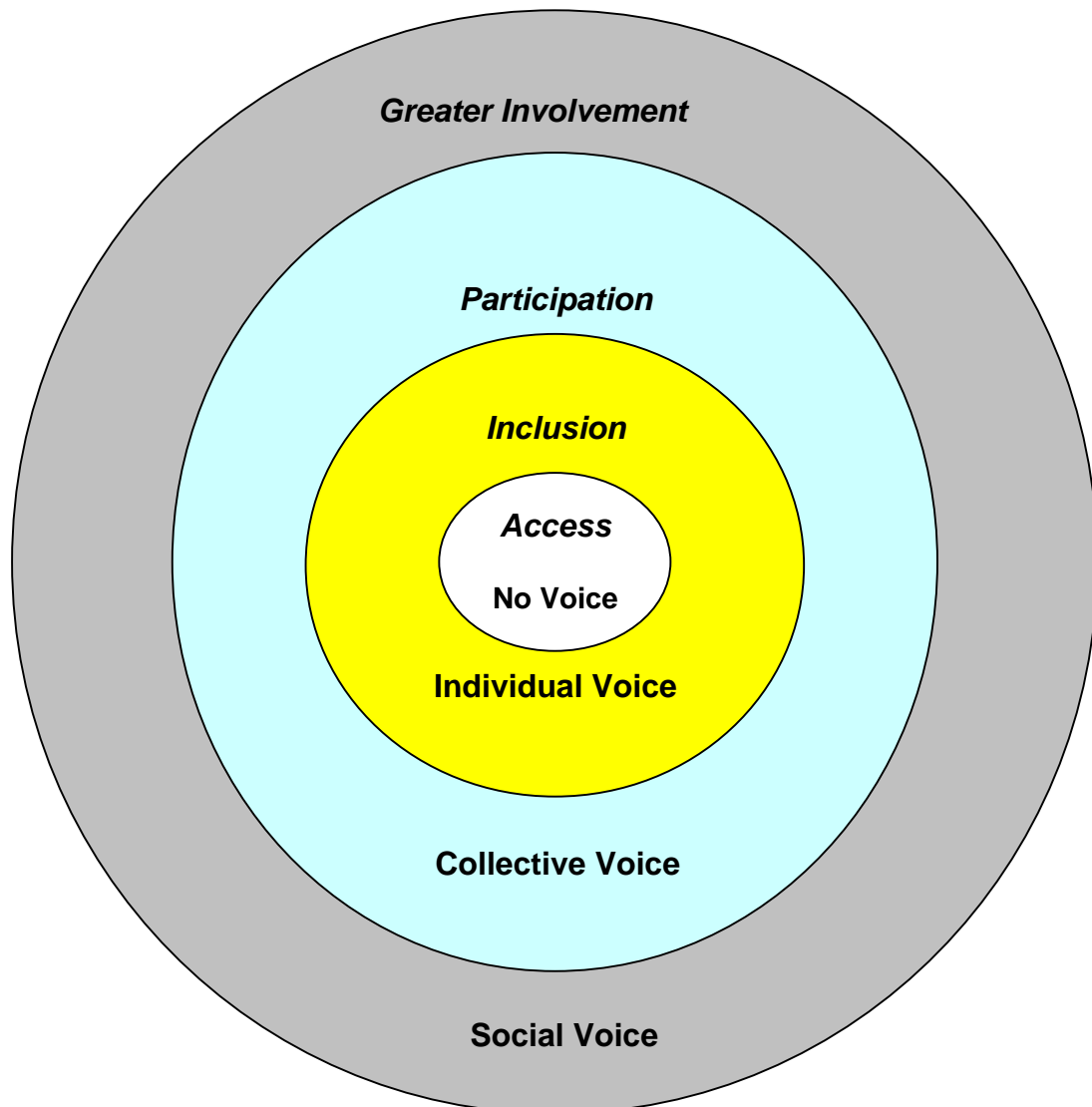
4.12.3 Strategies of disclosure of PLHA involved in NGOs and CBOs: Levels of visibility and “vocality”

The study observed that PLHA are involved with different degrees of visibility, of ability to be open about their HIV status and of “vocality” (the capacity of a PLHA to express himself or herself about a series of issues, such as living with HIV, positive living, the rights of PLHA and the involvement of PLHA in the fight against the epidemic).

Vocality

- **Access** “Vocality” is often non-existent when PLHA are only passive beneficiaries of services (*access*). They have “no voice” as PLHA.
- **Inclusion** In the *inclusive* type of involvement, PLHA who give testimonies from time to time or share their experience with other PLHA tend to talk only about their own story. They are individual voices.
- **Participation** Those who have been carrying out outreach education for some time and those who have counseled many other PLHA have a knowledge of living with HIV that goes far beyond their own personal experience. They have a collective memory of what it is to live with HIV and are able to formulate the problems of other PLHA and the solutions they have found. They are collective voices.
- **Greater involvement** PLHA involved in the management of NGOs usually speak on behalf of other PLHA, stand for the rights of a virtual community of PLHA and provide a social voice for HIV-positive people.

Graph 4.5: Types of involvement and levels of vocality



Visibility

Involvement may or may not be visible, and there are different levels of visibility. Inclusion, participation and greater involvement generally imply a higher level of visibility than access. However all PLHA are visible at some level:

- **Access** A major characteristic of *access* in all four countries is low visibility of PLHA beneficiaries. For example, in Zambia, many participants in the training courses run by Hope and Kara do not tell their families and friends that they attend the courses and are reluctant to carry out “advocacy” in the community because they do not want to disclose their HIV status. The study found that support groups, in addition to acting as a bridge between *access* and *inclusion*, can also be an important first step in promoting visibility.
- **Inclusion** Relatively few PLHA are visibly involved where the type of involvement is *inclusion*.
- **Participation** There are even fewer PLHA visible in service delivery, where the type of involvement is *participation*. For example, visible PLHA are absent from areas of service delivery such as medical care, and in some countries from “professional” counseling as opposed to informal peer counseling. Having said that, the level of visibility of PLHA who provide services formally is usually quite high, both within and outside the organization, to other service providers and to beneficiaries.
- **Greater involvement** The visibility of PLHA is usually very high within and outside the organization, including at national and international levels, although external visibility may be limited depending on the individual and his or her circumstances.

We directly say that we are a PLHA organization ... even the staff who are non-PLHA mention that this is a PLHA organization.
(PLHA staff member, MNP+, Mumbai, Maharashtra, India)

The study also analyzed the links between different types of involvement and the positive and negative effects of involvement for PLHA, their families and the organizations with which they are involved (see Chapter 5), and the factors that enhance and limit involvement (Chapter 6).

5. Positive and Negative Effects of PLHA Involvement: What is Meaningful Involvement?

This chapter summarizes the positive and negative effects of visible involvement on the individual PLHA who are involved, on the overall functioning of the NGOs, their services and activities and the quality of life of the beneficiaries, and on the families and communities of the PLHA involved. It provides a comparative analysis of the advantages and disadvantages for organizations and HIV-positive service providers and users of three types of involvement: *inclusion*, *participation* and *greater involvement*.

5.1 Methodology to measure the effects of PLHA involvement

“Service user involvement is not an end in itself. It is a means to improve the service you provide and the way in which you provide it,” says the former chair of the Service Users/People with HIV/AIDS Working Group that was formed in the United Kingdom in the mid-1990s.²⁵ The main reason why GIPA has been championed is that it is supposed to improve dramatically the response to the HIV/AIDS epidemic. One of the objectives of the study was therefore to assess the positive effects, and potential negative effects, of PLHA involvement in NGOs and CBOs on the:

- Activities and services of the organizations in which they are involved and quality of life of service beneficiaries.
- Structure and functioning of the organizations in which PLHA are involved.
- Quality of life of PLHA involved.
- Families and communities of the PLHA involved.

Identifying an appropriate methodology to measure the effects of PLHA involvement was a particular challenge, since it needed to address questions including: who evaluates the effects of involvement? When should effects of involvement be evaluated? What indicators should be used to measure these effects?

The study used the following methodology to **collect data** on the impact of PLHA involvement:

- **Interviews** with non-PLHA and PLHA service providers and service users to evaluate effects of involvement in terms of comparison and changes:
 - **Before and after the involvement of PLHA** To evaluate the effects of the involvement on PLHA, questions asked included: has your life changed since you became involved with the organization? In what way has it changed? Questions were also asked of relatives of PLHA involved in the NGOs in order to analyze whether they had observed changes in their loved ones since they were involved in the NGO.
 - **With or without the involvement of PLHA** To measure the effects of PLHA on activities, questions asked included: are there activities that PLHA do differently and better

²⁵ Bell, Michael (1997) *Principles, Policy and Practice: Guidelines For Service User/People With HIV/AIDS Involvement in AIDS Service Organisations*, London: Michael Bell Associates & Pan London HIV/AIDS Providers Consortium.

than other service providers within the organization? Do beneficiaries prefer to be seen by PLHA, and if so, why?

- **Focus-group discussions** on quality and impact of the services with small working groups of service providers in each participating NGO, in order to develop indicators to evaluate one of the services of the organization, to provide NGOs with a methodology and tools that they could use in their daily work, and to use the indicators to analyze the effects of PLHA on service delivery.
- **Direct observation** by researchers of activities in which PLHA were involved.
- In some countries, researchers carried out **surveys of small samples of service users** in a few organizations.

The study used the following methodology to **classify and analyze the data**:

- The researchers classified the data from transcripts of interviews and focus-group discussions, and listed the positive and negative effects mentioned by the respondents from NGOs and key informants. They also analyzed how many times each effect was mentioned (frequency).²⁶
- The opinions expressed by respondents were compared to data collected through other means, such as life stories and observation.

The **limitations** of the methodology used to collect, classify and analyze data were:

- **Short time for data collection**
The main limitation was the short timeframe for data collection. As a result, some activities could not be observed because they did not take place at the time that data was collected. In addition, the impact of activities is unlikely to be immediate, and the data collection timeframe did not allow for evaluation of medium-term and longer-term effects. There was also not enough time to refine and incorporate the indicators developed by the NGOs in the analysis of the effects of involvement.
- **Other factors have an impact on PLHA and on organizations**
When a PLHA is asked what has changed in his or her life since becoming involved in an NGO, some of the changes attributed to involvement may be the result of other processes. Changes in an organization may also be the result of factors in addition to PLHA involvement.
- **Comparing services provided by PLHA and by non-PLHA may be biased** For example, the same service, such as counseling, provided to the same person by an HIV-positive service provider and an HIV-negative service provider will be offered at two different times in the client's life and at different stages of his or her life with HIV. This makes it difficult to compare the effects of counseling by PLHA and non-PLHA counselors. Similarly, it is difficult to compare the same service provided simultaneously by an HIV-positive service provider and an HIV-negative service provider to different clients unless the clients have a similar profile and share the same concerns. There is therefore a risk that researchers compare data that is not in fact comparable.
- **Non-visible involvement**
Another limitation in evaluating the effects of involvement of PLHA in NGOs is that involvement is often not visible. Involvement may have positive and negative effects when it is

²⁶Frequencies are presented and analyzed in detail in the final study reports produced for three of the participating countries: Ecuador, India and Zambia.

not visible, but it is difficult to demonstrate what cannot be observed using a scientific approach.

- **Classification of qualitative data**

The data was collected through in-depth interviews and focus-group discussions, and the questions about the effects of involvement were open questions. Frequencies are the result of thematic classification of transcripts of interviews and group discussions by the research teams, and classification was therefore subject to the interpretation of each researcher. The timeframe did not allow for cross-checking by a second researcher. Frequencies did not have a statistical value; they only expressed trends of opinions, and in addition, the opinions of respondents did not always reflect reality.

5.2 Effects of involvement on PLHA

5.2.1 Positive effects: the therapeutic effect of involvement for PLHA

Improved psychological health

One of the most immediate consequences for PLHA of involvement in NGOs is usually an **increase in psychological support**, and in many cases **access to peer support**. PLHA have the opportunity to meet other HIV-positive people; for example, in support groups, positive living courses or during the activities they implement as service providers. As a result, PLHA realize that they are not alone and that they can share problems and solutions with other HIV-positive people. This often brings an **end to isolation**, in particular self-isolation and self-stigma. Peer support was identified as a key factor contributing to improved psychological, mental and emotional health.

I felt so alone. I thought I was going to die there and then ... The group helped me to get to know other people in the same situation and this has been a great psychological support ... So I haven't been to a psychologist but I have been helped by seeing a group of people in the same position; this has helped my self-esteem.

(HIV-positive service user, Siempre Vida)

The sharing of people who belong to the same group ... the same kind of problem that you have is a remedy somehow.

(HIV-positive woman, service provider, CHEP, Kitwe, Zambia)

For him, sharing with other people who had the same condition was a kind of therapy. He was able to take things better and cope with the disease. He had contact with other countries and other institutions that provided assistance to the organization.

(Male family member of a service provider, Fundación Vivir)

The group has really boosted my morale ... especially for some of us who have lost our partners ... when we meet as a group we feel better because the way we relate to each other is like one big family. You become a pillar of strength for those who have just been tested.

(Self-help group participant, PLHA ,supported by CHEP, Kitwe, Zambia)

When I say I'm HIV positive they realize they can talk with me. Otherwise, if they don't know you are HIV positive, they don't know whether or not to give in and talk openly, and they keep it all bottled up inside. When I say I'm HIV positive they feel more confident to talk more freely.

(HIV-positive man, service provider, Fundación Siempre Vida)

Respondents in all four countries mentioned **access to information** and **improved knowledge of HIV/AIDS** as positive effects of PLHA involvement. PLHA may receive information through:

- Counseling when they access services.
- Documents available in the NGOs.
- Informal and formal training, through courses like the PLAC of Hope and the Life Skills Training of Kara Counseling in Zambia. Many PLHA are also trained by NGOs in order to deliver services.
- Attendance at local, national and international meetings such as HIV/AIDS conferences.

The benefit of associating with the agency is that today I know so much. If I had sat at home, I would not have known so many things.

(PLHA service provider, MNP+, Mumbai, Maharashtra, India)

In most countries, HIV/AIDS is associated with death and the transgression of social norms. More information, and especially more accurate information, helps PLHA **change their perceptions of HIV infection**, and gives hope to those who used to think that a positive test was the end of their life. There is a **greater acceptance of being HIV positive**.

Before I got to know the organization, I thought I was cursed, or maybe that someone had put a jinx on me. But when I joined the organization, I realized that I was not alone in having this illness and that I could live with the virus without becoming ill.

(A young seropositive woman, member, ALAVI, Ouagadougou, Burkina Faso)

We also receive training in the field of AIDS ... which enables us to develop our knowledge of HIV. These are the positive consequences, because through this training I now have a view of AIDS which a lay person cannot have.

(A member, ALAVI, Ouagadougou, Burkina Faso)

Personally, it has helped me a great deal. I learned to live with the illness and I think this is quite an achievement ... I accepted the illness and I know that at any moment I may move into a terminal phase, and I have accepted that.

(HIV-positive service provider, Siempre Vida)

Data from Ecuador shows that PLHA involved in NGOs and CBOs usually have **better access to information regarding care**. They are better aware than other PLHA of what options exist in terms of treatments, where they can access care and who can provide them with good quality care.

Well, since I joined the organization a part of my life has changed a great deal. I have learned more about the disease, how to live with it and how to accept my

positive status. Now I am more aware of my own personal needs. Before joining the NGO we didn't know where to go for help, what to do, or which doctors treated us well and which ones didn't. Now that I have joined the organization I know where to go and what to do and who to get help from when I need it.
(HIV-positive man, service user, Fundación Siempre Vida)

Increased knowledge also encourages some PLHA to **share information about HIV/AIDS with other people in the community** and to get involved in activities such as awareness-raising or visiting the sick. Data from Burkina Faso and Ecuador reveals that PLHA use the NGOs as a “safe space” to prepare to deal with the outside world.

This gives a feeling of being responsible to members of our community who cannot help themselves ... We feel we are doing our own communities a great service.
(Male PLHA service provider, Salvation Army, Mazabuka, Zambia)

When they share their knowledge of HIV/AIDS and contribute to the community, PLHA command *greater respect and recognition from others*.

It is being a member of REVS+ which has given me back the will and strength to live. I have even had the strength to be able to raise people's awareness of AIDS at the office, because since the director told them I had AIDS nobody wanted to come near me. With what knowledge I have gained at REVS+, I have been able to raise their awareness and now they behave well towards me.
(Woman living with HIV/AIDS, member, REVS+, Bobo Dioulasso, Burkina Faso)

The most encouraging thing nowadays is that they have stopped mocking me or insinuating that I got the virus due to sleeping around.
(Man living with HIV, service provider of a care and prevention team, Salvation Army, Mazabuka, Zambia)

PLHA who are actively involved in the activities of NGOs have a greater sense of purpose and usefulness, which, together with recognition from the community, leads to an **increased confidence and self-esteem**.

Today it feels that there is a purpose in life. It is like at least we can do something for others. We have to live for others, so it feels good.
(HIV-positive woman employed by MNP+, Mumbai, Maharashtra, India)

When you are tested positive for HIV ... you are told that you have ... the killer disease and it is going to take away a lot of things from you. And if you start to participate in the community programs, you regain your confidence and self-esteem and you feel useful, and that improves the quality of life of PLHA.
(HIV-positive man, NGO coordinator, Lusaka, Zambia)

My family member who is a PLHA has also benefited. She has become more confident and her fears have reduced.
(Affected beneficiary of MNP+, Mumbai, Maharashtra, India)

For those people who are involved in decision-making and who have received training, involvement is an **empowering process**.

All these elements contribute to the **improved psychological health of PLHA**. This was mentioned by respondents in all four countries, and was the most frequently reported positive effect in Burkina Faso, Ecuador and Zambia. Manifestations of improved psychological health include less worry and depression, and feeling freer and no longer burdened by secrecy or a double life.

Since I've been with REVS+, there has been a great change. When I was not a part of the association I felt abandoned, I felt that I was guilty for what had happened to me. Since becoming a member of the organization, I have told myself – with the encouragement of the other organization members – that what is done is done. I have to come to terms with it, to fight it and not to give in. My husband also thinks that there has been a change because now I have a smile on my face.

(A seropositive woman, member, REVS+, Bobo Dioulasso, Burkina Faso)

She has put on weight and has become more open, especially to us children. She seems to have peace of mind despite her illness. Something has changed.

(Son of a seropositive woman, service provider, Hope, Ndola, Zambia)

In some cases, involvement is even seen as the factor that saved the life of a PLHA.

If I had not done this course, I most probably could have died ... I was taught and encouraged to live longer despite my HIV status. The only bad thing is that after the course we are “left in the cold”.

(Participant in the PLAC, Hope, Ndola, Zambia)

Improved physical health

In all four countries, PLHA reported **improved physical health** as a positive effect of involvement, and this was the most frequently reported benefit in India. In Zambia, respondents mentioned rarely getting sick and fewer opportunistic infections.

My health has really improved because I have now learned how to look after myself properly. I used to be sickly; I was in and out of hospital ... but now my health has really improved such that I even have the energy to cultivate. I know how to prevent some of these opportunistic diseases.

(Participant of a self-help group of PLHA, supported by CHEP, Kitwe, Zambia).

Physical health of PLHA improves for various reasons. PLHA have **more information** about what they should and should not eat and drink, and what physical activities they should or should not undertake. As a result, many PLHA eat a healthier diet and live a healthier lifestyle, providing they have the financial resources to afford the food they are supposed to eat.

I try to prepare what I learnt during the course. The only problem is that I do not have the money to buy what I learnt to cook. I find it very difficult to have balanced meals because I do not have enough money ... Sometimes the whole week elapses without having any proteins.

(Participant in the positive living course, Hope, Ndola, Zambia)

When I wake up in the morning and feel weak, I do the exercises and they help me to feel better, and all body pains go away through exercises.

(Participant in the PLAC, Hope, Ndola, Zambia)

Better health may be the result of **receiving financial remuneration** when PLHA are employed by an NGO, **or material benefits** such as food, as mentioned in India and Zambia.

Finally, better physical health was more specifically attributed to **better access to care and treatment**. It may result from improved knowledge of institutions that provide good quality care and increased contact with them through networking, as already mentioned, or from **free medical care or reimbursement for medical treatment** provided by the NGOs with which they are involved. Some organizations provide these benefits for employees who are HIV positive or for a small number of NGO members. Sometimes NGOs refer PLHA to other organizations that can provide treatments free of charge.



Through ALAVI, I obtained tritherapy treatment.

(HIV-positive member, ALAVI, Ouagadougou, Burkina Faso)

The positive consequence of being a member of La Bergerie is that I receive medicines free of charge.

(A member, La Bergerie, Ouagadougou, Burkina Faso)

A member of La Bergerie with a client at the outpatient care centre in Ougadougou

Income and other material benefits

In poor countries where unemployment is high and formal employment very scarce, PLHA employed by NGOs, or those who receive some form of financial or material compensation, find that involvement brings a more or less regular income. The remuneration they receive is essential to their well-being and that of their families, as they can buy medicines and food. Only respondents in Zambia and India mentioned obtaining employment and benefits such as allowances, meals and housing as a positive effect of involvement, because there were very few PLHA employed in the participating NGOs in Burkina Faso and Ecuador at the time of data collection. In two countries, Burkina Faso and Zambia, some NGOs have developed income-generating or entrepreneurial training for PLHA. Although few of these initiatives have been successful, a small number of PLHA have been able to find employment or earn an income using the training they have received.

Due to this program about six people have found formal employment and there are about 150 PLHA in support groups involved in income-generating activities. I am able to look after myself and my family ... I am now leading a very productive life because I have an income.

(HIV-positive man, service provider, CHEP, Kitwe, Zambia)

Better integration in the family

Positive effects of PLHA involvement include **greater acceptance by families** and, in some cases, less stigma. Increased acceptance and support of PLHA was only mentioned in Ecuador and Zambia. In Ecuador, this was attributed both to PLHA being able to provide relatives with accurate information about HIV/AIDS and to families realizing that PLHA can be active and productive.

Our parents ... find it difficult to accept our situation, but after seeing how positive we have been about it they slowly start accepting the situation and take care of us."

(Female PLHA service provider, Hope)

In Burkina Faso, PLHA reported that their involvement had helped them to raise the issue of HIV with partners and other family members.

When I go to REVS+ meetings, I bring home documents that I put on the table by the door on purpose. At first, my husband did not want to look at them; then he began to read them and ask me questions. I also asked him questions concerning the vocabulary in the documents. I think the fact that this has made my husband talk about the issue is already a benefit for me.

(A woman from REVS+ who doubts the faithfulness of her husband and is afraid of being infected, Bobo Dioulasso, Burkina Faso)

Although I have never managed to tell my husband directly that I am infected, when he knows that I am involved in an AIDS organization, he's going to get used to it. Slowly he will begin to be prepared.

(A young seropositive woman, member, ALAVI, Ouagadougou, Burkina Faso)

Safer sexual behavior

Only in Zambia and Ecuador did respondents report **changes in their sexual behavior**, mainly in terms of reducing the number of sexual partners, as a positive effect of involvement.

I have stopped sleeping around. I have changed in the way I used to behave.
(Workshop participant, supported by CHEP, Kitwe, Zambia)

Different positive effects are closely linked to the type of involvement. For example, all models, including **access** to services such as counseling, positive living courses and medical care, can contribute to increased knowledge, behavior change and improved physical health. However, **inclusion, participation and greater involvement** bring more financial and material benefits than *access* when PLHA are employed by an organization. **Participation and greater involvement** also have a greater impact on self-esteem, as PLHA are more active and have more responsibilities and power.

5.2.2 Negative effects of involvement on PLHA

Stigmatization and discrimination

PLHA in Zambia and Ecuador mentioned **stigma and discrimination** as a negative effect, particularly of visible involvement. In Zambia, PLHA reported being laughed at and pointed at. In India, fear of stigma and discrimination, resulting in rejection or loss of employment, was mentioned frequently. However, no concrete examples were given of discrimination resulting from visible involvement, perhaps because of the very selective visibility of most PLHA involved in NGOs in Maharashtra. Similarly, in Burkina Faso, few PLHA mentioned discriminatory reactions, despite the fact that fear of stigmatization appears to deter the majority of PLHA from visible involvement.

If you go out there, definitely I know the people will never be close to you, even your best friends. I have experienced this. I have even come out ... on TV. I had come on blurred, but yet I had problems. I came out with my name And then I had problems in my area because on the TV the voice comes very, very clear Those people in my area kept on saying "there was a similar person like you only because when that blurred thing came like a shadow" ... They could listen to the voice.
(PLHA service provider, Salvation Army, Mumbai, Maharashtra, India)

Rejection by families, friends and neighbors was mentioned in Zambia and Ecuador and was the most frequently identified negative effect of involvement. PLHA reported being chased away from home and being ignored by relatives and friends.

I have suffered a lot of discrimination since I decided to come out into the open, and especially since my decision to get involved. People really laughed at me. My friends stopped playing football with me ... shaking hands with me ... My parents-in-law succeeded in taking my wife away from me.
(Man living with HIV, service provider, Salvation Army, Mazabuka, Zambia)

There is a case of a young man who after going public had a serious quarrel with his father and he was disowned ... he committed suicide.

(Service provider, Kara Counselling, Lusaka & Choma, Zambia)

I left the neighborhood I was living in because there were rumors going around that I was HIV positive. People were asking to see a health certificate or for me to go and take tests. Even in the house I was living in the people told me that I was "sleeping in their bed" and they burned the mattress I had been sleeping on.

(HIV-positive man, service provider, Siempre Vida)

Through disclosing your status you can also lose out. I have a brother who doesn't want any contact with me. He told me that he's ashamed of me. It was my decision to be open. I am someone who thinks things through, so if he feels bad that's his problem.

(HIV-positive woman, service provider, Fundación Dios, Vida y Esperanza)

In Ecuador, researchers observed that the contrast between the accepting and supportive atmosphere of NGOs and the reality of the outside world was very difficult for some PLHA, who preferred to limit their visibility to the service providers of the organization in order to avoid stigma.

“Mirror” effect

Respondents in three of the four countries, Ecuador, India and Burkina Faso, mentioned the **“mirror effect”** – the adverse psychological impact on asymptomatic PLHA of identifying with PLHA who are ill or dying. This effect is most likely when PLHA are involved in activities that bring them into contact with other PLHA who are very sick or in the terminal stages of AIDS, such as home or hospital visiting.

Once a positive person ... was sitting down in the clinic and I was going for a hospital visit, and he forced me. He said, "I want to come, I want to come." This was a positive person. He was at the agency and he wanted to come and pay a visit to other positive people in the hospital ... I told him, "Do not come because this is my duty and I am going there ..." But the PLHA insisted on accompany me to the hospital "... I will come, I want to come." He came there, waited for ten minutes ... Later on the PLHA started crying because he had started to relate himself with the PLHA in the hospital. I asked him, "Why are you crying?" ... He replied, "Will my condition also be like that afterwards?"

(Service provider, Salvation Army, Mumbai, Maharashtra, India)

I took a young man who said he was prepared to go and visit someone in hospital. When we were leaving the hospital the young man broke down in tears and came over very depressed. He said he couldn't cope with it. I had to manage the situation very quickly, get him out of there and calm him down. I said to him, "Take it easy. If you get like this, what type of support are you going to be able to give? You have to show optimism, a will to live, happiness. If not, you are

going to kill them, yourself and all the others.” Sometimes it is hard for them to accept the situation and they want to continue, but we can’t let this happen and we have to work with them a lot.

(HIV-positive man, service provider, Fundación Siempre Vida)

For home visits to people infected, there are well-known limits. If, for example, I visit an infected person at home who is in the terminal stage of AIDS, seeing that person suffer I would say, “That’s how I will suffer one day.” So from that moment, you can understand that I cannot continue to carry out this activity any longer. PLHA can definitely participate in this activity, but up to a clearly given point, no matter how prepared they are.

(A PLHA, REVS+, Bobo Dioulasso, Burkina Faso)

Emotional impact of the death of HIV-positive colleagues

In Ecuador, the study observed that the death of HIV-positive service providers who are colleagues and friends can affect the psychological health of PLHA involved in NGOs.

Burn-out

The study observed in all four countries that there is a **high risk of burn-out** in small organizations where there are few people who are active and even fewer PLHA who are involved in the activities of the NGO. There are many demands on them and it can be difficult to deal with the pressure. This particularly applies to **participation and greater involvement**.

Impact on physical health

In Burkina Faso and India, respondents noted that PLHA involvement in activities that are physically tiring could result in **adverse impact on their physical health**.

Their health is very fragile and so they should not carry out activities which wear them out too quickly.

(PLHA CBO member, Burkina Faso)

Respondents in Ecuador, India and Zambia also mentioned the risk of contracting opportunistic infections when providing care to other PLHA, in particular in hospital settings, although there was no evidence that this had happened.

Community suspicion of motives

This negative effect was mentioned in Zambia and Burkina Faso, where respondents reported that **community members have questioned PLHA motives for involvement**, accusing them of pretending to be HIV positive to obtain money from donors.

The only thing is that people usually tease me that it's not true that I have the virus; that I just want to use the situation to woo money from donors.
(Woman living with HIV, service provider, Hope, Ndola, Zambia)

Some people were telling me that I should not have gone public as it was disgraceful. Others were saying that many people who are infected have not gone public ... Maybe you are being paid by Hope Humana for going public?
(Woman living with HIV, service provider, Hope, Ndola, Zambia)

It's not easy because people think that you are lying; people think that it's not real that you are sick.
(Female participant, a support group, CHEP, Kitwe, Zambia)

Feeling used by NGOs

Only respondents in Ecuador mentioned feeling **disappointment and anger when they feel used by organizations** in which they are involved.

Some negative effects can be linked to the type of involvement. For example, some forms of involvement involve higher visibility, which increases the potential for rejection, stigma and discrimination. This is the case with **inclusion**, when PLHA are used to give testimonies, as well as **participation** and **greater involvement**. However, in the *inclusive* model, PLHA have little training, including psychological preparation, and may find it more difficult to cope with stigma and discrimination. They are also more exposed when visiting other PLHA who are very sick or dying. Finally, they may be more likely to feel “used” by NGOs.

5.3 Effects of involvement of PLHA on the organizations and their services

5.3.1 Positive effects of involvement of PLHA on prevention and awareness-raising

Respondents in all four countries perceived that PLHA involvement, particularly in giving public testimony, had increased the success of outreach education in schools and workplaces and awareness raising activities in the community.

There was evidence in Burkina Faso, Ecuador and Zambia that involvement of PLHA in awareness raising activities tended to **change the perceptions that people have of HIV-positive people** by giving HIV/AIDS a “human face”. People understand the difference between HIV and AIDS, and that AIDS does not mean death. It helps them to appreciate that a person with HIV can look healthy. This way many people also realize that anyone can be at risk of infection, because it is not possible for example to identify a HIV-positive sexual partner just by the way she or he looks.

People nowadays do not have the fear that they used to... People had a lot of misconceptions about HIV/AIDS with the majority thinking that one could die within two to four weeks of testing positive.
(Male service provider, Salvation Army, Chikankata, Zambia)

In all the countries PLHA testimony was perceived to **increase the credibility of the information provided**, in particular about transmission, which reduces people's fears. It also helps people to understand that PLHA are able to live positively and to be active like "normal" people, demystifying the image of the bed-ridden AIDS patient. Attitudes towards PLHA usually become more open and accepting.

Previously we thought people living with HIV/AIDS were not people to associate with. We thought there are a lot of ways you can contract the disease ... so after we met with CHEP and the information was disseminated to us in detail, that's when we thought ... these people are not dangerous, we can assist them, they still remain our friends, our families and we have to treat them with the dignity they deserve.

(Beneficiary of workplace outreach education supported by CHEP, Kitwe, Zambia)

In Zambia, respondents said that better community understanding of, and greater openness and willingness to talk about HIV/AIDS, largely as a result of PLHA involvement in prevention and awareness raising activities, led to **increased acceptance and reduced stigma**. However, attitudes are changing slowly.

Previously in the communities people never thought that within the community people who are HIV positive can be found... it helped the community to start various sensitization programs to help understand what being HIV positive means.

(Male PLHA, service provider, CHEP, Kitwe, Zambia)

In addition, HIV-positive **educators act as role models**, encouraging other PLHA to get involved in outreach activities, and as **resource persons** in their own community.

Even the community seeks assistance from me. They come to my place. They have come to know me and what I do.

(PLHA, service provider, Kara, Lusaka, Zambia)

In Burkina Faso and Zambia the data showed that involvement of PLHA **increased the willingness of people to take an HIV test** because they felt encouraged when they saw that PLHA were able to live a positive life.

After the awareness raising session we found that the impact was quite significant amongst pupils. The pupils were very moved and there were even some who came to see me to tell me they intended to take a test.

(A leader of a religious school who organized an awareness raising session for pupils with HIV-positive members of REVS+ Bobo Dioulasso, Burkina Faso)

I am tempted to have a test done because if he is in good health it is because he takes care of himself.

(A man who attended an awareness raising session carried out by a PLHA from REVS+, Bobo Dioulasso, Burkina Faso)

In Zambia respondents claimed that there had been an increased demand for VCT as a result of PLHA involvement:

After the outreach education some people came and wanted to take the test.
(Female PLHA, service provider, Kara Counselling, Lusaka & Choma, Zambia)

However, the study found **no evidence that PLHA involvement** in outreach education and awareness raising activities **had really increased the actual number of people tested**, as there is a significant difference between being willing to take an HIV test, taking the test and collecting the results. In Zambia, an evaluation of the outreach program carried out with a small sample of employees of two companies visited a few months before the study by the team of positive outreach educators from one of the participating NGOs, showed that only one of the employees went for HIV test after the outreach session and then never picked up the results because of fear. It seems that NGOs obtain better results when PLHA provide encouragement to be tested to people in their own community and are able to take them through the whole process, including on-going support before and after testing. This is the model that Hope Humana has been trying to implement in Zambia with the involvement of Positive Living Advocates in community-based testing initiatives.

Respondents in Zambia exposed to workplace outreach education conducted by PLHA also reported positive outcomes ranging from intention to use condoms, and starting to talk about HIV/AIDS in the family and community. In India, respondents perceived that greater PLHA involvement could potentially result in more effective community interventions, including increasing community receptivity to messages about HIV/AIDS, and mobilizing community involvement in care and support.

5.3.2 Negative effects of involvement of PLHA on prevention and awareness-raising

Few negative effects were identified, although some respondents in Zambia and Ecuador had concerns about PLHA conveying inaccurate information if they are not well trained.

In Burkina Faso, some respondents noted that being a PLHA is not enough, and that PLHA involved in delivery of services, including awareness raising, also need training and skills.

5.3.3 Positive effects of involvement of PLHA on care and support services

Increased publicity and demand for services was mentioned as a positive effect in Zambia and India. In Zambia, for example, respondents believe that a positive effect of PLHA involvement is increased demand for services including counseling and testing, skills training and positive living courses. They also reported an increase in the number of people joining support groups. In India, respondents reported that personal testimonies by PLHA had encouraged other PLHA to seek support.

Now people come to us and say voluntarily that you should be visiting me or my son is sick. This is a step forward in home-based care activities.
(Service providers, CHEP, Kitwe, Zambia)

PLHA involvement in the planning and delivery of services helps to make these **services more responsive, relevant and demand driven**, according to respondents in all four countries.

The biggest benefit will be that we would come to know ... what kind of difficulties they face ... what are their feelings about it ... then it would be easier for us to work with them.

(Non-PLHA service provider, SOFOSH, Maharashtra, India)

They noted that PLHA involvement in care and support helps those who are supported to realize that they can live positively with HIV and that they are not alone, as well as to find solutions to their problems with others who are in the same situation. PLHA in all four countries specifically mentioned the **benefits of counseling services provided by other PLHA** (peer counseling) who can empathize with their situation. In settings where the level of stigma is high, including among health professionals, clients may prefer HIV-positive peer counselors because they are less likely to have judgmental attitudes.

The first counseling session I received was in hospital and it was with an HIV-positive person. He identified himself as such, and so ... the first thing you do is say: "Well if he is like that,... and if he's had the virus so long... I can be like that too."

(HIV-positive service user, Siempre Vida, Ecuador)

PLHA involvement is perceived to be particularly helpful in informing people about their HIV status and in providing psychological support.

In ... letting people know their results, people newly tested are a lot more reassured when they now that the person sitting opposite them is his or herself affected. They say to themselves: "Here is someone who is not going to judge me, who will understand me, who will not accuse me of deserving what I have got."

(A member of REVS+ not directly affected, Bobo Dioulasso, Burkina Faso)

I am convinced that you are more hopeful when the person who tells your HIV status ... is themselves infected ... Whatever you say, when you are told you are seropositive, you feel alone ... You think you are the only person with the problem. But from the moment you share your problem with someone else, you identify yourself with the world again.

(A woman living with HIV/AIDS, member, REVS+, Bobo Dioulasso, Burkina Faso)

In India, respondents also felt that counseling by PLHA could potentially **increase PLHA awareness of their rights** and give them the **confidence to be visible**.

I am also living with HIV. After seeing us [PLHA peer counselor] their perception towards life changes and fear goes out of them. They start feeling that they can also change and live life.

(PLHA staff member, MNP+, Mumbai, Maharashtra, India)

However, in Burkina Faso, while most respondents thought that counseling provided by PLHA had a positive effect on the quality of support, the study found that very few PLHA involved in care were open about their status with the people they are counseling. Similar contradictions were found in other study sites.

In Zambia and Burkina Faso, PLHA involvement was perceived to **improve the quality of care provided during home visits**. This may not have been reported in Ecuador or India, because of the limited extent of home care activities in these two countries.

Someone who is ill will carry out a home visit differently to someone who is well because they understand the problem. There will be a difference in the language. I say this because this is what I have noted during home visits.
(A man living with HIV, member, La Bergerie, Ouagadougou, Burkina Faso)

5.3.4 Negative effects of involvement of PLHA on care and support services

The main negative effect on care and support services of PLHA involvement, mentioned by respondents in Zambia and Ecuador, was the **potential disruption to service delivery** if PLHA service providers and volunteers are frequently sick or die. In Burkina Faso, Ecuador and Zambia some organizations use both HIV-positive and HIV-negative service providers in the same team in order to avoid disruption of care and support services if one or several service providers are sick at the same time or die.

Concerns were also raised about the risk that **PLHA might impose solutions** on others based on their own experience, or of client over-dependency or over-identification with a PLHA service provider, but there was no evidence to bear out these concerns.

5.3.5 Positive effects of involvement of PLHA on the general functioning of NGOs and CBOs

PLHA involvement can **improve understanding of the issues affecting PLHA and increase acceptance of PLHA among HIV-negative service providers**, and these effects were reported in all four countries. Changes in staff attitudes towards PLHA have helped to create a more conducive organizational environment among NGOs in Zambia while, in India, PLHA involvement was perceived to have increased organizational awareness of the perspectives and needs of PLHA.

I walked with them and interacted with them and that's why I came to realize that they were normal people just like any other human being. I could eat with them and share plates with them. Now I think I understand HIV much more than I did.
(HIV-negative service provider, Kara Counselling, Lusaka & Choma, Zambia)

Working with PLHA breaks down all the myths, you liberate yourself from the "you're going to get AIDS working alongside him or her because you hugged someone or gave them a kiss" syndrome...and you become a human being.
(HIV-negative service provider, Fundación Vivir, Ecuador)

Now I have the courage to mix with sick people. Before I joined REVS+ I was afraid. I thought that by eating with a sick person I ran the risk of catching the illness.

(A member of REVS+, Bobo Dioulasso, Burkina Faso)

In Zambia, CHEP established a specific PLHA Program within the organization and appointed a PLHA as the coordinator of the program. An HIV-negative service provider of CHEP explains how this person has managed to influence other staff members:

He was a mentor in terms of convincing the members ... so he mentored a lot of staff and also managed to create a conducive environment within CHEP as regards attitudes towards PLHA.

PLHA involvement has **increased awareness** among HIV-negative staff in Zambia and Burkina Faso **of the contribution that PLHA can make** to an organization and the quality of its services, and of the benefits of working together. At CHEP in Zambia this was largely attributed to the presence of the HIV-positive UN Volunteer who became the coordinator of the PLHA Program. In Ecuador, respondents perceived that PLHA involvement increases and **strengthens** organizational **human resources**.

The effect that the involvement of PLHA has had on the service providers is that they have realized the need to join forces with PLHA in the delivery of services.
(HIV-negative service provider, Salvation Army, Mazabuka, Zambia)

We were able to improve the skills of support groups, acceptance levels, formation was easier ... most of the things he brought up were good for our planning process and our own evaluations.
(Service provider, CHEP, Kitwe, Zambia)

The involvement of all HIV-positive people is always important. Why? Because the more people that join and work in the organization means that it continues to grow and in turn this increases the potential of the organization to carry out more activities and to offer more services. We want to improve the services and support we provide and increase the scope of our work. In order to do this it is important that more HIV-positive people are involved.
(HIV-positive man, service provider, Fundación Siempre Vida)

Increased credibility of the organizations and their services was mentioned as a positive effect in all countries. In Zambia, respondents at CHEP reported that PLHA involvement had improved the credibility of services with potential service users and other organizations, and had also increased the 'social legitimacy' of the NGO, which is now recognized by the community as an organization that can help PLHA. Similarly, respondents in Ecuador noted that PLHA involvement in activities or in running NGOs increased the internal and external credibility of these organizations, and respondents in India perceived that PLHA involvement could potentially help to create a positive image of the organization. Respondents from NGOs in all countries except Ecuador thought that involvement could help get funding from donors. In Ecuador, respondents thought that PLHA involvement would make it more difficult to obtain funds from donors because

they would prefer to fund causes seen as more acceptable, PLHA being seen as people who are “immoral”.

Other organizations have now recognized CHEP as one organization which is in a position to help people who are HIV positive.

(Man living with HIV, service provider, CHEP, Kitwe, Zambia)

As a result of PLHA involvement, organizations **tend to integrate advocacy for PLHA rights into their work**. This was observed in all countries. Respondents mentioned two main reasons to explain this phenomenon. PLHA involved in NGOs have inside knowledge of the needs of PLHA and they have a strong motivation to stand up for their rights. They are usually more aware and more motivated than service providers who are not living with HIV/AIDS.

PLHA approach the authorities better because you cannot fight for something unless you are yourself concerned.

(A seropositive woman, REVS+, Bobo Dioulasso, Burkina Faso)

They can take up issues far better because they are much more concerned with that. We are there to support.

(Service provider, Salvation Army, Mumbai, Maharashtra, India)

Some PLHA in India reported that involvement in support groups and related activities had empowered them to fight for their rights and the rights of other PLHA.

At the same time HIV-negative service providers have a better understanding of the issues affecting PLHA because they work with them and they have more confidence to argue against stigma and discrimination. We observed that NGOs with PLHA were involved in advocacy at the national and community level in Ecuador, and mainly at the community level in Burkina Faso, India and Zambia.

The positive effects of PLHA involvement on organizations and their services also depend on the type of involvement. The study findings suggest that the greater the level of involvement and, hence the more influence that PLHA have on the design, planning and implementation of activities, the greater the positive effect on the quality and effectiveness of services and on the attitudes of non-PLHA service providers. *Access* and *inclusion* provide limited opportunities for PLHA to influence organizations and the services that they provide, although there was room for consultation in some organizations where the *inclusive* model was dominant.

5.3.6 Negative effects of PLHA on the general functioning of NGOs and CBOs

In all four countries, respondents identified as a risk the **potential stigmatization of the NGO** because of the involvement of PLHA in the organization.

In Ecuador, where HIV prevalence is low, several NGOs suggested that organizations where PLHA are involved may potentially experience difficulties in obtaining funds or premises because some national donors prefer to give to “good causes” rather than sponsor organizations involving people seen as marginal and immoral.

Respondents in Africa expressed concerns that some people might not wish to use the services of an organization with visible PLHA because they might be identified as using these services and being HIV positive themselves. Similarly, in India, some organizations were worried about the negative effect on other services. For example, SOFOSH had had concerns that providing services to PLHA might deter prospective adoptive parents, although in fact this had not happened.

If we say that they [the babies] are from HIV backgrounds, we thought that they [adoptive parents] might stop coming. However, our experience shows that nothing like that happened.

(Service provider, SOFOSH, Pune, Maharashtra, India)

Organizations in Zambia also explained that this problem could be addressed by diversifying the activities of the NGO.

An example from Burkina Faso showed that the high level of visibility of one NGO member might result in identification of an NGO as a “PLHA organization” and stigmatization of all its service providers or members. A member of REVS+ was the first person who came out as HIV positive on national TV; he explained that he belonged to a “PLHA group”. This caused problems for other members who were not HIV positive or who were not ready to be visible, when they suddenly had to give explanations to relatives, friends and colleagues.

In some instances, visibility leads to some sort of “**stardom**” when there are very few PLHA willing to come out in the open. This can create tensions within an organization.

In Ecuador, respondents noted that the promotion of involvement of PLHA may lead to **undervaluing of the contribution of HIV-negative people**. However, examples from all four countries show that even organizations seen as “PLHA groups” welcome the participation of affected people and professionals with a range of skills. There are no organizations where 100 per cent of service providers are HIV positive. However, in Ecuador and India, **conflicts between PLHA and health professionals** in a couple of NGOs resulted in PLHA leaving the organizations and setting up their own groups. PLHA attributed the conflicts with health professionals to their paternalistic attitudes that kept PLHA in positions of “aides”, while they wanted more **participation or greater involvement**.

In Zambia, NGOs mentioned as a negative effect the **cost of training PLHA** to deliver services which increases when they die and have to be replaced by new service providers. This perhaps is explained by the very high HIV prevalence and the high HIV-related mortality rate that Zambia has experienced for many years. In India, some NGOs also believed that managing PLHA staff and volunteers, including orientation and training, would **increase the workload of the organization** and of supervisory **staff**.

Mortality of PLHA can also affect the sustainability of activities and organizations

The study observed in Zambia that support groups had to stop their activities because of an extremely high mortality rate among their members. In Ecuador, two of the participating NGOs were founded by HIV-positive people as self-help groups of PLHA. When the founders died, only the involvement of HIV-negative people, relatives, health professionals and social workers allowed

the organizations to survive, although they became ASOs with more *inclusion* and *participation* than *greater involvement* of PLHA. Mortality of PLHA affects the sustainability of NGOs run by PLHA (*greater involvement*), but it is more likely to only disrupt activities in organizations where PLHA provide services without holding management positions (*inclusion* and *participation*).

These blokes join the organization: they are trained but more often than not they pass away very quickly. Recently, many have died.

(HIV-negative woman, service provider, Fundación Siempre Vida)

5.4 Effects of involvement of PLHA on their families

5.4.1 Positive effects of involvement of PLHA on their families

Improvements were reported in all countries except Burkina Faso, where involvement was still a very recent phenomenon when the study was conducted. In Zambia, improvements in family life reported as a result of PLHA involvement included **increased capacity to cope with caring for PLHA** who are sick, **better communication** between family members, and the positive impact of **psychological and material benefits obtained by PLHA**. In India, the main positive effect mentioned was **improvement in the mental and psychological health of family members**, because they see changes in their loved ones as a result of their involvement. This has also resulted, in some cases, in better integration of PLHA and their families in the community. Some PLHA noted that they now paid more attention to their family.

I think I have come to love her more ... we have become very close; she tells me everything.

(Son of a woman living with HIV who is a service provider, Hope, Ndola, Zambia)

In Zambia, families also recognized the benefits of PLHA involvement in terms of **PLHA sharing knowledge with the rest of the family** and particularly raising awareness with younger family members.

I have an uncle who died some three months ago. The family asked for my assistance because they suspected that he was infected.

(PLHA, service provider, Kara Counselling, Lusaka & Choma, Zambia)

The family wish that I help the young ones especially, so that they grow well and not in the manner in which I grew up ... So the family is very happy for me coming out into the open ... because it is a lesson to the young ones.

(Man living with HIV, service provider, CHEP, Kitwe, Zambia)

In some cases in Ecuador and Zambia, PLHA involvement has **encouraged other family members to become involved** in prevention, care and support activities. In Ecuador, involvement of affected people has **helped them to learn how to relate to family members with HIV/AIDS** and how to give them support and care.

5.4.2 Negative effects of involvement of PLHA on their families

Stigma and discrimination, or fear of stigma and discrimination, was the main negative effect on families mentioned in all four countries, and of particular concern in Zambia. In Ecuador and Zambia, PLHA involvement has in some cases resulted in the family being stigmatized and discriminated against by the community. PLHA beneficiaries belonging to CHEP support groups reported that their children were mocked and teased. Children of PLHA in Zambia also mentioned fear of stigma and discrimination if a parent's HIV status becomes known through their involvement.

At first I didn't like it because I was scared that my friends would know that my mother is HIV positive.

(Daughter of PLHA service provider, Hope, Ndola, Zambia)

Other negative psychological effects on children of PLHA service providers in Zambia included having to face up to the reality of a parent's HIV infection and consequent **fears and worries about the future**.

I did not believe that my parents had AIDS. In short, I did not want to face the truth.

(Son of female PLHA service provider, Hope, Ndola, Zambia)

5.5 Conclusions: What involvement is the most meaningful?

In order to determine what types of involvement are the most meaningful, it is important to ask: meaningful to whom? PLHA involved, NGOs and CBOs in which they are involved, their families, the communities served by the NGOs and CBOs, society in general? The data presented in this chapter show that involvement has both positive and negative effects for all these categories, and that each type of involvement has advantages and disadvantages at different levels.

During data analysis workshops in three of the four countries,²⁷ representatives from participating NGOs and researchers compared the relative advantages and disadvantages of *access*, *inclusion*, *participation* and *greater involvement*. This section presents a summary analysis, highlighting the positive and negative effects of each type of involvement on PLHA, the organizations with which they are involved and their services, as well as the HIV-positive people who use these services.

5.5.1 Access

PLHA beneficiaries can benefit significantly from *access* to services, depending on the nature and quality of these services. Counseling, participation in courses such as the PLAC of Hope or the Life Skills Training Program of Kara in Zambia, have been shown to be of benefit to PLHA's psychological and physical health. They offer opportunities to obtain information and improve knowledge that also contribute to behavior change. In order to produce these positive effects, services should aim to

²⁷ The typology of involvement had not been developed yet when the data analysis workshop was conducted in Burkina Faso. In Ecuador the typology had been developed but the terminology was incomplete.

improve the quality of life of PLHA and empower them to take control over their lives and to take better care of themselves. For example, information about a healthy diet is of little use if people do not have the money to buy food. This means that NGOs must find a judicious balance between providing material support and development support. A strictly welfare approach is difficult to sustain in poor countries.

As Table 5.1 shows, *access* has more disadvantages than advantages for NGOs and CBOs, compared to other types of involvement. When service users are only beneficiaries, they usually have little say about the services they receive, which means that these services may not be relevant or appropriate to their needs. However, *access* can be meaningful in terms of involvement if it is used by as an entry point for further involvement of beneficiaries in the activities of the organization (see Chapter 4).

Table 5.1 Advantages and disadvantages of access

For HIV-positive service users	
Advantages	Disadvantages
⇒ Services provided by professionals with technical expertise.	⇒ No or little influence on the services they receive. ⇒ In some cases, they do not have the opportunity to meet other HIV-positive service users and share problems and solutions. ⇒ When the approach is very paternalistic, HIV service users see themselves as victims who need to be taken care of. This generates dependence on the NGO.
For NGOs and CBOs	
Advantages	Disadvantages
⇒ Requires less investment of resources; e.g. in training than other types of involvement. ⇒ Administration may be easier. ⇒ No disruption in service delivery because of high morbidity and mortality of service providers.	⇒ Less strong relationship with beneficiaries. ⇒ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning. ⇒ PLHA are a resource that the organization is not using.

Positive effects of *access* on the family are often the consequence of positive effects on PLHA themselves; for example, improvements in psychological and physical health as a result of access to counseling and medical treatment. Improvements in the well-being of a PLHA can have a positive impact on the well-being of the family, as we have shown earlier in this chapter.

5.5.2 Inclusion

Positive effects of *inclusion* on PLHA depend on how they are involved in the implementation of an organization's activities.

When PLHA are employed as support staff, they received a regular salary and usually also have access to benefits. This has positive effects on their health – for example, they can buy food – and on their psychological well-being – for example, they have greater confidence and self-esteem.

When PLHA are involved in service delivery on an informal, occasional and voluntary basis it is a different story. Material benefits are often minimal and this type of *inclusion* has fewer positive effects than *inclusion* that involves receiving a salary and other benefits. The main positive effects of this type of *inclusion* are in terms of psychological health and skills development. *Inclusion* is also convenient for those PLHA who are not able or willing to commit a lot of time to their involvement in the activities of an NGO. However, *inclusion* can have negative effects if PLHA expectations of immediate benefits from their involvement are not met; for example, they may feel used by the organization for which they volunteer, as in Ecuador. The data also reveals that it is important for NGOs and CBOs to have a good follow-up system for PLHA who have been trained in positive living courses, otherwise the benefits of the course are only short term, especially when PLHA have little support in their family or community. There is also a risk of stigma and discrimination for PLHA involved in outreach education. So, while *inclusion* of PLHA as volunteers can be empowering, it is not sustainable or meaningful for PLHA who lack resources and support, especially in very poor countries.

Inclusion may be seen as cost-effective because of the use of HIV-positive volunteers. However, volunteers who are poorly trained and rewarded may provide poor-quality services, and for this reason some organizations involve PLHA as “aides”, with other formal and professional service providers ensuring the overall quality of services. *Inclusion* of PLHA as volunteers is meaningful to NGOs and CBOs when volunteers are carefully chosen and receive adequate support. Otherwise the positive effects of involvement on the overall relevance and quality of services are limited.

Positive effects of *inclusion* when PLHA are employed as support staff can also lead to improvements for their families; for example, in health and nutrition. Unlike *access*, *inclusion* can also be meaningful to the community through the involvement of PLHA in outreach education.

Table 5.2 Advantages and disadvantages of *inclusion*

For PLHA involved in NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Increase in self-esteem when PLHA feel useful. ⇒ Greater respect from the community. ⇒ PLHA employed as support staff receive a salary and various benefits. ⇒ <i>Inclusion</i> is not time-consuming for volunteers. It does not require a high level of commitment to the activities. 	<ul style="list-style-type: none"> ⇒ They receive little training to deliver services and therefore capacity-building is limited. ⇒ Risk of stigma for PLHA used as “voices and faces” in testimonies. ⇒ The lack of influence on the decision-making process may lead to frustration. ⇒ Self-esteem can be affected negatively by the feeling of being used by the organization.
For HIV-positive service users	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Most services are provided by health professionals and/or social workers, who usually have theoretical expertise and experience. ⇒ No major disruption of services as a result of high mortality and morbidity of PLHA, since PLHA only contribute on an irregular basis and by supporting other service providers. 	<ul style="list-style-type: none"> ⇒ Information provided by HIV-positive volunteers may be of low quality if they have not been properly trained by the organization who uses them. ⇒ Volunteers have little information about the organization and its services, therefore referral is limited.
For NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ There is little or no training for HIV-positive volunteers and therefore no additional costs. ⇒ More people are involved in service delivery. ⇒ Potential to maximize use of human resources. ⇒ Volunteerism is cost-effective. 	<ul style="list-style-type: none"> ⇒ Could lead to discontinuity of service delivery because PLHA are not formally involved or fully committed to the organization. ⇒ Lower quality of services because of lack of training. ⇒ Planning may be difficult because of low commitment of volunteers. ⇒ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning. ⇒ Potential conflicts between PLHA and HIV-negative service providers if PLHA feel they have no opportunities for further involvement within the organization.

5.5.3 Participation

The positive effects of *participation* on PLHA include receiving remuneration and benefits when PLHA are employed, and a strong sense of achievement from helping other PLHA and the community. However, the *participatory* model gives limited scope for PLHA involvement in decision-making. This can cause frustration for those who have skills and experience but who are not offered the opportunity to influence the policies of the organizations with which they are involved. The main disadvantage is the risk of stigma and discrimination associated with a high level of visibility. *Participation* is therefore

most meaningful to PLHA who are satisfied with a technical rather than a managerial role and who do not fear discrimination.

Participation is meaningful to NGOs and CBOs that are ready to invest in mobilization, recruitment and training of PLHA, are willing to offer them the opportunity to be service providers in a conducive environment, and believe in the benefits of this involvement for the organization and its services.

Table 5.3 Advantages and disadvantages of *participation*

For PLHA involved in NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Increase in self-esteem when PLHA feel useful. ⇒ Greater respect from the community. ⇒ PLHA employed as service providers receive a salary and/or various benefits. ⇒ They learn new skills through training. 	<ul style="list-style-type: none"> ⇒ Risk of stigma. ⇒ “Mirror effect” and burn-out for those involved in care and support. ⇒ Their influence on the decision-making process is limited to the activities in which they are involved. This may lead to some frustration. ⇒ Volunteers need to be highly available to participate in activities on a regular basis. ⇒ Technical limitations to deliver services.
For HIV-positive service users	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Services are provided by mixed teams of health professionals, social workers and PLHA, which provides service users with more options and expertise. ⇒ Empathy between service users and service providers who are HIV positive. ⇒ PLHA service providers have received training. ⇒ PLHA can act as role models for other PLHA who are not visible or actively involved. 	<ul style="list-style-type: none"> ⇒ Possible disruption of services when HIV-positive service providers are sick or die.
For NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Improved planning and ownership because PLHA are integral part of the organization. ⇒ Improves relevance and quality of services because of training and PLHA involvement in design and planning. ⇒ Maximizes use of available human resources. ⇒ HIV-negative service providers are more aware of needs of PLHA. 	<ul style="list-style-type: none"> ⇒ Greater investment of resources; e.g. in training PLHA to support their participation, and higher costs of training to replace staff who become sick or die. ⇒ Negative effect on activities and services from high turnover and loss of staff due to illness and death.

The data reveals that families benefit from the *participation* of their relatives when they are employed by NGOs. Nevertheless, families need to be prepared to face stigma and discrimination in some settings. *Participation* is meaningful to the community in a similar way to *inclusion*, when PLHA are involved in awareness-raising.

5.5.4 Greater involvement

The material benefits of *greater involvement* for PLHA employed by NGOs are the same as the benefits of *participation*. *Greater involvement* is more meaningful than *participation* to PLHA who wish to shape the policies of their organization. As in the *participatory* model, PLHA have a high level of visibility, which can expose them to discrimination, but the level of personal acceptance and support is also very high for PLHA at the *greater involvement* level. PLHA *involved* have developed skills to cope with stigma and discrimination.

For NGOs, *greater involvement* is more meaningful than other types of involvement because it allows PLHA to influence the design and implementation of programs. As shown in Table 5.4, *greater involvement* requires investment and good planning of human and financial resources.

Table 5.4 Advantages and disadvantages of *greater involvement*

For PLHA involved in NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ Empowerment. ⇒ Strong ownership of the organization. ⇒ High self-esteem and respect from the community. ⇒ HIV-positive employees receive a salary and/or various benefits. 	<ul style="list-style-type: none"> ⇒ Risk of stigma. ⇒ PLHA need to be highly committed and available. ⇒ Burn-out. ⇒ Technical limitations to manage an organization.
For HIV-positive service users	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ PLHA have a stronger voice, can influence policies and decisions, and can ensure resources are allocated to services relevant to the needs of PLHA. ⇒ NGOs are likely to stand for the rights of PLHA and get involved in advocacy to improve the quality of life of PLHA. ⇒ PLHA can act as role models for other PLHA who are not visible or actively involved. 	<ul style="list-style-type: none"> ⇒ High levels of visibility within the organization may affect confidentiality.
For NGOs and CBOs	
Advantages	Disadvantages
<ul style="list-style-type: none"> ⇒ May increase donor funding if PLHA involvement is a donor priority. ⇒ HIV-negative service providers are more aware of needs of PLHA. ⇒ Helps to reduce stigma and discrimination in the workplace. ⇒ Improves effect of awareness campaigns. ⇒ Very high level commitment of PLHA to the organization. 	<ul style="list-style-type: none"> ⇒ High cost, especially if the organization provides treatment for PLHA. ⇒ High investment of resources and time; e.g. in training PLHA to support their involvement, and higher costs of training to replace staff who become sick or die. ⇒ Risk of stigmatization for the organization itself. ⇒ Disruption of activities from loss of staff due to illness and death. ⇒ End of the organization or change of its nature.

Like *participation*, *greater involvement* brings many benefits to families. PLHA *involved* are also very aware of their social mission and usually try to change society – through advocacy, for example – which benefits the whole community.

The study findings show that all types of involvement are meaningful at different levels. In general, the positive effects of involvement of PLHA appear to outweigh the negative effects.

There is strong evidence in all four countries that involvement has a positive impact on the psychological and physical health of PLHA who deliver services and/or manage organizations (*participation*, *greater involvement* and, to some extent, *inclusion*), although there are risks of stigma and burn-out. There is also substantial evidence of the positive effects of involvement of PLHA in care and support. However, methodological limitations did not allow the study to

demonstrate the impact of PLHA involvement in awareness-raising on demand for VCT and behavior change. We only have some evidence of the positive effects of involvement on the perceptions that people have of PLHA.

Some findings were difficult to analyze. For example, while some types of involvement can lead to discrimination, these types of involvement can also lead to increased support from the family and the community. More research is needed to understand better the circumstances in which PLHA suffer stigma and discrimination as a result of visible involvement. Another question that remains partly unanswered is the impact of involvement that is not visible. The study findings show that there are many levels of visibility and PLHA do not need to be visible at all these levels to contribute to the activities of NGOs. For example, members of support groups may be visible only to other members, and peer counselors may be visible only to their clients. The levels of visibility can be adapted to the activity in which PLHA are involved and the proposed impact of their involvement.

All the 17 participating NGOs in the four countries were convinced that some form of PLHA involvement and further involvement in their activities had benefited or would benefit the organization and its services. However, for each type of involvement to be really meaningful, there is a series of steps that PLHA and organizations need to take. If PLHA or NGOs do not take these steps, the positive effects of involvement tend to be limited and negative effects increase. Most factors that limit involvement of PLHA can also limit the impact of involvement, whichever way PLHA take part in the activities of NGOs and CBOs. The next chapter presents the factors that limit and enhance PLHA involvement and its impact on CBOs and NGOs.

6. Factors Limiting and Enhancing the Involvement of PLHA in Community-Based Prevention, Care and Support Services

6.1 Introduction

In all the countries where the study was conducted, visible involvement of PLHA in prevention, care and support in general, and at the community level in particular, is low, based on the number of CBOs and NGOs who actually involve PLHA and the number of PLHA involved. There are more PLHA involved in Zambia than in Ecuador, but the HIV prevalence in Zambia is almost 20 per cent of the adult population, whilst it is 0.29 per cent in Ecuador.

This chapter explores why it is that people who know that they are HIV positive are not more visibly involved in the activities of the CBOs and NGOs that serve them, focusing on the obstacles to their involvement as well as the factors that have made involvement possible in the organizations that participated in the study. The identification of these limiting and enhancing factors is essential to any attempt to strengthen current involvement, and to increase the number of organizations where PLHA involvement is relevant and meaningful and where PLHA can be open about their HIV status.

More specifically, the chapter presents the individual, institutional and social factors that were identified by the various categories of respondents as limiting and enhancing PLHA involvement. It explores the relationship between limiting and enhancing factors and the different types of involvement presented earlier in this report, and summarizes the individual and organizational steps necessary for involvement of PLHA in NGOs: the “pathways to involvement”.

6.1.1 Methodology

The following methodology was used to collect and analyze data on the factors that limit and enhance PLHA involvement.

Respondents were asked: what factors stop PLHA from getting involved in NGOs and CBOs working on HIV/AIDS? What factors encourage PLHA to get involved in NGOs and CBOs working on HIV/AIDS? In addition, NGO service providers were asked, in relation to PLHA involvement in their own organizations: what factors limit PLHA involvement in your organization? What factors encourage PLHA to get involved in your organization? HIV-positive service providers were also asked how they got involved in their organization in order to conduct an in-depth analysis of their life stories.

The researchers classified the data from transcripts of interviews and focus-group discussions, and listed the limiting and enhancing factors mentioned by the respondents from NGOs and key informants outside the participating NGOs. Factors were classified into three categories:

- **Individual factors**

These include characteristics of PLHA who are or who could be involved, such as health, education and skills.

- **Institutional factors**

These include characteristics of the organization in which PLHA are involved or willing to be involved, such as institutional policy, structure and management.

- **Social factors**

These include characteristics of the society and community in which the organizations operate, such as the level of stigma and discrimination towards PLHA. “Social” is used with a broad meaning and includes cultural, political and economic aspects.

Researchers analyzed how many times each effect was mentioned (frequency).²⁸ The opinions expressed by respondents and frequencies were compared to data collected through other means, such as life stories and observation.

6.2 Stigma and discrimination *versus* family and social support

Fear and reality of stigma and discrimination limit involvement

Stigma and discrimination, and fear of stigma and discrimination, were the limiting factors most frequently mentioned in all four countries, regardless of HIV prevalence and level of response to the epidemic.

We have people who cannot be involved due to the simple fact that they may be visible, people may find out about their positive serostatus in their workplace or their social circle.

(HIV-positive service provider, Siempre Vida, Ecuador)

It is vital that HIV-positive people lose the fear of being identified because it is fear that limits their involvement in all the activities. Once the fear is lost, there are no difficulties getting involved, whether it is giving testimonies, doing counseling or whatever; the fear is not there any more. But if this barrier is not overcome, this self-discrimination and not coming to terms to being HIV positive, there will be always lots of barriers that the person constructs herself, because it's not always society that puts obstacles.

(HIV-positive man, service provider, Fundación Siempre Vida)

Fear of stigma and discrimination is linked to **widespread stigmatization of HIV/AIDS and negative social attitudes towards PLHA**. As described briefly in Chapter 3, PLHA are highly stigmatized in all four countries, because of the association of HIV/AIDS with “immoral” behaviors and specific population groups, such as sex workers or homosexuals, and misconceptions about how HIV is transmitted and about AIDS. Stigma has sometimes been reinforced by negative messages from public awareness campaigns, such as “*What are you ashamed of: using nirodh (condom) or acquiring AIDS?*” and “*Nothing is left when you get AIDS*” in India.

There were reports from all four countries of PLHA experiencing stigma and discrimination in various settings. Sometimes PLHA have been **rejected by their family and community**. As a

²⁸Frequencies are presented and analyzed in detail in the final study reports produced for three of the participating countries: Ecuador, India and Zambia.

result many PLHA do not tell their family that they are HIV positive. They also fear that relatives might not be able to keep this information confidential.

I had a girlfriend [with] whom I was in love and had planned to marry. She was not positive. When I disclosed my HIV status to her ... she went and put forward a complaint in the police station and the place that I work.

(Male PLHA beneficiary, Salvation Army, Mumbai, Maharashtra, India)

They [PLHA] are afraid that the family might tell other relatives, who might tell some other relatives, and in this way the news might spread in the entire community. So, this fear of stigma and discrimination exists.

(PLHA service provider, Salvation Army, Mumbai, Maharashtra, India)

There are also examples of **discrimination at school and in the workplace**, especially in Ecuador and India.

I have not told my gharwali [brothel owner] ... She will throw me out of the brothel ... Where will I earn?

(HIV-positive sex worker, beneficiary, CCDT, Mumbai, Maharashtra, India)

Where I work there was a boy who was HIV positive. Nobody sits with him or gives him water when he comes to the canteen. Nobody touches his glass.

(PLHA beneficiary, Salvation Army, Mumbai, Maharashtra, India)

Regrettably, in Guayaquil and all over Ecuador it is mandatory to be tested for HIV in order to get work anywhere. Well, I have always worked in bank institutions and they told me I had to be tested, and because of this I couldn't get work.

(HIV-positive service provider, Fundación Siempre Vida)

At the moment I am by myself with no job. They kicked me out of my job after they found out about my status and now I don't have the means to be able to survive. In the neighborhood, they always find out where I am working and try and get me tossed out [of the job]. My sisters, my two sisters, who have nothing to do with my status also got kicked out of their jobs. I don't know who it could be making the phone calls, who could be causing all the trouble.

(HIV-positive woman, Ecuador)

Discrimination by health professionals appears to be a particular problem in Burkina Faso, Ecuador and India.

As I was about to give birth the doctor told me that he was going to tie my tubes because I wasn't going to be able to have any more children seeing that I am HIV positive ... Without consulting with me and without asking my husband, they performed the ligature. The doctor ... was one of the doctors that treated me really badly. One day he came to me and said: "You have HIV, live your life and leave us to live ours."

(HIV-positive woman, service user, Fundación Vivir)

She was in the hospital [a peripheral hospital run by Municipal Corporation of Greater Mumbai, which specialises in treatment of tuberculosis]. She was almost at the AIDS [symptomatic] stage ... I had gone to see her ... So I told the night doctor ... nurse that she has messed and to clean ... [they] said no [to cleaning] ... I said she did not have a bath ... I told the maushi [helper] ... the maushi refused to give her a bath.

(Service provider, CCDT, Mumbai, Maharashtra, India)

They ... cover the dead body [of a PLHA] with the plastic ... This way the society immediately knows that the person has died of this [HIV]. They do not help the family in conducting the last rites.

(PLHA, Maharashtra, India)

In Burkina Faso, India and Zambia, **women are more likely to experience negative reactions** if they disclose their status than men.

When I disclosed my HIV status to my mother-in-law she mentioned that I must have passed the disease to my husband [her son].

(Female PLHA beneficiary, SOFOSH, Pune, Maharashtra, India)

They give birth to the children, they look after the men when they are sick, they are the ones who inherit HIV when the man is no longer around ... and their in-laws come and take everything, leaving them with nothing but HIV and the children.

(A young seropositive man, member, REVS+, Bobo Dioulasso, Burkina Faso)

Because of the existence of stigma and discrimination in their society, **PLHA fear that by being involved in AIDS organizations they may be identified as PLHA** and as a results labeled and discriminated against (see discussion of negative effects of involvement in Chapter 5). Even if they decide to be involved without being visible, they are also afraid that NGOs will not respect confidentiality, stressing that confidentiality about HIV status is a necessary condition for involvement. As described in the previous chapter, the visibility of a single PLHA in an organization may lead to the suspicion by the public that all its members are HIV positive, especially in African countries.

In Africa ... it isn't easy. If people say you are involved in an organization of infected people, you know that you are labeled.

(PLHA, member of one of the participating NGOs, Burkina Faso)

They think that when people see them associating with this group, they will know that they are HIV positive.

(Support group, supported by CHEP, Kitwe, Zambia)

Maybe the strong initiatives are absent. People are busy with their own lives. It could also be they don't want to come out as a positive-people support group for fear of discrimination in society. They don't want to be visible.

(Service provider, Salvation Army, Mumbai, Maharashtra, India)

The degree of concern about stigma and discrimination and the reluctance to be involved appear to be **influenced by social status of PLHA**. In Zambia, respondents explained that PLHA of a higher social status felt less free to disclose because of social pressure to act as role models or because of concerns about compromising their position in society (since HIV/AIDS is associated with “immoral” behavior and with poor, marginalized population groups).

I was thinking to myself what my people were going to say about having a headman who was HIV positive. I thought to myself that it was not going to augur well with my position to be involved with a group of people who associate themselves with those that have HIV and AIDS.

(A member of a care and prevention team working with the Salvation Army Chikankata Hospital, Mazabuka, Zambia)

There was also a perception in India that it is **more difficult for people in rural communities** to reveal their status.

If you are in Mumbai, it is okay. But if you are in the village, the person will not touch you ... including the doctor. The medical officer does not have much knowledge.

(PLHA, Maharashtra, India)

In some settings, **religious beliefs also play a role in stigma**. For example, in Zambia, respondents stressed that the perception that PLHA are “sinners” fuels stigma toward them and makes their involvement more difficult. In the other study countries, religion also has a strong influence in daily life.

We are a Christian nation²⁹ and if one went to disclose to the churches or pastors, that would really shock everybody. It is like HIV/AIDS is equated to sin: that one has evil spirits tormenting him ... In some churches, HIV/AIDS is still being looked at as a punishment from God. That is limiting PLHA to come out in the open.

(Representative from a DHMT, Zambia)

How can an infected person come out in the open and decide to get involved in the delivery of services to those who consider him or her an immoral person?

(Male service provider, Kara Counseling, Lusaka & Choma, Zambia)

As explained in the previous chapter, there is **no systematic link between involvement, even visible, and stigma and discrimination**. However, PLHA involved in CBOs and NGOs in Burkina Faso, Ecuador and Zambia **reported experience of finger pointing, verbal aggression, labeling by the community and in some cases of discrimination**. In India, PLHA involved in participating organizations, including MNP+, have a very limited and selective visibility in order to avoid stigma. In Zambia, PLHA involved in outreach education have experienced stigma and discrimination and, as discussed in Chapter 5, some have been accused of pretending to have HIV

²⁹ The former President of the Republic of Zambia, Dr Frederic Chiluba, officially declared that Zambia is a Christian nation. In fact, as shown in Chapter 2, between 24 and 49 per cent of the Zambian population is Muslim and Hindu.

for financial gain. Lack of community support and appreciation – linked to inadequate knowledge and understanding – is demotivating and also deters other PLHA from becoming involved.

We do experience a lot of problems. Some do not even want to listen to what we have to say, they just start insulting us.
(Support group, CHEP, Kitwe, Zambia)

After a seminar we went to teach others. Some people became violent. We were scared. They didn't want to be talked to about HIV/AIDS.
(Woman living with HIV, service provider, Hope, Ndola, Zambia)

Respondents in Burkina Faso noted that some PLHA were concerned about **being labelled, even by fellow members within NGOs and CBOs**.

The PLHA are afraid of CBO members finding out their serostatus. They are afraid that if this happens they will be marginalized. It is above all the fear of being discovered and of being subjected to stigmatization.
(Service provider, AMMIE, Burkina Faso)

We observed in Burkina Faso and India that it was **particularly difficult to be visible for service providers who found out that they were HIV positive after they had worked with an NGO for some time**. There is a common belief that those who do prevention work cannot get infected themselves, otherwise they have “failed” to do what they preach and may be judged severely by their colleagues as a threat to the credibility of the organization.

It is better to see a positive person get involved in awareness-raising than to see somebody doing awareness-raising who becomes seropositive. Those who do prevention work and then get infected ... they sully the reputation of the organization. People would wonder why those who do awareness-raising work do not protect themselves.
(Service provider, AAS, Ouagadougou, Burkina Faso)

In Ecuador and in India, the study found that sometimes **PLHA were stigmatized because of their sexual orientation**. Although there was a MSM group in one of the participating NGOs in Mumbai, group members were barely visible in the organization.

It is important to note that in some cases, however, experience of **stigma and discrimination** has had the opposite effect on PLHA. For some individuals – in Ecuador and Zambia, for example – it **has been an enhancing factor**, prompting them to help others avoid similar experiences and encouraging them to become more involved in the fight for the rights of PLHA.

Family and social support, reduced stigma and increased acceptance

As already mentioned, despite people's fears, involvement in the activities of NGOs and CBOs does not necessarily lead to stigmatization and discrimination, and not all PLHA experience negative reactions from their family and community. In many settings, fears are not borne out by actual experience, and in some cases, involvement can lead to a decrease in stigma and discrimination,

especially if it is linked with efforts to improve public awareness and advocacy to support PLHA rights and involvement. In several countries, there were examples where involvement had enhanced PLHA integration within the family and the community.

Sometimes **family and community support** has been even **instrumental in encouraging PLHA to become more involved**, and HIV-positive relatives or those affected have themselves become involved. In India, support from family, friends and neighbors was the most frequently mentioned social factor encouraging PLHA involvement.

I have support from my child. She is always behind me.
(Female service provider, CHEP, Kitwe, Zambia)

Actually, for most of the people who are here, their families do not know about their status. For those who know, their family support is quite good as mine.
(HIV-positive service provider, MNP+, Mumbai, Maharashtra, India)

My parents made it easier for me when they accepted my HIV-positive status.
(PLHA, service user, Kara, Lusaka & Choma, Zambia)

My husband used to come here. That is what encouraged me to join the group.
(Woman living with HIV, service user, Hope, Ndola, Zambia)

Support from churches and religious leaders has also encouraged PLHA to become involved. Some churches have preached compassion and care, and this has helped PLHA to speak out as well as to create a more supportive community environment. For example, in Zambia, the Catholic Diocese in Ndola has been instrumental in the formation of support groups, and some PLHA give testimonies in church. In Burkina Faso, NGO and CBO members consider that tackling stigma and discrimination will depend on the involvement of religious and political authorities, which has been relatively limited to date.

Reduced stigma and increased acceptance of PLHA in the community has enabled PLHA in Zambia to participate in service delivery or to become involved in other ways. When PLHA are accepted – usually because of more accurate community knowledge of HIV/AIDS – people begin to appreciate what they do and PLHA in the community are able to act as role models.

What motivates us is that ... sometimes when you go to other places you get encouragement from other people for the education and testimonies we give. That encouragement makes us want to continue.
(PLHA service provider, Kara Counseling, Lusaka & Choma, Zambia)

We gave a talk at the state university and since then people say “Hi! How are you doing?” when they see me. They don’t point their fingers at me and say, “There goes that guy who has AIDS.”
(HIV-positive man, service provider, Fundacion Siempre Vida)

6.3 Being involved: an individual choice

6.3.1 From denial to acceptance: a personal journey

Difficulty in accepting their HIV status and the possible consequences of HIV infection can be a reason for PLHA not getting involved. In Zambia, this was described as “denial”, and in some cases attributed to the unwillingness of PLHA to make changes in their lifestyle. However, stigma and discrimination, and lack of effective counseling to help PLHA accept and cope with their HIV status, may also explain denial.

Fear of stigma and discrimination is also a **barrier to uptake of HIV testing**. In Burkina Faso, for example, those who suspect they may have HIV are reluctant to take a test – the fear of finding out that one is HIV positive often prevails over the desire to know the truth – and this is exacerbated by lack of access to appropriate counseling services.

Here, whilst PLHA are not suffering from any illness, they refuse to recognize their HIV status. Even someone ill with AIDS, and who knows full well that he is suffering from this sickness, will never tell you he is infected. When talking of his/her sickness, he will tell you it is a jinx.
(Community assistant, AMMIE, Ouahigouya, Burkina Faso)

Not all PLHA want to be reminded that they are HIV positive through involvement with NGOs and CBOs working on HIV/AIDS.

The ‘**mirror effect**’, described in Chapter 5, can also deter sustained or greater PLHA involvement, especially if asymptomatic PLHA are not well prepared to deal with other PLHA who are ill.

It has been difficult ... you may set out to visit someone and when you reach that person's home they tell you about their problems, which makes you think about yourself and what will happen to you as well.
(PLHA service provider, Hope, Ndola, Zambia)

Conversely, personal acceptance of HIV status and the desire to be free from the burden of secrecy – linked to positive effects on psychological health – was also an important motivating factor for involvement. In India, respondents mentioned self-confidence and a sense of not being alone as factors motivating them to get involved.

One is free when he or she becomes visible. The fact that you are not visible means that you are not at peace with yourself ... you will always be worried about your situation and scared that somebody may come to know about your status.
(Participant of a support group, PLHA, CHEP, Kitwe, Zambia)

6.3.2 Receiving versus giving: Motivation for involvement

It is important not to think you are the only one in need, but that there are many others who need much more support. That is what I like about the visits ... helping other people.

(HIV-positive woman, service user, Fundación Dios, Vida y Esperanza)

Many PLHA approach NGOs to receive information, care and support, not to give their time to deliver services. In all four countries, service providers of NGOs thought that most HIV-positive users of their services lacked the motivation and interest to be involved. However, as the discussion of poverty below highlights, many PLHA cannot afford to work voluntarily.

Dependence on NGOs is also a factor limiting individual and community involvement. Some do not seek to break this dependence and perceive that they do not need to play an active role because NGOs and CBOs are providing services for PLHA. However, sometimes PLHA do not receive the support needed to empower and enable them to develop greater independence.

We are trying to support the support group ... and if they come up with new ideas, we encourage them ... However, the initiative should come from them and then we can proceed to encourage them. We on our own are not taking the initiative.

(Staff member, Salvation Army, Mumbai, Maharashtra, India)

An important factor encouraging PLHA involvement is the **desire to support other people** with HIV and to fight the epidemic by educating others. As noted above, personal experience of stigma and discrimination had often motivated PLHA to help others.

My wife and my sister died of AIDS. I thought my enlightenment on the dangers of HIV would reduce the spread of the disease.

(Man living with HIV, service provider, Kara Counseling, Lusaka & Choma, Zambia)

It was observed in Burkina Faso, Ecuador and India that PLHA formed organizations to provide services that they thought were not delivered by other organizations and would be better adapted the needs of HIV-positive people. The **identification of gaps in the availability and quality of services offered to PLHA has been a decisive factor** in the mobilization of HIV-positive people and their involvement.

Only three of the participating NGOs were church-based organizations. However, in most NGOs, service providers, whether they were HIV positive or HIV negative, had strong religious faith. Their **religious beliefs have provided encouragement to a significant number of PLHA** in their personal journey and decision to get involved.

Although motives of PLHA to get involved are mainly altruistic, other factors include personal fulfillment and, **in some cases, financial and material interest**, as explained later in this chapter.

6.4 Development, empowerment and involvement

6.4.1 Lack of access to care and poor health are major obstacles to involvement

Lack of availability and accessibility of VCT, in addition to the fear of stigma and discrimination, means that few people know that they are HIV positive. In Zambia and Burkina Faso, access to testing is limited and most people cannot afford to pay for an HIV test.

The majority of PLHA find out that they are HIV positive when they become sick. **Poor health** was cited in all four countries as a factor that makes involvement difficult or that limits involvement to certain types of activities or to activities that are not too mentally or physically demanding.

I would not like to get involved in the agency. We do not have that much strength. If I had energy I would have worked in the agency.

(Male PLHA beneficiary, Salvation Army, Mumbai, Maharashtra, India)

Inadequate care provided by the public health system, especially in Burkina Faso, India and Zambia, **contributes to the poor health of PLHA**. Even in Ecuador, where access to care is much better, many respondents, including policymakers and health professionals, noted that the lack of national policies on access to care for HIV-positive people is a hindrance because most PLHA do not feel that their right to care is guaranteed.

In Burkina Faso and in Zambia, service providers noted that **PLHA often wait until they are very sick or dying before they seek services from NGOs**. As a result, some HIV-negative service providers perceive that PLHA can only be involved as beneficiaries. Similarly, in Ecuador, many respondents felt that the health problems of PLHA may make their involvement difficult and that only asymptomatic PLHA can be actively involved.

All our beneficiaries are people in the sick stage of the illness, so it is difficult for them to be involved in the activities, even if they want to be.

(Community assistant, AMMIE, Ouahigouya, Burkina Faso)

They will only accept to register when they are completely finished and almost dead.

(Participants in a group of PLHA and affected people, supported by CHEP)

If some people don't turn up at the organization it is because they have serious health problems ... If I don't come to meetings it is because I am ill.

(PLHA member, ALAVI, Ouagadougou, Burkina Faso)

High mortality and morbidity rates among PLHA affect the sustainability of their involvement, and can, as a result, affect the activities in which they are involved and organizations whose members are mostly PLHA or whose leaders are HIV positive, as described in Chapter 5.

Higher rates of illness and death among PLHA, and the impact of this on service delivery or NGO costs, **may limit the willingness of some organizations to involve or employ more PLHA**.

We had a PLHA helper ... at the drop-in-centre ... but she would go on leave ... often ...
(Service provider, CCDT, Mumbai, Maharashtra, India)

In India, respondents expressed concerns about the **risk of exposure to infections** during activities such as hospital visiting and potentially adverse effects on the health of PLHA.

We used to send PLHA to visit other PLHA admitted in hospitals. But then we found it would be unwise to do so because there is a lot of infection in the hospital environment and we would be exposing them to these infections. So now they are not going anymore.
(HIV-negative service provider, Salvation Army, Mumbai, Maharashtra, India)

However, many of the PLHA involved in the NGOs that participated in the study cannot be described as asymptomatic. What makes their involvement possible and sustainable is access to treatment.

Access to medical treatment and care enhances involvement

As described in Chapter 5, one of the benefits of involvement is **better access to care and treatment**. It is a **strong motivating factor for PLHA involvement**. In Burkina Faso, being able to obtain medical care was cited as an important reason for involvement by PLHA.

We know that those who come to us in the sick stage of their illness come in search of medicines. They hope to find treatment and to be immediately cured.
(A leader of REVS+, Bobo Dioulasso, Burkina Faso)

Many respondents in Burkina Faso perceived that more PLHA would get involved if membership of a CBO enabled them to have access to antiretroviral treatment, and see increasing access to such treatment as an important role for NGOs and CBOs.

Some PLHA who were informed of the possibility of having antiretrovirals joined ALAVI or other CBOs. In our country it is difficult for individuals to gain access to antiretrovirals.
(One of ALAVI's leaders, Ouagadougou, Burkina Faso)

In Ecuador, the majority of PLHA service providers involved in the NGOs that participated in the study have **access to antiretroviral therapy**, mainly provided by the social security system, which reduces their susceptibility to illness. In Burkina Faso, some of the most active members of the NGOs had access to combination therapy through solidarity networks. In Zambia, some of the NGOs made ARVs accessible to their HIV-positive employees.

Access to free testing and counseling was an important factor for some PLHA in Zambia. NGOs and CBOs in Burkina Faso also identified the need to improve access to HIV testing and counseling through providing counseling training, working in collaboration with existing testing facilities and

community-based organizations, reducing the cost of testing, improving referrals and involving PLHA in encouraging people to be tested, supporting them while they wait for their result and informing them of their serostatus. In Bobo Dioulasso, for example, there are close links between REVS+ and the testing and counseling center. Some counselors at the center are active members of the CBO and refer people with a positive result to the organization, where they can meet other PLHA.

Lots of us did the free HIV test and were happy because we didn't have the money to pay for the test.

(Woman living with HIV, service provider, Hope, Ndola, Zambia)

6.4.2 A long way to involvement: the limitations of poverty

Most PLHA beneficiaries of NGO services in all four countries are from **low-income groups and, because they are poor, need to earn an income**. This prevents them becoming involved in activities on a voluntary basis. However, those who most need employment with NGOs are often the least likely to be engaged in salaried positions, except as support staff as in India or Zambia (*inclusion*). Most PLHA involved in service provision or organizational management have completed secondary education and are from better-off socio-economic groups in society.

There is no food, there is nobody working, so what do they do? This limits their input because they have to look after their own families at the same time...

(Male service providers, CHEP, Kitwe, Zambia)

The majority of PLHA are penniless. They think that by joining a NGO they will get help on all levels, whether materially, financially, morally or medically.

(A member, ALAVI, Ouagadougou, Burkina Faso)

The majority of people living with HIV that are part of the organization are people with limited financial resources and limited education, therefore they are able to help but only up to a certain point.

(HIV-negative woman, service provider, Funcacion Dios, Vida y Esperanza)

Some respondents, particularly in India, perceived that involvement was about providing jobs or money. **When expectations of material support by NGOs are not met, this can discourage sustained involvement**. In one organization in Zambia, for example, PLHA are not necessarily offered a job after training as counselors, so some drop out of training when they realize they will not be employed.

PLHA who visit the agency want to do some kind of job ... They are ready for involvement if employment and other benefits are provided to their family.

(PLHA beneficiary, MNP+, Mumbai, Maharashtra, India)

A lot of our members were coming from very far and most of them were unemployed ... they were hoping to benefit in some way or another, but there was nothing to take back home.

(PLHA service provider, Hope, Ndola, Zambia)

They share their experiences and want financial aid from the agency ... this is not the agency's objective. We tell them we can't do anything; we refer them ... It is difficult to make them understand.

(A staff member in charge of the forum for women, MNP+, Mumbai, Maharashtra, India)

Poverty contributes to poor health, which, as described above, is also a factor limiting PLHA involvement. For example, PLHA in Zambia reported that they could not afford to buy drugs or to put into practice what they had learned about a healthy diet.

In all four countries, **lack of money to cover transport costs**, either to travel to the NGO or to carry out activities, was cited as a factor limiting involvement. Inadequate public transport is also a problem, especially in rural areas. Many PLHA reported walking long distances to access or provide services. This is not feasible for those who are sick and can adversely affect the health of those who are not sick. In India, respondents cited distance between the organization and their home as a limiting factor.

We stay far off, so going and coming costs us a lot of money ... sometimes we tell the agency that we are not able to come.

(Female PLHA beneficiary, CCDT, Mumbai, Maharashtra, India)

For home visits or for some meetings, if people have transport provided there is no problem. But once transport is not provided, only those who are convinced come. When they know there is some support, they come. This is perhaps linked to the economic situation of the country: there is extreme poverty, it is difficult ... It is understandable.

(A member, ALAVI, Ouagadougou, Burkina Faso)

As a result of the poverty of most PLHA, **financial and material benefits** – for example, the opportunity to earn an income or to receive food or medicines – are an **important incentive for involvement**, unlike the situation in high-income countries, where financial reward is usually not an important motive for involvement in ASOs and in NGOs. However, it is important to distinguish between PLHA who want to join an organization only because of the potential benefits, either real or imaginary, and PLHA who have been working on HIV/AIDS for some time on a voluntary basis and at some point consider being employed if the opportunity arises. For these PLHA, there is also the issue of their skills being recognized by NGOs and remunerated adequately.

The vast majority of people who we work with are from extremely impoverished backgrounds ... so for them, the primary motivation is financial.

(Service provider, Kara Counseling, Lusaka & Choma, Zambia)

I am ready to be visible in the media ... provided they [service providers] give me money ... I will tell that I am HIV+.

(PLHA beneficiary, CCDT, Mumbai, Maharashtra, India)

If I get job and money to fill our stomach ... then I will get involved.
(Male PLHA beneficiary, MNP+, Mumbai, Maharashtra, India)

On a different level, involvement of PLHA from higher-income groups is limited because of what they perceive as a risk to their social status. In Ecuador, some HIV-positive professionals also claimed that it was difficult for them to find enough time after work to commit seriously to any form of voluntary work.

6.4.3 Knowledge is power and involvement

Lack of education, training and skills were identified as one of the major factors that limit involvement of most PLHA, and conversely the more education and skills PLHA have, the *greater* their *involvement*. **PLHA who are poor are also less likely to have had access to formal or vocational education.** In India, illiteracy is a particular problem and creates a gap between PLHA and service providers who are educated. In addition, many PLHA cannot afford to pay for training provided by NGOs when it is not free, as in some organizations in Zambia.

The major problem that I see in the organization I work with, most of the people that come forward tend to be socio-economically disadvantaged. So they don't have the resources to, for example, do the training.
(Director, Zambian NGO)

Inadequate education and training is not a major obstacle to *access* or *inclusion*, but definitely limits *participation* and *greater involvement* in NGOs and CBOs, because these types of involvement **require levels of knowledge and skills that go beyond personal experience of living with HIV/AIDS.** For example, in Zambia, over 75 per cent of service providers in the four participating NGOs had completed higher education. Only one had completed only primary education. Inadequate formal education, training and skills were frequently mentioned as factors limiting PLHA involvement in activities other than outreach education, as well as a constraint on the entrepreneurial activities of support groups. Similarly, in Burkina Faso, poorer and less educated PLHA lack the skills required for formal involvement in prevention and care activities. Most PLHA who are actively involved in NGOs and CBOs are health and social workers or have completed secondary schooling.

Unless I am sent out for further education, there is no way I can take that post.
(PLHA service provider, Kara Counseling, Lusaka & Choma, Zambia)

Limited skills and knowledge about HIV/AIDS also contribute to **PLHA lack of confidence about their ability to become involved or visibly involved.** For example, in Zambia, some PLHA reported that they do not feel equipped to go public or become involved in activities that require a specific knowledge of HIV/AIDS. In India, PLHA service providers identified areas where they lack skills and, hence, are not comfortable with visible involvement.

If I become visible I will be asked to speak or address meetings ... or forums ... I do not have the skills.
(Male PLHA service provider, MNP+, Mumbai, Maharashtra, India)

We are not so educated ... Sometimes I speak but I feel hesitant ... I do not know how to speak.

(Female PLHA beneficiary, CCDT, Mumbai, Maharashtra, India)

Previous experience in other HIV/AIDS organizations, self-help groups and networks is an important enhancing factor, providing PLHA with skills and experience for involvement.

The opportunity to obtain increased knowledge about HIV/AIDS and to improve capacity through **information and training provided by NGOs** was an important factor encouraging involvement.

6.4.4 The influence of gender on involvement

Gender inequalities impact women's *access* to services. In addition to the particular difficulties facing women who are open about their HIV status, there are cultural, social and economic reasons that make it difficult for women to access services. For example, in some areas of India, women traditionally do not go outside the home. In Burkina Faso, many women are financially dependent on men, and priority is given to treatment and care of men who are ill.

In some rural areas, when some women discover their HIV+ status, they may not necessarily come out. For men it is easier. Women are usually expected to get permission from their husbands.

(A representative, Zambia Integrated Health Program, Zambia)

In our house ... women are not allowed to go out and work ... we leave the house only to visit the doctor, relatives, take children to school ... but not work.

(Female PLHA beneficiary, CCDT, Mumbai, Maharashtra, India)

When I am ill my partner refuses to pay for medicines.

(A young women with HIV, supported by ALAVI, Ougadougou, Burkina Faso)

Gender roles also mean that women have less time to take part in the activities of NGOs or to work as volunteers. In all four countries, domestic, household and childcare responsibilities limit women's opportunities for involvement. In India, for example, widows and women who have to take care of a sick husband have additional responsibilities. It may also be more difficult for women to work as service providers (*participation*) or in management positions (*greater involvement*), because women generally have fewer educational and training opportunities and are therefore less likely to have the required qualifications and skills.

Some PLHA may not be free to make decisions about their time. This applies especially to female sex workers in India, who are "owned" by brothel keepers and have little control over their lives.

Box 6.1 Socio-demographic characteristics of PLHA involved

In the *inclusive* type of involvement, the majority of PLHA involved are women, except in Ecuador where there are as many men as women. In Africa and India, many of the women have no formal education or only primary education. A lot of them are widows with children. Men have a primary level of education. They usually belong to low-income groups.

PLHA who *participate* more formally in service delivery and management (*greater involvement*) are more likely to be men in Ecuador, India and Zambia. Only in Burkina Faso are there more positive women than men visibly involved in the care and support, outreach education services and decision-making processes of NGOs.

In Ecuador, nearly half of the men identify themselves as homosexual or bisexual. In India, MSM involved are a minority and are not visible.

Men and women have completed secondary education and some of them have been to university. In Burkina Faso, a significant number of PLHA were also health and social workers, particularly nurses. In general, they are middle-income professionals, except in Ecuador where many PLHA run their own business in the informal sector and have limited financial resources.

The age of PLHA involved ranges between 25 and 45 years.

Comparisons between mobilization and involvement of PLHA in high-income countries (used as a reference in terms of PLHA activism and the important role PLHA have played in programs and policies since the very beginning of the epidemic) and in low-income countries should be made carefully. Any strategies to promote GIPA in developing countries should take into account the social context, especially poverty and its effect on PLHA, their families and communities, and society in general. Poverty prevents the mobilization and involvement of those who are most affected by HIV/AIDS, and promoting involvement of PLHA is also about fighting poverty.

6.5 Organizational factors that limit the involvement of PLHA in NGOs

Many PLHA are not involved in NGOs and CBOs because of their personal circumstances and the individual and social factors highlighted above. However, the characteristics of the organizations themselves can also be obstacles to PLHA involvement.

6.5.1 Inadequate resources to support PLHA involvement

Lack of resources – mainly financial resources – to support the involvement of PLHA was an organizational limiting factor mentioned in all the countries. In Burkina Faso, for example, respondents cited the limited capacity of NGOs and CBOs to provide medical care and material support to their “members”. In India, NGOs mentioned lack of funds to provide employment opportunities, reimbursement of travel expenses for PLHA from rural areas, and other forms of financial support. In Ecuador, NGOs explained that the lack of funding is a result of the stigmatization of organizations where PLHA are visible by national donors. It is also related to the low priority of HIV/AIDS as a public health problem in Ecuador (see Chapter 5).

At times, when NGOs refer cases to us, they send the people with the impression that all your material needs will be fulfilled: like you'll get rations, you'll get medical bills. That is the kind of impression that they come to us with. So it is very difficult to initiate any other discussion with them because they say: "Are you going to give me money for this or not? ...I do not want anything else. I know everything about HIV/AIDS" ... It is very difficult to break the ice with them and if we are not fulfilling those needs, they won't come back to us.

(Service provider, CCTD, Mumbai, Maharashtra, India)

They don't get a salary, just a small allowance to enable them to travel here and there and buy lunch ... there are no finances right now.

(Service provider, Kara Counseling, Lusaka & Choma, Zambia)

What we must remember is that most of our women really are from the lower-income group and unless their basic needs are satisfied, they can't see issues of forming a self-help group.

(Service provider, CCTD, Mumbai, Maharashtra, India)

PLHA who visit the agency want to do some kind of job ... they are ready for involvement if employment and other benefits are provided to their family.

(PLHA beneficiary, MNP+, Mumbai, Maharashtra, India)

Reducing economic benefits can also be a disincentive to involvement.

Earlier they used to give us Rs 15000 and groceries, school bags and clothes for children ... Now they do not give us much ... That is why many women have stopped coming to the agency.

(PLHA beneficiary, member of support group, Maharashtra, India)

Those who graduated have not been supported, so they stopped because they found coming for meetings a waste of time ... time that could be used for other businesses.

(Woman living with HIV, service provider, Hope, Ndola, Zambia)

Inability to meet the needs of PLHA is also related to the wider context, in particular the **relative scarcity of NGOs providing services for PLHA** and the **inaccessibility of NGOs to PLHA**, especially those living in rural areas.

Some NGOs in the four countries perceive **the costs of involving PLHA to be high**. While the study shows that initiating, promoting and sustaining PLHA involvement does have costs as well as benefits for organizations, the main additional costs are associated with providing training and with providing medical treatment to HIV-positive people employed by the organization in contexts where health services are inadequate. Expenditure appeared to be higher in organizations where the study observed *participation* and *greater involvement* or involvement ranging from *access* to *greater involvement*.

It appears that some of the participating NGOs do have the financial capacity to support greater PLHA involvement than at present, but **have not allocated available resources to provide incentives for PLHA involvement** or to sustain involvement.

6.5.2 Judgmental attitudes of management and staff and discriminatory policies

Judgmental and discriminatory attitudes among HIV-negative management and staff of NGOs were cited as a barrier to PLHA involvement in Ecuador and Zambia. For example, one key informant, who is HIV positive himself, explained that he has noticed that in NGOs, as in the rest of society, some people still fear direct contact with PLHA.

Some people are not comfortable, they would rather deal with papers, publish AIDS books and AIDS magazines ... but not get in touch or too close with people who have AIDS.

Counselors are part of society. If something is stigmatized, and a counselor lives in that situation, they are part of the stigma. Maybe we don't know it yet as counselors ... maybe we are part of this force that puts them off.
(Counselor, Kara Counseling, Lusaka & Choma, Zambia)

They haven't even been able to manage their lives without AIDS, therefore managing their lives with AIDS is even harder.
(HIV-negative woman, member of one of the participating NGOs)

In India, one NGO has a **policy of non-involvement of PLHA** in some areas of activity such as childcare, because of concerns for the health of the children.

I don't think we would be able to employ that person in a childcare position because of our concern for the child. The childcare workers feed them, bathe them, look after them, treat them and they are totally involved all the time. At this point of time I don't think that we will employ any positive person for childcare services.
(Service provider, SOFOSH, Pune, Maharashtra, India)

6.5.3 Failure to consider PLHA potential and offer opportunities for involvement

In general, the study suggests that **NGOs and HIV-negative service providers often have a limited vision of areas where PLHA can be involved**. In participating NGOs in Zambia, PLHA reported that opportunities for involvement were often limited to outreach education and awareness-raising activities, and that management did not consider them for other roles. Conversely, in India PLHA are most likely to be involved in informal support rather than in prevention, education or advocacy, except in the local PLHA network.

HIV-positive patients are not involved in our organization because we don't have well-defined plans for them, and as a result of this there hasn't been the opportunity to incorporate them in the NGO.
(HIV-negative woman, service provider, Fundación Esperanza)

In some organizations, service providers, especially **health professionals, perceive that PLHA do not have the ability to contribute to services and activities because they lack education and skills.** There is also a competition between the expertise of health professionals, based on their academic background and work experience, and the expertise of PLHA, based on their experience of living with HIV. Health professionals are reluctant to recognize this as a valid expertise. This attitude limits opportunities for PLHA involvement in the implementation of simple tasks or support to service providers who are health professionals (*inclusion*).

There is a young woman who has nice grades ... but she is just doing outreach program. She is just giving personal experience. Our certificates need to be considered. We need to be asked what we think we can do in future.

(PLHA, service provider, Kara Counseling, Lusaka & Choma, Zambia)

Some respondents in India and Zambia had the perception that NGOs were unwilling to engage PLHA formally, including those with appropriate education and skills, or do not recognize or use the skills of PLHA service providers. For example, respondents in India felt that PLHA service providers are given fewer opportunities to represent the organization externally. In Ecuador, several PLHA mentioned that **they do not want to be used as tokens by NGOs** who need credibility and are seeking funding. These are characteristics of organizations where PLHA mostly have access to services and a few PLHA are *included* in the activities (*inclusion*).

They [the NGOs] want people living with HIV in their organizations so that they can say, "My organization involves HIV-positive people" as though they "own" HIV-positive people. When HIV-positive people want to form organizations or networks where they are totally in control ... it is when they [the NGOs] put limits on them, they disable them because they think they are going to leave and they would lose their guinea pigs.

(Service provider from one of the NGOs, Ecuador)

The type of organization is linked to attitudes of service providers and also influences potential opportunities for PLHA involvement. For example, charitable or welfare models of organization, where services are provided by health or social care experts, offer fewer opportunities for involvement of non-professionals. Such organizations may take a more paternalistic approach and view PLHA as passive recipients of services. PLHA involvement is generally limited to *access* or *inclusion*, where PLHA are beneficiaries and take part in supporting activities and services as helpers or volunteers.

6.5.4 Failure to promote PLHA involvement

In India, **lack of information about opportunities for PLHA** to be involved in activities was the organizational limiting factor mentioned most frequently. PLHA who access services are not always told by service providers what services the organization provides or how they can become more involved, and there is little or no orientation for those willing to get involved. Respondents in Burkina Faso, Ecuador and Zambia also reported that some NGOs do not actively publicize their services and activities or potential opportunities for PLHA to become involved. In Zambia, poor linkages and referrals to other organizations also deny PLHA information about opportunities for involvement.

If you do not know that there are NGOs there to help PLHA, it's a bit difficult to consider joining a NGO.

(Member, ALAVI, Ouagadougou, Burkina Faso)

Most NGOs do not have mechanisms to inform and orient people who are willing to be involved on a voluntary basis in their activities, particularly their HIV-positive service users. As a result, these human resources are underused or lost.

They suggested to me that I could come and help, but when I came they didn't know what I could do ... I don't know what I can do or how I can help.

(HIV-positive service user, Quito, Ecuador)

I want to achieve something ... to do something ... but got nobody to guide me. I asked them [the authorities at SOFOSH] but they ignored me.

(PLHA beneficiary, SOFOSH, Pune, Maharashtra, India)

Another organizational factor limiting involvement is the **failure to provide training and other skills development opportunities for PLHA**. There is also a tendency to provide PLHA with basic knowledge of HIV/AIDS but not with the technical skills necessary to deliver services. This may be because of perceptions that it is not worthwhile training PLHA because of higher levels of illness and death or because PLHA cannot sustain regular involvement. Health professionals may be also unconsciously reluctant to transfer their skills to PLHA and share their knowledge and their power. In many cases, only a few individuals – always the same ones – are sent to workshops. Lack of training does not limit PLHA *access* or *inclusion*, but does limit *participation* and *greater involvement*.

The other thing that makes some members not to be active is because they have not had any opportunity of attending any workshops or seminars so that they can be exposed and have a chance to meet other PLHA from different areas of the country and the world at large. If only the seminars could be held at local level, so everyone is involved.

(Participant, support group of PLHA, CHEP, Kitwe, Zambia)

The problem is I am not trained and people do not think about taking someone who is HIV positive for training. They will only send you for a simple workshop.

(PLHA service provider, Kara Counseling, Lusaka & Choma, Zambia)

In the beginning everyone is enthusiastic, but later it fizzles out. So, keeping up the motivation level [is difficult], not only among the PLHA but also among social workers, because they are also likely to feel frustrated that "We trained four. Now only one is coming or no one is coming." Then they do it all over again. Then they are going to drop out. Then a stage comes when the social worker feels that it is much better that she does it herself; why bother about anybody else.

(PLHA service provider, SOFOSH, Pune, Maharashtra, India)

None of the NGOs and CBOS that participated in the study, even those who have been more active in promoting PLHA involvement, **had institutional policies that clearly spell out what they wish to achieve in terms of involvement** or what strategies will be employed to achieve this.

6.5.5 Lack of organizational policies that take gender and sexuality into account

The study found that **service providers of most NGOs think that PLHA have the same needs, regardless of gender and sexual orientation**. Consequently, NGOs fail to promote organizational policies that include a gender perspective and to provide services that meet the specific needs of, for example, heterosexual women and men, or homosexual/bisexual men. This acts as an obstacle to accessing services for many PLHA, who feel that they do not receive services adapted to their needs. In Burkina Faso and Ecuador, many positive women said that they would like to receive more information on prevention of mother-to-child transmission. Very often they are only told to avoid pregnancy, which is difficult for many women, especially in Africa where the social status of a woman depends on her capacity to have children. NGOs are usually concerned about potential discrimination against specific groups of positive people, if the involvement of these groups in the organization were to be highlighted. But by not addressing their specific needs another form of discrimination is created.

MSM in Ecuador said that the contents and language of prevention material were not always adapted to their specific needs in terms of sexuality. They sometimes preferred not to mention their sexual orientation to service providers because **they feared discrimination**. In fact, two of the participating NGOs acknowledged that some of their members might have **homophobic attitudes** and said that gay men or transvestites, for example, were referred to other NGOs who were used to working with these populations.

We have a different mentality to straight men, and so if they involve us in the chats we take it as chit chat ... but if they give us something specific to our needs, we will take it more seriously and we will be able to undertake prevention [activities] and help other people.

(Homosexual HIV-positive service provider, Siempre Vida)

There are gay men who aren't open about their sexuality, in fact they cover it up, and within the organization give the impression that they are heterosexual.

(HIV-negative man, service provider, Fundación Vivir)

In general, it was observed that many PLHA in Ecuador and, to some extent, in Burkina Faso expressed a **preference for being counseled by people of the same sex or sexual orientation**.

Gender balance also influences the capacity of NGOs to meet the needs of PLHA and to encourage their involvement. Staff at one of the participating NGOs in India, where most service providers are women, noted that it is more difficult to involve men. In contrast, another NGO has a majority of male staff and, perhaps unsurprisingly, only 5 per cent of the beneficiaries are women. The same observation was made in one NGO in Ecuador and another one in Burkina Faso. It was noted that women are less likely to be involved in organizations seen as male-dominated.

Few NGOs have considered ways in which they could provide practical support to enable more HIV-positive women to be involved; for example, through provision of childcare facilities.

6.5.6 Organizational stigma and secrecy

As discussed in Chapter 5 and earlier in this chapter, **stigma associated with organizations perceived to be PLHA NGOs may deter involvement of PLHA** who do not want to disclose their HIV status.

The organization is associated with HIV. For example, when I joined, some people thought I was HIV positive. In essence, people believe that everybody associated is HIV positive.

(HIV-negative service provider, Kara Counseling, Lusaka & Choma, Zambia)

In order to avoid stigma, in most NGOs the HIV status of PLHA involved in the organization is confidential information, shared by a limited number of people. Although **confidentiality** is important, as we will explain in the following section it **can have negative effects when it becomes a policy of secrecy**. Two organizations in Ecuador and India realized, for example, that they did not give the opportunity to their HIV-positive service users to meet other PLHA because they wanted to maintain strict confidentiality rules. However, several beneficiaries expressed the desire to know other positive service users and to be known by them.

6.6 Organizational factors that enhance the involvement of PLHA in NGOs: How to build a supportive environment

The extent to which PLHA are involved depends on the type of organization, including how and why it was established and the extent to which the organization gives priority to involvement of PLHA. The study found that PLHA involvement was significantly greater in rights-based organizations, particularly those created by PLHA themselves with a self-help approach, and development organizations that focused on the empowerment of the community they supported. In some cases, the emphasis of organizations can also change when members of an NGO discover that they are seropositive, as was the case with AAS in Burkina Faso.

While a supportive environment for PLHA involvement may not arise in the same way in all organizations, the study identified three broad categories of organizational factors that contribute to building an environment that is conducive to PLHA involvement. These are provision of material support, psychological support and information and skills building (see Box 6.2).

Box 6.2 What is a supportive environment for PLHA involvement?

Material support

- For PLHA who are employed, in addition to their salary:
 - access to care, particularly drugs, through insurance schemes or access free of charge to health facilities;
 - flexible sick leave.
- For PLHA who are not employed – for example, volunteers:
 - reimbursement of expenses related to their involvement – for example, money for transport;
 - incentives when they are involved in activities – for example, meals;
 - referrals for free treatment and care.

Psychological support and non-discrimination

- No mandatory testing for recruitment.
- PLHA are not forced to disclose their status.
- HIV status is kept confidential.
- Non-judgmental attitudes of staff and management, regardless of gender, sexual orientation, social background.
- Positive attitudes of staff and management towards active PLHA involvement as service providers.
- Friendly atmosphere.
- Availability of counseling.
- Peer support made available within or outside the organization.

Information and training

- Information for service users on training opportunities and referral to activities with which they can become involved.
- Providing up-to-date information for PLHA service providers.
- Pro-active training in coping with HIV status and positive living, basic facts about HIV/AIDS and for delivery of services or management positions.

6.6.1 Material support

Many social factors linked to underdevelopment and poverty limit the involvement of PLHA. **Material support provided by NGOs is therefore an important incentive for involvement.** Material support can include financial remuneration and other benefits, such as food, drugs and medical care. Material support is also a way to get PLHA involved in activities.

*We called them either to settle their nutrition bills or whatever ...
Initially we had to really get them to come for the meeting, and before we
settled their bills we would sit together and spend time giving them
information or talking to them about varied issues. From this, support
groups were formed.*
(Service provider, CCDT, Mumbai, Maharashtra, India)

As discussed in Chapter 5, **employment brings significant benefits to PLHA and their families**, and many PLHA perceive the *prospect of paid employment as a significant motivating factor* for involvement. However, at the time of the study, only a few visible PLHA were employed full time or part time by NGOs. Participating organizations in Burkina Faso and Ecuador had very few staff members, compared to the very large NGOs involved in the study in India and Zambia, who employ many people and where paid PLHA involvement is more likely to happen.

The advantage is that CHEP has helped me to look after my children.
(Female PLHA service provider, CHEP, Kitwe, Zambia)

Positive workplace policies are also critical. In India, for example, respondents mentioned the fact that PLHA who work for one of the participating NGOs still receive their salary if they are sick. The organization recognizes that PLHA will sometimes be unable to work but sees payment of their salary as a right.

PLHA who take part in service delivery on a voluntary basis may be offered **reimbursement of expenses**, such as transport or meals. This provides some incentive for involvement, but less so than employment or proper remuneration for the time given.

It is important to note that the issue of material support was more important to respondents in Burkina Faso, India and Zambia, which are much poorer countries than Ecuador.

6.6.2 Psychological support and non-discrimination

Confidentiality about the HIV status of PLHA in NGOs is essential to their involvement, as was stressed in all four study countries. This is obviously linked to the context of stigmatization and PLHA fears of discrimination.

*You gain more and more confidence in sharing your private life when the
details of it remain within the organization and don't get let out, as they do
in other organizations. For this reason I decided to stay with the NGO
because of the security I had with the people there.*
(HIV-positive man, user, Fundación Vivir)

Non-judgmental and non-discriminatory attitudes among management and staff encourage PLHA involvement. PLHA are motivated to become more involved in organizations where they feel accepted and valued, and where their involvement is viewed positively.

We want to show that by caring for the HIV-positive person one does not get infected with the virus. We shake hands with him, drink from the same glass.
(Service provider, Salvation Army, Mumbai, Maharashtra, India)

You have to see that they [PLHA] are equal to you and they can also contribute.
(Service provider, Salvation Army, Mumbai, Maharashtra, India)

Non-discrimination should also consider gender and sexuality issues. The study observed that NGOs scarcely considered these issues when they designed and delivered services to PLHA. However, a few organizations have adapted some of their services to make them more gender sensitive, which has facilitated access to these services and further involvement. In India, CCDT progressively set up support groups for women only, and there are even separate groups for HIV-positive sex workers and other positive women, based on the observation that they had different needs. MNP+ also had a specific support group (“forum”) for women and another one for MSM, although the latter was inactive because of fears of discrimination expressed by HIV-positive MSM. In all the countries except Zambia, many other participating NGOs also planned to form separate support groups based on gender, and NGOs in Ecuador planned to establish support groups based on sexuality.

When we have a meeting and mothers come with their children I realize the importance of having a place for children where they can play with toys and have fun so that their mothers can relax ... something like a support crèche that is not permanent but temporary and available at training sessions, courses, seminars or any other type of event.
(HIV-positive woman, service provider, Fundación Dios, Vida y Esperanza)

Beyond non-judgmental attitudes, a supportive environment is characterized by a **friendly atmosphere**, as mentioned by respondents in all the countries.

Everybody mixes easily and well. There is a spirit of togetherness and love. We stay together, eat together and sit together. We are joking and laughing with each other.
(Female PLHA beneficiary, MNP+, Mumbai, Maharashtra, India)

Positive attitudes may need to be engendered through **training and sensitization of staff**.

I don't think that PLHA involvement is a bad thing, but it is preferable that some work is done beforehand within the organization. We all need to have our awareness raised in order to clear our minds. If not, some people within the NGO will be very wary.
(A member, AAS, Ouagadougou, Burkina Faso)

Support and **encouragement from service providers for PLHA involvement** in activities was also cited as an important institutional factor in Zambia and in India.

Management makes it a point that at least every day they speak to me: how are you? How are your programs? Just that motivates me.

(Female PLHA service provider, CHEP, Kitwe, Zambia)

There should be activities where **PLHA feel that they have the ownership of the decisions** made or where their decisions are respected by the rest of service providers and management. A service provider of the Salvation Army in India explains how support group meetings organized by the NGO are spaces where PLHA can make their own decisions.

Although it is our positive group, we have no say ... because the group belongs to them ... We do not interfere because they are the beneficiaries and they are the ones who have a problem ... If they like something we don't, they can go ahead because it is their right.

(HIV-negative service provider, Salvation Army, Mumbai, Maharashtra, India)

In the development organization CHEP in Zambia, the management decided to host a UN positive volunteer as part of the GIPA initiative in Southern and Eastern Africa. Afterwards, the NGO **set up a PLHA program led by a HIV-positive person** (the former UN volunteer), which boosted *greater involvement* in the organization. In this case, non-discrimination was translated into affirmative action.

A **non-hierarchical organizational structure** that encourages team work, especially team work between HIV-positive and HIV-negative service providers, and PLHA participation in decision-making helps to promote a conducive environment for PLHA involvement.

If they want to come and become a member of the team ... they don't come as ... HIV-positive people. They come as a team. That is ... very important. So there is no difference.

(Service provider, Salvation Army, Mumbai, Maharashtra, India)

It is better that PLHA put forward their special needs themselves rather than a third person talking about our needs. Decisions in the agency are taken keeping PLHA perspectives in mind ... Decisions are taken in consultation.

(PLHA service provider, MNP+, Mumbai, Maharashtra, India)

The study found that **types of organizations influence the openness to involvement** of service users and other PLHA in NGOs. In organizations that have more of a focus on community development, PLHA involvement is more likely to encompass *participation* as well as *access* and *inclusion*, since this type of organization gives greater emphasis to empowerment and self-help. However, self-help is often “assisted” or led by HIV-negative staff and management, and PLHA do not have always the opportunity to take responsibility for management, policymaking and strategic decisions. The study observed *greater involvement* of PLHA in both development and rights-based models of organization, that are more likely to have been established by rather than for PLHA.

Peer support from other HIV-positive service providers was cited as an enhancing factor in Ecuador, India and Zambia. PLHA beneficiaries specifically mentioned the existence of support groups.

We were able to see that he himself is living a positive life ... His life has been a model to other positive people. Looking at him, people should be encouraged. If he is like this then why not I?

(Service provider, Salvation Army, Mumbai, Maharashtra, India)

Role models are also an important motivating factor. For example, some PLHA in Zambia decided to get involved because they have seen PLHA holding positions as service providers or program coordinators, or doing outreach education.

They see them [the outreach educators] as people who have passed through the stages of being HIV positive. This helps them to see what they can do as people living with HIV. In fact, we have had people joining the outreach education after observing what the others do in the outreach teaching.

(A service provider, Kara Counselling, Lusaka & Choma, Zambia)

The **availability of good counseling**, which helps PLHA to cope with their HIV status and learn to live positively, was cited as a factor encouraging PLHA involvement in Zambia.

We became involved with Hope because when we first went there the counseling sessions were very good and encouraging ... This has built us emotionally and eventually we became involved in other activities.

(Female PLHA service provider, Hope, Ndola, Zambia)

6.6.3 Information, orientation, training and supervision

As explained earlier, “Knowledge is involvement”. The more PLHA know and the more skills they have, the greater their involvement. As described in Chapter 4, the types of involvement are directly linked to the kind and level of knowledge used by PLHA and provided by NGOs to those PLHA involved in their activities.

The following box lists the various components that may be included in training for PLHA involved in CBOs and NGOs, based on what was observed in the four study countries.

Box 6.3 What information and training for PLHA involved in NGOs?

General skills

- Coping skills: how to come to terms with HIV infection and how to cope with stigma and discrimination.
- General information about HIV/AIDS: transmission routes, epidemiology.
- Positive living and information on:
 - nutrition and healthy diet;
 - sexuality (safer sex), including reproductive health, adapted to gender and sexual orientation;
 - care and treatment available, including side-effects of treatments.

Skills for PLHA involved in AIDS service-delivery (*Inclusion and Participation*)

Like any other service provider, PLHA should receive training adapted to the kind of service they deliver, whether it is awareness-raising, counseling or home-based care. However, training might be adapted to the particular circumstances of HIV-positive service providers:

- PLHA involved in care and support should receive specific training to avoid the “mirror effect” and deal with the emotional consequences of identification with other PLHA who are seriously or terminally ill.
- PLHA involved in giving testimonies for awareness-raising and advocacy should receive training in communication. They should also be prepared to deal with stigma and discrimination that may arise from their visibility.

Not only training but also supervision and ongoing support are needed for PLHA involved in these areas of service delivery.

You can't change overnight ... to carry out awareness-raising; for example, you have to be trained. Whether you are HIV negative or positive, you have to have basic training.

(Leader, ALAVI, Ouagadougou, Burkina Faso)

It is important to prepare people living with HIV before they visit someone in hospital because they can get depressed. It's not a question of sending them for the sake of sending them. It is the same for HIV-negative people: they have to be prepared before going to visit someone in hospital because it is an experience that impacts greatly.

(HIV-positive man, service provider, Fundación Siempre Vida)

Skills for PLHA involved in the decision-making process (*Greater Involvement*)

Many PLHA who set up organizations that they end up managing often have little experience of management. For them, training is necessary in the following areas:

- Project cycle and development of project proposals.
- Budget management and financial reporting (accountability).
- Documentation of activities.
- Monitoring and evaluation of services.

Vocational training

In Africa and India, many HIV-positive women are widows, who are the only breadwinner for themselves and their children. The majority of these women have never worked outside of the house or have not been able to market their skills. Some of the participating NGOs in Burkina Faso, India and Zambia offer income-generating programs in which PLHA can learn new skills that they can use to earn an income.

As discussed earlier in this report, knowledge can be transferred to PLHA formally and informally in many ways.

In Zambia, positive living and life skills training programs have been a useful way to recruit PLHA beneficiaries for involvement in informal or formal service delivery. However, this type of training is only one step in the process of involvement, and PLHA who are more formally involved have usually received additional training to develop the skills required for service delivery. In Zambia, organizations where PLHA *participation* and *greater involvement* were observed give a high priority to staff training.

I was trained in skills training. Then I started training on basic facts of HIV/AIDS. That was when I gathered the courage to tell anybody. So I did it through the press. And when my relatives came, I just convinced them that this is that.

(Male PLHA service provider, Kara Counseling, Lusaka & Choma, Zambia)

When we graduated, it was easy because they said whoever was willing to go public would be fused into the outreach team. So it was easy for us.

(PLHA outreach educator, Kara Counseling, Lusaka & Choma, Zambia)

Providing training courses and other skills-building opportunities **free of charge facilitates PLHA involvement**, especially in settings where most PLHA are living in poverty.

Practical support also encourages PLHA participation in training courses. For example, in Zambia, Hope provides trainees of the PLAC with meals and money to pay for transport to and from the organization headquarters.

There should be individual follow-up provided by the organization to the participants in workshops or courses, in terms of opportunities to use the skills learned or in terms of support, otherwise training is not always effective.

The data also shows that **impact of training is limited when it is not adapted to the capacities of the PLHA**. In Zambia, PLHA reported that they were frustrated because they had learned everything about a healthy diet but were not able to buy the food because they were too poor.

There have been mixed results of vocational training. Often it is more occupational therapy than vocational training because contents do not take into account the experience, characteristics and motives of the PLHA trained and/or there are already too many people with the same skills who are not able to make any money out of these skills. Therefore **vocational training for PLHA should always meet the needs of both the learners and the market**.

Participants in India and Zambia cited the **importance of opportunities for PLHA to attend conferences and workshops**, since networking with other PLHA and organizations is a good way to access a lot of information.

Information about opportunities of involvement may be obtained through referrals between different organizations and services; for example, to HIV testing and counseling services, home-based care, training courses, support groups and PLHA networks, like in Zambia.

When the volunteer from the HBC [home-based care] team came to visit me, they informed me that those who had been tested had formed a group. I decided to join them.

(PLHA, service user, Hope, Ndola, Zambia)

6.7 Specific factors that limit and enhance the formation and sustainability of self-help groups of PLHA

As described in Chapter 4, some of the participating NGOs have supported the formation of self-help groups of PLHA and people affected. Four of the participating NGOs in India and Zambia have used this strategy, and three NGOs in the same two countries were in the process of trying to establish such groups.³⁰ These groups remain linked to the NGOs that provide them with technical and sometimes financial assistance (“assisted self-help”). However, the strategy of transforming support groups into more autonomous self-help groups of PLHA has not been particularly successful in these countries.

This section analyzes the reasons why these groups succeed or fail. Although the analysis is based mainly on data that was collected in Zambia, the study found that this analysis also applies to groups in other countries.

Box 6.4 Definition of self-help groups

Self-help or support groups, defined as groups of people who share common interests or goals and who come together to address common problems, can be differentiated by their membership of their beneficiaries:

- Self-help groups can consist of PLHA only, PLHA and affected people or PLHA, affected people and other members of the community.
- Self-help groups can benefit their members only, provide services to the community or provide self-help and services to those who do not belong to the group.

Self-help groups observed during the study were either groups of PLHA only or mixed groups of HIV-positive and affected people. Members usually support each other, but they may also support other HIV-positive people who do not belong to the group, and many of the groups try to raise awareness in the community. Membership is usually small, and rules regarding membership are usually extremely flexible or non-existent.

³⁰ NGOs in Burkina Faso and Ecuador were too small to promote external involvement of PLHA.

6.7.1 Why self-help groups fail

The study identified the following reasons for the failure of support groups, related to group dynamics and to the relationship between support groups and the NGOs that support them:

- Lack of common objectives and expectations among members.
- Some members just want to receive material benefits but are not aware of any obligations.
- Lack of clarity about roles and responsibilities of members.
- Too many leaders, lack of leadership skills or leaders lack legitimacy.
- Mixed membership of PLHA and affected people can make sharing experiences difficult because PLHA do not feel comfortable.
- Exclusive PLHA membership can result in stigmatization by the community.
- Trying to carry out too many activities or activities outside the local area, with unsustainable costs; for example, transport.
- Only a few members participate in training or other opportunities and fail to share outcomes with others.
- Ill health of members, lack of succession planning and lack of mechanisms to cope with the death of support group members.
- Inappropriate or unsustainable income-generating activities.
- Mismanagement of funds or competition between members for resources.
- NGOs impose objectives and direct activities, for example trying to turn a self help group into service providers.
- NGOs fail to provide adequate or appropriate funds, training and other forms of practical support.
- Dependence on NGOs for funds, management and technical support.
- NGOs use support groups as a strategy to raise funds.
- Lack of clarity about the role and responsibility of the NGO, especially when the NGO has established the support group.

We try to encourage them ... "Make groups, do not depend on us! Be independent!" We are trying to do the same thing in our forum. We tell them that we have our own needs, problems, and if we come together and do something, then there will be more effect. We will not remain dependent ... we will be independent ... not depend on NGOs, including MNP+.
(PLHA service provider, MNP+, Mumbai, Maharashtra, India)

6.7.2 Why self-help groups succeed

The study identified factors that enhance the formation and sustainability of support groups. These factors include those related to support group membership and process, and to the relationship between the group and the NGO:

- Members have clear common objectives and expectations, are aware of the benefits and costs of their participation, share common experience and background, have a real sense of belonging, have an individual motivation and interest in participating, obtain material and psychological benefits from involvement, have enough time to devote to group activities, have strong leadership and/or decision-making processes, and income-generating activities are well planned and managed, appropriate and meet basic needs.

- Support groups are based in the community and, if they provide services, limit the scope of these services to the local area and are accepted by the community.
- Support groups receive technical support and training from an NGO; the roles and responsibilities of the group and the NGO are clear from the start; the NGO responds to group needs rather than directing activities; and the group is able to continue independently of NGO support.

In Burkina Faso and Ecuador, the study observed that some of the participating NGOs started as self-groups of PLHA and affected people, although without direct and close support from an NGO. These groups have become sustainable organizations that provide HIV/AIDS services to the community, although in some cases they still identify themselves as self-help groups of PLHA and affected people. These groups had a mixed membership including PLHA, affected people, and HIV-negative, and in Burkina Faso HIV-positive, health and social workers, which was identified as a factor that was essential to the sustainability of the organizations. As mentioned before, two of the organizations in Ecuador would have ceased functioning without the involvement of other people.

6.8 From *access* to *greater involvement*: A continuum of involvement for PLHA and NGOs

Two important major questions that this study tried to answer are: what are the minimum conditions that need to be present for PLHA involvement to happen? What strategies could NGOs and CBOs employ to achieve PLHA involvement? Based on the types of involvement described in Chapter 4, and the factors that enhance and limit involvement described in this chapter, these are as follows:

- Minimum conditions and strategies depend on what PLHA and NGOs are trying to achieve in terms of involvement. For example, the necessary conditions and strategies to achieve these will depend on whether an NGO aims to provide basic information and positive living skills for PLHA beneficiaries (*access*) or to involve PLHA more formally in service delivery (*participation*).
- The number of conditions and steps tends to increase both for NGOs and PLHA as they move from *access* to *greater involvement*. The series of steps required, or “pathways to involvement”, are described below. These steps were identified during data analysis workshops in Ecuador, India and Zambia, where NGOs that participated in the study, together with researchers, identified the conditions that had made PLHA involvement in their organizations possible and defined the minimum conditions for any NGO or CBO to achieve *inclusion*, *participation* and *greater involvement*. Although there were some differences between the steps identified by NGOs and researchers depending on the country, the pathways were relatively similar. We present here a summary of the results from the three countries, as well as some complementary analysis conducted in Burkina Faso.

6.8.1 Mobilization of PLHA and types of involvement

The analysis of the sample of NGOs who participated in the study reveals that PLHA get mobilized and organizations mobilize PLHA in different ways:

- PLHA set up organizations, often together with other people (affected people, health and social workers), as it was the case of five of the NGOs involved in the study. These NGOs are rights-based organizations and/or self-help groups. The dominant models of involvement are *greater involvement* and *participation*, but there are also PLHA who access the services. These organizations can evolve depending on the composition of the membership. In two NGOs, HIV-positive founders died and the organizations became more service orientated and less focused on rights. *Greater involvement* of PLHA may be replaced by some form of *participation* and *inclusion*.

In NGOs where there were originally no visible PLHA, such as secular or religious welfare organizations and development NGOs:

- Organizations empower their HIV-positive service users and turn them progressively into service providers through *inclusion* and sometimes *participation* (continuum of involvement described below). This rarely leads to *greater involvement*, unless there is a clear policy within the organization, as we saw in one NGO in Zambia. This scenario was observed in six NGOs in Burkina Faso, India and Zambia.
- Organizations recruit PLHA who are not their service users and who are already visible and have enough experience and skills to be involved in formal service delivery and/or management (*participation* and *greater involvement*). This scenario was observed in one development NGO in Zambia.
- Sometimes staff or volunteers of NGOs find out that they are HIV positive when they are already involved and they may choose to become visible. However, we explained that this is a very difficult process for these PLHA. It happened only in one organization of the sample.

All the mobilization processes described above apply to involvement of PLHA as volunteers and staff in the activities of the NGOs (internal involvement).

As discussed in the previous section, some NGOs support the formation of self-help groups of PLHA to increase mobilization of PLHA and scale up their involvement. These organizations are either development NGOs or PLHA networks.

6.8.2 Pathway to involvement for PLHA: a summary of conditions and steps for PLHA to be involved (individual process)

For PLHA, steps or conditions for *inclusion* in NGO service delivery are:

- Undergo VCT.
- Accept HIV status by building self-esteem.
- Visibility, even if this is limited to service providers or support group members.
- Awareness of the existence of the NGO or CBO and perception of some benefit of involvement.
- Have the desire and drive to help others and to contribute to the fight against the epidemic.

- Have basic knowledge about HIV/AIDS.
- Take the initiative.
- Have informal or formal training, including in life skills, to build confidence and self-esteem.
- Disclose to family and/or friends and/or work colleagues.
- Have material and emotional support.
- Undergo training for service delivery.
- Make time available.

For PLHA, additional steps or conditions for *participation* in NGOs are:

- Formal contract as a service provider.
- Being associated with the NGO or CBO.
- Visibility to a wider group, within and outside the organization.
- Undergo formal training for service delivery.
- Use the experience of being a service provider in design and planning.
- Have emotional support.
- Capacity building.

For PLHA, additional steps or conditions for *greater involvement* in NGOs are:

- Capacity building on organizational issues.
- Literacy and numeracy.
- Have managerial skills and program experience.
- Be responsible and creative.
- Have strong communication, representation and advocacy skills.
- Build an in-depth knowledge of the organization.

6.8.3 Pathways to involvement for NGOs and CBOs: a summary of conditions and steps for organizations to facilitate the involvement of PLHA (organizational process)

Steps or conditions for NGOs to have PLHA *inclusion* in service delivery are:

- Sensitize management and staff about involvement of PLHA by discussing advantages and disadvantages for the organization, its services and beneficiaries to ensure that they are open to PLHA involvement.
- Identify possible areas of involvement and develop policies for involvement.
- Review policies that may limit involvement, such as mandatory testing of care providers.
- Inform PLHA, especially the HIV-positive users of the organization, of the possibilities of being involved in activities, and which activities they could be involved in – this is the responsibility of the organization overall and of individual service providers.
- Provide orientation by presenting the organization's objectives and activities clearly, and explain what advantages and obligations are entailed in involvement in activities.
- Establish support group meetings to enable PLHA to exchange experience and provide mutual support.
- Provide basic training on HIV/AIDS and positive living, and build self-esteem of PLHA.
- Assess and take into consideration PLHA health, skills and motivation.

- Create opportunities for PLHA beneficiaries and other PLHA to be involved in service delivery close to where they live and/or allocate budget to reimburse expenses related to *inclusion* in service delivery and provide compensation; for example, for travel costs.

Additional steps or conditions for NGOs to have PLHA *participation* are:

- Identification of PLHA with potential to become formal service providers.
- Recruit PLHA as paid employees (if PLHA are employed by the organization) or unpaid volunteers with clearly defined roles.
- Allocate budget for training PLHA in service delivery.
- Design specific training programs and put in place a structure, including provision for training on delivery of services.
- Provision for specific positions for PLHA; for example, give responsibilities for psychological care and support to PLHA without medical skills.
- Promote teamwork.

Additional steps or conditions for NGOs to have PLHA *greater involvement* are:

- Extension of non-discriminatory employment policies to management and decision-making positions.
- Provision for management positions to be held by PLHA.
- Identify PLHA with leadership skills.
- Provision for management training.
- Conduct training and capacity-building to develop skills for service delivery, advocacy, management and strategic planning.
- Respect PLHA and their views.
- Allocation of budgets for specific activities to be managed by PLHA.
- Open competition for jobs but encourage PLHA to apply for positions.
- Sensitize partner organizations to increase acceptance of PLHA service providers.

Based on the analysis of the “pathways to involvement”, participating NGOs, including those where PLHA only access services, concluded that involvement is a process than can be planned internally. **Many obstacles to involvement are strictly organizational and structural, which can be tackled by the organizations themselves.**

Moving from access to greater involvement

The analysis of the “pathways to involvement” suggests that **there may be a continuum of involvement** for PLHA involving:

- **Access** – where PLHA can learn how to accept their HIV status, learn the basic facts about HIV/AIDS and learn how to cope with the infection – is an entry point for further involvement. For example, in some of the participating NGOs, PLHA who were initially beneficiaries have been progressively integrated into the organizations. Disclosure of HIV status to a few people – for example, close relatives or friends – is essential to the process of acceptance. *Access* is characterized first by exposure to information and psychosocial support, including self-help,

which are important factors enhancing involvement. Through this, some PLHA find the desire and capacity to help other people.

- ***Inclusion*** – characterized by a certain level of acceptance and PLHA taking action to fulfill the desire to help others, perhaps by sharing their experience within or outside an organization. Most commonly, this takes the form of informal involvement in outreach education activities or informal peer support. With *inclusion*, PLHA have greater access to peer support through support groups or interaction with other PLHA involved in the activities of the NGOs, and generally receive some material benefits for their efforts. Peer support and material benefits are important incentives for involvement.
- ***Participation*** – the stage where PLHA have accepted their status and use their personal experience of living with HIV/AIDS, as well as skills gained during more formal training in service delivery. *Participation* is generally characterized by formal, salaried employment or highly committed voluntary work, and is the opportunity to use skills and experience to provide services to others.
- ***Greater involvement*** – characterized by participation in design, planning and management of programs and in organizational strategic planning – depends on PLHA experience, training and skills. The study observed that PLHA involved at this level have usually been involved in the fight against the epidemic for several years and have had considerable training and exposure to national and international workshops and conferences. Many have overcome significant obstacles and are often passionate fighters.

In several of the participating NGOs in India and Zambia, the study found that the organizational process of involving PLHA followed the same continuum.

- At Hope, for example, the organization started by offering services to PLHA, such as testing, counseling and medical care (*access*). Subsequently, Hope started a nutrition course, which evolved into a broader PLAC. The graduates of the PLAC became involved as volunteers in outreach education and giving testimonies (*inclusion*). Some have been recruited as service providers (*participation*). Further training in project management has led to *greater involvement*, with some PLHA taking program responsibilities.
- At Kara, the process of involvement has been similar. PLHA who were originally clients of counseling services (*access*) have been empowered through participation in life skills training courses. Some have become involved as volunteers, supporting other service providers (*inclusion*); others as outreach educators, who work with the organization (*participation*). One PLHA is now the coordinator of the outreach program (*greater involvement*).
- In the Salvation Army (Mumbai), the only visible HIV-positive service provider employed by the organization was originally a support group participant (*access*). He was chosen to facilitate meetings on a voluntary basis (*inclusion*) and was eventually recruited as a counselor and coordinator of the support group (*participation*).
- At CCDT, *access* to services has also been used as an entry point for the formation of support groups and *inclusion* of PLHA in these activities.

Not all PLHA involved go through the continuum of involvement in the same organization. The study observed in Ecuador and India that sometimes PLHA used the services of an organization (*access*), started to carry out activities within this organization (*inclusion*) and became frustrated

because of the lack of opportunities for *participation* and *greater involvement* in these NGOs. They finally decided to set up their own organizations. This is illustrated by the examples of MNP+ and Siempre Vida, which were formed mostly by PLHA with a self-help approach and can be described as rights-based groups.

In other cases, NGOs may be lucky enough to identify and recruit PLHA who have been through the continuum of involvement in several organizations beforehand and have enough experience and skills to be employed immediately in service delivery. A good example is CHEP in Zambia, who took advantage of the GIPA initiative to boost involvement without going through the process of transforming progressively its service users into service providers, although this is also something that the organization is pursuing in parallel.

6.9 Scaling up involvement through the creation of self-help groups: Lessons learned

The steps and conditions described above will allow NGOs, CBOs and networks to scale up “internal involvement”, either by transforming their own HIV-positive service users into service providers or by bringing other PLHA into the organizations for service delivery or at the management level.

However, as discussed earlier, the capacity of NGOs to increase internal involvement of PLHA as volunteers or employees is limited. Lessons learned about scaling up involvement through self-help groups include:

- The need to strike a balance between independence and sustainability of support groups and adequate support from NGOs, especially at the formation stage.
- The need to provide sufficient technical support related to issues such as fundraising, budgeting, starting and sustaining income generation, financial management and reporting. One NGO in Zambia has linked up with a micro-finance institution to enable it to provide this type of assistance to support groups.
- The need to provide adequate support and training in formation and running of support groups, including leadership skills.
- The need for clarity about mutual roles and responsibilities of NGOs and support groups.

6.10 How to promote visible involvement of PLHA: Minimum conditions for visibility

Another essential issue regarding involvement is the level of visibility of PLHA involved in programs. As explained earlier, the study observed that there are many levels of visibility and that PLHA do not need to be visible at all these levels to contribute to the activities of NGOs.

Visibility can be of different types ... in family, society, in the organization, in the media. A person may be visible in the organization and the family but not to society. People must be aware of the problems that may arise.

(PLHA staff member, MNP+, Mumbai, Maharashtra, India)

However, we also identified some of the conditions that may make visible involvement easier, more useful and less traumatic for PLHA, their families and organizations with which they are involved:

- When PLHA wish to give testimony in public, it is useful if they ask first: what are the advantages for me, my family, the NGO and society? What are the disadvantages for me, my family, the NGO and society?
- The initiative for visibility must come from the PLHA.
- PLHA may be visible at different levels and in different areas. The choice of the level and areas of visibility is up to the PLHA, in coordination with the NGO.
- The confidentiality about the HIV status of PLHA should be maintained by the NGO.
- Visibility must not be against the interests of the PLHA.
- PLHA must be prepared for public testimony – for example, through counseling and identification of strategies to increase self-esteem – and cope with possible stigma and discrimination. They should be sufficiently knowledgeable about HIV/AIDS to overcome misconceptions and provide accurate information.
- PLHA may be prepared to be visible to each other first; for example, in support groups. This can be a step before further visibility.
- PLHA may learn from other PLHA who came out in the open before.
- The family and loved ones of PLHA must also be prepared. They should be provided with accurate information (with the direct or indirect intervention of NGO) and with support.
- The PLHA should have their own resources in case of rejection by the family. The basic needs of PLHA must be fulfilled and they should be provided with an appropriate standard of care and support services.
- The NGO must be prepared for the possible effects of visibility of PLHA on other beneficiaries and service providers.
- There should be a legal framework to protect PLHA who decide to give public testimony.

In order to be able to give testimony, you first of all have to be prepared to face up to rejection. You have to be financially independent, but your family also needs to be prepared to put up with the criticisms which will be made against you.

(Leader of one of the participating NGOs, Burkina Faso)

In Burkina Faso, NGOs also suggested a series of practical strategies to help PLHA face and overcome stigma and discrimination when they are visible. These strategies include:

- NGOs provide psychological support and concrete information in order to reduce PLHA fear of stigma and discrimination and to help them cope with stigma and discrimination if they occur.
- NGOs raise awareness among health and social workers involved in VCT, treatment, care and support for PLHA.
- NGOs provide information to PLHA about the organization and about procedures for maintaining confidentiality to reduce their fears about joining or becoming involved.
- NGOs make it clear to PLHA that they can choose whether or not to disclose their status within and outside the organization.
- NGOs create support groups that are just for PLHA.
- NGOs choose communications strategies and activities that prevent them being identified as PLHA organizations.
- NGOs carry out community awareness-raising activities.
- NGOs collaborate with legal and human rights organizations to promote the rights of PLHA.

7. Recommendations

Involvement can have both positive and negative effects for PLHA, for organizations with which they are involved and for their families and communities, although in general the positive outweigh the negative. The effects depend on the types of involvement.

PLHA can benefit significantly from *access* to services, depending on the nature and quality of these services. *Access* is more meaningful if it is used as an entry point for an empowerment process of service users that may lead to further involvement in the activities of an organization.

The positive effects of *inclusion* depend on how PLHA are involved in the implementation of activities. Where PLHA are employed and receive a regular income, the positive effects are greater than if they are involved on an informal, occasional and voluntary basis. Inclusion of PLHA as volunteers is meaningful to NGOs if volunteers are carefully chosen and receive adequate training and support.

Participation brings PLHA greater benefits in terms of remuneration and sense of achievement, but gives limited scope for decision making and has a greater risk of stigma and discrimination because of higher visibility. *Participation* is meaningful to NGOs if they are ready to invest in recruitment and training of PLHA and provide them with opportunities to be service providers in a conducive environment. *Greater involvement* is more meaningful for PLHA who wish to shape policies and programs, and can strengthen the quality of services.

However, for each type to be meaningful, PLHA and NGOs have to take a series of steps, which the study calls “pathways to involvement”. In addition, if PLHA or NGOs do not take these steps, positive effects tend to be limited and negative effects increase. For example, if a PLHA is involved in outreach education without receiving the necessary training and support, this can adversely affect the quality of the service and can be harmful for the PLHA. The following section includes specific recommendations for action by PLHA and by NGOs to achieve meaningful involvement.

7.1 Recommendations for NGOs and CBOs

Change negative and discriminatory attitudes towards PLHA

- NGOs should not consider PLHA, including their HIV-positive beneficiaries, as only passive recipients of care and support.
- NGOs should assess the attitudes of management and service providers and provide them with sensitisation and training where necessary.
- NGOs should consider how to provide support in a way that empowers PLHA and does not create dependency on the NGO.

Behavior change is not only about sexual behavior and prevention of transmission of HIV and other sexually transmitted diseases, but also about changing attitudes toward those who are infected. Any serious behavior change program should aim to prevent stigma and discrimination as well as transmission of HIV. This cannot be achieved without bringing together those who are infected and those who are not.

Build the capacity of PLHA for involvement

- NGOs should provide accurate information about HIV/AIDS, its prevention and treatment, as well as about services available to PLHA in the organization and from other sources.
- NGOs can use their counseling services as a starting point for empowering beneficiaries, providing PLHA with accurate and up-to-date information and options so that they can make their own choices.
- NGOs should promote PLHA empowerment that includes self-development and the building or rebuilding of confidence and self-esteem.
- NGO capacity-building for PLHA should comprise knowledge, skills and attitudinal training related to the following:
 - living with HIV/AIDS, including coping skills;
 - basic facts about HIV/AIDS;
 - technical skills related to the delivery of HIV/AIDS services, including stress management for PLHA involved in care and support;
 - vocational issues, including income generation;
 - organizational development, including communication and advocacy;
 - information about the structure and functioning of the organization.
- NGOs should plan individual follow-up to training for each participant and supervision, otherwise training may only have very short-term benefits.
- NGOs should ensure that PLHA who plan and provide services or manage programs and organizations receive training relevant to their activities like any other staff member or volunteer.

Offer psychological support, including peer support, to PLHA

- NGOs should be sensitive to the emotional needs of PLHA and ensure that counseling is available.
- NGOs should ensure that care and support provided by “professional” service providers is complemented by peer support.
- NGOs should provide PLHA beneficiaries with the opportunity to meet other PLHA, whether through peer counseling or support-group meetings, and should make sure that PLHA have the choice of individual or group support.

Material support is essential to the involvement of PLHA who have few resources

- NGOs should provide some form of remuneration or other material support, depending on the amount of time spent by the PLHA, the skills they use and the efforts they make, particularly when PLHA have limited financial resources.
- NGOs who promote income-generating activities and micro-credit schemes for PLHA and are not familiar with these issues should seek guidance from other organizations with experience in this field.
- NGOs involving PLHA need to be sensitive to their physical needs and capacity.

- NGOs should make sure that PLHA involved in their activities have access to health care and to treatment for opportunistic infections as a minimum – for example, through including health insurance as one of the benefits of PLHA who work for them – ensuring access free of charge or at low cost to their own care facilities when available, or referring PLHA to other organizations or public services who provide care.

Flexibility is required regarding visibility and involvement

- NGOs should not force PLHA involved in their activities to be visible at all levels and need to be flexible about different levels of visibility.
- NGOs should consider in which activities visibility has the most impact. A positive counselor can be visible only to his or her clients and colleagues within the organization. Members of support groups can disclose their status only to other members and possibly the service provider who has referred them to the group. However limited, this visibility may still have a significant impact.
- NGOs should respect confidentiality and allow PLHA to make their own decisions about disclosure of HIV status, including helping each individual to become visible where and when they wish to.
- NGOs should help to prepare PLHA, through counselling before they give public testimony, and also ensure that the family of the PLHA is properly prepared before a PLHA gives public testimony or becomes more widely visible.
- NGOs should be prepared for the impact on the organization and other service providers and volunteers of the public visibility of individual PLHA.
- NGOs should also advocate for a legal and policy framework that protects PLHA who decide to give public testimony.

To help PLHA overcome their fear of stigmatization and discrimination

- NGOs should provide psychological support and concrete information for PLHA who are or wish to become involved in order to reduce their fear of stigmatization and discrimination, and develop strategies to cope with the experience of stigma and discrimination.
- NGOs should raise awareness among health and social workers involved in testing and counseling, so that they refer PLHA to NGOs as quickly as possible following testing, provide information to PLHA about the activities and services provided by NGOs and help to reduce their concerns about joining an NGO.
- NGOs can diversify their activities and choose communication strategies carefully to avoid the organization being identified as a “PLHA organization”.
- NGOs can also take steps to reduce stigma and discrimination at community level, through promoting messages of tolerance and compassion, improving community knowledge and awareness about HIV/AIDS, and efforts to sensitize community and religious leaders, as well as by collaborating with organizations working to defend the legal and human rights of PLHA.

Planning and implementing involvement

- NGOs should first reflect on the benefits and positive effects of different types of involvement for themselves and the community.
- NGOs should decide and plan how they want PLHA to be involved in their activities.
- NGOs should identify the institutional factors that limit these types of involvement and analyze how they can tackle these obstacles as an organization, especially in terms of human and financial resources.
- NGOs should ensure that management and service providers inform PLHA who access the services of the organization about the opportunities to be involved and refer them to the relevant individuals and structures.

Taking gender and sexuality issues into account

- NGOs should make efforts to ensure gender equity in their organizations.
- NGOs should be sensitive to the particular problems faced by HIV-positive people depending on gender and/or sexual orientation and ensure that all management and staff are sensitized to these issues.
- NGOs should ensure that PLHA have the opportunity to meet other HIV-positive people who share the same sexual orientation and/or gender in a safe environment. They should also make sure that, for example, HIV-positive women and MSM are involved in orienting and sensitizing other women and MSM on issues they share in common and in the design and planning of services that aim to meet their specific needs.
- NGOs should ensure that women are given responsibility for developing strategies for increasing the involvement of other PLHA women and establish separate support groups for women.
- NGOs should provide information and training for their own service providers and volunteers and other service providers such as health workers, to ensure that they have accurate and up-to-date knowledge about issues that concern PLHA women, such as motherhood and sexuality, and provide specific training in counseling women who are PLHA.
- NGOs should provide childcare and support services for children.

Assisting the formation of support groups to scale up PLHA involvement

- NGOs should focus on building the capacities of group members in the following areas: planning (definition of objectives, basic timeline for activities), management of human resources (group dynamics, leadership skills) and financial resources (fundraising, budgeting, basic accounting and reporting, micro-credit), depending on the needs of each group.
- NGOs should try to train as many people as possible and avoid selecting only a few individuals, otherwise capacity-building may have limited positive effects because PLHA who have been trained can be sick or die prematurely, and PLHA may not always have the skills or will to share their knowledge with their peers.
- NGOs should make clear from the start the role of the NGO and its links with support groups.
- NGOs should try to meet the immediate needs of support group members rather than use them for other purposes, such as giving testimonies, bearing in mind that the first objective of a support group is the well-being of its members.

Networking between NGOs and referral systems are important to foster the involvement of PLHA

- NGOs should be involved in networks at the community and national level, and provide PLHA with accurate information about services and opportunities for involvement in other organizations.
- NGOs should set up referral systems so that PLHA have continuing support.

Advocacy

- NGOs that are well established within their community and integrated with local networks can develop advocacy in collaboration with local partners, and this localized action can have a more immediate impact than more generalized actions.
- NGOs should network with other organizations, especially to address stigma and discrimination and its consequences on PLHA involvement at national level.

7.2 Recommendations for PLHA

PLHA can play an important and active role in facilitating their own involvement by:

- Taking the initiative and asking NGOs where and how they can be involved in their activities.
- Attending as many meetings, workshops and conferences as possible, since exposure to new ideas and people, including other PLHA, is a good way to gain experience.
- Asking NGOs that provide care and support whether it is possible to meet other PLHA, through group meetings or peer support.

Forming networks and support groups

PLHA who form their own networks and support groups to help themselves and other positive and affected people should:

- Agree common objectives and expectations and communicate these to any new PLHA who join the network or group.
- Make sure all members know the benefits and “costs” of their participation in the network or group, and are clear about their roles and what they can and cannot do based on time, health and skills.
- Agree on a decision-making process at an early stage.
- Plan what may happen if group leaders are sick or die prematurely.
- Decide whether they are networks of PLHA (individuals) or PLHA groups (organizations), in order to clarify their functions and the roles of their members.
- Decide whether or not they want to be involved in service delivery, and for whom. If a group decides to provide services to beneficiaries who are not members, these services should be provided in a community which is accessible in order to avoid transport costs, excessive fatigue for members and disruption of services.

- Ensure that if technical and financial support is provided by local, national or international NGOs, expectations, roles and levels of commitment of the partners are clear to the group, its members and the organizations that support them.
- Work with other partners at the community level in order to organize referrals for their members and beneficiaries when necessary.

7.3 Recommendations for organizations that provide NGOs with technical and financial support

Organizations that provide NGOs and CBOs with technical and financial support should:

- Support projects that address stigma and discrimination.
- Provide NGOs and CBOs with no or little PLHA involvement with specific technical support to help them reflect on the benefits of PLHA involvement, how to plan it and encourage types of involvement in their activities that are adapted to their characteristics.
- Provide self-help groups and networks with technical support adapted to their needs in terms of strategic planning and sustainability (see above).
- Take into account specific costs related to involvement of PLHA – for example, training, access to care – when funding projects. They should not isolate the theme of PLHA involvement from other development issues.
- Promote visibility carefully with respect of individuals and grassroots organizations.
- Encourage sharing of experiences between NGOs and CBOs with different types of involvement of PLHA.

It is important to note that, although these recommendations are based on data collected in developing countries and are therefore adapted to the context of low-income countries, some of them may suit ASOs and other NGOs in high-income countries. We found similarities with guidelines and recommendations that arose from research and other assessment processes carried out in western countries.³¹

³¹ Michael Bell. 1997. Principles, Policy and Practice- - Guidelines For Service User/People With HIV/AIDS Involvement in AIDS Service Organisations. London: Michael Bell Associates & Pan London HIV/AIDS Providers Consortium

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Other reports of the multi-country diagnostic study on the involvement of PLHA

Research summaries

1999. *Positive, Engaged, Involved: PLHA Participation in Community-based Organizations in Burkina Faso*, Washington DC: Horizons (English, French).

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1999. *La participation des Personnes Vivant avec le VIH/SIDA dans les activités communautaires de prévention et de prise en charge au Burkina Faso*, International HIV/AIDS Alliance, Horizons (French).

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NGO profiles

Profiles of the 17 participating NGOs are available in English (India, Zambia), French (Burkina Faso) and Spanish (Ecuador).

Practical resources on PLHA involvement

Asia-Pacific Network of People Living with HIV/Aids (1999) *Lifting the Burden of Secrecy: A Manual for HIV-Positive People Who Want to Speak out in Public*, Singapore: Asia Pacific Plus.

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Global Network of People Living with HIV/AIDS (GNP+) (1998) *Positive Development*, Amsterdam: GNP+ (also in French, Portuguese and Spanish).

The International Community of Women Living with HIV/Aids (ICW) (1999) *A Positive Woman's Survival Kit*, London: ICW (also in French and Spanish).

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Annexes

Declaration of the Paris AIDS Summit, 1 December, 1994 – The Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

We the Heads of Government or Representatives of the 42 States assembled in Paris on 1 December, 1994:

I. MINDFUL that the AIDS pandemic, by virtue of its magnitude, constitutes a threat to humanity, that it spread is affecting all societies, that it is hindering the social and economic development, in particular of the worst affected countries, and increasing disparities within and between countries, that poverty and discrimination are contributing factors in the spread of the pandemic, that HIV/AIDS inflicts irreparable damage on families and communities, that the pandemic concerns all people without distinction but that women, children and youth are becoming infected at an increasing rate, that it not only causes physical and emotional suffering, but is often used as a justification for grave violations of human rights,

MINDFUL ALSO that obstacles of all kinds – cultural, legal, economic and political – are hampering information, prevention, care and support efforts, that HIV/AIDS prevention and care support strategies are inseparable, and hence must be an integral component of an effective and comprehensive approach to combating the pandemic, that new local, national and international forms of solidarity are emerging, involving in particular people living with HIV/AIDS and community based organizations,

II. SOLEMNLY DECLARE our obligation as political leaders to make the fight against HIV/AIDS a priority, our obligation to act with compassion for and in solidarity with those with HIV or at risk of becoming infected, both within our societies and internationally, our determination to ensure that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms without distinction and under all circumstances, our determination to fight against poverty, stigmatization, and discrimination, our determination to mobilize all of society – the public and private sectors, community-based organizations and people living with HIV/AIDS – in a spirit of true partnership, our appreciation and support for the activities and work carried out by multilateral, intergovernmental, nongovernmental and community-based organizations, and our recognition of their important role in combating the pandemic (...)

III. UNDERTAKE IN OUR NATIONAL POLICIES TO protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through the legal and social environment, fully involve nongovernmental and community-based organizations as well as people living with HIV/AIDS in the formulation and implementation of public policies, ensure equal protection under the law for persons living with HIV/AIDS with regard to access to health care, employment, travel, housing and social welfare, intensify the following range of essential approaches for the prevention of HIV/AIDS:

- Promotion of and access to various culturally acceptable prevention strategies and products, including condoms and treatment of sexually transmitted diseases.
- Promotion of appropriate prevention education, including sex and gender education, for youth in school and out of school.
- Improvement of women's status, educational and living conditions.
- Specific risk-reduction activities for and in collaboration with the most vulnerable populations, such as groups at high risk of sexual transmission and migrant populations.
- The safety of blood and blood products.
- Strengthen primary health care systems as a basis for prevention and care, and integrate HIV/AIDS activities into these systems, so as to ensure equitable access to comprehensive care.
- Make available necessary resources to better combat the pandemic, including adequate support for people infected with HIV/AIDS, nongovernmental organizations and community-based organizations working with vulnerable populations.

IV. ARE RESOLVED TO STEP UP THE INTERNATIONAL COOPERATION THROUGH THE FOLLOWING MEASURES AND INITIATIVE. We shall do so by providing our commitment and support to the development of the joint and co-sponsored United Nations program on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and worldwide leadership in the fights against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and co-sponsored program and other appropriate fora:

1. Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments (...).

7. Strengthen national and international mechanisms that are concerned with HIV/AIDS related human rights and ethics, including the use of an advisory council and national and regional networks to provide leadership, advocacy and guidance in order to ensure that non-discrimination, human rights and ethical principles form an integral part of the response to the pandemic (...).

Countries which were represented at the Paris Summit and signed the Declaration:

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

The Denver Principles – Statement written in June 1983 by the National Association of People with AIDS (USA)

We condemn attempts to label us as “victims”, a term which implies defeat, and we are only occasionally “patients”, a term which implies passivity, helplessness, and dependence upon the care of others. We are “People with AIDS”.

Recommendations for All People

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.

Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

Recommendations for People with AIDS

Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.

Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

Rights of People with AIDS

To as full and satisfying sexual and emotional lives as anyone else.

To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.

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.

To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.

To die – and to LIVE – in dignity.

This statement is considered as a founding text for the PLHA self-empowerment movement.