The involvement of people living with HIV/AIDS in the delivery of community-based prevention, care and support services in Maharashtra, India

A diagnostic study
The International HIV/AIDS Alliance is an international Non Government Organisation that supports community action on HIV/AIDS in developing countries. It currently has programmes in 19 countries, including India.

Horizons is a global operations research program designed to identify solutions to improve prevention, care and support programs, and service delivery.

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- The Maharashtra Network of Positive People (MNP+)*, Mumbai
- The Salvation Army Mumbai HIV/AIDS Community Development Programme
- The Society of Friends of Sassoon Hospital (SOFOSH), Pune

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## Abbreviations and acronyms

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AVERT</td>
<td>AIDS Education and Research Trust</td>
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<tr>
<td>CARAT</td>
<td>Cell for AIDS Research Action and Training</td>
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<tr>
<td>CBO</td>
<td>Community-Based Organisation</td>
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<tr>
<td>CCDT</td>
<td>Committed Communities Development Trust</td>
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<tr>
<td>CIDA</td>
<td>Canadian International Development Agency</td>
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<tr>
<td>DFID</td>
<td>UK Department for International Development</td>
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<tr>
<td>GIPA</td>
<td>Greater Involvement of PLHA</td>
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<tr>
<td>GOI</td>
<td>Government of India</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-Based Care</td>
</tr>
<tr>
<td>IDA</td>
<td>International Development Association</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, Education and Communication</td>
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<tr>
<td>IGA</td>
<td>Income-Generating Activity</td>
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<tr>
<td>ILO</td>
<td>International Labour Organisation</td>
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<tr>
<td>INP+</td>
<td>India Network for Positive People</td>
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<tr>
<td>KAB</td>
<td>Knowledge, Attitudes and Behaviour</td>
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<tr>
<td>MNP+</td>
<td>Maharashtra Network for Positive People</td>
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<tr>
<td>MPSW</td>
<td>Medical and Psychiatric Social Work</td>
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<tr>
<td>MSM</td>
<td>Men who have Sex with Men</td>
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<tr>
<td>NACO</td>
<td>National AIDS Control Organisation</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>PHC</td>
<td>Primary Health Care</td>
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<tr>
<td>PLHA</td>
<td>Person or People Living with HIV/AIDS</td>
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<tr>
<td>SA</td>
<td>Salvation Army</td>
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<tr>
<td>SACS</td>
<td>State AIDS Control Society</td>
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<tr>
<td>SOFOSH</td>
<td>Society of Friends of Sassoon General Hospitals</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>TISS</td>
<td>Tata Institute of Social Sciences</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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<tr>
<td>UNFPA</td>
<td>United Nations Family Planning Association</td>
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<tr>
<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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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:
- PLHA or persons affected by HIV/AIDS who request and use the care or support services of one or several NGOs or CBOs on a regular or occasional basis.
- PLHA or persons 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 persons affected by HIV/AIDS.

**Community-Based Organisation (CBO)** – Group and association formed by people living within specific communities that work at the local level, and mostly seek to ensure benefits for their members. The organisation should be registered under the relevant Acts with the commissioner of charities or societies.

**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 where PLHA, or other groups that are marginalised 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 of the issue, be recognised, 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 People Living with HIV/AIDS during the study. This does not mean that they always know their HIV status, or they might know that they are HIV positive but they 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”, or “GIPA”, in the response to the HIV/AIDS epidemic. Since then most stakeholders, such as UN agencies and AIDS activists, have used the word “involvement” rather than, for example, “participation”. For this reason, this study uses the term “involvement”, although “participation” is more commonly used in social science.

While the Paris Summit noted that PLHA can be involved in a range of areas and at different levels¹, this study has analysed PLHA involvement with specific reference to prevention, care and support services of NGOs and CBOs.

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

(a) As a generic word to describe any way in which PLHA take part in the activities of NGOs and CBOs.
(b) As a specific way in which PLHA take part in the activities of NGOs, or type of involvement, the other types being access, inclusion and participation.

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

Non-Governmental Organisation (NGO) – Formally registered not-for-profit organisation that seeks to address a particular need or cause. NGOs are generally larger than CBOs and may be local, national or international. The organisation should be registered under the relevant Acts with the commissioner of charities or societies.

Person affected by HIV/AIDS – In this study and report, 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.

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).
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 are 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 they have taken a test, but for a variety of possible reasons, do not know the result. In this report, the terms **seropositive, positive** and **HIV positive** are used interchangeably. Other people refer to PLHA as **PWA**, People With AIDS.

**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 individual responsibility in the search for solutions to his or her problem, and that the sharing of information, experience, knowledge 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 on a regular basis, to the service users or beneficiaries of the NGO. Those carrying out activities on an unplanned, informal or occasional basis or as a result of their own individual actions, are not included in the definition of service provider.

**Stigma** toward PLHA – Several authors 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/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. Enacted stigma, on the other hand, refers to the real experience of discrimination. For example, the disclosure of an individual’s HIV positive status could lead to loss of a job or of health benefits, or social ostracism. Felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma, such as when people deny their risk of infection or fail to disclose HIV status in order to avoid being ostracised.²

**Types of involvement (Typology)** – Various ways for PLHA to be involved and for organisations to involve them, see Involvement. **Models** and types are used interchangeably in this report.

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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 organisation, where the PLHA is either a service user or a service provider.
- 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 AIDS 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.
Map of India and Maharashtra
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Executive summary

Background

Despite recognition of the importance of involvement of people living with HIV/AIDS (PLHA) in the response to the epidemic, there has been little research to explore how PLHA involvement in the delivery of prevention, care and support services at the community level can contribute to improving the quality of life of PLHA and people affected by HIV/AIDS and to preventing the transmission of HIV. To address this situation, the Horizons program and the International HIV/AIDS Alliance conducted a study of PLHA involvement in community-based programs in Burkina Faso, Ecuador, Zambia and Maharashtra State in India, with funding from USAID.

The study objectives were to:

- Describe the ways in which PLHA take part in the activities of NGOs and CBOs and develop a typology of involvement.
- Identify the factors that limit or enhance PLHA involvement.
- Understand the effects of involvement on the quality of life of HIV positive service providers and users, on families and communities, on the NGOs and CBOs, and on the relevance, quality and effectiveness of the services they provide.
- Identify strategies to increase PLHA involvement and the forms of PLHA involvement that can have beneficial effects on NGO and CBO services.

This Executive Summary highlights the findings from Maharashtra, India. This site was chosen because India has more PLHA than any other country in Asia and Maharashtra is among the Indian states with the highest HIV prevalence.

HIV/AIDS in India and Maharashtra State

The first AIDS case was reported in India in 1986. By 2000 the National AIDS Control Organisation (NACO) had reported 15,606 cases of AIDS, 3,657 of them in Maharashtra. In 1999, NACO estimated HIV prevalence to be 2.46%, but prevalence in Maharashtra was 10.26%. Although national HIV prevalence rates are relatively low, the country’s large population means that almost 4 million people in India, and more than 400,000 in Maharashtra, are infected. The epidemic is driven mainly by heterosexual transmission, with important sub-epidemics among men who have sex with men and injecting drug users.

The government is implementing the second phase of the National AIDS Control Programme, which emphasises a multi-sectoral approach involving government, NGOs and civil society, and a decentralised framework with responsibility
devolved to State AIDS Control Societies. The Draft National AIDS Control Policy highlights the need to establish a continuum of care, since most PLHA do not have access to high quality care and support, and there are few home-based care initiatives. NGOs and CBOs have played an important role in HIV/AIDS social mobilisation. Mobilisation of PLHA is a relatively recent phenomenon, but there is a national PLHA network, the Indian Network for Positive People (INP+) and networks at state level.

While India does not have any legislation protecting the rights of PLHA, the Draft Policy acknowledges the problem of stigma and discrimination and emphasises the rights of PLHA to health care, employment and education. However, widespread ignorance about HIV/AIDS is reflected in negative attitudes and behaviour towards PLHA in the home, community, school, workplace and health facilities.

**Study methodology**

In order to study the involvement of PLHA at the community level in Maharashtra State, four local NGOs were invited to participate in the study, which was conducted by a team of local researchers with support from the Tata Institute of Social Sciences. The four NGOs were:

- Committed Communities Development Trust (CCDT) and Project CHILD.
- Maharashtra Network for Positive People (MNP+).
- Salvation Army Mumbai HIV/AIDS Community Development Programme.
- Society of Friends of Sassoon Hospitals (SOFOSH).

During the design of the study, the decision was made to adopt a participatory methodology. In accordance with this approach, the four NGOs were actively involved in planning and in the collection, validation and interpretation of data. Particular importance was attached to respect for the rights of study participants, and the NGOs ensured that researchers adhered to the principles of voluntary participation, informed consent and confidentiality.

An orientation workshop at the start of the study familiarised the participating NGOs with basic research concepts, explored the study rationale, relevance and process, and adapted the methodology and tools to the Indian context.

The study mainly used qualitative data collection methods, including in-depth one to-one and short key informant interviews, group interviews, focus group discussions, as well as observation and participatory research techniques. A total of 140 respondents, 55% of whom were PLHA, took part:

- 132 respondents from the four participating NGOs:
- 48 service providers (NGO management, salaried staff and volunteers).
- 61 PLHA beneficiaries.
Executive summary

- 10 affected beneficiaries.
- 11 beneficiaries who are neither infected nor affected.
- 2 relatives of PLHA service providers.

- 8 key informants (health and social sectors professionals, community leaders, and PLHA unrelated to the four NGOs).

Qualitative data was supplemented by a literature review, quantitative data about services and activities, and socio-demographic profiles of service providers and beneficiaries based on information collected by a questionnaire.

The researchers used the data collected to prepare organisational profiles, which were shared with the respective NGOs to enable them to validate the findings. This was followed by a data analysis workshop to discuss the preliminary results, review the typology of PLHA involvement, refine the organisational profiles, and identify strategies to increase PLHA involvement.

Participating NGOs

The four NGOs were selected because they had a range of structures, approaches and types of PLHA involvement. The study analysed the characteristics of each NGO, to identify what type of organisational model (secular welfare, religious welfare, development, rights-based) they represent.

Project CHILD (CCDT)

CCDT, a secular NGO established in 1990, is an example of a development model of organisation, but has some characteristics of secular welfare and rights-based models because of its focus on service provision and empowerment. Project CHILD is a CCDT programme that aims to meet the needs of children and families affected by HIV. Project activities, carried out by 21 professional staff, include temporary shelter for children, counselling, home-based care, home and hospital visits, support groups, and practical, psychological and social support. Some PLHA are employed as support staff; some belong to support groups. CCDT has good links with INP+ and MNP+.

Maharashtra Network for Positive People (MNP+)

MNP+, established by a group of PLHA in 1998 to empower PLHA through sharing experience and information, advocating for PLHA rights, supporting the establishment of self-help groups, and networking, was an example of a rights-based organisation. (MNP+ has been dissolved since the completion of the study.) MNP+ had 11 paid staff, 64% of whom were HIV positive, 10 volunteer service providers, and 500 members of the Maharashtra Major Group, a PLHA network. Activities included peer counselling, referral, support group meetings, information dissemination, awareness-raising activities with health professionals, government and non-government agencies.
Salvation Army Mumbai HIV/AIDS Community Development Programme
The Salvation Army, an international Christian movement, started working on HIV/AIDS in Mumbai in 1989, and is an example of a religious welfare organisation, but also has some characteristics of the development model because it aims to empower and mobilise communities to respond to HIV/AIDS. Activities of the HIV/AIDS Community Development Programme include counselling, referral, transport to hospital, medical treatment, hospital visits, peer support, support groups, home-based care and awareness-raising. The Programme has nine salaried staff, and volunteers. Some service providers, support staff and volunteers are visible PLHA.

Society of Friends of Sassoon Hospitals (SOFOSH)
SOFOSH, an NGO established in 1964 to provide support to low-income hospital patients, is an example of a secular welfare organisation. SOFOSH integrated HIV/AIDS into its work in 1995, providing patients and families with counselling, psychological support and guidance on home care, adapting its shelter and adoption programme to include infected and affected children, and its programme for single mothers to include HIV testing and provision of antiretrovirals. SOFOSH has 65 professional and support staff, and 35 volunteers. Most PLHA are referred from the TB outpatient department of the hospital.

Types of PLHA involvement
The study identified potential areas of PLHA involvement in NGOs and CBOs:

- Utilisation of the services of the NGO
- Support to services
- Delivery of HIV/AIDS services
- Planning and design of services
- Management, policy making and strategic planning

A range of criteria was used to describe the characteristics of involvement in each area. These criteria included the time PLHA spend taking part in activities, the financial and material remuneration they receive, the extent to which their skills or expertise are used, their involvement in decision making, and their visibility within and outside the organisation. Using this framework, the study identified four types of PLHA involvement (access, inclusion, participation and involvement\(^3\)), described the types of involvement observed in the four NGOs, and analysed the relationship between different types of organisational models and the types of PLHA involvement.

\(^3\) Involvement is defined in two ways: 1. Generically, to describe any way in which PLHA take part in NGO and CBO activities; 2. Specifically to describe one of the ways on which PLHA take part in NGO and CBO activities. When used to refer to the latter, involvement is italicised.
Access
Access is where PLHA take part in NGO activities only as service users, for example as clients of counselling or recipients of medical care. This is particularly the case with NGOs where most service providers are trained professionals, as with three of the NGOs in Maharashtra. Although access was not the only type of involvement observed in the participating NGOs, most PLHA are involved only as beneficiaries. Access benefits service users and their families, and can be an entry point for further involvement.

Inclusion
Inclusion is where PLHA are service users, and are also employed as support staff in non-HIV/AIDS activities or act as “aides” to service delivery on an informal, occasional, volunteer basis. Inclusion has a positive effect on PLHA if they are employed and receive remuneration and other benefits, improving their health and self-esteem; there are fewer benefits if inclusion is voluntary and irregular. 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.

Inclusion was observed in all four participating NGOs, although the number of PLHA visible involved is small. Some PLHA are employed as helpers, attendants or support staff in non-HIV/AIDS activities. Some PLHA support HIV/AIDS-related activities, including providing informal peer counselling and support, organising recreational activities, raising awareness in the community, giving testimony, and carrying out hospital and home visits. While a few receive an honorarium for their contribution, most are volunteers. Formal training for PLHA involved on an informal basis is limited, and most mainly use their experience of living with HIV/AIDS. These PLHA are not involved in service planning or design. In one NGO, involvement in support groups has evolved from access to inclusion, as PLHA have taken on responsibility for organising and facilitating meetings.

Participation
Participation is where PLHA are service users, support the activities of the organisation, and also deliver HIV/AIDS-related services on a formal, regular basis. As service providers, their expertise is recognised by the NGO and they receive financial compensation for their work. PLHA may be involved directly in planning the services they deliver and consulted about other services. The benefits to PLHA of participation include earning an income and a sense of achievement, but they may get frustrated by lack of involvement in decision-making and may be at risk of stigma and discrimination because they have higher visibility. Participation is meaningful to NGOs, if they are ready to invest in recruitment and training of PLHA.

In three of the participating NGOs, PLHA are involved as service providers in counselling, home and hospital visits, supporting community volunteers, community awareness raising, and facilitating support groups. In only one of
these NGOs are PLHA involved in planning and design of their activities. In the other two, PLHA are involved indirectly in planning and design, through consultation with support groups about the services they receive. With the exception of MNP+, very few PLHA are visibly involved in formal service delivery in these NGOs. Participation mostly takes the form of involvement in peer support and outreach education, and visible PLHA are not involved in activities that require higher levels of education and qualifications, such as medical care. While PLHA who work in service delivery have received more training than volunteers or beneficiaries, this is often informal rather than formal training. Again with the exception of MNP+, PLHA have limited inputs into the design of other services and into organisational decision-making.

**Involvement**

Involvement is where PLHA are service users, support the activities and services of the organisation, deliver HIV/AIDS-related services, and also take part in management, policy making and strategic planning as directors, trustees or programme managers. In addition to making organisational and programmatic decisions, PLHA may also represent the NGO externally. Involvement is more meaningful than participation for those PLHA who have the desire to shape the policies of their organisation. It allows PLHA to influence the design and implementation of programmes and therefore may have greater impact on the relevance of services to the needs of beneficiaries. However, again, high visibility can expose PLHA to stigma and discrimination, although the level of personal acceptance and support is also very high for PLHA involved. Involvement requires investment and planning by NGOs.

The study observed visible involvement in MNP+, the only participating organisation where PLHA hold senior management positions. In contrast to inclusion and participation, where PLHA involved were less educated and from lower-income groups, PLHA involved in management, policy making and strategic planning had completed a higher level of formal education and were from middle-income groups.

**Factors limiting and enhancing PLHA involvement**

Analysis of PLHA involvement in the four participating NGOs suggests that relatively few PLHA are visibly involved in community-based prevention, care and support services in India, and that access and inclusion are the most common types of involvement.

In order to develop strategies to increase PLHA involvement, it is necessary to identify what factors limit or enhance involvement. The study categorised these factors for the four NGOs as individual, institutional and social factors:
• **Individual factors** – These include characteristics of PLHA who are or who could be involved, such as health, education, skills, etc.

• **Institutional factors** – These include characteristics of the organisation in which PLHA are involved or willing to be involved, such as institutional policy, structure, management, etc.

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

**Individual factors that limit PLHA involvement**

**Fear of stigma and discrimination** from neighbours, relatives and friends was the limiting factor mentioned most frequently. This was related to more specific concerns about labelling, loss of job or home, or impact on the family as a result of visibility or association with an organisation working with PLHA, and about respect for confidentiality by NGOs. Fear of stigma and discrimination limits in particular types of involvement that require a higher level of visibility, such as participation and involvement.

**Poor health**, particularly in symptomatic PLHA, is perceived to limit involvement in physically and mentally demanding activities and regular, sustained involvement. This is also linked to concerns that activities, such as hospital visiting, could involve a **risk of contracting opportunistic infections** or adversely **affect the psychological health** of asymptomatic PLHA who have to deal with other PLHA who are ill.

**Lack of education** and language differences, are factors limiting participation and involvement in NGOs, since these types of involvement require levels of knowledge and skills that go beyond personal experience of living with HIV/AIDS.

**Poverty**, the need to earn a living and inability to meet even basic needs, let alone the costs of travelling to and from an NGO, prevents many PLHA from becoming involved.

Other individual factors limiting involvement, possibly related to fear of stigma and discrimination, lack of education and low socio-economic status, include **limited awareness about HIV/AIDS** and **lack of interest and motivation**.

**Individual factors that enhance PLHA involvement**

The most common factor encouraging PLHA to be involved is the desire to help other PLHA, in some cases to help others avoid the stigma and discrimination that they themselves have experienced. Related factors include being inspired by
role models, by seeing how service providers help PLHA, peer support and a sense of "not being alone", and compassion for others.

Since most PLHA are poor, the availability of employment opportunities or other benefits resulting from involvement are or would be important incentives for involvement. Other practical factors that would encourage involvement include time, being literate, being asymptomatic, and the opportunity to work in settings with minimal risk of contracting opportunistic infections.

Organisational factors that limit PLHA involvement

By far the most significant institutional limiting factor is lack of information about opportunities for PLHA to be involved. Linked to this is a lack of information about the range of services provided by the NGOs, and lack of organisation policies for PLHA involvement or policies that discriminate against PLHA or exclude them from certain activities.

Another limiting factor, which may be related to concerns about visibility and confidentiality, is mandatory HIV testing during recruitment for service providers.

Lack of funds to support PLHA involvement, for example, employment opportunities, monetary compensation, reimbursement of travel expenses and other material incentives, is also important. This is also linked to the perception in some NGOs that it is not cost-effective to invest in training PLHA. NGOs also lack the resources and staff required to train and support PLHA. Staff attitudes and gender also play a role. Judgmental attitudes within NGOs are reflected in non-acceptance of PLHA as service providers or failure to recognise and use the skills of PLHA service providers. Some respondents noted that it is difficult to involve female PLHA in organisations where staff are predominantly male, and vice versa.

Organisational factors enhancing PLHA involvement

The most frequently mentioned institutional factor was a supportive environment, characterised by openness, non-discrimination and the availability of peer support. Related institutional factors that contribute to such an environment include supportive workplace policies, non-judgmental attitudes among service providers, teamwork, acceptance and support for PLHA involvement among management, service providers and co-workers, and willingness to involve PLHA on the basis of their skills and capacity and to develop their skills and capacity, including providing opportunities to attend conferences and workshops. For many PLHA, scope for non-visible involvement and confidence that an organisation will maintain confidentiality about HIV status are critical factors.
Executive summary

Given the poverty of most PLHA in India, institutional capacity to provide **employment opportunities** and other **financial and material assistance**, such as access to free drugs and medical care, travel expenses and meals, is also an important factor encouraging involvement. Another practical factor that encourages PLHA involvement is the **opportunity to receive information** about HIV/AIDS.

<table>
<thead>
<tr>
<th>Box E1</th>
<th>Relationship between different models of organisation and PLHA involvement</th>
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</thead>
<tbody>
<tr>
<td><strong>Secular welfare model</strong> – in this type of organisation, illustrated in the study by SOFOSH, PLHA involvement takes the form of <strong>access</strong> and <strong>inclusion</strong>. PLHA are beneficiaries and take part in supporting activities and services. The main obstacle to <strong>participation</strong> and <strong>involvement</strong> in this organisational model is that beneficiaries are seen as passive recipients of services provided by trained professionals.</td>
<td></td>
</tr>
<tr>
<td><strong>Religious welfare model</strong> – in this type of organisation, illustrated in the study by the Salvation Army, PLHA involvement takes the form of access, inclusion and participation. PLHA are beneficiaries, take part in supporting activities and services and are employed as service providers. The Salvation Army places considerable emphasis on community empowerment, which may explain the level of participation observed. The main obstacle to involvement is that decision and policy makers belong to the “religious” hierarchy. If members of this hierarchy are HIV positive, it might not be easy for them to come out as HIV positive because of their religious and moral commitment and the fact that HIV/AIDS is still associated with sin and immoral behaviour.</td>
<td></td>
</tr>
<tr>
<td><strong>Development model</strong> – in this type of organisation, illustrated in the study by Project CHILD, PLHA involvement takes the form of <strong>access</strong>, <strong>inclusion</strong> and, to some extent, <strong>participation</strong>. PLHA are beneficiaries, take part in supporting activities and services, and are consulted during planning and design of services. It is expected that there will be a greater level of participation in this model compared with welfare-oriented organisations because on the focus on empowerment and self-help.</td>
<td></td>
</tr>
<tr>
<td><strong>Rights-based model</strong> – in this type of organisation, illustrated in the study by MNP+, PLHA involvement takes the form of <strong>access</strong>, <strong>inclusion</strong>, <strong>participation</strong> and <strong>involvement</strong>. PLHA are beneficiaries, service providers and decision-makers. Involvement is encouraged because the mission of a rights-based organisation working on HIV/AIDS is precisely to empower PLHA to help each other and advocate for their rights.</td>
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</table>

**Social factors that limit PLHA involvement**

Many obstacles to involvement are related to the social context and widespread negative attitudes towards PLHA in India, in particular **stigma** and
**Executive summary**

Discrimination by relatives, friends and neighbours, and in health care and workplace settings. Stigma and discrimination are linked to misinformation and misconceptions about HIV/AIDS among health professionals as well as the general public. Public awareness campaigns that have emphasised fear and shame have contributed to misconceptions and discouraged visible PLHA involvement.

Other social factors that limit PLHA involvement include poverty and gender. In the Indian context, many people struggle to meet their basic needs and women have considerable domestic responsibilities, so time for other activities is limited. In addition, women are not always free to make their own decisions or to travel outside their homes.

**Social factors that enhance PLHA involvement**

Support from family, friends and neighbours was the most frequently mentioned social factor, and this is linked to other social factors including advocacy and education to improve public awareness of HIV/AIDS and reduce stigma and discrimination.

**Box E2**

Pathways to involvement for PLHA

- Acceptance of HIV status.
- Awareness of the existence of the NGO.
- Visibility, even if this is limited to support group members or service providers.
- Accessing and sharing information and experience.
- Training on HIV/AIDS issues.
- Building self-esteem.
- Making time.
- Being associated with the NGO.
- Becoming visible to a wider group.

Pathways to involvement for NGOs and CBOs

- Sensitising management and staff on HIV/AIDS issues
- Creating a conducive environment.
- Developing policies for involvement and identifying areas of possible involvement.
- Sharing information about opportunities for involvement.
- Identifying PLHA potential and provide training.
- Providing opportunities for involvement in all areas.
- Respect for PLHA and their views.
- Teamwork.

Analysis of the experience of the participating NGOs in Maharashtra indicates that involvement is both an individual process for PLHA and an organisational process for NGOs and CBOs and that, in many cases, this process is a continuum from access to inclusion to participation to involvement. Access can
be an entry point for further involvement, enabling PLHA to accept their HIV status, to learn about HIV/AIDS and learn how to cope. Growing acceptance and confidence can lead to inclusion, where PLHA feel able to share their experience with other people. PLHA also learn new skills, in particular through informal involvement in a wider range of activities. Further experience and skills development can lead to the opportunity for employment and participation in an NGO. Given a conducive environment and training to develop the required skills, PLHA can move on to involvement in an NGO.

For two of the NGOs, the individual and organisational process has followed this continuum, starting with access and moving towards participation. For example, in one of these organisations, the only visible PLHA service provider started as a support group member (access), then started to facilitate meetings on a voluntary basis (inclusion), and was subsequently recruited as a counsellor and support group co-ordinator (participation). The “pathways to involvement” – the steps or conditions necessary to achieve PLHA inclusion, participation and involvement – are highlighted above.

Effects of PLHA involvement

The study also assessed the positive and negative effects of PLHA involvement – on the quality of life of PLHA involved in the four NGOs, the activities, services, structure and functioning of the organisations, and the families and communities of the PLHA involved – and analysed the advantages and disadvantages for NGOs of different types of involvement.

Positive effects on individual PLHA

One of the positive effects of involvement was improved physical health, as a result of receiving financial remuneration, food or reimbursement for medical treatment, as well as increased knowledge about HIV/AIDS services provided by hospitals and other agencies. Involvement has also empowered PLHA, increasing their confidence and self-esteem, and giving them a sense of purpose, which has improved their psychological health. Improved psychological health is also associated with other positive effects of involvement, including peer support from other PLHA.

Negative effects on individual PLHA

The most frequently mentioned negative effects on individuals were possible stigma and discrimination, in the form of rejection and loss of employment. However, there were no examples of stigma and discrimination resulting from visible involvement and this is more of a limiting factor than a negative effect.
Another negative effect mentioned was adverse psychological impact on asymptomatic PLHA of identifying with PLHA who are ill or dying.

**Positive effects on organisations**

PLHA involvement was perceived to have increased organisational awareness of the perspectives and needs of PLHA and to have improved services such as counselling. It has also helped to publicise and increase uptake of services. Respondents perceived that PLHA involvement could also potentially help to create a positive image of the organisation and ensure proper utilisation of funds.

**Negative effects on organisations**

Few negative effects were reported, apart from concerns that PLHA involvement might have adverse effects on other services and result in stigmatisation of the organisation. Other potential negative effects mentioned included difficulties for supervisors in managing PLHA staff and volunteers, and improvements in quality of services resulting in increased workload as other agencies shift cases to NGOs.

**Positive effects on families and communities**

The main positive effect of PLHA involvement on families was improved mental health of family members. PLHA involvement, for example in home visits, has also improved the effectiveness of community interventions.

In conclusion, the study findings show that all types of involvement are meaningful at different levels. However, for each type to be really meaningful, there are a series of steps to take for PLHA and organisations (see Pathways to involvement). If PLHA or NGOs fail to take these steps, positive effects of involvement tend to be limited and negative effects increase. We saw that for example different kinds of skills are necessary for PLHA depending on the type of involvement. If a PLHA is involved in service delivery, for example outreach education, without the skills required for this: his/her involvement can be harmful to him/her, by exposing him/her to discrimination, and the quality of the activity can be very poor, preventing messages from reaching the community. Most factors that limit involvement of PLHA (see chapter 4) also limit the impact of involvement, even when PLHA are involved.

In general it seems that the positive effects of involvement of PLHA outweigh the negative effects. Organisations do see the benefits of PLHA involvement in the delivery of services to other PLHA with services being more user friendly and
therefore more effective. In turn, PLHA seem to favour their involvement in NGOs and CBOs as they feel more empowered and able to accept their condition more easily. However some results remain difficult to analyse. We saw for example that involvement may lead to some form of discrimination and we also observed that involvement can increase support from the family and the community. More research is needed to understand better in what circumstances PLHA suffer stigma and discrimination as a result of their visible involvement.

Another question that remains partly unanswered is the impact of involvement when it is not visible. We observed 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. Members of support groups can be visible only to other members, peer counsellors can 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.

See also recommendations on pages 137 to 142.
Introduction

Background

Greater Involvement of PLHA (GIPA) in policy formulation and service delivery was identified as a critical aspect of the response to the HIV/AIDS epidemic in the Final Declaration of the Paris Summit in 1994. In the Declaration, 42 governments made a commitment to support “full involvement” of PLHA in the “common response to the pandemic at all – national, regional and global – levels”.

However, there has been little if any systematic research to explore how PLHA involvement in the delivery of prevention, care and support services at community level can contribute to improving the quality of life of people infected and affected by HIV/AIDS and to preventing the transmission of HIV, in particular in the developing world.

This report summarises the methodology, findings and conclusions of a diagnostic study on the involvement of people living with HIV/AIDS (PLHA) in the delivery of community-based prevention, care and support services in Maharashtra State in India. The study was carried out in three other developing countries – Burkina Faso, Ecuador, and Zambia – between September 1998 and August 2001. In India, the study was undertaken between January 2000 and August 2001, following a rapid assessment conducted in late 1999 to determine needs and to identify the study site and partners.

The diagnostic study is one of the activities of Horizons, a global operations research programme funded by the United States Agency for International Development (USAID) and implemented by the Population Council in collaboration with five partner organisations, including the International HIV/AIDS Alliance which co-ordinated the study.

Horizons carries out operations research to identify solutions to improve prevention, care and support programmes and service delivery. Its current portfolio includes more than 60 operations research activities in Asia, Africa, Latin America and the Caribbean. The International HIV/AIDS Alliance is an international Non-Governmental Organisation that supports community action on HIV/AIDS in developing countries. It currently has ongoing programmes in 19 countries, including India.

India was chosen because it is the country in Asia with the largest number of PLHA (in spite of a relatively low HIV prevalence in the global population).

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5 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’.
Maharashtra is amongst the Indian states with the highest prevalence. Mobilisation of PLHA is still a recent phenomenon but there is already a national network of PLHA, the Indian Network for Positive people (INP+) and other networks at the state level.

**Study objectives**

The objectives of the study were:

- To describe the current ways in which PLHA are involved in Non-Governmental Organisations (NGOs) and Community-Based Organisations (CBOs), and to develop a typology of these different forms of involvement.
- To identify the factors that limit or enhance PLHA involvement in these organisations.
- 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 generally have effects on the relevance, quality and effectiveness of the services provided by NGOs and CBOs.
- To identify the types or models of involvement that can have beneficial effects on the relevance, quality and effectiveness of services delivered by NGOs and CBOs.

A better understanding of these issues is 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 have an impact?
- What strategies could NGOs and CBOs employ to achieve PLHA involvement and an improvement in the quality and effectiveness of the services they deliver?
- Under what circumstances does PLHA involvement not have positive effects, or does it have negative consequences for the PLHA themselves – either as service providers within NGOs or CBOs or as beneficiaries of these services – or for the community?

**Stakeholders in Maharashtra and India**

In order to study the involvement of PLHA at the community level in Maharashtra, four NGOs – three based in Mumbai and one based in Pune – were invited to participate in the research:
• Committed Communities Development Trust (Project CHILD)
• Maharashtra Network for Positive People (MNP+)
• The Salvation Army Mumbai HIV/AIDS Community Development programme
• Society of Friends of the Sassoon General Hospitals (SOFOSH).

The selection of these four NGOs was based on the following criteria:

• 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 organisations that either already have different forms of PLHA involvement in their activities or are open to the possibility of such involvement.
• They are interested in the issue of PLHA involvement and in any lessons that could be learnt from the study and used to improve their services.

Information about the organisations, their structure and management, services and activities, is included in Chapter 3.

The study was conducted by a research team based in Mumbai, which consisted of a National Research Co-ordinator, a Research Officer and three Research Assistants. The researchers were supported by a Principal Investigator for India, Dr Vimla V Nadkarni, head of the Department of Medical and Psychiatric Social Work (MPSW) at the Tata Institute of Social Sciences (TISS), which carries out both teaching and research activities. The Cell for AIDS Research Action and Training (CARAT), a project of the Department of MPSW, provided office space and support for administration, translation and literature review elements of the study. Further training and technical support was received from the study co-ordination team at the International HIV/AIDS Alliance in the United Kingdom and the South and South-east Asia Regional Office of the Horizons/Population Council in New Delhi, which is currently implementing five operations research programmes in India and Nepal.

Contents of the report

The first chapter of this report describes the unique participatory process that was used to implement the study and the rationale for the development of this innovative methodology.

The second chapter will focus on the main characteristics of the HIV/AIDS epidemic in India and Maharashtra and the response of government and civil society.

In the third chapter, we will describe what forms of involvement of PLHA we observed in the NGOs and CBOs who participated in the research, introducing a
new general typology of involvement and the corresponding terminology developed by the study in the four countries where it was conducted.

In the fourth chapter, we will analyse the obstacles to the various types of involvement of PLHA in NGOs and CBOs presented in the previous chapter, as well as the factors that have made involvement of PLHA possible and that could strengthen it.

Finally, the fifth chapter will discuss the reasons why involvement of PLHA can make a difference for PLHA and the organisations in which they are involved, by offering an overview of the positive and negative effects on the individuals, the organisations themselves and the community in general.
Chapter 1
Methodology

1.1 Participatory approach

1.1.1 Participatory approach: the rationale

The methodology, which had been successfully piloted in Burkina Faso and also used in Ecuador before it was adapted in India, put a strong emphasis on the participation of study respondents, in particular the management and service providers of the four NGOs involved in the study, in various stages of the research process (see box below).

The principle of involving research subjects in studies is not new. It has often been used for ideological, programmatic and/or methodological purposes. However, in research on HIV/AIDS and with PLHA, the practice has often lagged behind the rhetoric. Research in HIV has often claimed to use, or at least encourage the use of participatory methodology, but has not always done so. The decision to use a participatory methodology for this study was made for three main reasons:

**Ethical rationale** – Researchers are in general increasingly aware of the rights of study participants, although some of them may still overlook these rights, which include:
- Information about the study.
- Information about the possible risks and benefits incurred by participation in the study.
- Respect of confidentiality by researchers.
- Voluntary participation and right to withdraw from the process at any time.

Rights of participants in this study were particularly important because many of them were HIV positive or people affected by HIV/AIDS, and any breach of confidentiality by the researchers would have put them at risk in a context where they are still stigmatised and discriminated against. We assumed that the involvement of HIV positive service providers, together with other members of the four partner NGOs, in the design, implementation and monitoring of the informed consent process would help guarantee the rights of study respondents.

**Scientific rationale** – The purpose of any study is to collect a reasonable amount of data of high quality from the right respondents in order to provide the relevant scientific evidence to the community. In this study, the challenge was to identify and access a relatively large number of HIV positive respondents who trusted researchers enough to have in-depth discussions with them about

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6 The study was conducted simultaneously in India and Zambia.
sensitive issues. This was made even more difficult by a very tight timeline that generally did not allow for several in-depth interviews to be conducted with the same respondent.

The underlying hypothesis was that involving PLHA and other members of NGOs in the study would help other HIV positive people, whether service providers or users, to overcome their fear of stigma and agree to be interviewed. NGO members would play a major role in the identification and recruitment of study respondents. Finally, the close co-operation between representatives from NGOs and researchers since the beginning of the study would be a way to build trust in a short period of time.

**Programmatic rationale** – As an operations research project, the study aims to have an effect on programmes, in particular on the way PLHA are involved in the delivery of services of the participating NGOs and other similar organisations. A key assumption was that the active involvement of the people who deliver and use these services in the research process would increase their interest in the findings and their willingness to use them.

Finally, given the experience of the International HIV/AIDS Alliance in mobilising the expertise of communities to respond to the HIV/AIDS epidemic, it seemed appropriate to conduct a study on the involvement of PLHA in CBOs and NGOs that would reflect the specific expertise of PLHA, people directly affected by HIV/AIDS and other NGO members by involving them in the process.
1.1.2 Participatory approach: the process

The table below presents the main steps in the participation of NGOs in the study and how NGO representatives were actively involved.

Table 1.1
Summary of the participation of NGO representatives in the research process

<table>
<thead>
<tr>
<th>What</th>
<th>How</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design and preparation of the study</strong></td>
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<tr>
<td>Discussion on the relevance of the study for the participating NGOs and Maharashtra</td>
<td>⇒ Meetings during rapid assessment</td>
</tr>
<tr>
<td>Adaptation of the study methodology and data collection tools to the Indian context</td>
<td>⇒ Participation in a five-day orientation workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study co-ordination team)</td>
</tr>
<tr>
<td>Presentation of the study to other stakeholders in Maharashtra</td>
<td>⇒ Participation in a one-day meeting with stakeholders</td>
</tr>
<tr>
<td>Appointment of “contact persons” within each organisation to liaise with research team</td>
<td>⇒ Meetings within each NGO</td>
</tr>
<tr>
<td>Definition of sample population for each organisation (categories and numbers of respondents)</td>
<td>⇒ Meetings between contact persons and research team</td>
</tr>
<tr>
<td>Identification and mobilisation of study respondents</td>
<td>⇒ Work carried out by contact persons within each NGO</td>
</tr>
<tr>
<td>Adaptation of informed consent forms and preparation for the utilisation of the forms</td>
<td>⇒ Participation in a one-day workshop facilitated by the Lawyers Collective(^7)</td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td></td>
</tr>
<tr>
<td>Circulation of consent forms and monitoring of informed consent process</td>
<td>⇒ Work carried out by contact persons together with researchers within each NGO</td>
</tr>
<tr>
<td>Use of Photovoice(^8) to collect information</td>
<td>⇒ Photographs taken by representatives of NGOs to illustrate PLHA involvement in their organisation or services delivered to PLHA</td>
</tr>
<tr>
<td>Development of indicators to assess the quality and impact of one of the area of activities of each organisation</td>
<td>⇒ Meetings of group of 3-5 service providers of the corresponding area of activities facilitated by researchers</td>
</tr>
<tr>
<td><strong>Data analysis</strong></td>
<td></td>
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<tr>
<td>Validation of data</td>
<td>⇒ Review by contact persons and</td>
</tr>
</tbody>
</table>

\(^7\) 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.

\(^8\) See detailed explanation of Photovoice under 1.3.
management of summaries of findings (organisational profiles) prepared by researchers for each NGO
⇒ Participation in a four-day data analysis workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study co-ordination team)

Interpretation and analysis of data
⇒ Participation in a four-day data analysis workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study co-ordination team)

Writing of reports
⇒ Review and editing of the summaries of key findings produced for each NGO

It is important to note that there were no visible PLHA among researchers\(^9\), although HIV positive people had been encouraged to apply. However, there were people directly affected by HIV/AIDS in the national and international research teams, as well as people with not only academic qualifications and research skills but also a significant experience in the delivery of care and support services - in particular counselling - at the community level.

1.2 Adaptation of the study methodology

A major step in the preparatory phase of the study in India was an orientation workshop held in February 2000. Representatives of the four NGOs, the International HIV/AIDS Alliance, Horizons/Population Council, TISS, INP+, as well as the research team participated in the workshop.

The purpose of the workshop was to familiarise participants with basic research concepts and terminology, explore the study rationale and process, and ensure the relevance of the research to the Indian context and the participating organisations. Participants discussed:

- Objectives and expected outcomes of the study.
- Research questions.
- Roles and expectations of the different stakeholders.
- Data collection methods.
- Rights of study participants that should be respected by the researchers and practical mechanisms to ensure the respect of these rights.

\(^9\) Obviously, researchers were not requested to disclose their HIV status, whether positive or negative, to their colleagues and supervisor.
Proposed dissemination and utilisation of the study findings.

Participants explored their understanding of PLHA involvement and identified key questions to be answered. These discussions led to consensus about how to adapt the methodology used in Burkina Faso and Ecuador to the Indian context.

The workshop brought representatives of NGOs and researchers together in a safe and supportive learning environment so they could get to know each other before fieldwork started. It was also an opportunity to test the communication skills and attitudes toward PLHA of the applicants to the position of research assistants. Based on the observation of their behaviour during the workshop, the study co-ordination team finalised the selection only at the end of the workshop.

Following the orientation workshop, each participating organisation designated at least two people (i.e. the contact persons) to co-ordinate data collection with the research team. Researchers then met with the newly appointed contact persons to plan and prepare for data collection, including determining sample population, reviewing some data collection tools and choosing a specific area of the organisation’s activity for which the organisation would develop indicators to evaluate the quality of the selected services and their impact on beneficiaries (see introduction to Chapter 5).

“We learned from the orientation workshop … now research is a more friendly word for us.” A representative from CCDT evaluating the study.
1.3 Data collection

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\(^{10}\). Interviews were used more than other techniques because they provide a safe environment for discussion of sensitive issues which cannot be addressed in public (see box below).
- 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 organisational meetings, where possible.
- Photovoice: Photovoice is 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 is easily accessible, so that they can analyse it in a process of “self-research”. A camera was given to each NGO and they were asked to take pictures that illustrated visible or non-visible involvement of PLHA in their organisation. HIV positive service providers were encouraged to take pictures of their own involvement. NGOs were told how to use consent forms when they took pictures. The process itself was as important as the outputs because it was a way to stimulate reflection on confidentiality and visibility of PLHA, which were two major themes in the study.

Besides Photovoice, data collection was entirely carried out by the research team, without participation of NGO representatives as interviewers and/or facilitators of group discussions. This division of roles had been discussed during the orientation workshop and thought to be suitable for the following reasons:

- NGO service providers do not have enough time.
- Interviews of NGO members by other NGO members are not ideal for confidentiality.
- Interviews of service users by service providers can influence interviewees and cause bias.

Qualitative data was supplemented by quantitative data about the organisations’ services and activities and socio-demographic profiles of service providers and

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\(^{10}\) Number of interviews and Focus Group Discussions is presented in table 1.2.
beneficiaries, which was collected by questionnaire (see Table below on socio-demographic profile of respondents).

1.4 Study population

The study sought to collect information from those who might influence the process of involvement, both within and outside the organisations. The study participants and key informants included:

- NGO management and service providers, whether staff members or volunteers (for example, trustees and committee members, counsellors, social workers and other care providers, and support staff).
- PLHA and persons affected by HIV/AIDS who are beneficiaries of the services delivered by these NGOs (including support group members, clients of counselling, HBC patients).
- Other beneficiaries (for example, adoptive parents of affected children).
- PLHA who are neither members nor beneficiaries of the NGOs.
- Relatives of the PLHA who are involved in the participating NGOs.
- Key informants (for example, health care professionals, policy makers).

The NGO contact persons and the local research team identified potential study participants to ensure representation of a diverse range of views and a gender balance among respondents.

Box 1.1
Selection of study respondents from NGOs

In order to chose respondents from the four NGOs, we looked at the range of services provided to PLHA and affected people by each NGO and decided to focus on the activities in which PLHA are already involved and other core services of each organisation:

- **Committed Communities Development Trust (CCDT)** – Support to groups of PLHA and affected people, counselling, child care
- **MNP+** – Support groups of PLHA and affected people, capacity-building of PLHA, counselling
- **Salvation Army** – Counselling, support group meetings, awareness activities in the community
- **SOFOSH** – Counselling, adoption services, child care

We then tried to recruit providers of each category of services based on the following criteria:

- As many visible HIV positive service providers as possible in the sample.
- Gender balance in the sample if possible.
• Minimum of 20% of staff of each organisation.
• Availability of respondents and willingness to participate in the study.

Criteria for the selection of service users were:

• Services they had access to.
• Exposure to HIV positive service providers for beneficiaries of outreach activities.
• Gender balance in the sample.
• Availability of respondents and willingness to participate in the study.

Relatives of HIV positive service providers were recruited by the service providers themselves and there were no particular criteria except their availability and consent.

The research team tried to recruit HIV positive respondents who are Men who have Sex with Men (MSM), whether they are service providers or beneficiaries of the organisations. However, those who identified as MSM did not feel comfortable with being interviewed by the research team.

A total of 140 participants, 132 respondents from the four participating NGOs (see Tables below) and eight key informants, were involved in the study:

### Table 1.2
Sample of study respondents from the four participating NGOs

<table>
<thead>
<tr>
<th>Population</th>
<th>CCDT</th>
<th>MNP+</th>
<th>Salvation Army</th>
<th>SOFOSH</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service providers</td>
<td>14</td>
<td>11</td>
<td>9</td>
<td>14</td>
<td>48</td>
</tr>
<tr>
<td>PLHA beneficiaries</td>
<td>18</td>
<td>12</td>
<td>17</td>
<td>14</td>
<td>61</td>
</tr>
<tr>
<td>Affected beneficiaries</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Beneficiaries who are neither infected nor affected</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td>Relatives of PLHA service providers</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>38</strong></td>
<td><strong>27</strong></td>
<td><strong>29</strong></td>
<td><strong>38</strong></td>
<td><strong>132</strong></td>
</tr>
</tbody>
</table>

As far as service providers are concerned, the sample represented between 20% and 100% of staff members in all NGOs.

Given the relatively small number of PLHA involved as staff and volunteers in the NGOs, we were able to include the majority of them in the sample.

Approximately 55% of the study participants were visible PLHA, whether service providers and users of the four NGOs, or PLHA outside the NGOs.
Table 1.3
Sample of study participants from outside the participating NGOs

<table>
<thead>
<tr>
<th>Population</th>
<th>Pune</th>
<th>Mumbai</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA who are neither service providers nor beneficiaries</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Community leaders</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Policy makers</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Health and social sector professionals</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1</td>
<td>7</td>
<td>8</td>
</tr>
</tbody>
</table>

More interviews with policy makers and health professionals were planned, but they could not be conducted by the researchers.

Table 1.4
Data collection techniques used with participants from the four participating NGOs

<table>
<thead>
<tr>
<th>Techniques</th>
<th>CCDT</th>
<th>MNP+</th>
<th>Salvation Army</th>
<th>SOFOSH</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-depth interviews with trustees and service providers</td>
<td>10</td>
<td>6</td>
<td>7</td>
<td>7</td>
<td>30</td>
</tr>
<tr>
<td>In-depth interviews with PLHA beneficiaries</td>
<td>10</td>
<td>6</td>
<td>12</td>
<td>12</td>
<td>40</td>
</tr>
<tr>
<td>In-depth interviews with beneficiaries who are neither infected nor affected</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>In-depth interviews with affected beneficiaries</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>In-depth interviews with relatives of PLHA service providers</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total in-depth interviews</strong></td>
<td>87</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group interviews with trustees and service providers</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Group interviews with PLHA beneficiaries</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Group interviews with affected beneficiaries</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total group interviews</strong></td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus group discussions with trustees and service providers</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Focus group discussions with PLHA beneficiaries</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total FGD</strong></td>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workshops with trustees and service providers on development of Quality</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>
Qualitative data was supplemented by **quantitative data** about the organisations’ services and activities, and socio-demographic profiles of service providers and beneficiaries, which was collected by questionnaire. The following table presents the profile of the respondents from NGOs.

### 1.5 Data classification, analysis and validation

The national research team was responsible for transcription, translation and classification of the data collected, using the approach jointly agreed with the participating NGOs. Data from interviews and focus groups from each NGO was classified according to the following themes:

- Characteristics of involvement of PLHA in the organisation.
- Factors that limit and enhance PLHA involvement.
- Impact of involvement.
- Gender issues, including links between gender and involvement.
- Characteristics of the organisation.
- Characteristics of services of the organisation.
- Views on prevention, care and support and knowledge, attitudes and behaviours related to HIV/AIDS and PLHA in Maharashtra.

The findings for each theme and each NGO were then assembled in organisational profiles, one for each of the four organisations. These four documents provided the preliminary analysis of the data by the researchers for each NGO.

These draft reports were shared with the respective organisations to enable them to review and validate the data, and discuss preliminary analysis during the data analysis workshop in which the researchers, representatives of the participating NGOs, the International HIV/AIDS Alliance and Horizons discussed the preliminary findings for each NGO and general trends.
Chapter 1: Methodology

Box 1.2
The data analysis workshop

The workshop was attended by national and international researchers as well as at least two representatives from each NGO, including at least one contact person.

Analysis of the data at the level of each NGO
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 since the data was “owned” only by each NGO and the researchers until they agreed on the analysis. This level of confidentiality helped NGOs work in a non-competitive atmosphere, focusing on their own data without trying to compare themselves to the other participating NGOs.

Researchers and NGOs had the right to disagree in their analysis. When there was a disagreement, they had to check which interpretation was supported by existing data. In very few cases, NGOs and researchers still disagreed and both interpretations of the data were kept in the organisational reports.

Identification of strategies
Based on the results, each NGO also identified strategies to improve the involvement of PLHA in the organisation as well as the quality of their services.
Chapter 1: Methodology

**Analysis of the data at the general level**
Participants discussed the typology of involvement (see Chapter 3) as well as some general trends. Activities were conducted in a participatory and accessible way, which allowed all representatives from NGOs to be involved in the analysis.

“We now have a technical expertise about what things should be done in research.” A representative from MNP+

The profiles were further refined and finally transformed into summaries of findings.\(^{11}\)

**Box 1.3**
**Some key principles for the involvement of NGOs in research: lessons learned from the study**

- Research, and researchers, should not be intimidating for the NGOs: terminology, concepts and processes should be explained in a way which is **accessible** to non-researchers.

- NGOs should be **involved in the design** of the study or its adaptation before the actual implementation.

- Respective roles of researchers and NGO members in the study should be **clear** from the start.

- Researchers should be **accountable** to NGOs for the respect of the rights of study participants.

- NGO members should have **access to the data in a way that protects the confidentiality of respondents**, including other NGO members and service users, and that does not represent a threat for these respondents, whether in relation to their work in the organisation or the quality of the services they receive.

- Research **should not disrupt** the on-going activities of NGOs, in particular the services they deliver.

- NGOs should **benefit from the research**: they should learn not only from the **results** but also from the **process** itself.

- Discrepancies between NGOs and researchers may emerge from their joint analysis of the data. Only the **quantity and quality of supporting data**

\(^{11}\) The four Summaries of findings are available.
should determine who is right when interpretation of the data differs. In some cases, interpretation of both NGOs and researchers should be presented in reports.

**1.6 Ethics of research: strict respect of the rights of study participants**

The study involved strict respect for the principles of voluntary participation, informed consent and confidentiality. The participating NGOs were involved in ensuring that the confidentiality and other rights of study participants were respected by researchers. 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.

Representatives of the participating organisations and the Lawyer’s Collective HIV/AIDS Unit adapted the consent forms used in Burkina Faso and Ecuador, at a workshop following the orientation workshop. The forms were translated into Marathi. For respondents who understood neither English nor Marathi, the forms were translated verbally into their mother tongue. NGO staff and local researchers were trained in the use of informed consent forms.

All the respondents the researchers interviewed as PLHA, whether they were NGO members or beneficiaries of the services of the NGOs, were aware that they were HIV positive. They were recruited by the participating NGOs and agreed to disclose their HIV status to the research team.

The wishes of those who chose not to participate were respected. Neither names nor job titles of participants were given when their comments were quoted in reports. Consent forms were used at every stage of data collection and copies were given to respondents. Access to data was restricted to the local researchers, Alliance and Horizons teams.

An evaluation conducted among NGO representatives at the end of the study showed that there was a very high level of satisfaction regarding the way the rights of study participants had been respected. As two HIV positive service providers said:

“Yes, the confidentiality was respected throughout and the PLHA felt that for the first time their consent was truly valued.”

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12 There are people who are HIV positive or have AIDS who receive care and support from NGOs without knowing their HIV status.
“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.” Representatives from MNP+ during the data analysis workshop

1.7 Limitations of the methodology

- There were many partners involved in the process and their availability was limited. This, combined with the participatory nature of the study, put a lot of pressure on the participating organisations and researchers and caused delays in the completion of the project.

- There was not enough time for the national research team to field test all the data collection tools they had adapted before they started to collect data, hence the necessity to make significant changes during data collection itself.

- Translation of some concepts such as “involvement” in local languages was difficult.

- In spite of the collaboration of “contact persons” in each NGO, it was not always easy to identify and mobilise the right categories of respondents.

- It was also impossible to identify PLHA who were “drop-outs” of the participating organisations, i.e. PLHA who had been involved in an NGO or had used its services and were no longer involved or accessing its services.

1.8 From research to action

This research was designed as a diagnostic study. However, the study design tried to ensure that the findings will be translated into action by the participating NGOs, by:

- Encouraging the participation of the NGOs at every stage to promote ownership of the findings and encourage their use in informing changes in policies and programmes.

- Encouraging the participating NGOs to use the data analysis workshop to identify strategies to increase PLHA involvement in their organisations.

Feedback at the data analysis workshop indicated that the study had succeeded in increasing awareness of PLHA involvement. For example, a senior service provider from SOFOSH noted:
“We were not even conscious that there was involvement (of PLHA in the organisation). We came to know several areas where PLHA are already involved.”

Representatives of another organisation pointed out:

“We know about others’ perception of involvement … understanding things from their (PLHA) point of view. It has helped us to focus.”

Other organisational representatives felt that the study had been useful in advocating the goals of GIPA and increasing the visibility of PLHA issues. Some who had felt initially that PLHA are just concerned about their immediate, personal needs, said that the study had made them “aware that they (PLHA) have come together in a wider perspective”. In addition to analysing current forms of involvement, the study was also a catalyst for organisations to consider further PLHA involvement. As one service provider said: “This study has made us think about the involvement of PLHA. Hopefully now it will enable us to work towards it”.

The four organisations plan to follow up the study by sharing their respective profiles with other staff and management, with the intention that “The positive and negative aspects of the agency’s work will be studied and efforts made to reinforce and change these”. Horizons and the International HIV/AIDS Alliance are exploring how best to provide technical support to participating organisations to help them implement strategies for improving PLHA involvement.

Service providers also noted that they had learnt about the process of research. In some cases the Quality and Impact assessment enabled them to evaluate whether or not their activities were on track. The study has also provided participating organisations with tools that they can use in future. For example, a service provider from one organisation said: “We are still using the Venn diagram to explain (about our work and interactions) to delegates who come from other countries”.

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### Box 1.4
Lessons learned from the methodology

The participatory methodology was successful in the following areas:

- In spite of the tight timeline and the context of stigma, a significant number of PLHA were identified and mobilised by NGOs and agreed to participate in interviews and focus group discussions.
- It helped guarantee the rights of study participants.
- There was a high level of interest in the study and its results among participants.
• Involvement of NGOs from the beginning to the end of the process, in particular in the analysis of the data, increased ownership of the findings and willingness to use them.

However, a process of such a participatory and qualitative nature takes more time and requires more human resources than had been originally estimated.
Chapter 2
HIV/AIDS in India and Maharashtra

2.1 Introduction

India is one of the most populous countries in the world, with a population of more than one billion and a population density of 324 people per square kilometre. The sex ratio is skewed, with 933 females for every 1000 males. The national literacy rate is 55.3%. (www.censusofindia.net). While the pace of urbanisation in India is increasing, 74% of the population live in rural areas.

The state of Maharashtra, which was the site for the study, is situated on the West Coast of India. Its capital city is Mumbai. Maharashtra has a population of more than 96 million and a population density of 314 people per square kilometre. The sex ratio is lower than the national average, with 922 females for every 1000 males. Literacy rates are higher than the national average at just over 77% (www.censusofindia.net).

2.2 Epidemiology of HIV/AIDS

2.2.1 India

AIDS cases, HIV prevalence and incidence

The first case of AIDS was reported in India in 1986. By 2000, the National AIDS Control Organisation (NACO) had reported 15,606 AIDS cases.

In December 1999, NACO reported a national seroprevalence rate of 2.46%, based on identifying 85,666 cases of HIV infection among 3.48 million people screened between 1986 and May 1999 (www.naco.nic.in). Although rates of HIV infection are relatively low, the size of the population means that the number of people infected is very high. In 2000, UNAIDS estimated that 3.86 million people in India were infected with HIV and noted that the infection is spreading rapidly from urban to rural areas and from “high risk” groups to the general population (UNAIDS India Annual Report 2000).

As the Prime Minister of India stated in December 1998 “HIV/AIDS today is the most serious public health problem facing India”. The epidemic is having an impact on individuals, families, communities and society, and is creating additional demands for social and health care support.
HIV transmission

The routes of transmission of AIDS cases reported by NACO to 2000 are shown in Table 2.1. UNAIDS figures confirm that the epidemic is primarily driven by heterosexual transmission, but with important sub-epidemics among men who have sex with men (MSM) and injecting drug users (IDU) (UNAIDS India Annual Report 2000).

For example, a 1999 study showed that injecting drug use is increasing and that nearly 45% of those attending an IDU treatment centre in New Delhi were HIV positive. Little reliable data is available about HIV among MSM, although informal estimates suggest rapid increases in this vulnerable group (India Responds to AIDS: A Strategic Response to the HIV Epidemic by the Government of India, UN Agencies and Development Partners in India, 1999).

<table>
<thead>
<tr>
<th>Category of transmission</th>
<th>No. of cases</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual</td>
<td>12,735</td>
<td>81.60</td>
</tr>
<tr>
<td>Perinatal</td>
<td>226</td>
<td>1.45</td>
</tr>
<tr>
<td>Blood and blood products</td>
<td>724</td>
<td>4.64</td>
</tr>
<tr>
<td>Injecting drug use</td>
<td>760</td>
<td>4.87</td>
</tr>
<tr>
<td>Others (not specific)</td>
<td>1,161</td>
<td>7.44</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>15,606</strong></td>
<td><strong>100.00</strong></td>
</tr>
</tbody>
</table>

*Source: www.naco.nic.in*

Age and sex data

At the end of 1999, seroprevalence rates in men aged 15-24 were predicted to reach 0.58% compared with 0.14% in previous estimates. The respective figures for women in the same age group were 0.82% and 0.40%. The prevalence pattern is shifting towards women and young people, resulting in an increase in mother-to-child transmission and paediatric HIV infection. Women now account for 25% of new infections (UNAIDS India Annual Report 2000), and 50% of new infections occur in those aged less than 25 years (India Responds to HIV/AIDS).

Geographical distribution

HIV infections have been reported by all States and Union Territories. The epidemic is most advanced in Maharashtra, Tamil Nadu and Manipur, but there has been a sharp rise in HIV infections in Andhra Pradesh and Karnataka, and these States now have a higher prevalence than Tamil Nadu.

NACO started sentinel surveillance at 55 sites in 1994, expanding to 180 sites in 1998. (However, it should be noted that, relative to the size of the country and the population, 180 sites are inadequate to provide comprehensive data about
HIV seroprevalence in India.) Surveillance includes “high risk” groups, such STI clinic attendees and IDU, and women attending antenatal clinics. In 2000, a sentinel surveillance survey was conducted in 232 sites (57 new sites were included and five existing sites were excluded), including 109 STI clinics, 110 antenatal clinics, 11 sites for IDU and two sites for MSM. Based on analysis of data collected from these sites, State epidemics can be categorised into three groups:

- **Group I (Generalised epidemic/High prevalence)** – includes States (e.g. Maharashtra, Tamil Nadu, Karnataka, Andhra Pradesh, Manipur and Nagaland) where the HIV infection rate is more than 1% in women attending antenatal clinics. In Manipur and Nagaland, injecting drug use plays a significant role in the spread of HIV.

- **Group II (Concentrated epidemic/Moderate prevalence)** – includes States (e.g. Gujarat, Goa and Pondicherry) where the HIV infection rate is more than 5% in “high risk” groups but is less than 1% in women attending antenatal clinics.

- **Group III (Low epidemic/Low prevalence)** – includes the remaining States where the HIV infection rate is less than 5% in “high risk” groups and less than 1% in women attending antenatal clinics.

However, there is a significant risk that HIV could spread rapidly in Group III States that currently have low infection rates, because of factors including labour migration, low awareness and literacy levels, gender inequalities and the high prevalence of sexually transmitted infections.

### 2.2.2 Maharashtra

By 1998, Maharashtra had reported 400,000 cases of HIV infection, more than any other state in India. In 2000, Maharashtra accounted for 3,657 of the 15,606 AIDS cases reported by NACO (www.naco.nic.in).

Table 2.2 shows that HIV seroprevalence in Maharashtra is far higher than the national figure (10.26% compared with 2.46%), and in 1999 the State had the highest prevalence of HIV infection among STI clinic attendees and among women attending antenatal clinics. Data from sentinel surveillance sites in Maharashtra indicated that the rate of HIV infection in STI clinic attendees is 14-60% and in women attending antenatal clinics is more than 2%. 1999 data from sentinel surveillance sites also showed that in Maharashtra, unlike some other States, there was little difference in prevalence rates in antenatal clinic and STI clinic attendees in rural and urban areas. The highest seroprevalence was found in antenatal clinic attendees aged less than 20 years. In contrast the highest seroprevalence found in STI clinic attendees was among those aged 30-44 years, including female STI patients.
### Table 2.2
HIV surveillance data for Maharashtra and India

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood units screened</td>
<td>NA</td>
<td>3,480,395</td>
<td>22,021</td>
</tr>
<tr>
<td>No. of Elisa reactive blood units</td>
<td>NA</td>
<td>49,570</td>
<td>379</td>
</tr>
<tr>
<td>Elisa reactivity rate</td>
<td>NA</td>
<td>1.42%</td>
<td>1.72%</td>
</tr>
<tr>
<td>No. of persons tested</td>
<td>3,480,658</td>
<td>566,708</td>
<td>16,059</td>
</tr>
<tr>
<td>No. of persons HIV positive</td>
<td>85,666</td>
<td>58,188</td>
<td>2,272</td>
</tr>
<tr>
<td>HIV seroprevalence rate</td>
<td>2.46%</td>
<td>10.26%</td>
<td>14.15%</td>
</tr>
<tr>
<td>No. of AIDS cases</td>
<td>7,451</td>
<td>3417</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA = Not available

In the city of Mumbai, seroprevalence is higher still at 14.25%, with an estimated 60% of sex workers infected with HIV and the rate of HIV infection in pregnant women as high as 6% in some slum areas (Hawkes S and Santhya K 2001). HIV-associated illness also accounts for 20-40% of bed occupancy in Mumbai hospitals (UNAIDS India Annual Report 2000).

However, there are only 20 sentinel surveillance sites in Maharashtra, with just five in Mumbai (HIV/AIDS Status in Maharashtra, Annual Progress Report, 1999-2000), and some districts are not covered at all so, again, caution is required when interpreting data.

### 2.3 Knowledge, attitudes and behaviour

#### 2.3.1. HIV/AIDS

There is limited information available on knowledge about and attitudes towards HIV/AIDS in India. Various studies have reported on sexual behaviour (see below), including a series of behavioural surveillance surveys (BSS) to observe trends in high-risk behaviour among population sub-groups, such as sex workers, truckers, factory workers and students (all studies cited in Hawkins S and Santhya K 2001).

BSS have been launched in West Bengal, Andhra Pradesh, Gujarat, Kerala and Orissa, and a nationwide behavioural surveillance survey of truckers has been undertaken by Family Health International. Since 1996, four BSS have been conducted in Tamil Nadu to collect data on knowledge of HIV transmission and HIV/STI prevention measures; sexual behaviour with non-regular partners and condom use during such encounters; prevalence of self-reported STI symptoms and treatment-seeking behaviour; and perception of risk of HIV/AIDS. Findings from
the first three BSS in Tamil Nadu indicates that knowledge of methods of HIV/STI prevention has increased among all sub-populations, and misconceptions about HIV transmission have reduced among all groups except female sex workers; truckers and factory workers have reduced sexual encounters with non-regular partners and condom use with non-regular sex partners has gradually increased for all groups; self-perceived risk of contracting HIV has increased for population groups engaging in high-risk behaviour. Between the first and the third BSS in Tamil Nadu, condom use among female sex workers increased from 56% to 80% and among truck drivers from 44% to 66%.

Pre-marital chastity and marital fidelity are valued in India, predominantly for women. However, studies of sexual behaviour among unmarried school and college students, mostly in urban centres, have reported sexual activity among 8-39% of male students and 1-20% of female students. Studies in the general population in rural and urban areas have reported pre-marital sexual activity among 7-48% of male respondents and 3-10% of female respondents. Small-scale studies among STI clinic patients – many of them teenagers – and truck drivers, have found higher levels of pre-marital sexual experience, ranging from 81-98%, suggesting that pre-marital sex and sexual activity outside marriage at a young age are more common than generally believed.

The few studies that have investigated extra-marital sexual activity have found relatively low reported levels in the general population with higher levels among STI clinic attendees (30-60% diagnosed with an STI were married and 50-98% reported extra-marital relationships). Similar reports found that between one in five and one in two female STI patients mentioned husbands as the source of their STI.

NGOs working with commercial sex workers estimate that there may be up to 400,000 female sex workers in the major cities of India, with male clients representing all socio-economic strata of Indian society. Different studies have estimated that sex workers see between three and 12 clients a day, and that between 8% and 29% of men have paid for sex. A recent study conducted in the Wazipur Industrial Area near New Delhi (cited in Bharat S, 1999), reports high prevalence of paid sex and multi-partner sex and low condom usage among industrial workers, most of whom are away from their families. Other studies have shown that men in all income groups are at risk, for example 27% of men found to be HIV positive in one study had completed high school or higher education and 41% were skilled workers (cited in Bharat S, 1999).

Male - to - male sexual activity is mostly hidden and there is little data about the extent of MSM practices. Two studies found that most men reporting MSM were married, most reported non-penetrative sex and that, perhaps because of this, use of condoms was relatively infrequent.

An analysis of gender differences in psycho-social issues affecting PLHA conducted in 1999 among 210 individuals using the services of the Freedom
Foundation HIV/AIDS care and support facility (Rau A and Rajagopalan N), asked male PLHA about condom use. Almost all (98.5%) of the men said that they did not use condoms, of whom 22% thought condoms were only for birth control and 15% did not know about condoms.

In general, use of condoms in marital and non-marital sexual relationships is very limited in India, in part due to the predominance of permanent contraceptive methods such as sterilisation (Hawkes S and Santhya K 2001). The 1998-1999 National Family Health Survey (NFSH) reported that 48.2% of married couples were using any method of contraception and that, among 71% of these couples, the wife had undergone a tubectomy (i.e. 34% of married women aged 15-49 years are sterilised). The NFSH also found that only 3.1% of married couples were currently using condoms as a method of family planning. The proportion of couples using condoms to prevent transmission of infection is not known. Use, especially consistent use, of condoms in non-marital sexual relations is also reported to be very low. Studies among the male general population who reported non-marital sexual experience found that 50-88% never used condoms and only 4-13% reported always using condoms during such encounters. Among “high-risk” groups, such as sex workers and their clients, between 4% and 23% reported always using condoms.

2.3.2 PLHA

Several studies have investigated knowledge, attitudes and behaviour towards PLHA in India. Their findings, summarised below, show high levels of ignorance among all sectors of the population, and significant stigma and discrimination associated with HIV/AIDS, including among health professionals. Both inaccurate media reporting and mass campaigns intended to increase awareness of HIV/AIDS have caused public fear and concern, contributing to negative attitudes and behaviour towards PLHA. Common responses include ostracism and rejection. Positive responses from relatives appear to be relatively infrequent, and are more likely to occur when male household members rather than women are affected. HIV infection is associated with sexual “wrongdoing” and women are commonly blamed for transmission of HIV and other sexually transmitted infections. Stigma and discrimination reinforces the tendency for PLHA to make themselves invisible, enabling employers and others to deny that HIV is a problem.

The Rau and Rajagopalan study cited above found that 87% of PLHA interviewed had had no knowledge that they were being tested for HIV and 80% had no knowledge of what being HIV positive meant – the remainder thought that they had AIDS or that HIV was connected to AIDS. Almost a third reported that they had been shunned by doctors and other hospital staff after being diagnosed as HIV positive, and had been discharged immediately, and only 12% were treated by doctors they visited without being discriminated against. Almost all (92%) reported that their HIV status had been revealed to a relative without prior consent.
As a result of stigma and discrimination, the effects of their diagnosis included fear of early death, pain, isolation, anger and guilt and, in some cases, depression and thoughts of suicide. Women were particularly concerned about what would happen to their children in future. Almost 90% reported concerns about inability to earn an income and to afford medication.

Negative reactions from the family were a common experience, and 40% of PLHA interviewed said that they had been isolated or abandoned by relatives. Although 15% were still in contact with the family, they had to stay away from the house. Two per cent of the women said that they had been ill-treated by their in-laws, with one reporting that she had been locked up and physically abused.

Another study (HIV/AIDS Related Discrimination, Stigma and Denial in India, 1999, Bharat S, TISS) also found that PLHA – most of whom first discover their HIV status in a hospital setting – often experienced stigma and discrimination from health providers. Many reported differential treatment, sudden changes in treatment, and emotional and social distancing after their HIV status was discovered. Health professionals associate HIV/AIDS with particular groups, such as truck drivers, commercial sex workers, slum dwellers and illiterate people, and attribute HIV infection to immoral behaviour and “bad habits”. The study also reports that health professionals acknowledge that stigma and discrimination occurs in health facilities, despite reasonably good knowledge of the basic facts about HIV/AIDS. Doctors in public hospitals tended to blame private practitioners and vice versa. However, health professionals in both public and private facilities felt that PLHA experience most stigma and discrimination from the family, because of lack of adequate knowledge about HIV/AIDS.

The Bharat study also found examples of experienced or feared discrimination in other contexts, in particular schools and childcare institutions and with regard to life insurance. Cases were reported where infected and affected children had been forced to withdraw from school, and of institutions that test and segregate HIV positive children. PLHA also highlighted concerns about denial of life insurance. The Life Insurance Company of India has added the HIV test to the list of medical tests required when individuals apply for a policy, and policies are declined for those who test HIV positive. However, the insurance company honours policies that were taken prior to a person testing positive.

Those interviewed for this study reported that PLHA are subject to discriminatory behaviour even after death. Differential treatment because of fear of contagion is a “great source of anguish and distress to positive people”. PLHA report that dead bodies of AIDS patients “are packed in black plastic bags and handled with disrespect and a casual attitude” by mortuary and ambulance staff.

This study also cites cases where NGOs have failed to respect the rights of PLHA. For example, one NGO was reported to have taken photographs of PLHA without their consent, to publicise an AIDS programme, and another NGO
refused to provide services to a regular PLHA beneficiary because this PLHA had sought help from a rival NGO.

The impact of discrimination and stigma, as in the Rau and Rajagopalan study, includes – at the individual level – fear, anxiety, depression, isolation and thoughts of suicide – and – at the societal level – fear, suspicion, and a backlash against PLHA.

An investigation of HIV/AIDS-related stigmatisation, discrimination and denial (UNAIDS 2000) in Mumbai, New Delhi and Bangalore focused on three settings: the health care system, the workplace, and the home and community. The findings confirmed those of the Rau and Rajagopalan, and Bharat studies. PLHA and health professionals reported differential treatment, changes in treatment, and transfer from private to public hospitals after being diagnosed positive. As the wife of a man diagnosed in hospital in Bangalore recounted:

“The staff were looking after my husband well, but after they tested his blood for HIV their behaviour changed… they pushed him to a corner of the room and talked about us in hushed tones. I couldn’t understand why their behaviour had become so cold.”

And as a surgeon in a public hospital explained: “In a private hospital the news of HIV positive patients once detected is closely guarded and the patient is conveniently transferred to a government hospital.”

In many hospitals, HIV positive patients could be clearly identified – either because HIV is written in the file, or because specific beds are earmarked for patients with HIV – and there were numerous accounts of medical and nursing staff breaking confidentiality, telling relatives about the diagnosis before the patient himself or herself. Relatives were not always supportive. As in the other studies, young women in particular reported being blamed and rejected by in-laws and other family members. Men were dealt with more positively and supportively.

PLHA interviewed in this study also reported that they kept their HIV status secret in the workplace, because of shame or fears about being dismissed. The experience of those who had revealed their HIV status was not reassuring: “They point at me and say ‘Look, he is the HIV fellow’. They keep their distance from me and remain aloof.”

Most businesses contacted during the study denied that HIV was or might be a problem, because their staff are “highly educated” and “do not have the behaviour which makes them suspect for HIV”. The level of discrimination, stigma and denial in the informal sector is likely to be higher. Examples were given of small businesses, e.g. food vendors, barbers, being shunned by customers when they discovered that an employee was HIV positive, reflecting
widely held views in the community about PLHA and about HIV infection being the result of "immoral" behaviour.

<table>
<thead>
<tr>
<th>Box 2.1 Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative attitudes and behaviour are also strongly associated with gender. For example, within the family, discrimination by parents-in-law against daughters-in-law was most common. Female PLHA reported that they had experienced blame, anger and rejection from parents-in-law. Women tend to be blamed for transmitting HIV. Even if it is acknowledged that a woman has been infected by her husband, she is still blamed for not being able to keep “her husband under control”.</td>
</tr>
</tbody>
</table>

2.4 Government policies on HIV/AIDS

2.4.1 Government structures dealing with HIV/AIDS

At central level, the Government of India (GOI) established a National AIDS Committee (NAC) in 1986 and launched the National AIDS Control Programme (NACP) in 1987. The NAC, which includes representatives of various ministries, NGOs and private institutions, is chaired by the Ministry of Health and Family Welfare and is responsible for oversight of the performance of the NACP, providing overall policy direction and promoting multisectoral collaboration. The National AIDS Control Organisation (NACO), established in 1991, is responsible for, among other things, co-ordinating inputs from external partners.

At state level, governments in all 32 States and Union Territories have established State AIDS Control Societies (formerly known as State AIDS Cells). The cities of Mumbai, Ahmedabad and Chennai have established Municipal AIDS Control Societies. Central government provides support to State and Municipal AIDS Control Societies through a network of Technical Resource Groups. Societies are overseen by State AIDS Committees, which are constituted in a similar way to the National AIDS Committee and are responsible for policy decisions and for approving financial and administrative actions that would normally be subject to approval by the State Ministry of Finance. Each State has developed a Programme Implementation Plan, based on consultation with different ministries, NGOs, and community groups.

The State government of Maharashtra has decentralised implementation of the policies outlined in 2.4.3 to district level, and is establishing local committees to oversee implementation.
2.4.2 Government response to HIV/AIDS

In 1989, with support from the World Health Organization (WHO), the Government of India (GOI) developed a medium-term plan for HIV/AIDS control and the first phase of the National AIDS Control Programme (NACP I) was launched in 1991 with support from the World Bank.

NACP I focused initially on strengthening programme management capacity, information, education and communication, and surveillance activities in Maharashtra, Tamil Nadu, West Bengal, Manipur and Delhi. The period 1986-1992 has been characterised as one marked by denial of the threat of HIV to India, and the NACP was accelerated only after 1992.

The period 1992-1997 saw increased emphasis on awareness raising and condom promotion, measures to ensure blood safety and control hospital infection, and strengthening STI and HIV/AIDS clinical services. However, the scope of these efforts remained limited to a “medical approach” to HIV control.

The GOI is currently implementing the second phase (1999-2004) of the National AIDS Control Programme (NACP II), with resources mobilised from the GOI, International Development Association (IDA), major bilateral donors and the United Nations (UN) system. NACP II, which was developed in consultation with a wide range of stakeholders through state level planning workshops, emphasises a multisectoral approach involving government, NGOs and civil society, and a decentralised framework where responsibility is devolved to the State AIDS Control Societies.

The overall objectives of NACP II are to reduce the spread of HIV infection in India and to strengthen India's capacity to respond to HIV/AIDS on a long-term basis. The specific objectives are:

- To keep HIV prevalence below 5% of the adult population in Maharashtra, below 3% in Andhra Pradesh, Karnataka, Manipur and Tamil Nadu, and below 1% in the remaining States.
- To reduce blood-borne transmission to less than 1%.
- To achieve an awareness level of not less than 90% among youth and others in the reproductive age group.
- To achieve condom use of not less than 90% among high-risk groups such as commercial sex workers.

The key components of NACP II are:

- **Targeted interventions for communities at high risk** – identifying groups at high risk and providing peer counselling, condom promotion and STI treatment, with a major role for NGOs and CBOs in implementation of intervention programmes with marginalised populations.
• **Prevention of HIV transmission among the general population** – Information, Education and Communication (IEC) and awareness campaigns at national level through the mass media and at local level through traditional media, with the involvement of the community in social mobilisation and twice-yearly Family Health Awareness Campaigns at grass-roots level and of democratic institutions (Panchayat Raj) and youth organisations at district, block and village level; providing voluntary testing and counselling; reducing transmission through blood transfusion and occupational exposure.

• **Strengthening institutional capacities** – strengthening NACO leadership capacity and State and Municipal implementation capacity, with greater ownership of the decentralised NACP by States; improving sentinel surveillance; training; and strengthening capacity for monitoring and evaluation, and research.

• **Provision of low-cost care** – providing funding for home-based and community-based care, and increasing the availability of cost-effective interventions for common opportunistic infections.

• **Intersectoral collaboration** – between the public, private and voluntary sectors and mobilising the capacity of the private sector and civil society.

In 1998, the total budget for NACP II was estimated to be Rs 14,250 million, comprising Rs 11,550 (US$ 229.8 million): US$ 38.8 million from GOI and IDA assistance of US$ 191 million (1999-2004); Rs 1,660 million from USAID to the Government of Maharashtra for the AIDS Education and Research Trust (AVERT) project (1999-2006); and Rs 1,040 from UK Department for International Development (DFID) for projects in Andhra Pradesh, Orissa, Kerala and Gujarat (1999-2004).

NACP II is being implemented under the draft National AIDS Control Policy, which has been formulated and approved by the NAC (and which has been submitted for deliberation prior to legislation).

### 2.4.3 Prevention policies

National HIV/AIDS prevention policies are outlined in the draft National AIDS Control Policy. Prevention policies in Maharashtra are similar to national prevention policies. The main components of the Draft National AIDS Control Policy are:

• **Programme management** – The policy clearly states that HIV/AIDS is not merely a public health issue but needs to be “treated as a developmental issue which impinges on various economic and social sectors of governmental and non-governmental activities”. Recognising that the extent of the problem varies within the country, it notes that states need to “develop strong ownership of the HIV/AIDS prevention and control programme” and also encourages the creation of adequate infrastructure at the district level.
“Only large-scale mobilisation at the centre, state, district and sub-district levels through organised sections of the community, including non-governmental organisations, can help in effectively preventing further spread of the disease”.

- **Advocacy and social mobilisation** – The policy also recognises that “a strong advocacy campaign needs to be launched at all levels for these opinion leaders, policy makers and service providers to make them understand and feel motivated about the need for immediate prevention of the disease”. It also emphasises the need “for adopting a human approach towards those who have already been infected with HIV/AIDS” and the need to reach out to youth. Workplace programmes and electronic and print media are seen as important strategies for communicating messages. In 2000, NACO held a Family Awareness Week to generate awareness about HIV/AIDS and STI and encourage early detection and treatment of STI at Primary Health Care (PHC) level, reaching an estimated 34 million people in 100 districts.

- **Participation of NGOs and CBOs** – The policy emphasises co-operation with NGOs and CBOs and includes a five-step approach for helping them to build the capacity to fight the epidemic. The important role of NGOs and CBOs in social mobilisation and condom promotion are highlighted.

- **HIV testing** – The policy clearly states that there shall be no mandatory testing for HIV, including testing related to employment or obtaining health services. A separate national policy on HIV testing has been developed to address these issues.

- **Counselling services** – The policy states “counselling services for suspected cases of HIV infection and for PLHA should be expanded to increase their reach to those who need them”.

- **PLHA** – The policy also addresses the rights of PLHA and services for PLHA, stating “The HIV-positive person should be guaranteed equal rights to education and employment as other members of the society. HIV status of a person should be kept confidential and should not in any way affect the rights of the person to employment, his or her position at the workplace, marital relationship and other fundamental rights”. In addition, the policy says “The government would actively encourage and support formation of self-help groups among the HIV-infected persons for group counselling, home care and support of their members and their families”.

- **Surveillance and monitoring** – The policy proposes refining sentinel surveillance for HIV to cover both “high-risk” and “low-risk” groups.

- **STI control** – The policy recommends syndromic management of sexually transmitted infections (STI) at all levels of the health service as an effective measure to control the spread of HIV.

- **Promotion of condom use** – The policy includes promotion of condom use as an effective strategy in the absence of a preventive vaccine, social marketing, quality control, and involvement of NGOs.

- **Blood safety** – A separate national blood safety policy has been developed (see also 2.4.5). Apart from mandatory licensing of blood banks, “testing of all
blood units used in the blood banks for HIV, hepatitis B, malaria and syphilis has been made mandatory”. In Maharashtra, the blood safety programme is being implemented through 221 licensed blood banks, and promotion of voluntary blood donation has resulted in a 10% increase in donations. Other related activities include training of blood bank staff and setting up blood component separation units.

In addition to these components, the policy includes references to indigenous medicine, co-operation with other countries on research and development, and co-operation with international agencies.

In Maharashtra, information, education and communication (IEC) is used to support the components outlined above. IEC has included, for example, AIDS prevention programmes in educational institutions, establishing helplines at seven locations, and activities to raise awareness among health professionals and the general public about prevention and treatment of STI. In addition, the state government is currently providing support for over 30 NGOs and CBOs to implement interventions, mainly with commercial sex workers and truckers (HIV/AIDS Status in Maharashtra: Annual Progress Report 2000-2001).

2.4.4 Care and support for PLHA

While both central and state governments have responsibility for policy and legislation related to health, responsibility for implementation of health programmes and services rests with state and local governments.

National directives set out guidelines for health services at local and district levels. In rural areas, the Primary Health Centre (PHC) is the basic unit of care in the government health system. There should be a PHC for every 50,000 people in non-tribal areas and for every 30,000 people in tribal areas. Some PHCs have Primary Health Units (PHU) for community outreach. Each district should have a referral hospital, which is often called the civil hospital. Cases that cannot be managed at PHC level are referred to the civil hospital. Each state also has teaching hospitals, with associated medical colleges, to which cases requiring specialist care are referred by PHCs or civil hospitals. In urban areas, local bodies, such as municipal corporations, are responsible for running PHCs, which are often called health posts. The municipal corporations of cities like Mumbai also run specialist hospitals with medical colleges attached to them. Hospitals in urban areas that do not have a medical college are called peripheral hospitals. Most of the services provided by public health facilities are free or only a nominal amount is charged, and charges are often waived for people who cannot afford to pay.

In 1996, the Maharashtra state government managed 741 hospitals and 1,423 PHCs or health posts, and there were 143 hospital beds per 100,000 population.
The shortage of hospital beds is likely to worsen as the number of people with HIV/AIDS increases.

Health facilities are also run by NGOs, charitable trusts or co-operative societies, and these usually charge more than government facilities. However, they are less expensive than corporate or private health facilities that are run as profit-making enterprises and that cater for middle and upper income groups.

Although PHC services have been intended to be relatively comprehensive in scope, reproductive health services have until recently focused on achieving government family planning targets rather than on preventing or treating other sexual and reproductive health problems. This has changed since the 1994 International Conference on Population and Development and the 1995 Beijing Women's Conference, and the current emphasis is on provision of comprehensive integrated reproductive health care, including syndromic management of STIs, counselling and condom distribution.

As stated earlier, HIV/AIDS is beginning to make an impact on health services in States where the epidemic is more advanced, and provision of high-quality care and support will be a significant challenge. Home-based care is still limited in most parts of the country. Although antiretroviral drugs are produced by Indian pharmaceutical companies and sold at prices well below those in industrialised countries, only 3-5% of known HIV-infected individuals are currently able to afford such therapy (Hawkes S and Santhya K 2001) and many PLHA rely on “alternative” medicines.

However, the Draft National AIDS Control Policy states, with regard to care and support, that the policy is to “build up a continuum of comprehensive care comprising clinical management, nursing care, counselling and socio-economic support through home-based care”.

The policy recognises that PLHA face stigma and discrimination from communities and health services. The latter often results in denial of health care to PLHA, and the policy proposes to address this through sensitisation of health professionals. As described above, measures intended to improve care and support include establishing additional counselling centres, making more widely available free drugs for management of opportunistic infections, and supporting NGOs and CBOs in providing hospice care.

GOI, UNAIDS, WHO and other partners have prepared a strategy paper on care and support and are developing a policy paper on compulsory licensing of HIV drugs in India. In collaboration with WHO, NACO has been conducting pilot programmes on care and support for PLHA in Manipur, Maharashtra and Tamil Nadu.
2.4.5 Legal framework for HIV/AIDS

There is no specific law on HIV/AIDS in India, although there is legislation that is relevant to disclosure and transmission of HIV. The Indian Penal Code, under Sections 269 and 270 provides:

- **Negligent act likely to spread infection of disease dangerous to life** “Whoever unlawfully or negligently does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life shall be punished with imprisonment of either description for a term which may extend to six months or with a fine or with both” (Section 269).

- **Malignant act likely to spread infection of disease dangerous to life** “Whoever malignantly does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life shall be punished with imprisonment of either description for a term which may extend to two years or with a fine or with both” (Section 270).

In 1996, the Supreme Court of India made a ruling aimed at improving the safety of blood transfusion services, which included compulsory licensing of blood banks, banning professional blood donation, and consideration of separate legislation to regulate the operation of blood banks.

In 1998, the Supreme Court of India, when asked to consider a case of involuntary disclosure, ruled that HIV positive persons do not have the right to marry and imparted legal sanction to the physician’s act of disclosure of the HIV positive spouse to his or her partner. The Court ruled that disclosure of the HIV positive status of a person is permissible in order to protect the health of an identifiable person, such as a fiancée, even if such a disclosure led to the suspension of the marriage (Reproductive Health Matters). The Court further concluded that any person with HIV who knowingly marries and transmits the infection to another person would be guilty of offences under Sections 269 and 270 of the Indian Penal Code. This ruling is currently being contested by a group of lawyers, concerned about protecting the fundamental right of an individual to marry (which is recognised internationally under the Universal Declaration of Human Rights), and that the ruling will do nothing to reduce the stigma and discrimination associated with HIV infection (Grover A).

In 1999, it was reported that the Ministry of Social Welfare of the Delhi government was proposing to introduce mandatory HIV testing for women and children in state shelters and welfare homes, despite the fact that this would violate human rights and national policy on HIV testing. This proposal, which met with considerable opposition, indicates the need to convince policy makers that prevention of HIV transmission is best advanced by protecting the rights of PLHA.
India does not appear to have any policies or legislation protecting the rights of PLHA. However, the Draft National AIDS Control Policy emphasises ensuring the protection and promotion of the human rights of PLHA, including their right to equal access to health care, education, employment, privacy and other fundamental rights, stating that: “The HIV-positive person should be guaranteed equal rights to education and employment as other members of the society. HIV status of a person should be kept confidential and should not in any way affect the rights of the person to employment, his or her position at the workplace, marital relationship and other fundamental rights”.

It further states, “HIV-positive women should have complete choice in making decisions regarding pregnancy and childbirth. There should be no forcible abortion or even sterilisation on the ground of HIV status of women. Proper counselling should be given to the pregnant woman to enable her to take an appropriate decision either to go ahead with or terminate the pregnancy” (www.naco.nic.in).

Supportive efforts and models are required to counter public misconceptions, tackle discrimination in health and other services, and to ensure non-discrimination in the workplace (India Responds to HIV/AIDS) since, in practice, it appears that the rights of PLHA are infringed in these and a number of other contexts. The Lawyers Collective, for example, has been involved in several cases related to the violation of PLHA rights in areas of employment, divorce and medical care.

2.5 Civil society response

2.5.1 Social mobilisation

NGOs, CBOs, the National Service Scheme (NSS\textsuperscript{13}), and other programmes have all played an important role in social mobilisation for HIV/AIDS in India and in Maharashtra. The number of NGOs and CBOs working on HIV/AIDS in India has grown dramatically. Between 1995-1996 and 1998-1999, the number of NGOs and CBOs supported by NACO and State AIDS Control Society (SACS) increased from six to over 200. Types of NGO and CBO intervention range from IEC to home-based care for PLHA. For example, the Sonagachi intervention among sex workers in Kolkata has become internationally recognised for its innovative approach to risk reduction, which seeks to address a wide range of social, economic, health and other concerns of women working in brothels. HIV rates in women selling sex have remained relatively stable at around 5%, in

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\textsuperscript{13} NSS is a scheme of the Ministry of Youth Affairs, wherein Universities are funded to involve students in tackling issues of social importance. HIV/AIDS has been identified as one such issue. The programme involving students was initially called Universities Talk AIDS, and is now a peer education programme called Students Talk AIDS.
comparison with data from Mumbai which found an increase in HIV prevalence in
female sex workers from 21% to 51% between 1990 and 1994.
Other targeted interventions have concentrated on IDUs and truck drivers. The
Government of India has also been collaborating with NGOs to expand access to
voluntary counselling and testing.

As mentioned earlier, in Maharashtra, over 30 NGOs and CBOs are receiving
support for HIV/AIDS programmes. These mostly involve preventive interventions
targeting commercial sex workers, truckers and men who have sex with men, but
there is little focus at present on care and support interventions.

Various ministries and departments have implemented plans for HIV/AIDS
prevention and control with support from NACO, including Indian Railways, Steel
Authority of India Ltd, Employees State Insurance Company Ltd, Department of
Youth Affairs, and of Defence. More recently, the Government of India has
started to encourage more active involvement of other sectors. For example, on
World AIDS Day 2000, the Prime Minister called for the formation of a Business
Coalition on HIV/AIDS.

2.5.2 Background to PLHA involvement

The Salvation Army established a support group for PLHA in Mumbai in 1993
(see Chapter 3). However, the creation of support groups by PLHA and their
involvement in NGO management and policy making is a more recent
development.

A national network of people with HIV/AIDS (INP+), set up mostly by positive
people, started functioning as a formal organisation in 1997. There are also
networks in several states, including Maharashtra, who are affiliated to INP+ The
Maharashtra Network for Positive People was established in 1998. As mentioned
in the introduction, it was one of the four NGOs who participated in the study in
India (more information on MNP+ is available in the following chapters).

As networks, INP+, MNP+ and other PLHA organisations in various Indian states
have set objectives that focus on networking between positive people and
advocacy for their rights. However, activities of many networks also include the
direct delivery of services, such as counselling and other forms of psychological
support. Even INP+ has been considering becoming a provider of care and
support services for PLHA, although not all its members agree about this strategy
and the articulation between services provided by a national network and its
affiliates at the state level is not clear.

Generally, relationships between national and state networks have been
complex, and, at the time of data collection, they were still in the process of
defining what exactly “affiliation” means and their respective roles.
There is also little clarity about how these organisations are structured - whether they are networks of either individuals who are HIV positive or of grass-root organisations of PLHA, such as community-based support groups or self-help groups, or both. As a result of this imprecision, it is sometimes difficult to understand what membership means in terms of the roles of the groups and individuals who belong to the networks, and the rights and obligations that arise from membership.

A PLHA representative was first included in the National AIDS Committee that oversees NACO in 1999. UNAIDS is encouraging Greater Involvement of PLHA initiatives by government, private sector and civil society institutions and, in 2000, proposed a range of actions to promote involvement including media orientation workshops, and linkages between networks of positive people and public and private health services.

2.6 Other stakeholders: international co-operation

Many multilateral agencies, bilateral agencies, and international NGOs operate in India. UN and bilateral partners are contributing to NACP II in the following ways (India Responds to HIV/AIDS).

Major bilaterals, such as USAID, DFID, Canadian International Development Agency (CIDA) and Ausaid, are focusing on capacity building at State level in different States and developing partnerships with NGOs and other implementing agencies. Different bilaterals are also supporting other components of NACP II. For example, DFID, USAID and CIDA are also focusing on targeted interventions for communities at highest risk and prevention of HIV transmission among the general population, and Ausaid on targeted interventions and provision of low-cost care. USAID has been supporting targeted interventions in Tamil Nadu through the AIDS Prevention and Control Project, and DFID has been supporting targeted interventions in West Bengal, and the Health Highways Project, a nationwide initiative targeting truck drivers and their sexual partners. Under NACP II, USAID is focusing on support for interventions in Maharashtra, and DFID on interventions in Orissa, Gujarat, Kerala and Andhra Pradesh. The components of the USAID AVERT project in Maharashtra include:

- Interventions in the sex industry, including availability, access and use of condoms.
- Improving comprehensive health services.
- Reducing high-risk behaviour in priority populations.
- Developing NGO and CBO capacity to respond to STI/HIV/AIDS.
- Developing communications support programmes.
- Establishing pilot programmes for out-of-school youth.
The European Union is providing support to the Lawyers Collective for activities related to advocacy and law and to protect the human rights of PLHA and those affected by the epidemic.

UN agencies are focusing on specific contributions related to their mandates and mainstreaming HIV with their development partners. For example, WHO focuses on surveillance, blood safety, clinical care and syndromic management of STI; UNICEF has been actively supporting interventions to prevent mother-to-child transmission of HIV, developing strategies to work with youth, and research related to the vulnerability of orphans and street children; the International Labour Organisation (ILO) is focusing on workplace initiatives; and the United Nations Family Planning Association (UNFPA) is strengthening condom programming, reproductive health and adolescent reproductive health, and conducting research related to the female condom and microbicides; UNESCO, UNICEF and UNFPA are assisting with school-based AIDS education.

UNAIDS India performs four key functions: co-ordinating the UN system response through the UN Theme Group; advocacy; building and strengthening partnerships; and providing information. UNAIDS provides technical support to NACO and SACS, and promotes collaboration between its UN co-sponsors, the GOI, bilateral agencies and civil society organisations. UNAIDS India has also given high priority to tackling stigma and discrimination through Greater Involvement of PLHA (GIPA) initiatives, locating the response to HIV/AIDS within a human rights framework, and working with marginalised groups. Activities in 2000 included organising the first National Conference on Human Rights and HIV/AIDS14; advocacy with young parliamentarians; campaigning to raise awareness of gender and HIV/AIDS; and strengthening links between networks of PLHA, MSM and sex worker groups.

International NGOs, such as the International HIV/AIDS Alliance are working with multilateral and bilateral agencies as well as with indigenous NGOs and CBOs. The Alliance was a key partner in preparation of the care and support strategy paper, and is documenting best practice in care and support in India.

USAID is a major donor for interventions in Maharashtra.

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14 Involving SACS, State Human Rights Commissions, NACO, UN agencies and the Lawyers’ Collective.
Chapter 3
Types of PLHA involvement in community-based prevention, care and support services

3.1 Introduction

This research is based on the assumption that PLHA can take part in the activities of NGOs and CBOs in many different ways. One of the main objectives of the study has been to develop a conceptual framework to describe the different types of involvement and their characteristics, as they have been observed and analysed not only in India but also in the three other countries where the research was conducted. The ultimate aim of the research is to offer a general typology of involvement that can be used as a framework to look at how PLHA take part in HIV/AIDS programmes at the community level in any developing country in the world.

This chapter presents this general typology using examples taken from the data collected in India\textsuperscript{15}.

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

To our knowledge, this is the first time a study has tried to describe involvement of PLHA in a systematic way by using a scientific approach. The rationale for doing this is both theoretical and practical, and as well as providing a conceptual framework, the typology aims to help NGOs and CBOs think through how they can improve the involvement of PLHA in their own organisations.

A thorough knowledge of the different ways in which PLHA are involved at community level is essential in order to:

- Analyse which type(s) of involvement really make a difference in the lives of PLHA who are involved in NGOs and CBOs, and how organisations in which they are involved and their services benefit or not from this involvement.
- Understand what makes one form of involvement possible and another one difficult to achieve.

Distinguishing types of involvement therefore helps analyse whether some types of involvement are more meaningful than others and if so which ones (chapter 5), and what obstacles have to be overcome in order to achieve what really works for PLHA and NGOs (Chapter 4).

\textsuperscript{15} Examples from the four research sites are presented in the final international study report, available in 2002.
A typology of involvement is a useful tool that NGOs can use to assess involvement in their organisations (what they are doing in terms of involvement of PLHA) and for strategic planning (what they would like to do).

As far as donors and organisations who provide NGOs and CBOs with technical assistance are concerned, they can use the typology to evaluate how PLHA are actually involved in the NGOs and CBOs they fund and support technically, and decide whether these are the types of involvement they really want to encourage.

We think that the lack of a typology, and the resulting vagueness around what “involvement of PLHA” really means, have contributed to misunderstandings between stakeholders interested in the issue of the participation of PLHA in the response to the HIV/AIDS epidemic. While AIDS activists for example, mean one thing by “involvement”, other key players such as governments or NGOs use the same term to refer to a completely different reality. We hope that the typology developed by the study will be used as a common language, although we do not claim that it is the only way to analyse the involvement of PLHA.

3.1.2 Outline of the chapter

After a brief presentation of the four organisations who participated in the study, this chapter will describe the methodology used to develop the typology of involvement, in particular the criteria selected to differentiate the forms of involvement of PLHA in NGOs and CBOs.

The general typology of involvement will be introduced in a table that summarises the main characteristics of the four types of involvement identified by the study. Each type will then be defined and described in detail using examples from the four Indian NGOs who participated in the study.

3.2 Characteristics of the four participating organisations

The four NGOs that participated in the study were selected because they represent a cross-section of organisations with different structures, approaches and forms of PLHA involvement in their activities. The study analysed the characteristics of each NGO in order to identify what type of “organisational model” they represent. Four models were identified:

- Secular welfare model.
- Religious welfare model.
- Developmental model.
- Rights-based model.
This section presents the main characteristics of the four organisations that participated in the study and identifies the models they illustrate. The purpose of identifying organisational models is to analyse the extent to which the characteristics of an organisation have a positive or negative influence on PLHA involvement. Organisational factors that enhance or limit PLHA involvement of PLHA are analysed in more detail in Chapter 4.

3.2.1 Project CHILD (CCDT)

CCDT, established in 1990 to implement health programmes with marginalised groups on behalf of the Municipal Corporation of Greater Mumbai (MCGM), describes itself as a secular trust functioning as an NGO. A development organisation, it aims to increase self-reliance through holistic programmes that emphasis quality of life, and sees its primary role as mobilising communities through participation and self-help rather than provision of welfare services.

CCDT currently has various programmes, including Project CHILD (Children of HIV + Individuals Living in Dignity), which was initiated in 1995 to meet the needs of children affected by HIV. The mission of Project CHILD — the focus of the diagnostic study — is “To promote home care for restoring hope and enhancing the quality of life of persons and families affected by HIV/AIDS and their dependants, especially children”.

Project CHILD takes a holistic approach to HIV/AIDS, basing interventions on comprehensive, professional assessments of families and their needs, and providing physical, psychological and social support to affected children. Services include post-test counselling, home-based care, home visits, hospital visits, a drop-in centre, support groups, economic and other support to those affected by HIV/AIDS, and “Ashray”, a temporary home for affected children who do not have family or community support.

CCDT is a relatively large organisation that employs 122 staff. It is governed by a board of six trustees and is managed by a director.

Activities at Project Child are carried out by 21 staff members, the vast majority of them are women. Staff involved in service delivery are mostly trained social workers, para-professionals and other professionals.

The main funding agency for Project CHILD is Terre des Hommes, and a range of individual donors provide financial and material assistance to Ashray.

CCDT collaborates with many government institutions and other NGOs and has developed a strong referral network. CCDT has good links with PLHA organisations, such as the India Network of Positive People (INP+) and the Maharashtra Network for Positive People (MNP+).
Some PLHA are employed as support staff by Project CHILD and other PLHA belong to support groups. CCDT can be described as an example of the “developmental model” of organisation, although it also has some characteristics of the “secular welfare model” and the “rights-based model”, because of its focus on provision of services and empowerment.

3.2.2 MNP+

MNP+ was a voluntary PLHA organisation that was registered as a charitable trust in 1998. (Since the completion of the diagnostic study, MNP+ has been dissolved.) MNP+ was established by a group of PLHA with the support of INP+, a national umbrella organisation for PLHA groups throughout India, the Maharashtra SACS, and Municipal Corporation of Mumbai.

MNP+ aimed to improve the quality of life of PLHA by providing opportunities for PLHA to share information and experience, empowering them, advocating for the rights of PLHA, supporting the establishment of self-help groups, and networking with PLHA groups and a wide range of other HIV/AIDS agencies. Through the Maharashtra Major Group (MMG), MNP+ aimed to provide a platform for PLHA in Maharashtra to have a “collective voice” and to create PLHA networks in the Pune, Thane and Nagpur districts of Maharashtra.

Other MNP+ activities included peer counselling, referral, support groups and forum meetings, information dissemination, and awareness-raising activities with health professionals and a range of government and non-government agencies, to improve the care and support provided by other institutions.

MNP+ presented itself as a “PLHA organisation” and preference was given to PLHA when new employees were recruited. However, it was a network for Positive People and not of Positive People, which means that people who were not HIV positive were also welcome, at least at the level of the Mumbai offices, where 64% of the organisation’s 11 paid employees were PLHA and 36% were HIV negative.

Other service providers included volunteers (approximately 10). There were also 500 PLHA who had joined the MMG, but it is not very clear what membership implied in terms of rights, obligations and involvement in the activities of the network. There was no membership fee. The only condition to belong to the network was to be HIV positive and fill in a form.

MNP+ can be defined as an example of “rights-based” organisation.

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16 For practical reasons MNP+ is referred to in the present tense in the rest of this report.
3.2.3 Salvation Army HIV/AIDS Programme

Founded in 1865 in the UK, the Salvation Army is an international Christian movement operating in 104 countries. The objectives of the organisation are “the advancement of the Christian religion… of education, the relief of poverty, and other charitable objects beneficial to society or the community of mankind as a whole”.

The Salvation Army has been working in India since 1882. The country is divided into six functional “territories”\(^{17}\) by the Salvation Army, with the India Western Territorial Headquarters based at Byculla in Mumbai. The Western Territory started work on HIV/AIDS in 1989 and this has subsequently evolved into the Mumbai HIV/AIDS Community Development Programme, which is the focus of this profile.

The Mumbai HIV/AIDS Community Development Programme functions like one of the Salvation Army centres described above. It aims to mobilise and empower communities to respond to the epidemic and, more specifically:

- To involve individuals and communities in HIV/AIDS prevention, care and support.
- To share strategies and provide mutual support through networking with other government and non-government organisations.
- To demonstrate a commitment to care, which is an entry point for prevention.
- To facilitate behaviour change through counselling individuals and communities.

The Programme carries out activities at the Byculla centre and in seven communities in Greater Mumbai. Services provided by the Byculla centre include voluntary and anonymous HIV testing, face-to-face and telephone counselling, referral and transport to hospital, medical care at the centre and at home, free or subsidised medicines, and homeopathic treatment. Other forms of support include hospital visits, monthly support group meetings for PLHA, recreational activities, and informal peer support for PLHA who come to the Byculla centre. The centre also provides educational, material and psychological support to the children of sex workers.

Community activities include home visits to PLHA and affected beneficiaries, home-based care for PLHA, and awareness raising. Home visits are used as an opportunity to provide information, encourage discussion of issues, and mobilise the community. Home-based care is provided for PLHA who are unable to visit the Byculla centre or who are very ill. Awareness raising aims to address misconceptions, change attitudes towards PLHA, and encourage behaviour change.

\(^{17}\) Terminology used by the Salvation Army.
In response to requests, the Programme also carries out awareness raising activities in schools, colleges, workplaces and prisons.

Activities are carried out by staff (nine employees at the time of data collection) and volunteers. Volunteers based in communities reached by the HIV/AIDS programmes can be Salvationists (Corps Community volunteers) or not. There are also a few volunteers at the Byculla centre.

Most staff involved in service delivery are social workers, but the Programme has also encouraged recruitment of members of the community.

There are visible PLHA among staff, including service providers and support staff, and volunteers. HIV positive volunteers at the Byculla centre also attend support group meetings for PLHA.

We would describe the Salvation Army as a “religious welfare” organisation. It focuses on providing services to disadvantaged groups in society, although it also emphasises the empowerment of communities like a developmental organisation.

### 3.2.4 SOFOSH

SOFOSH, established in Pune in 1964 to provide assistance to patients of the Sassoon General Hospitals (SGH), describes itself as “a voluntary, private, non-profit and non-political organisation”. The beneficiaries of SOFOSH services are low-income groups from urban and rural areas within a 100-mile radius of Pune.

SOFOSH’s main areas of activity are patient welfare, child care, rehabilitation and adoption services. It has become one of the leading adoption agencies in Maharashtra through its work with abandoned children. Specific activities include material and financial assistance to needy patients, counselling patients and their families, a nutrition clinic and health education programme, short-term crisis care for abandoned children and children whose parents are hospitalised, and a programme for single and deserted mothers.

The organisation started working on HIV/AIDS in 1995, as many patients were diagnosed with HIV/AIDS. The focus of SOFOSH was to provide PLHA with counselling, emotional support and guidance on self care, and to provide families of PLHA with guidance on home care, preventive measures and help on coping with psycho-social problems. With the exception of testing and counselling, which is a new area of activity, SOFOSH has integrated HIV/AIDS work into its existing activities, and PLHA and affected beneficiaries receive the same services as other beneficiaries of the organisation. For example, short-term crisis care is provided for HIV positive and negative children who have been abandoned by their families, and the adoption programme places affected children with
alternative families. The programme for single or deserted mothers provides antiretroviral therapy to HIV positive pregnant women through the SGH to reduce the risk of mother-to-child transmission. SOFOSH has conducted training on HIV/AIDS issues, such as bio-safety, for its staff and the service providers of the SGH to improve attitudes towards PLHA in the hospital.

The majority of PLHA registered with SOFOSH are referrals from the TB outpatient department (OPD) of SGH.

SOFOSH is a large organisation with 65 employees and 35 volunteers. Employees who provide services are mainly social workers, nurses, teachers and child care helpers.

Funding is mostly obtained from individual donors and occasional donations from international adoption agencies.

When SOFOSH decided to participate in this study, involvement of PLHA was a new theme for the organisation, although management and service providers realised that a few PLHA had been involved in a limited way in its activities.

SOFOSH is therefore an hospital-based organisation whose focus is the provision of psycho-social support to its beneficiaries. It can be seen as a good example of a “secular welfare” organisation.

Family counselling at SOFOSH
3.3 Methodology used to develop the typology of PLHA involvement

There were several methodological challenges for the description of involvement of PLHA in NGOs and CBOs and the development of a typology of involvement:

- Absence of previous research on the involvement of PLHA that could be used as a reference for definitions.
- Necessity to have a very general definition of involvement as a starting point\(^{18}\) (in particular for research teams in each country), but also necessity of a definition broad and loose enough to accommodate the assumption that involvement can have many different forms.
- Choice of criteria to distinguish and characterise the forms of involvement.
- Choice of a terminology to name the different kinds of involvement.

As a result of these constraints, the approach was to avoid pre-definitions of involvement developed by the international research team and let research teams and participating NGOs in each country explore and discuss concepts and terminology based on their research observations. The role of the principle investigator was to make sure that concepts and terminology could be shared between countries and that one global and consistent typology would finally emerge from the process.

The typology presented in this chapter has therefore benefited from the input of researchers in India, Zambia and to some extent Ecuador\(^{19}\). The bases of the current typology and terminology were actually set during the rapid assessment in India. In India and Zambia 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\(^{20}\).

We believe that the participatory process used to develop the conceptual framework gives extra validity to the typology because of the number and diversity of stakeholders involved in its development. In particular, the typology has been validated by giving the community the opportunity to discuss and contribute to developing the concept of involvement of PLHA.

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\(^{18}\) The general definition is ‘the various ways for PLHA to take part in the activities of NGOs and CBOs’ (see Terminology).

\(^{19}\) The involvement of the research team in the analysis of the data was limited in Burkina Faso where the study was piloted.

\(^{20}\) In Burkina Faso and Ecuador, the data analysis workshops were scheduled too early and did not allow NGOs and researchers to discuss these issues.
3.3.1 “Areas” of involvement

Since the main focus of the research is the involvement of PLHA in service delivery, we first looked at the relation between PLHA and services of NGOs and CBOs and identified three broad “areas” of involvement:

- **Utilisation** of services of NGOs and CBOs.
- **Implementation** of activities / **Delivery** of services offered by NGOs and CBOs.
- **Decision-making** on the services delivered by NGOs and CBOs.

However, further analysis led us to distinguish between:

- **Implementation** of:
  - **HIV/AIDS activities** (delivery of HIV/AIDS services), such as prevention, care and support.
  - **Non HIV/AIDS-related activities**.

and between:

- **Decision-making** that affects:
  - The design and planning of activities and services.
  - The overall **functioning** of the organisation, and its **policies**.

We finally catalogued five potential “areas” of involvement and corresponding roles for PLHA:

<table>
<thead>
<tr>
<th>Areas of involvement</th>
<th>Roles for PLHA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Utilisation</strong> of the services of the NGO</td>
<td>⇒ PLHA are <strong>service users</strong> or <strong>beneficiaries</strong></td>
</tr>
<tr>
<td><strong>Support</strong> to services</td>
<td>⇒ PLHA support non-HIV/AIDS related activities such as administration, maintenance and other technical tasks (cooking, gardening, etc.) as <strong>support staff</strong> or <strong>volunteers</strong></td>
</tr>
<tr>
<td><strong>Delivery</strong> of HIV/AIDS services</td>
<td>⇒ PLHA are <strong>service providers</strong></td>
</tr>
</tbody>
</table>
### 3.3.2 Criteria to describe the involvement of PLHA in each area

The involvement of PLHA in an NGO or CBO can be seen as an economic relationship between the organisation and individuals whereby PLHA give their time, use their skills and make efforts in order to produce something, e.g. a service. The organisation in exchange can reward this by a remuneration that can be financial (e.g. salary, allowance), material (e.g. food, drugs), intellectual/technical (e.g. training) and/or psychological (e.g. support). How much time is spent, what skills are used and how this is rewarded by the organisation 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.

Based on this definition, we looked at the main components of the exchange between organisations and PLHA: **time given, remuneration, use of skills, decision-making influence** as well as **visibility**. A unique characteristic of the involvement of PLHA is that it can be visible or non-visible, because of the stigma toward PLHA and their fear of discrimination. For this study, visibility was a key element of the criteria used to establish the typology.

The study analysed the balance and relative importance of each of these components in order to develop the typology:

- The amount of **time** that PLHA spend taking part in the activities of the organisations.

- The level of **remuneration given by the organisations to PLHA** in exchange for their expertise, time and efforts.

- The categories of **skills** or **expertise** used when PLHA take part in the activities of NGOs and CBOs:
  - From the perspective of PLHA, the skills they bring to the organisations and they use when involved in the activities.
• From the perspective of the organisations, the skills that the organisations provide PLHA with.

In the particular case of involvement of PLHA in the decision-making process, the other factors we investigated are:
• The scope of the decisions PLHA make.
• The autonomy of the decisions they make.

3.3.2.1 Time and remuneration: formal versus informal involvement

• PLHA can give some of their time to an organisation in order to produce something, usually a service. The level of involvement or commitment of PLHA in terms of time spent with an organisation can be:
  • Either regular, whether it is full-time or part-time.
  • Or occasional, when involvement is not occurring at fixed or prearranged intervals.

PLHA involved on a regular basis can be either full-time or part-time employees of an organisation, or volunteers.

• The types of financial and material remuneration that PLHA receive in exchange for their involvement in the activities of an organisation (in particular the time they give) can be the following:
  • Salary.
  • Fees or allowances.
  • Reimbursement of expenses (e.g. transport).
  • Material compensation (e.g. meals).

On a different level, training and support can be considered as respectively intellectual/technical and psychological kinds of remuneration. In some cases, PLHA do not receive any remuneration.

The combination of the criteria “time” and “remuneration” helps establish levels of formality and informality of involvement:

• We will qualify as formal involvement which is regular and financially or materially rewarded.
• “Informal” will describe any form of involvement which is occasional or regular but not or hardly rewarded on a financial or material level.

Levels of formality and informality of involvement are closely linked to the concepts of “voluntary” versus “professional” involvement. The general assumption is that voluntary involvement refers to unpaid activities; however the study has shown that the meaning of “voluntary work” can vary depending on countries and organisations.
3.3.2.2 Knowledge and involvement

PLHA involved in NGOs and CBOs may have to use different sorts of skills or categories of expertise, which for the purposes of this study are defined as knowledge. Categories are as follows:

- Experiences of living with HIV/AIDS, e.g. coping skills.
- Knowledge of basic facts on HIV/AIDS, e.g. ways of transmission of HIV.
- Technical skills related to the delivery of HIV/AIDS services. e.g. counselling skills.
- Other technical/professional skills.
- Organisational skills, e.g. in management.
- Knowledge of the organisation in which they are involved.

The first category of expertise, living with HIV/AIDS, is mainly empirical since it derives from the personal experience of PLHA, while the other forms of knowledge can be learned theoretically, as well as by observation and practice.

We also considered the kind of knowledge provided to PLHA by the organisations in order for them to be involved as an important criteria to distinguish types of involvement, whether NGOs and CBOs consider the transfer of knowledge as a remuneration of involvement or not (see above). Knowledge can be transferred to PLHA in various fields:

- Information on HIV/AIDS, e.g. epidemiology.
- Information on life with HIV/AIDS, e.g. nutrition.
- Delivery of HIV/AIDS services, e.g. provision of Home-Based Care.
- Vocational issues, including generation of income.
- Organisational development issues, e.g. documentation, communication, advocacy skills.
- Information on the structure and functioning of the organisation in which they are involved.

Knowledge is transferred, whether formally, through orientation and training, or informally.

3.3.2.3 Scope and autonomy of the decision-making process

We tried to characterise further the involvement of PLHA in the decision-making process by analysing the following elements: scope of decisions and autonomy of decisions. Several categories were identified:

- Direct involvement of PLHA in decision-making.
- Indirect involvement of PLHA in decision-making, i.e. consultation by the organisation.
• Decisions of PLHA limited to activities in which they take part.
• Decisions of PLHA on organisation-wide activities, including activities in which they do not take part.

On another level it was important to examine whether:

• PLHA take the initiative when they are involved in activities, or
• PLHA are requested to take part in the activities by the organisations.

3.3.2.4 Visible or non-visible involvement

The involvement of a PLHA in NGOs and CBOs can be visible or non-visible\(^{21}\). It is visible when the PLHA involved is open about his or her HIV status at some 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 organisation, where the PLHA is also 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 paid particular attention to the level of visibility of PLHA within the NGO or CBO (internal visibility) versus the level of visibility outside the NGO or CBO (external visibility).

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

<table>
<thead>
<tr>
<th>Box 3.1</th>
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<td>Visibility in the study(^{22})</td>
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</table>

**Respondents selected as PLHA**

• All the respondents the researchers interviewed as PLHA, whether they were NGO

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\(^{21}\) A definition of visibility is also included in the general terminology.
\(^{22}\) See 1.6 Ethics of research.
members or beneficiaries of the services of the NGOs, were aware that they were HIV positive.

- All of them had been recruited by the participating NGOs and they had agreed to disclose their HIV status to the research team.

**Other respondents**

- In very few cases, people disclosed that they were HIV positive during an interview with a researcher, although other people in their organisation 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 it outside the organisation and inside, with exception of one or few colleagues.

This information was not included in the analysis, in order to maintain confidentiality.

This report therefore presents only the levels of visibility that the researchers were able to observe within the ethical framework of the study. Obviously this excludes PLHA involved in NGOs who do not know their HIV status and those who chose not to disclose it to their organisations.
3.4 The four types of involvement of PLHA in the NGOs

The typology of involvement, as shown in the table below, is based on the analysis of the following elements observed in the participating NGOs and CBOs in India and other countries:

- An assessment of the observed combinations of areas of involvement of PLHA and corresponding roles of PLHA in NGOs and CBOs (see table 3.1).
- Main characteristics of involvement in each area, using the criteria described earlier (3.3.2).

3.4.1 Terminology

Four types of involvement were identified by the study. We will use the following terminology to name and differentiate them: *access*, *inclusion*, *participation* and *involvement*.

The word involvement will be used in two ways:

(a) Generically to describe any way in which PLHA take part in the activities of NGOs and CBOs, as it has been used since the beginning of this report.
(b) Specifically, to describe one of the ways in which PLHA take part in the activities of NGOs, or type of involvement. When used with this particular meaning, it will be italicised (*involvement*).

The other terms *access*, *inclusion*, and *participation* will also be italicised when they refer to types of involvement.

Table 3.2
General typology of PLHA involvement

<table>
<thead>
<tr>
<th>TYPES OF PLHA INVOLVEMENT</th>
<th>AREAS OF INVOLVEMENT FOR PLHA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PLHA use the services of the NGO</td>
</tr>
<tr>
<td>Access</td>
<td>Yes</td>
</tr>
<tr>
<td>Inclusion</td>
<td>Yes</td>
</tr>
</tbody>
</table>
We chose “involvement” as the generic term to refer to any way for PLHA to take part in the activities of NGOs and CBOs because most stakeholders, such as UN agencies and AIDS activists, have used this word since the Declaration of the Paris AIDS Summit on the “Greater Involvement of PLHA” (GIPA) in the response to the HIV/AIDS epidemic.

We also chose involvement to refer specifically to the situation where PLHA take part in all the areas of activity of an NGO, as suggested by the expression GIPA. The term “type” has been preferred to “level” because “level” implies that there can be low and high levels of involvement, “low levels” being seen as depreciable and high levels being seen as desirable for both PLHA and organisations. After discussions with partner NGOs in two countries, we found that this could lead to a misinterpretation of the meaning of the typology and cause competition between participating organisations, which is not the objective of the study. We will also use other “neutral” words such as “models” and “forms” in this report.

### 3.4.2 Involvement as an individual and organisational process

- Where involvement refers to the way(s) a person living with HIV takes part in the activities of an organisation, it describes an **individual process**.
• It can also refer to how PLHA take part generally in the activities of an NGO and how the organisation involves PLHA – its philosophy, policies and practices. It then describes an organisational process.

The typology of involvement applies to both individuals and NGOs. A PLHA can be a trustee of an organisation (involvement), while another PLHA works as a counsellor in the same organisation (participation) and many other HIV positive people come to this organisation to see this counsellor as clients (access). There can be as many individual types of involvement as PLHA in a single NGO.

Although several types of involvement can therefore co-exist in the same organisation, one or two types may be predominant. When an NGO provides services to PLHA but, for example, does not seek to involve its beneficiaries or other PLHA further in its activities, its approach to involvement can be characterised as access. Another NGO might have the same number of PLHA who are only beneficiaries, but if some of the staff who provide services are also HIV positive, then the approach of this NGO to involvement can be characterised as participation, whatever the number of PLHA actually involved.

Patient guide at Sassoon Hospital: an activity where PLHA are involved
Finally, a PLHA can also be at the same time a beneficiary and a service provider in the same organisation.

The characteristics of each type of PLHA involvement – access, inclusion, participation, and involvement – based on the study findings in India, are described in more detail below.

3.4.3 Access

Table 3.3  
Definition of Access: Areas of involvement of PLHA

<table>
<thead>
<tr>
<th>Definition of Access: Areas of involvement of PLHA</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA utilise services of the NGO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHA support activities and services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHA take part in the delivery of services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHA take part in the planning and design of programmes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLHA take part in management, policy making and strategic planning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In none of the four organisations who participated in the study, was access the only type of involvement of PLHA. However, all NGOs offer a wide range of services to PLHA (see below), and for the vast majority of these PLHA who are beneficiaries, using services is the only way to take part in the activities of the organisations.

Table 3.4  
Services offered to PLHA by the four NGOs

The specific services and activities utilised by PLHA in the organisations are as follows:

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>Project Child (CCDT)</th>
<th>MNP+</th>
<th>Salvation Army</th>
<th>SOFOSH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counselling:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone counselling</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Other forms of counselling</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Care:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alternative treatments</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Ambulance service</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Community visits</td>
<td></td>
<td></td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Home visits</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Home-based care</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital visits</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Medical care</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Nutrition clinic</td>
<td></td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>Referrals</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

**Training for PLHA**

| Skills and capacity-building workshops for PLHA | Y |

**Support groups**

| Groups for affected families | Y | Y |
| Groups for MSM | | Y |
| Groups for women | Y | Y |
| Other support groups | Y | Y | Y |

**Other services**

| Advocacy and networking | | Y |
| Anonymous HIV testing | | Y |
| Assistance for income generation | Y | |
| Adoption for affected children | | Y |
| Developing IEC material for PLHA | Y | |
| HIV/AIDS helpline | | Y |
| HIV/AIDS information | Y | Y | Y | Y |
| Material and economic support | Y | | Y |
| Recreational activities | Y | Y |
| Short-term crisis care, and temporary shelter for PLHA single mothers | | Y |
| Temporary shelter home for children of PLHA | Y | |
### Box 3.2
**Profile of PLHA beneficiaries**

**Project CHILD (CCDT)** – Beneficiaries are predominantly urban, from Mumbai city and suburbs. Most are young single or widowed PLHA mothers with children who may or may not be seropositive, who live with their families in one-room dwellings. Some beneficiaries are sex workers. The majority of beneficiaries have completed primary education\(^{23}\) and are from low-income groups.

**MNP+** – Beneficiaries using counselling and support services are predominantly urban. Equal numbers of men and women use the services. Most beneficiaries are married and have children. The majority have completed secondary education\(^{24}\) and are employed, but are from low-income groups.

**HIV/AIDS Programme (Salvation Army)** – Beneficiaries are predominantly urban. Most are young men. The majority have completed secondary education and are unemployed.

**SOFOSH** – Beneficiaries are from urban (55%) and rural (45%) areas. The majority of men have completed primary education and are employed, but are from low-income groups.

If access is analysed in terms of an exchange between an NGO and PLHA, the main characteristic of the exchange is that PLHA are in a position of recipients. The relationship between service providers and PLHA beneficiaries can be described as vertical. The skills and time of HIV positive beneficiaries are not used by themselves or by the organisation to help other beneficiaries for example, either for individual or organisational reasons (see following chapter of factors that limit and enhance involvement).

For a PLHA, access can provide a time to reflect on his or her HIV status and what it means for his or her life, through counselling for example.

### Box 3.3
**Access … in brief**

Access describes the situation where PLHA take part in NGO activities as beneficiaries of services or service users. They may be clients of counselling 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 organisation. In these NGOs and CBOs the only organisational type of involvement is therefore access.

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\(^{23}\) Primary level of education is equivalent to Grade I to V.

\(^{24}\) Secondary level of education is equivalent to Grade X.
In other organisations, while some PLHA access services as beneficiaries, others also take part in the delivery of services and in other activities (see *inclusion, participation* and *involvement*). Therefore, while some PLHA are only involved at the level of *access*, other types of involvement co-exist in the NGO.

When NGOs or CBOs provide services aimed at empowering PLHA, such as counselling and training, *access* can be a starting point for further involvement.

### 3.4.4 *Inclusion*

**Table 3.5**

*Inclusion: Areas of involvement of PLHA*

<table>
<thead>
<tr>
<th><em>Inclusion: Areas of involvement of PLHA</em></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA utilise services of the NGO</td>
<td>Yes</td>
</tr>
<tr>
<td>PLHA support activities and services</td>
<td>Yes</td>
</tr>
<tr>
<td>PLHA take part in the delivery of services</td>
<td>Informally Occasionally</td>
</tr>
<tr>
<td>PLHA take part in the planning and design of programmes</td>
<td>No</td>
</tr>
<tr>
<td>PLHA take part in management, policy making and strategic planning</td>
<td>No</td>
</tr>
</tbody>
</table>

In the four NGOs who participated in the study in Maharashtra, we found that some PLHA were not only beneficiaries but were also involved in other ways in the implementation of the activities of the organisation, whether they are HIV/AIDS or non HIV/AIDS-related activities.

**Support groups: from access to inclusion**

Staff of Project CHILD observed that many of their HIV positive beneficiaries had common problems and thought that bringing them together for sharing experiences might benefit them in some way, which led to the formation of support groups.

There was originally only one support group for PLHA, including both female sex workers and other HIV positive women. However, the Project Child team realised that sex workers and other women would discuss different issues and they set up two groups. Issues discussed by sex workers include: personal hygiene; Sexually Transmitted Infections (STIs); issuance of ration card\(^{25}\); availability and use of condoms. Other positive women are more concerned about pregnancy and about how to explain the importance of condoms and their use to spouses. Common issues are: children, in particular the disclosure of one’s HIV status to the children; nutrition; care, including experiences in health settings; legal matters.

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\(^{25}\) An identification document issued by the Government, which allows access to subsidised food. It also gives a legal proof of residence and citizenship for Indian citizens.
There are now several support groups: two for PLHA and two for affected people. Participants in support group meetings share feelings and knowledge. However, recreational activities and yoga are also important components of the meetings held once a month.

When support groups were started in 1995, they were designed and facilitated entirely by service providers of Project CHILD. Five years later, participants are usually able to decide on their own agendas and some of them may facilitate meetings. In addition, some support group members take the initiative to visit on a voluntary basis other PLHA who are too sick to attend meetings. Project CHILD views identification of leaders and their involvement in planning support group meetings as part of a process of PLHA mobilisation, and as a concrete strategy for involvement. As a service provider said:

“We also identify leaders, then get them involved in the planning of support group meetings … leaders can then take this group into a self-help group”.

Although members of support group meetings have become more autonomous, support groups do not have their own resources and it would be difficult for them to remain active and sustainable without the assistance of Project CHILD. This is why this form of self-help is termed as “assisted self-help”. Project CHILD is currently exploring how MNP+ can assist support groups to evolve into independent self-help groups.

**PLHA deliver HIV/AIDS services informally and occasionally**

Some PLHA beneficiaries of Project CHILD also assist with other activities on a voluntary basis, such as organising recreational activities and informal peer counselling. A beneficiary of the project, who uses the drop-in centre, is involved in service delivery as a “community health volunteer” for another CCDT project. This PLHA, who is also a sex worker, provides health information and condoms to sex workers, and encourages them to come for check-ups at the CCDT-managed health post. She receives an honorarium for this work. She has had not formal education, but has basic literacy skills.

At MNP+, some PLHA beneficiaries provide informal peer support, and others take part in awareness raising activities, on a voluntary and irregular basis.

Some of the PLHA who attend support group meetings provide informal peer support at the Byculla centre by sharing their experience with newly diagnosed PLHA and encouraging them to attend support group meetings. They also accompany other PLHA on a voluntary basis when they are admitted to hospital. They carry out home, hospital and hospice visits, and refer other PLHA to the Salvation Army Programme’s services. However, the volunteers are not always visible. They may choose to disclose their HIV status to other individual PLHA,
for example during hospital or home visits, but it depends on the circumstances. They usually carry out their activities as part of a team rather than as openly HIV positive people. Some of them occasionally give testimony during awareness raising sessions.

The Salvation Army Programme estimates that approximately five per cent of community-based volunteers are directly infected with and affected by HIV/AIDS\textsuperscript{26}. Most of them are women. However, they are usually not open about their HIV status.

It is interesting to note that one of the support staff members of the Byculla centre is HIV positive and provides informal support to PLHA beneficiaries while they are sitting in the waiting area. However, he does not have a formal role in service delivery – he was not requested to provide support to PLHA and is not paid for this particular contribution.

**PLHA support non HIV/AIDS-related activities**

At Project CHILD (CCDT), two HIV positive women are employed as helpers and attendants, one at “Ashray”, the temporary shelter for children of PLHA, and one at the drop-in centre for PLHA. At “Ashray” the PLHA works as a night attendant, and her duties include feeding and dressing children, and cleaning utensils. The PLHA worked at the drop-in centre in a temporary position while the permanent worker was on leave, and her duties included preparing tea, keeping the centre clean and similar work. Both women are widows with children, who have completed primary education, and are from low-income groups.

As mentioned above, one of the support staff members employed by Salvation Army at the Byculla centre is a PLHA.

The case of MNP+ is specific, where HIV positive staff members do everything, which means that they are involved in support to activities as well as in delivery of services.

At SOFOSH, there are no staff members who are visible PLHA but there are some HIV positive beneficiaries who support the activities of the organisation on a voluntary basis. A PLHA is a patient guide at the SGH outpatient department. This involves helping patients attending the hospital find their way around and does not necessarily require the PLHA to utilise her personal experience of living with HIV/AIDS. She receives a cash honorarium rather than a regular salary. One seropositive woman volunteer refers single mothers and PLHA to SOFOSH through her work for the People’s Health Organisation. She also helps with the transfer from Pune to Mumbai of children adopted by families in Mumbai, for which she receives reimbursement of travel expenses. Finally, all beneficiaries of

\textsuperscript{26} This does not include the Community Corps Volunteers who are Salvationists.
the programme for single and deserted mothers, including those with HIV, are involved in support activities, such as domestic chores, although HIV positive women are not allowed to take part in child care. Most of them are young, single mothers from urban slums or rural areas who have sought shelter from SOFOSH, and many discovered their HIV status during their pregnancy. They are usually illiterate or in some cases have completed primary education, and they are from low-income groups. PLHA who are helpers, volunteers or beneficiaries are visible to service providers within the organisation, but they are not really visible to each other and even less outside the organisation. There is therefore no real peer support at the moment.

Analysis of the main characteristics of inclusion
Using the criteria identified for the development of the typology, we can summarise the main characteristics of inclusion in the following way:

- Involvement of PLHA in the delivery of HIV/AIDS services is informal, which means occasional and poorly rewarded on a financial and material level. This is important because it can affect involvement negatively, as we will explain in the following chapter. The remuneration of the contribution of PLHA to service delivery is actually not only linked to its occasional nature, it is also related to the level of skills and expertise used by PLHA.
- The data shows that PLHA who contribute informally to service delivery do not use any technical and theoretical expertise on HIV/AIDS, because they do not have this expertise and/or they are not requested to use it. They may use their own experience of living with HIV/AIDS, by either giving testimonies or sharing their experience with other PLHA. This can explain why the level of remuneration is low: “empirical expertise” is generally less valued than technical and theoretical expertise.
- PLHA have not received specific training to deliver HIV/AIDS services.
- In some cases inclusion is seen in terms of occupational therapy by the organisation.
  
  “The single and deserted mothers at the shelter need to be occupied...otherwise they will sleep all day or fight”, pointed out a service provider of SOFOSH.

- When the role of PLHA is to be living testimonies and share their empirical knowledge of HIV/AIDS, other service providers bring the technical and theoretical knowledge. PLHA act as “aides” and assist other “regular” service providers of the organisation. These “regular” service providers can be health professionals or social workers but they can also be other PLHA who have received further training, as we will explain in the following sections on participation and involvement.
The relationship between service providers and PLHA beneficiaries is vertical but it also emphasises PLHA empowerment – Beneficiaries are viewed as having the capacity to become independent, help themselves and others.

PLHA are usually visible within the organisation, mainly to service providers, and in some cases to other PLHA. Visibility to family and community can vary considerably, depending on individuals and their circumstances.

PLHA who are involved in service delivery in an informal or occasional way are not involved in the planning or design of these services.

**Box 3.4**

Inclusion … in brief:

*Inclusion* describes the situation where PLHA are not only beneficiaries but are also involved in the implementation of the activities of an organisation 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, e.g. maintenance, administration, cooking, gardening.

“Aides” are PLHA who are usually service users taking part on a voluntary basis and occasionally in activities at the request of the organisation, for example peer support or outreach education. They assist service providers by talking about their own experience and give a “human face” to HIV/AIDS. PLHA are not considered as 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 organisation in which they work.

Given their limited involvement in service delivery, PLHA do not play a part in the design and planning of these services.
3.4.5 Participation

Table 3.6

<table>
<thead>
<tr>
<th>Definition of Participation: Areas of involvement of PLHA</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA utilise services of the NGO</td>
</tr>
<tr>
<td>PLHA support activities and services</td>
</tr>
<tr>
<td>PLHA take part in the delivery of services</td>
</tr>
<tr>
<td>PLHA take part in the planning and design of programmes</td>
</tr>
<tr>
<td>PLHA take part in management, policy making and strategic planning</td>
</tr>
</tbody>
</table>

In two NGOs – MNP+ and Salvation Army – we found that besides HIV positive service users, volunteers or support staff, there are also PLHA who are employed by the organisation as service providers, some of them being visible inside and outside the organisation.

Delivery of services

Sixty-four percent of staff members at MNP+ are PLHA. They are full-time salaried employees. These PLHA are involved in activities including face-to-face peer counselling, telephone counselling, home and hospital visits, and information dissemination, facilitating empowerment of other HIV positive people through skills and capacity building programmes, support groups and forums. A few provide testimonies on an occasional basis. There are almost equal numbers of male and female PLHA service providers. Most are single and are educated to secondary level or above. PLHA are visible within the organisation. Peer counsellors, for example, reveal their HIV status to their clients as appropriate during counselling sessions.

The only PLHA who is visible inside and outside the Programme is a part-time employee. He was originally a support group participant (access), then started to facilitate the meetings on a voluntary basis (inclusion) and was eventually recruited as a counsellor. He is also the official Co-ordinator of the support group meetings. Like the rest of the staff, he carries out awareness raising activities in schools, colleges, workplaces and prisons on request. He also takes part in the activities in the community, supporting the community-based volunteers. He is visible to colleagues and, as a counsellor, to clients, and has also given testimony in public forums, on the radio, in newspapers and on television. He does not allow the use of photos and his image was blurred on television, because of the fear that this degree of visibility will result in stigma and discrimination. He is from an urban area and has completed secondary education.
Planning and design of services
At MNP+, staff members are involved to some extent in the planning and design of all activities, together with the trustees of the organisation. These PLHA are educated to secondary school or graduate level, and are mostly from urban areas and middle-income groups. HIV positive staff members at the Byculla centre contribute to the planning and design of the activities they are involved in. However, important programmatic decisions are made by Salvation Army authorities at the territorial headquarters.

In MNP+, Project CHILD and Salvation Army, there are some mechanisms to consult beneficiaries on the services they receive. At Project CHILD, the positive women who are members of the support groups are consulted about what they would like to discuss during meetings and what kind of other activities they would like to be involved in. At Salvation Army, PLHA who attend support group meetings are also consulted on the way meetings should be conducted and on the services provided by the Byculla centre. Changes made as a result of consultation included introduction of homeopathic treatment and recruitment of a medical doctor to provide services. However, the organisations are not bound to implement the suggestions made during the consultation process.

"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 programmes", explains a service provider of the Salvation Army Programme.

Analysis of the main characteristics of participation
• Participation of PLHA in service-delivery is formal, which means regular and financially or materially rewarded, although the time spent with the organisation and the remuneration can vary, from part-time to full-time and from allowances to a salary with full benefits. Compared to inclusion, the remuneration is higher because the expertise of PLHA is broader and is acknowledged by the employer.

• It is worth noting that the vast majority of PLHA in the participatory model are involved in peer support and outreach education. The researchers did not come across any visible PLHA employed as doctors, nurses or lab technicians. One explanation is that, even when they know that they are HIV positive, PLHA in these categories might be reluctant to disclose their HIV status, including to their patients or clients because of various reasons (see following chapter, Factors that limit involvement). Another explanation is that it is easier to be an outreach educator or peer counsellor without any training.
or with minimum training than to be a doctor. In these activities, PLHA can use mostly their personal and empirical expertise of living with HIV/AIDS, which is not possible in other fields like medical care, for which a lot of theoretical expertise is needed. Having said that, PLHA outreach educators and counsellors also use other skills since their role is not only to give testimonies but also to give general information about HIV/AIDS and Positive Living. In many cases, they do not speak only about how they have been living with HIV but also about other people who live with HIV: the experience is individual and collective. They also have to have some theoretical knowledge of HIV/AIDS and practical skills such as communication.

- The data reveals that in this participatory model, HIV positive employees have received more training from their organisation than PLHA who are beneficiaries and volunteers, although training is more informal than formal. Employees usually have a better knowledge of the organisation and its services than volunteers.

- Because they have received training, PLHA who participate in service-delivery are also more autonomous: they can carry out activities on their own, unlike in the inclusive model in which PLHA act as aides of other service providers.

- The level of visibility of PLHA who participate in NGOs is usually quite high, both within and outside the organisation, to other service providers and to beneficiaries. However, it is an extremely selective visibility.

- The relationship between service providers and PLHA beneficiaries is horizontal and emphasises empowerment – Service providers consider beneficiaries as equals. The objective of the relationship is the generation of services to meet PLHA needs and PLHA empowerment through advocacy and self-help rather than through dependence on charity or welfare.

- As far as the involvement of PLHA in the decision-making process is concerned, participation is characterised by a limited scope of decisions and also a limited autonomy. PLHA who participate in delivery of services make some direct decisions on the services in which they are involved. They and other PLHA may be consulted about other services.
Box 3.5  
*Participation* … in brief:  

*Participation* describes the situation where PLHA actively implement HIV/AIDS-related programmes as regular service providers, usually employees, of an NGO. They receive financial compensation for their work, since their expertise is officially acknowledged by the organisation. They may be involved directly in the planning of services, but only of the services they deliver and usually in co-operation with a supervisor. The NGO may also request the opinion of PLHA about other services, but always on a consultative mode, since the final decisions lie with the management of the programmes and the organisation.

### Table 3.7  
**Definition of involvement: Areas of involvement of PLHA**

<table>
<thead>
<tr>
<th>Definition of Involvement : Areas of involvement of PLHA</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA utilise services of the NGO</td>
<td>Yes</td>
</tr>
<tr>
<td>PLHA support activities and services</td>
<td>Yes</td>
</tr>
<tr>
<td>PLHA take part in the delivery of services</td>
<td>Formally Regularly</td>
</tr>
<tr>
<td>PLHA take part in the planning and design of programmes</td>
<td>Yes</td>
</tr>
<tr>
<td>PLHA take part in management, policy making and strategic planning</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Visible *involvement* of PLHA was observed in one organisation, MNP+, where all three trustees, who are responsible for management, policy making and strategic planning, are PLHA (two male and one female). Other HIV positive staff and HIV negative staff are consulted about decisions and participate in strategic planning, but the trustees make final decisions. The trustees are from urban areas, are educated to secondary school level or above, and are from middle-income groups.

PLHA have significant visibility outside the organisation. Some PLHA service providers are visible outside the organisation, through mass media, posters, giving testimonies, and as consultants to other organisations.

**Analysis of the main characteristics of involvement**
- As for *participation*, *involvement* of PLHA in service-delivery is *formal*, which means *regular* and *financially or materially rewarded*. Most PLHA *involved* are actually *full-time* employees, in contrast to what was observed in some cases for *participation*. Because PLHA who are *involved* in NGOs usually work full-time, the *remuneration* is likely to be *higher* than for PLHA who
participate. The remuneration is also based on the level of responsibilities and expertise of the PLHA who are involved, and is higher than in the other types described thus far. At MNP+, one of the trustees is the director of the organisation and another one is a Project Co-ordinator-cum-accountant.

- PLHA involved in NGOs use a very wide range of skills, including those already observed for other models as well as organisational skills, such as management. They also have a very good knowledge of the organisation in which they work and of other AIDS organisations.

- Their visibility is very high within and outside the organisation, at the national and even regional or international level for some of them. They may represent their organisation in external forums. They also usually speak on behalf of other PLHA, using their personal experience/expertise of living with HIV/AIDS and transcending it into a collective and even social voice.

- Most PLHA involved have usually received training and have been exposed to a vast amount of information on HIV/AIDS in workshops and conferences.

- As for participation, the relationship between service providers and PLHA beneficiaries is horizontal and emphasises empowerment – At MNP+, most service providers are HIV positive like the beneficiaries of their services.

- Compared to participation, involvement is characterised by a broader scope of decisions for PLHA and also a broader autonomy. PLHA who are involved make direct programmatic decisions. Their decisions may also affect organisational, policy and strategic planning issues.

<table>
<thead>
<tr>
<th>Box 3.6</th>
</tr>
</thead>
</table>

**Involvement ...in brief**

*Involvement* describes the situation where PLHA take part in areas including management, policy making and strategic planning. PLHA make decisions that affect organisational, strategic and programmatic issues, as trustees or directors or as programme co-ordinators or managers, and may represent the NGO in external forums.

*Involvement* may also refer to self-help groups, which are run for and by PLHA.
Table 3.8
Types of PLHA involvement in the participating organisations

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Use of services</th>
<th>Support to activities and services</th>
<th>Service delivery</th>
<th>Planning and design of services</th>
<th>Management, policy making and strategic planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Project CHILD (CCDT)</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Indirectly through support groups</td>
<td>No</td>
</tr>
<tr>
<td>MNP+</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Salvation Army</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes Indirectly through support groups</td>
<td>No</td>
</tr>
<tr>
<td>SOFOSH</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

3.5 **Exclusion** and tokenistic involvement

Table 3.9
Definition of **Exclusion**: Areas of involvement of PLHA

<table>
<thead>
<tr>
<th>Definition of Exclusion: Areas of involvement of PLHA</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>PLHA utilise services of the NGO</td>
<td>No</td>
</tr>
<tr>
<td>PLHA support activities and services</td>
<td>No</td>
</tr>
<tr>
<td>PLHA take part in the delivery of services</td>
<td>No</td>
</tr>
<tr>
<td>PLHA take part in the planning and design of programmes</td>
<td>No</td>
</tr>
<tr>
<td>PLHA take part in management, policy making and strategic planning</td>
<td>No</td>
</tr>
</tbody>
</table>

**Exclusion** is where a person who identifies himself or herself as HIV positive or is identified as HIV positive by the NGO cannot access the services provided by the NGO and cannot take part to any degree in the activities of the organisation.

Tokenistic **involvement** is defined as where PLHA are assigned management positions only 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 organisation, but do not make decisions or influence the organisation or have responsibility for budgetary matters. Tokenistic involvement includes visibility within and outside the organisation, and PLHA may attend local, national and international meetings, but usually only give testimony and do not speak on behalf of the organisation in which they are involved.

None of the NGOs that participated in the study demonstrated characteristics of either exclusion (because all NGOs who participated in the study were supposed not only to carry out prevention activities but also to provide care and support services to PLHA and affected people) or tokenistic involvement. However, many...
NGOs and CBOs in India do exclude PLHA, at least those who are visible. Reasons for exclusion will be analysed in the following chapter.

3.6 Conclusions

- The study shows that there are many ways for PLHA to take part in the activities of NGOs and CBOs (internal involvement). The four types of involvement we have identified - *access*, *inclusion*, *participation* and *involvement* - embrace a wide range of roles.
- Involvement can be visible or not and there are many levels of visibility. Most PLHA are visible at some level but very few of them agree to disclose their HIV status to colleagues, beneficiaries and the community.
- Quantitatively, the most common type of involvement of PLHA in the NGOs we have observed is *access*, which means that PLHA are only recipients of services.
- There is a small number of PLHA visibly involved in service delivery. The study reveals that the area of services in which most of them are involved is peer support, through formal or informal peer counselling and support group meetings. Some PLHA are also involved in awareness raising.
- The number of visible PLHA formally employed by NGOs (*participation*) is even smaller and represents only a tiny proportion of their service providers, except for MNP+. The majority of PLHA involved in service delivery contribute only occasionally and on a voluntary basis.
- Visible PLHA are absent of areas of services that require higher level of formal education and highly technical skills, such as medical care.
- No visible PLHA holds a senior management position, except in a network for positive people like MNP+.

The situation observed in the four NGOs who participated in the study is not exactly representative of the situation in Maharashtra and India because at least two of the organisations were selected on the basis of existing involvement of PLHA prior to the study. We believe that in the vast majority of NGOs and CBOs in India the current forms of involvement are mainly *access* and *inclusion*, and many NGOs who carry out prevention or IEC activities still exclude PLHA.

However, our purpose is not to claim that all NGOs and CBOs working on HIV/AIDS in Maharashtra and India should promote any on type of involvement rather than others. We also observed that the four types can actually co-exist in the same organisation. The different types have advantages and disadvantages depending on organisations and individuals. Some comparative advantages and disadvantages of different types of involvement for NGOs and CBOs are analysed in Chapter 5.

*Access*, *inclusion*, *participation* and *involvement* are both individual processes, for the PLHA who take part in the activities of an organisation, and institutional
processes for the organisations in which they are involved. It is important for PLHA who want to be involved and organisations who wish to promote various types of involvement to understand these processes. They are explored in the following chapter (“pathways to involvement”).
Chapter 4
Factors that limit and enhance PLHA involvement in community-based prevention, care and support services

4.1 Introduction

An increasing number of people are infected with HIV in India and we saw that Maharashtra is one of the states with the highest prevalence in the country. Nevertheless, visible involvement of PLHA in prevention, care and support in general and at the community-level in particular remains very low, based on the number of community-based and non-governmental organisations who actually involve PLHA and the number of PLHA involved.

Why is it 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 in Maharashtra? This chapter explores the obstacles to their involvement as well as the factors that made this involvement possible in the organisations who participated in the study.

We believe that the identification of these limiting and enhancing factors is essential to any attempt to strengthen current involvement and increase the number of organisations where PLHA are involved and can be open about their HIV status, when and where this involvement is relevant and meaningful (see Chapter 5).

4.2 Methodology

To identify the factors that limit or enhance the involvement of PLHA, respondents were asked the following questions:

- 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 organisations:

- What factors limit PLHA involvement in your organisation?
- What factors encourage PLHA to get involved in your organisation?

HIV positive service providers were also asked how they got involved in their organisation in order to conduct an in-depth analysis of their life stories.

Limiting and enhancing factors were classified into three categories:
Chapter 4: Factors that limit and enhance PLHA involvement

- **Individual factors** – These include characteristics of PLHA who are or who could be involved, such as health, education, skills, etc.
- **Institutional factors** – These include characteristics of the organisation in which PLHA are involved or willing to be involved, such as institutional policy, structure, management, etc.
- **Social factors** – These include characteristics of the society and community in which the organisations 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.

It is important to keep in mind that data was collected through in-depth interviews and Focus Group Discussion (FGD). Questions regarding factors were open questions and the researchers did not suggest any answer to the respondents. No questionnaire was administered to explore these themes. Researchers listed the factors that were the most often mentioned by respondents (frequencies). However, opinions of respondents do not always reflect the reality. Only a comparison of the opinions expressed by respondents and data collected through other means such as life stories and observation can provide a serious analysis of what limits and encourages involvement in NGOs. Data from these different sources was also collected during the study.

This chapter:

- Summarises the individual, institutional and social factors that were identified by different categories of respondents as limiting and enhancing PLHA involvement.
- Presents a critical analysis of the factors identified by respondents based on the “triangulation” of the data collected, in particular through the life stories of PLHA and observation.
- Explores the relationship between limiting and enhancing factors and the different types of involvement presented in the previous chapter.
- Includes a summary of the analysis of individual and institutional steps that seem to be the patterns in the involvement of PLHA in NGOs: “pathways to involvement”.

### 4.3 Factors that limit the involvement of PLHA in NGOs

#### 4.3.1 Individual factors

As explained above, individual factors refer to the characteristics of PLHA involved or willing to be involved in NGOs, whether they are psychological or socio-demographic. Obviously, many of these characteristics are linked to the social characteristics of the Indian context that will be explored further in this report. The fact that, for example, many PLHA have a very low income is linked to the critical socio-economic situation in India and the huge number of people
living in poverty (see Chapter 2). Poverty in the country itself is a social factor and the circumstances of PLHA who are poor are considered as an individual factor.

**Fear of stigma and discrimination** (as opposed to stigma and discrimination actually experienced by PLHA) was the factor mentioned most frequently by respondents. Fear of stigma and discrimination encompassed a range of more specific concerns, about visibility or disclosure of HIV status, and about visibility leading to labelling, loss of job or home, or stress on the family. Some respondents also noted that to be visible as a PLHA is a matter of **shame**.

“... 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 of CCDT.)

“If they (PLHA) tell that they are positive then they might lose their job... and what can they do...” (Male PLHA beneficiary of MNP+.)

“It is nearly 12 years that I have left my family... I have the (HIV) disease and I am suffering... Why should I tell my family about it and give them tension?” (Female PLHA beneficiary of MNP+.)

“A person feels shame... so does not want to speak to another person... To say that in public ... is not good, it is as insult.” (PLHA beneficiary of the Salvation Army.)

Fear of stigma and discrimination due to concerns about visibility and disclosure of HIV status was mentioned by seven HIV negative service providers, three PLHA service providers, 11 PLHA beneficiaries, and two respondents in focus group discussions with both PLHA and HIV negative service providers. Eight of the 13 respondents who specifically mentioned fear of stigma and discrimination at the workplace were PLHA.

One male MNP+ PLHA beneficiary remarked that merely being seen at an organisation working for positive people could cost him his job. “If I tell them ... that I go there, they will remove me from (my) job”. Even self-employed people fear the effect of stigma and discrimination on their livelihood. “If I become open (about my HIV status) the people will not come to my shop. The people are still not open. They still fear from this illness.” (PLHA beneficiary of MNP+.)

Nine of the 13 respondents who expressed specific fears about stigma and discrimination from **neighbours, friends and relatives** were PLHA. A PLHA service provider (of the Salvation Army) said:

“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.”

An adoptive parent of an affected child noted that there could be varying degrees of acceptance and discrimination. “Some will be accepting. People like friends, family, even neighbours will accept. They will take it. But if you tell to a person walking on the road that this child is affected, they will be standing 50 metres away from the child.”

Eight respondents stated that fear of stigma and discrimination from society is also a factor limiting PLHA involvement. Speaking in the context of giving testimonies, a PLHA beneficiary of SOFOSH remarked:

“If they (service providers) ask me to speak regarding the illness to others I will not do it… People will think I only have (HIV) … it will spread and create fear in others’ minds. If there is a PLHA in somebody’s house there is always tension and that person will die.”

Some PLHA fear that NGOs will not respect confidentiality, and this may limit their willingness to become involved.

Fear of stigma and discrimination limits in particular types of involvement that require a higher level of visibility, such as participation and involvement. Inclusion in support groups, for example, does not require a high level of visibility outside the group. A support group even offers a protective environment. The Salvation Army failed when they wanted to give more autonomy to their support group and transform it into an independent self-help group, partly because of the concerns of members that this would lead to a need to be visible outside the group.

Poor health was another frequently mentioned limiting factor. Nine respondents, six of whom were PLHA, felt that it would be difficult to involve a PLHA who is symptomatic, especially in activities that are physically and mentally demanding. As a female PLHA beneficiary of CCDT remarked: “I can… do work. But if we are … ill then we cannot do any work. If I fall ill at home I go to sleep”. Another male PLHA beneficiary of Salvation Army talking about his health said:

“I would not like to get involved in the agency. We do not have that much strength. And what the agency will give us is not enough. If I had energy I would have worked in the agency…”

Another factor mentioned, also linked to health, is the risk of contracting opportunistic infections while at work. However, of the nine respondents who mentioned this as a limiting factor, six were HIV negative service providers and only one was a PLHA beneficiary.
“At the moment I am not ill. If I have to go to the hospital and provide services, this is not okay for me. I might get infection from there. That is why I cannot go inside the hospital and do anything.” (PLHA beneficiary of the Salvation Army.)

“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 of the Salvation Army.)

This factor may also be linked to other factors, such as stigma and discrimination towards PLHA in hospital settings (see Chapter 2) and, in the case of one organisation, a policy of mandatory HIV testing for care providers.

Nine respondents, six of whom were PLHA, mentioned lack of skills among PLHA as a limiting factor. PLHA service providers who are not visible identified certain areas where they lacked skill and hence they are not comfortable with visible involvement.

“If they do not have skills they should be built .... And it (skill building) should be done as it is done for all non-positive people.” (Service provider of SOFOSH.)

“We are not so educated … sometimes I speak but I feel hesitant … I do not know how to speak …” (Female PLHA beneficiary of CCDT.)

“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 of MNP+.)

Lack of education, specifically illiteracy of PLHA was mentioned as a limiting factor by six respondents (two PLHA beneficiaries and four HIV negative service providers). As one male PLHA beneficiary of MNP+ said “… I am not educated like them (service providers).”

The actual problem is that most PLHA who are educated are even more reluctant to be visible than HIV positive people who are less educated.

Inadequate formal education and training is not really an obstacle to access – in some NGOs, services even target PLHA without education and training.

Nor is it a major obstacle to inclusion: PLHA who are support staff are usually employed in jobs that do not require a high level of qualifications. PLHA involved informally in service delivery do not need to have a theoretical knowledge of HIV or particular technical skills to deliver services, since they do not deliver “highly
technical” services. When involved in outreach education, they are always with someone who knows more and can provide accurate “technical” information.

However, lack of education and training definitely limits participation and involvement in CBOs and NGOs, because these types of involvement imply levels of knowledge that go beyond the personal experience of living with HIV/AIDS. Professional service delivery, design and planning of most services also require a wider range of skills, including numeracy and literacy for budgeting, reporting, accessing written material as well as general analytical skills.

Five respondents mentioned low socio-economic status of PLHA beneficiaries of the participating organisations as a factor limiting involvement.

“… your basic needs like you do not get food for that day, you are not going to think about bigger issues (like involvement) …” (Service provider of CCDT.)

“What do I have to help others? My status (economic) prevents me.” (PLHA beneficiary of CCDT.)

Distance between the organisation and home limits access and is an obstacle to greater involvement. Of the five respondents who mentioned this as a limiting factor, three were PLHA.

“… 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 of CCDT.)

“I want to do something … but I stay very far … I will get tired.” (PLHA beneficiary of MNP+.)

Some respondents also lack understanding of what is meant by involvement. It is often perceived to be about either providing jobs or money to PLHA, and four respondents (two PLHA beneficiaries and two HIV negative service providers) shared this view. As one PLHA beneficiary of CCDT said “I am ready to be visible in the media… provided they (service providers) give me money… I will tell that I am HIV+.”

Limited awareness about HIV/AIDS is also a limiting factor. Of the four respondents mentioning this factor, three were HIV negative service providers and one was a PLHA beneficiary of SOFOSH, who remarked “I felt that I will get cured from this disease. This is like TB. When people go for treatment (of TB), they get cured”.

Although most PLHA interviewed were aware of how HIV is transmitted, those from rural areas were less likely to be able to explain how they got the disease or about HIV infection, with some believing that a person can only get it if they visit
a red light district. For example, one remarked “I have a disease, which has not been heard of”, while another said “There is a disease AIDS that makes the blood bad in the same way as cancer”.

Three HIV negative service providers cited lack of motivation and interest as a factor.

“They do not want to do any work. They meet their children and go.” (Service provider of CCDT.)

“We do not want to take decisions for them ... but they do not understand ... they do not attend the forum regularly.” (Service provider of MNP+.)

Two HIV negative service providers also mentioned inability of PLHA to take leave from their work and the need to earn a living as a factor limiting the capacity of PLHA to be involved in the NGO’s activities and services. In at least two of the organisations, Salvation Army and MNP+, PLHA who volunteer are mostly men who have a professional activity. They have the same constraints as any person who works full-time as well as specific constraints that are directly related to their status.

“I go to work at eight in the morning and return at 10 at night. On those days I do not have any time.” (Female PLHA beneficiary of SOFOSH.)

Emotional vulnerability was also identified by two service providers, one of whom is a PLHA, as an obstacle to PLHA involvement in activities such as hospital visits. A PLHA who is not psychologically or mentally strong may identify with a patient in the hospital and start to worry about his or her future (‘mirror effect’) “if he or she has to visit the hospital again and again then they might get a negative feeling in the mind”. A similar factor, mentioned by two respondents, including one PLHA beneficiary, is the lack of preparedness of some asymptomatic PLHA to deal with other PLHA who are in ill.

“I get scared staying here (in the hospital). I get scared of people (PLHA). People die here now ... We see it every time.” (Female PLHA beneficiary of SOFOSH.)

Other limiting factors mentioned by PLHA and HIV negative service providers included inability to meet the demands of the job or to make a sustained commitment, lack of PLHA willingness to accept jobs that they perceive to be detrimental to their health status, irregularity of volunteer involvement, in part because volunteers do not receive financial compensation, which disrupts the continuity of activities, the need for PLHA to earn an income, which means that they may not be able to afford to lose a day’s wages to participate in support
group meetings, and lack of experience and speaking a different local language.

“… We had a PLHA helper … at the drop-in-centre … but she would go on leave … often …” (Service provider of CCDT.)

“… I had a case where the person was not much educated but just because he had HIV he asked for a desk job in an office … (I said) I am getting you a job of a worker in a small scale industry. I feel it is good enough … (quoting the PLHA) ‘No, No, madam you know I am HIV+ … why can’t you get me a desk job?’ … At times (referring to counsellors at SOFOSH) start treating them as china dolls.” (Service provider of SOFOSH).

“Where maximum information is in English … or they don’t follow what work is in process … they have limited experience … or no experience so their involvement is very restricted.. (Male PLHA service provider of MNP+.)

“…the sisters (service providers of the agency) when they speak in Marathi, I do not understand much. When they speak little in Hindi, I am able to understand.” (PLHA beneficiary of CCDT.)

4.3.2 Institutional factors

Many PLHA are not involved in NGOs and CBOs because of their own personal circumstances, such as the ones we have just listed. However, it is also important to take into account the structural characteristics of the organisations themselves, which can be obstacles to involvement. For organisations willing to strengthen or even initiate some involvement of PLHA in their activities, it is crucial to assess these organisational or institutional barriers and reflect on strategies to tackle them.

The factor mentioned most frequently was lack of information about opportunities for PLHA to be involved in the organisation’s activities. Respondents noted that PLHA who access services are not always told by service providers of NGOs about how they can become more involved and that there is little or no orientation for PLHA willing to get involved. Ten respondents, all of whom were PLHA beneficiaries, mentioned this factor. PLHA beneficiaries may not be aware that an organisation employs PLHA service providers, because the HIV status of these service providers is kept confidential and they are not visible. In one organisation, a PLHA beneficiary sought involvement in terms of employment but the NGO did not provide any concrete information.
Chapter 4: Factors that limit and enhance PLHA involvement

"I asked them regarding work but they said ‘we shall see’ … they haven’t said anything so far." (PLHA beneficiary of SOFOSH)

Linked to this is a lack of information about the range of services provided by the organisations. This was mentioned by Six PLHA beneficiaries, who said that they did not know what they could do because they do not know what services the organisation provides.

In addition, in organisations where this is feasible, PLHA are not always told that they have the option to see a PLHA counsellor and they are usually encouraged to attend support group meetings. This may deter those PLHA who would prefer initial one-to-one dialogue from greater involvement.

Service providers at the data analysis workshop noted that the participating organisations lack policy on involvement of PLHA. The researchers also noted that NGOs and HIV negative service providers often have a limited vision of areas where PLHA can be involved, and that PLHA are most likely to be involved in care and support activities, not in prevention, education or advocacy.

Mandatory HIV testing for care providers at the time of recruitment and thereafter is another factor that limits involvement. Six respondents, all of whom were HIV negative service providers, mentioned this. It should be noted that this factor is specific to one of the organisations participating in the study.

“… We get all our people tested for HIV. As far as I know we have periodic testing … First we have the initial testing followed by a three-month repeat just to check whether it was in the window period or not … I think we decided once a year …” (Service provider of SOFOSH.)

Three HIV negative service providers also mentioned that, in this particular organisation, there was no policy regarding care and support for service providers who are found to be HIV positive during mandatory testing. This may be an additional factor deterring PLHA involvement.

Institutional policy and attitudes towards PLHA are also limiting factors. For example, three HIV negative service providers from one organisation mentioned that the NGO has a policy of non-involvement of PLHA in some activities with children. They perceive that children might be at risk of infection if they are in contact with PLHA at the symptomatic stage, explaining that PLHA cannot be involved in the care of children, because of the risk of exchange of body fluids.

“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 of SOFOSH.)

Service providers also perceive a risk for PLHA. “The children that we get and number of infections they (carry), pneumonia is one of them … so it will not be a healthy atmosphere to work (for PLHA).” And one HIV negative service provider felt that a PLHA cannot be involved in occupations like cutting vegetables as they might harm themselves in the process.

The gender of service providers may also limit PLHA involvement. For example, service providers in one organisation with mostly female staff noted that it is more difficult to provide services to and to involve men.

“… At least for women there are shelters ... They will have a place but what about the men, we have no home for men ... it's very difficult ... where are we going to put the men if they come to us? So far whichever men we had they had roof ... Those who don’t have a home? Who will look after them....” (Service provider of CCDT.)

A service provider of one participating organisation highlighted the difficulty of getting men involved in support group meetings, although this is mainly because of high mortality rates among the NGO’s male PLHA beneficiaries.

In another organisation, where 80% of service providers are men, it may be difficult for female PLHA to identify the NGO as a women-friendly environment. In fact only 5% of the beneficiaries of this organisation are women, and the NGO is considering the recruitment of a female counsellor to improve access to its services for women.

The staff of SOFOSH mentioned that the absence of a mandate for working in the community was potentially an obstacle, as it limits the scope for PLHA involvement to hospital-based activities.

Respondents mentioned a range of factors associated with lack of support for PLHA and their involvement or inability to fulfil the conditions for involvement. Some noted that if PLHA are not attended to properly or do not get the ongoing support they need, for example because of a high turnover of counsellors, this may create a negative impression of the organisation and deter greater involvement.

Two HIV negative service providers specifically mentioned lack of funds to reimburse travel expenses as a limiting factor, particularly for rural and low-income PLHA. Other similar institutional factors mentioned included inability to provide financial support, inability to provide employment opportunities, and inadequate monetary compensation. PLHA often look to NGOs to provide financial support or employment. Organisations that cannot provide such support often refer them elsewhere, and PLHA seldom return just to get involved.
“During forum meetings ... most of the women want financial assistance for their families apart from medicine ... we refer them.” (PLHA service provider of MNP+)

“They come with several problems but we cannot resolve all their problems ... we refer them ....” (PLHA service provider of MNP+)

“Many a times after knowing his HIV status, the individual leaves his job ... we encourage him to work ... sometimes they say employ us here...” (PLHA beneficiary for MNP+)

“...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 of MNP+)

Monetary compensation does not always cover the expenses involved in carrying out activities. For example, PLHA sometimes need to travel long distances to do their work. Those who cannot walk long distances have to take taxis or rickshaws but the salary or allowance they receive does not cover this kind of expenditure.

Two HIV negative service providers identified low cost-effectiveness of investment in training of PLHA, due to their life expectancy, as a limiting factor. Both of these service providers were from an organisation that receives PLHA when they are symptomatic and their perception is that PLHA life expectancy is short.

Six respondents (three PLHA beneficiaries and three HIV negative service providers) stated that, if an organisation reduces economic and material benefits, this could be a disincentive to involvement.

“Earlier they used to give us Rs 1,500 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....” (HIV positive woman, member of a support group)

Other institutional limiting factors mentioned are related to attitudes towards PLHA. For example, one organisation was perceived to have a discriminatory policy of employment towards PLHA. One of the beneficiaries reported that she had heard someone in the organisation say that PLHA are not welcome as employees.

Two respondents suggested that there is a judgemental attitude towards PLHA in NGOs in general, and that this is a factor limiting PLHA involvement in service delivery. Linked to this is lack of time spent with PLHA, mentioned by two respondents.
“If a person has this (HIV) illness … people start looking at in a different manner. And in an agency if a person has this illness HIV … they will laugh etc. This we cannot tolerate. There is no fault of ours.” (PLHA beneficiary of SOFOSH.)

And in one organisation, it was felt that the NGO does not recognise or use the skills of PLHA service providers in seminars, workshops or conferences and that PLHA are not given the opportunity to represent the organisation externally. Other respondents reported that non-acceptance of PLHA as service providers by health professionals in other agencies was a limiting factor. Even if the NGO itself involves PLHA as service providers, other agencies might not accept them. As one service provider of SOFOSH commented “… I can appoint but everybody has to accept”.

Other institutional factors limiting PLHA involvement that were mentioned include lack of trained staff, in particular trained social workers to orient, train and support PLHA, and difficulties in sustaining staff motivation while the organisation goes through the process of increasing PLHA involvement.

“In the beginning everyone is enthusiastic but later fizzes out. So, keeping up the motivation level, 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 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 of SOFOSH.)

Due to lack of resources and workload, organisations rely on PLHA to work as volunteers, but PLHA may not come forward as volunteers for various reasons.

“Sometimes we face problems about pressure for providing services when we are not having much volunteers … PLHA are not understanding that what should be done or this is only our work…” (Male PLHA service provider of MNP+.)

In addition, some service providers felt that PLHA are not able to sustain demanding jobs, based on their experience of PLHA helpers taking frequent leave due to illness.

It was also noted that the organisations and PLHA have a different understanding of the term involvement. For example, PLHA perceive involvement with an organisation to mean having a job with a salary. They do not see making decisions in support group meetings as involvement.
Lack of physical space was mentioned as a limiting factor, but only in relation to one of the participating organisations.

The study also analysed the characteristics of the four organisations and the areas of PLHA involvement in these organisations, to determine whether there was a relationship between different organisational models and the types of PLHA involvement.

- **Secular welfare model**
  In the “secular welfare model” of organisation, illustrated by SOFOSH in this study, PLHA involvement takes the form of access and inclusion. PLHA are beneficiaries and some take part in supporting activities and services, for example as childcare helpers or as a patient guide. Responsibility for delivery, planning and design of services, and for making management, policy and strategic planning decisions rests with HIV negative staff members and management – due to the mandate and structure of the NGO.

  The major obstacles to participation and involvement in the welfare model are that beneficiaries are usually seen as passive recipients of services, while service providers are trained professionals with both a theoretical knowledge of HIV/AIDS as well as a wide range of technical skills to deliver services. Empirical expertise does not really count in this kind of model, which excludes PLHA who do not have the same background as the other service providers.

- **Religious welfare model**
  In the “religious welfare model” of organisation, PLHA involvement takes the form of access, inclusion and participation. PLHA are beneficiaries, some take part in supporting activities and services, some are employed as service providers, for example as a peer counsellor, and take part in design and planning of the services they are responsible for. Support group members and staff are also consulted during the process of planning and design of other activities. The Salvation Army represents a religious welfare model but the organisation also places considerable emphasis on community development and empowerment. This might explain the level of participation found in the Mumbai HIV/AIDS Community Development Programme.

  The major obstacle to greater visible involvement of PLHA in management and policy-making process is that decision and policy makers belong to the Salvation Army hierarchy. If some officers are HIV positive, it might not be easy for them to come out as HIV positive because of their religious and moral commitment and the fact that HIV/AIDS is still associated with sin and immoral behaviour.

- **Development model**
  In the “community development model” of organisation, represented in this study by Project CHILD (CCDT), PLHA involvement takes the form of access, inclusion
and to some extent, participation. PLHA are beneficiaries, some take part in supporting activities and services, and PLHA support group members are consulted during the process of planning and design of activities. It is expected that there will be a greater level of participation in this model compared with welfare-oriented organisations, because of the focus on empowerment, and CCDT emphasises enabling PLHA to address their needs through self-help. However, responsibility for management, policy and strategic planning decisions still rests with HIV negative staff and management.

- **Rights-based model**

In the “rights based model” of organisation, represented in this study by MNP+, PLHA involvement occurs in various ways: access, inclusion, participation and involvement. PLHA are beneficiaries, service providers and decision-makers. This can be explained by the fact that the mission of a rights-based organisation working on HIV/AIDS is precisely to empower PLHA and give them the opportunity to help each other and advocate for their own rights.

It seems therefore that the way PLHA take part in NGOs can be influenced by the type of organisation in which they are involved, although organisations are often influenced by mixed models.

### 4.3.3 Social factors

NGOs and CBOs can do a lot to address their own structural barriers to involvement. Nevertheless, they cannot ignore the community and society in which they operate. Many obstacles to involvement are directly linked to the social context in India.

**Stigma and discrimination** – by relatives, friends and neighbours, in health care settings, and at the workplace – was the most frequently mentioned social factor limiting PLHA involvement.

The diagnostic study confirmed the findings of other studies regarding stigma and discrimination – revealing a mix of positive and negative attitudes and behaviours regarding both HIV/AIDS and PLHA (see Chapter 2).

Negative attitudes towards PLHA are common among the general public. A widely held view is that PLHA are to blame for their infection – they must be promiscuous or they have “made a mistake and they should die”. Some PLHA reported discrimination, stigma, and lack of respect: for example, people do not even want to sit next to them. Women are often blamed for transmitting HIV “Even if the wife gets infected from her husband, most often she is blamed for transmitting the disease”.

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Respondents, notably the majority of PLHA beneficiaries of the NGOs interviewed during the study, reported that many health professionals behave in a discriminatory manner towards PLHA. Six PLHA beneficiaries and one PLHA service provider had experienced or witnessed stigma and discrimination in health care settings.

“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 of CCDT.)

One female PLHA beneficiary described the reaction of hospital staff when she wanted to send her husband’s clothes for washing: “... Keep his clothes separately. Do not mix them with other clothes from the ward ....” (Female PLHA beneficiary of CCDT.)

Respondents noted that PLHA are often refused treatment by both private medical practitioners and some public health facilities.

“The doctor (private practitioner) told me … do not bring your sister (PLHA) here. If you bring her here … other patients will not visit the clinic.” (Affected female beneficiary of CCDT.)

“I accompany other PLHA sometimes … there is a TB hospital where I had taken the patient for treatment … The doctor, when he saw the report, said that this person does not have TB. You may take him. Other PLHA … who go there have to hide their HIV status in order to get treated for TB…” (Female PLHA beneficiary of MNP+.)

A PLHA reported that:

“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 also noted that there are differences depending on the setting.

“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”.

The attitudes of relatives and friends of PLHA vary. Some PLHA beneficiaries reported that their family members treated them nicely whereas others reported negative attitudes. Sixteen respondents (11 of whom were PLHA) mentioned
stigma and discrimination by family, friends and neighbours, citing examples such as not offering a customary glass of water, denial of proper funeral rituals, physical violence, blame and rejection.

“When I sometimes go to my relatives’ place … they do not offer me even a glass of water.” (Female PLHA beneficiary of CCDT.)

“They (relatives) did not put a shroud … They did not even come close to the body … they just tied (the body) and took him … only his father-in-law put a garland. They treated him like a destitute …” (Affected beneficiary of CCDT.)

“When I came home from the hospital all the people around started treating me with contempt … My children also started behaving differently. My eldest son hit me in my face.” (PLHA beneficiary of SOFOSH.)

“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 of SOFOSH.)

Some said that they lived away from their family and that family members refused to visit them:

“My own parents did not allow me to stay in the house. They felt it (HIV) might spread in their house.” (HIV positive woman, beneficiary of one of MNP+)

“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 of the Salvation Army.)

Some PLHA reported that family members share things where no body contact is involved, such as toothpaste, but not articles like towels. It was also noted that initial acceptance of PLHA changed as they began to show symptoms of illness.

“Initially the person (PLHA) is looked after and when they are about to die, the family gives up. They say that they have no relationship with him. Ultimately we (service providers) have had to do the funeral rites also”. (Service provider of CCDT)

Stigma and discrimination in the workplace was mentioned by three PLHA beneficiaries.
“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 of the Salvation Army.)

Respondents felt that stigma and discrimination was especially likely to be a social factor limiting PLHA involvement in rural areas.

“… Their (PLHA) first reaction is that (to) tell the spouse (of HIV status) is OK, to reveal it to the family is also fine … but suppose a social worker comes to a village and all of us (referring to other PLHA) come together, how much is it possible (without visibility and associated stigma)?” (Service provider of SOFOSH.)

All the manifestations of stigma and discrimination described above, although not a direct result of involvement, cause fears among PLHA. Consequently, they are reluctant to be involved in NGOs because they think that this will force them to be open about their HIV status. As far as PLHA who are already involved in NGOs, few of them are actually visible and when they are visible, their visibility is limited.

“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” says a HIV positive service provider of MNP+.

Stigma and discrimination are linked to misconceptions which can be caused by misinformation. The extent to which health professionals and social workers give accurate information varies considerably. For example, one beneficiary reported that “The counsellor mentioned that you have termites in your body and this will eat up your body from inside. You will die within 2-3 years”, while another said that a doctor had told him that PLHA only live for a year. Another PLHA beneficiary said that a doctor advised him not to have sex with his wife and that the doctor had also informed his mother about his HIV status, asking her to make sure that he and his wife did not sleep together.

“I have kept my things for bathing, eating separately … so that others do not get it (virus). They told me this in the hospital” said another PLHA.

In some cases, doctors do not disclose test results to PLHA, telling them “There is not a problem. Only your blood is bad. It will be OK after taking medicines”. Many health professionals also advise PLHA not to reveal their HIV status.

“The doctor told me ‘do not tell anybody. Nowadays people get defamed because of this … It might happen that people will neglect you and keep away … This might affect your mind. From this point of view keep it a secret’.”
PLHA also reported that misconceptions about HIV/AIDS and its transmission are widespread among the general public. For example, one said that: “People still think that it is spread through touching, eating from the same plate”, while another remarked that “Society thinks they will get infected if they stay with HIV people”. Some relatives and friends of PLHA had attributed their HIV to “black magic”. A female PLHA, who is also a sex worker, reported that many people, including health professionals, believe that certain groups, such as sex workers, are responsible for “spreading” the virus: “They (health workers) tell us why do this (sex work) business. They say because of you this (HIV) is spreading”.

Four respondents said that their **domestic responsibilities** limit their involvement. This is particularly the case for women, because of **gender roles**. Widows, women who have to take care of a sick husband, and women with children have added responsibilities. In addition, customs and traditions in certain communities mean that women are not permitted to travel outside their homes.

“I reside far off from the agency … nobody to take care of my children … find it sometimes difficult to come here … have to leave my children alone … or with somebody.” (PLHA beneficiary of CCDT.)

“In our house … women are not allowed to go out and work … we leave the house only to visit doctor, relative, leave children to school … but not work …” (Female PLHA beneficiary of CCDT.)

Three respondents, of whom one was a PLHA service provider and one a PLHA beneficiary, mentioned **inability to fulfil basic survival needs because of poverty**.

“Some people can’t come here so we ourselves go to them and find out what are their problems and requirements … we have usually seen that their basic needs are only their big issue. Their status is lower due to the fact that they are women, and above that if they are positive then it is all the more problematic to meet the basic requirements…” (PLHA service provider of Salvation Army.)

Many PLHA are **not free to make decisions**. This factor was mentioned with particular reference to sex workers, who often have little control over their lives. “The brothel keeper really owns you and does not allow you to have space to go out wherever you want…so even when you want to do something you…are may not be able.” (Service provider).

Another social factor that limits PLHA involvement is the approach taken by public awareness campaigns, with negative messages that emphasise fear or shame, for example “What are you ashamed of – using nirodh (condom) or acquiring AIDS?” and “Nothing is left when you get AIDS”. Such messages may
Encourage PLHA to hide their HIV status and deter them from getting involved in NGOs.

4.4 Factors that enhance the involvement of PLHA in NGOs

4.4.1 Individual factors

The most common factor encouraging PLHA to be involved was motivation to help others, mentioned by 20 respondents (five HIV negative and six PLHA service providers, and nine PLHA beneficiaries). In some cases, personal experience of stigma and discrimination had motivated PLHA to try to help other people avoid similar experiences. For some the motivation to help others is inspired by seeing service providers helping PLHA or by interaction with PLHA service providers.

“Looking at the work these agency workers do, one feels to get involved and it would help others also…” (PLHA beneficiary of CCDT.)

“(I would like to) work with the agency and go to villages and inform people and clarify their misconceptions regarding HIV … We have become (positive) … see that you do not get it (HIV).” (Male PLHA beneficiary of MNP+.)

A related factor, mentioned by three respondents (one HIV negative and one PLHA service provider, and one PLHA beneficiary) is the presence of a role model. A positive person who is already involved with the organisation can encourage others to become involved.

“We were able to see that he himself (is) living a positive life, he is a very good model. The way that he is responding to his own life, the way that he is taking HIV you know mentally and emotionally. He has strong points to share with others. He is not weak in that. His life has to be a model to other positive people. Looking at him people should be encouraged. If he is like this then why not I?” (Service provider of the Salvation Army.)

Involvement is likely to result in some degree of visibility, and two respondents noted that PLHA might be encouraged to become involved if they perceive some benefit from being visible.

The second most common factor was the availability of employment opportunities, mentioned by 13 respondents (five HIV negative and two PLHA service providers, and six PLHA beneficiaries).
“If I get job and money to fill our stomach … then I will get involved.” (Male PLHA beneficiary of MNP+.)

This was qualified by some respondents, who noted that a job with the organisation would need to pay more than the wages they currently receive.

“If they (MNP+) give us more pay than our present job.” (Female PLHA beneficiary of MNP+)

**Self-confidence**, linked to a sense of belonging and “not being alone”, was mentioned by five respondents (three PLHA service providers and two PLHA beneficiaries).

“I feel that I am not the only one. Along with me there are many others who have this disease (HIV) … You feel nice when you sit and interact with them (agency workers)…” (PLHA beneficiary of MNP+)

Another important factor is **availability of time**, mentioned by three PLHA beneficiaries.

“If they open an agency elsewhere and want my help for a couple of hours, and if I have the time I would help them. I would provide information on HIV like how to use condom … to other HIV person.” (PLHA beneficiary of MNP+)

Factors related to the **health** of PLHA were also mentioned. Three respondents noted that PLHA who are asymptomatic are more likely to be able to be involved than PLHA who are symptomatic. Two respondents felt that providing opportunities for PLHA to work in settings where they have minimal risk of contracting opportunistic infections would also encourage involvement.

Respondents also mentioned various characteristics of PLHA as important factors encouraging involvement. **Compassion for others** – similar to motivation to help others – was cited by a HIV negative service provider and a PLHA service provider, as a factor encouraging involvement. Two HIV negative service providers also felt that being **literate** was a prerequisite for PLHA involvement, and the researchers observed that in some organisations it appears to be easier for PLHA with a reasonable level of education and income to become involved. **Previous or present involvement in non-HIV self-help groups** may also encourage PLHA involvement, as they have experience of the benefits of such involvement.

“I am (a) member of Alcoholics Anonymous and Narcotics Anonymous. So there I get little some peace of mind when I go out and share with someone and I try to bring this person (PLHA) on the AA or NA program, so that he can quit or kick the habit of alcohol or
drugs. I get a lot of satisfaction.” (PLHA service provider of one of participating NGOs.)

“My friend with HIV is still my friend” (poster realisation by MNP+)
4.4.2 Institutional factors

The most common institutional factor was a supportive environment – characterised by a friendly or homely atmosphere “like a family”, by openness, and by service providers treating PLHA like friends and showing concern for their families. This factor was mentioned by 48 respondents (34 PLHA beneficiaries, nine HIV negative service providers, and five PLHA service providers).

“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 of MNP+.)

“When you come here all feelings of sadness go away … They make us understand…” (PLHA beneficiary.)

“We have been very open from the start because our community-based work is totally voluntary. Those who have concern and interest can come and work.” (Service provider of Salvation Army.)

The second most common institutional factor, which also helps to create a supportive environment, was the existence of support groups, mentioned by 24 respondents (12 PLHA beneficiaries, nine HIV negative service providers, and two PLHA service providers). As one PLHA beneficiary said “we share with each other, eat and entertain ourselves”. Attending support group meetings encourages PLHA to take care of themselves and of others, which in turn helps to promote involvement.

A third institutional factor, which is also associated with a supportive environment, is a non-judgemental attitude among service providers and other employees. This factor, characterised by behaviour that does not discriminate between PLHA and HIV negative beneficiaries, was mentioned by 24 respondents (11 PLHA beneficiaries, 11 HIV negative service providers, and two PLHA service providers).

“When they visit our home … they drink water at our house.” (PLHA beneficiary of CCDT.)

“A person who does not have proper clothes to wear is also respected here.” (PLHA beneficiary of the Salvation Army.)

“She is also a human being … she also needs to earn her livelihood.” (Service provider of CCDT)

“You have to see that they (PLHA) are equal to you and they can also contribute.” (Service provider of Salvation Army.)
Another important factor encouraging involvement, mentioned by 19 respondents (10 HIV negative service providers, five PLHA beneficiaries, and four PLHA service providers), is that the organisation and its staff maintain confidentiality about HIV status, ask PLHA for permission before disclosure of their HIV status, and that there is scope for non-visible involvement – with no pressure on people to reveal their HIV status.

Fifteen respondents (eight HIV negative service providers, six PLHA beneficiaries, and one PLHA service provider) stated that providing employment opportunities is an institutional factor that encourages PLHA involvement. However, the four participating organisations have different recruitment policies. For example, one of the organisations sees itself as an equal opportunity employer, while another gives first preference to PLHA.

"... they had kept the option that the first preference will be given to PLHA. They had written in their advertisement also that first preference will be given to PLHA." (Female PLHA service provider of MNP+.)

Institutional capacity to provide material and financial assistance was mentioned by 11 respondents (nine PLHA beneficiaries and two HIV negative service providers) as a factor that could encourage involvement. Specific examples include access to treatment and medicines, treatment, partial reimbursement of medical bills, meals and reimbursement of expenses for rural
PLHA who have to travel long distances, and monetary compensation for involvement.

“…Sometimes they send us to this health post … if we require medicines, for our treatment … we produce the bill … they give us some money…” (PLHA beneficiary of CCDT.)

Ten respondents (both HIV positive and HIV negative service providers) cited acceptance and support from colleagues and co-workers as an institutional factor encouraging PLHA involvement. Although acceptance of PLHA was seen as crucial by respondents from all the participating organisations, support from colleagues was mentioned more frequently by respondents from organisations that already have significant PLHA involvement.

A similar factor, mentioned by nine PLHA and HIV negative respondents, was teamwork between HIV positive and HIV negative service providers. In one organisation where there is active PLHA involvement, service providers consider themselves to be a team. As one HIV negative service provider remarked “There is no difference. We eat, travel and live together … as family members”. And a PLHA service provider emphasised that he received a “lot of love and care…” and gets satisfaction while working in this organisation. Teamwork is also seen as a way of protecting confidentiality about HIV status and allowing non-visible involvement, which is particularly important for PLHA who provider their services on voluntary basis.

“If they want to come and become a member of the team and go … they don't come as … HIV positive people. They come as a team. That is … very important. So there is no difference.” (Service provider of the Salvation Army.)

Another institutional factor that encourages involvement, mentioned by eight respondents (including five PLHA beneficiaries) is that the organisation involves PLHA in recreational activities.

The opportunity to receive information was reported to be a factor encouraging involvement, by six respondents (three PLHA beneficiaries, one PLHA service provider and one HIV negative service provider), who said that organisations that disseminate up-to-date and accurate information are more likely to remain in contact with PLHA and that this facilitates involvement. As one PLHA service provider noted, “the motivation to join the agency was receiving information on HIV/AIDS”, and the organisation has recognised this and is disseminating information through different channels, including a telephone helpline.

“The biggest thing here is about giving the information … Whatever up to date information we receive, we try to tell them. They come to know
about the progress. There are lot of people who ask what difference has come up, what has happened, how much, etc. They do not come because they have problem but for information. They call us every week to know the latest. We do this job of transferring information, whatever we receive. We even update through Internet and one of our colleagues has this assignment and we try to provide weekly updates. Not just information, correct information.” (Service provider of MNP+.)

Support and encouragement from service providers was cited as an important institutional factor by five respondents (three PLHA beneficiaries and two HIV negative service providers). They reported that service providers in their organisation continuously provide support and encourage PLHA to participate in different activities and to make decisions, in particular at support group meetings.

Three respondents mentioned involving PLHA on the basis of their skills and capacity as an institutional factor encouraging involvement. As one service provider said:

“Why should we give a particular slot to PLHA that you work on this? If they have the capability, they will work from start to end … They are also human beings. They can do anything. Seeing their capacity, wherever you put them, they will work. If they have educational background and even if they have not done stable jobs, and if we put them in NGO management, they will do it.” (Service provider of MNP+.)

This is also related to other factors that were mentioned by respondents, including willingness to involve PLHA at all levels, in particular in decision-making positions. This, together with organisational management that accepts the idea of PLHA involvement, encourages the involvement of other PLHA. Three HIV negative service providers mentioned this factor, explaining that non-acceptance of an issue by management can be a barrier in India, where organisations are often managed by non-service providers. Support for the idea of PLHA involvement from trustees and management is important if involvement is to be put into practice.

Two respondents mentioned positive workplace policy regarding PLHA staff as a factor encouraging involvement. For example, PLHA who work for one of the participating organisations still receive their salary if they are sick. The organisation recognises that PLHA will sometimes be symptomatic and unable to work, and in some cases has taken the salary to a sick PLHA service provider at home. According to one service provider “(It is) their right and they should have (it)”.

Willingness to empower PLHA and to develop their skills and capacity for participation in service delivery – for example, an individual who would like to
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conduct AIDS awareness programmes may need training to develop the necessary communication skills – was mentioned by two respondents as a factor encouraging involvement.

A related institutional factor, mentioned by two PLHA service providers, is **providing opportunities for PLHA to attend conferences and workshops**. Representing the organisation in this way gives PLHA a sense of self-worth and builds skills, which encourages involvement.

Other institutional factors encouraging involvement include **equal employment opportunities**, mentioned by one PLHA beneficiary, and **decisions based on a PLHA perspective**, mentioned by one PLHA service provider.

“**I had asked them (service providers) to give me a job … they gave me a job at Ashray … I was able to pass my time with the children … My provident fund is still with them … They ask me to come and collect it…”** (PLHA beneficiary of CCDT.)

“**… it is better that PLHA put forth their special needs themselves rather than a third person talking about our needs. Decision in the agency is taken keeping PLHA perspective in mind … decision is taken in consultation.”** (PLHA service provider of MNP+.)

The researchers also noted that other important institutional factors include effective post-test and ongoing counselling, links with PLHA networks and organisations (a strategy employed by one of the participating organisations, the formation of an advocacy network that provides a collective voice and assists other organisations to establish self-help groups, has encouraged PLHA involvement) experience of working with marginalised groups, and a perception that HIV/AIDS is a developmental and rights issue rather than just a health problem.

Many of the institutional factors described above put together create a conducive environment for the involvement of PLHA. In the table below, we have classified factors into three categories that are the main components of what is usually termed as a conducive environment.

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**Box 4.1**

**In brief … What is a conducive environment?**

**Material support**

- For PLHA who are employed by NGOs, on top of their salaries:
  - Access to care, particularly drugs, through insurance schemes and/or access free of charge to health facilities run by the organisations
  - Flexible sick leave
- For PLHA who are not employed by NGOs, e.g. volunteers:
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4.4.3 Social factors

The most frequently mentioned social factor that encourages PLHA involvement was support from family, friends and neighbours. This factor was mentioned by 11 PLHA beneficiaries and three PLHA service providers, and also during a focus group discussion with PLHA beneficiaries.

“My family members treat me nicely although they know about this disease (HIV/AIDS).” (PLHA beneficiary.)

Three HIV negative service providers suggested that improved public awareness of HIV/AIDS and of the issues affecting PLHA will help to reduce stigma and discrimination, which will in turn encourage PLHA involvement.

Another similar factor, mentioned by two PLHA service providers, is encouraging a positive response from society, through advocacy, IEC and links with civil society organisations. Such efforts could create an environment that supports PLHA rights and involvement. Finally, one PLHA service provider
Box 4.2 Visibility

**Process of disclosure of HIV status**

The study shows that the prevalence of stigma and discrimination makes disclosure of HIV status difficult for PLHA. However, while most PLHA respondents are visible to their families, there is no consistent pattern in disclosure of HIV status. In many cases, disclosure is not a matter of personal choice. Examples were cited of PLHA discovering their HIV status after being tested for HIV without their knowledge or consent, and of HIV status being disclosed with permission.

“I was admitted in the hospital because my blood platelets had reduced. Different tests were conducted. The social worker informed me about my HIV status.” (PLHA beneficiary of MNP+.)

“I wanted to join meditation at a centre…They have a procedure of HIV testing…I came to know I was positive… I was asked to go for a confirmed test (Western Blot) and got my result.” (Male PLHA service provider of MNP+.)

“When my wife was pregnant she was found positive … then I was also asked to get myself tested. The agency disclosed my HIV status.” (Male PLHA beneficiary of MNP+.)

Sometimes, family members were present when test results were given. Other times, PLHA informed their relatives later on.

“… The agency disclosed my HIV status. I did not have to speak to anybody at that time; my sister, father-in-law and mother-in-law were there along with me.” (Male PLHA beneficiary of MNP+.)

“The social worker told me my status and referred me to this agency. I spoke about my HIV status and later on spoke about it to my parents.” (Male PLHA beneficiary of MNP+.)

In some cases, where PLHA felt unable to tell their relatives, another relative or a health professional informed them. For example, one PLHA beneficiary did not have the courage to inform his father, so his uncle did the job of informing him. Another PLHA beneficiary said: “The doctor said that my wife, son and myself have this illness … The doctor later disclosed the status to our family members. But not in front of us.”

mentioned the importance of support from other PLHA as a factor encouraging PLHA involvement.
Respondents noted that family, friends and neighbours often accept PLHA after some time, even if the initial reaction is negative. As a female PLHA beneficiary said, “After I was found positive I informed my in-laws. Initially they were not talking … but now everything is fine. They do not ill-treat me … they are nice”.

Although some respondents reported positive reactions after disclosure, others felt that wider social acceptance is less likely. One PLHA beneficiary said:

“I did not want trouble to be caused to anyone because of me so I told my employer … he said nothing happens, only see that your blood doesn’t touch anybody else. He would give me a lot of rest between work and help me materially also.”

But the adoptive father of an affected child explained, “Society does not accept. That is the main thing. Coming to the front and telling that I have HIV, the society will not accept it. And it will become that the society will only kick the person out”.

**Conditions for disclosure of HIV status**

The study shows that the process of disclosure is a complex one, and that meeting the conditions for disclosure of HIV status can encourage PLHA involvement in an organisation. PLHA beneficiaries and PLHA service providers identified the following conditions for disclosure of HIV status:

- The confidentiality of PLHA is maintained.
- The basic needs of PLHA are fulfilled and PLHA are provided with an appropriate standard of care and support services.
- There is no social stigma and discrimination, and the family is accepted and supported.
- PLHA are prepared to be visible to each other, for example in support groups.
- PLHA are sufficiently knowledgeable about HIV/AIDS to overcome misconceptions and to change their attitudes towards other PLHA.
- There can be disclosure in the media, provided that this is done with informed consent, and PLHA confidentiality is maintained, for example, the face is not shown.
4.5 From access to involvement: individual and organisational processes

Two of the major questions that this study has been trying to answer are: What are the minimum conditions that need to be present for PLHA involvement to happen? And what strategies could NGOs and CBOs employ to achieve PLHA involvement?

Based on the types of involvement described in Chapter 3 and the description of the factors that limit and enhance involvement we have presented in this chapter, the first answers to these questions are:

- Minimum conditions and strategies depend on what PLHA and NGOs try to achieve in terms of involvement. Depending on the type of involvement desired, conditions and strategies vary. Whether an NGO aims at providing courses to some of its HIV positive beneficiaries (access) or involving PLHA formally in service delivery (participation) will determine which conditions are necessary and the corresponding strategies to make this happen. Whether a positive woman wants to attend meetings with other positive women from time to time or wants to become a counsellor will influence the steps she needs to take to achieve her goals.

- The number of conditions and steps tends to increase for both NGOs and PLHA when moving from access to inclusion, and from inclusion to participation and involvement. During the data analysis workshop, representatives from each NGO first looked at the conditions that had made involvement of PLHA possible in their organisation. Afterwards they came together to discuss what they could define as the standard minimum conditions for any NGO and for PLHA to achieve respectively inclusion, participation and involvement. These series of steps are what we have called the “pathways to involvement” (see below).

4.5.1 “Pathways to involvement” for PLHA

The conditions or steps required for PLHA to get involved in NGOs are:

1 Acceptance of HIV status – A PLHA needs to accept his or her HIV status. Without acceptance of HIV status a PLHA cannot begin to get involved.

2 Awareness of existence of the NGO – A PLHA needs to be aware of the existence of an NGO, CBO or support group that provides opportunities for involvement. At the same time, the PLHA must perceive some benefit in getting involved with the NGO. This benefit can be intrinsic, e.g.
feeling safe and accepted in the organisation, or extrinsic, e.g. obtaining monetary compensation or access to medical care.

3 Visibility – A PLHA needs to be visible, even if this visibility is limited, e.g. to service providers or support group members.

4 Accessing and sharing information and experiences – A PLHA needs to be able to access information about HIV/AIDS and other issues related to positive living, and to share information and experiences with other PLHA.

5 Training on HIV/AIDS issues – A PLHA needs training so that he or she is aware of relevant issues e.g. voluntary HIV testing, counselling, sex work, MSM.

6 Building self-esteem – A PLHA needs capacity building to develop self-respect, confidence, and positive attitudes and to develop skills e.g. communication, teamwork.

7 Making time – A PLHA needs to make time available for involvement, e.g. as a volunteer, a support group participant.

8 Being associated with the NGO – A PLHA needs to associate himself or herself with the NGO, CBO or support group to be involved, e.g. as a volunteer, an employee.

9 Becoming visible to a wider group – More meaningful involvement requires a PLHA to be visible to a larger group, both within and outside the organisation.

All these conditions or steps are necessary for PLHA involvement.

4.5.2 “Pathways to involvement” for NGOs

The conditions or steps required for NGOs to involve PLHA are:

1 Sensitising the NGO on HIV/AIDS issues – An NGO needs to initiate a process of sensitising the organisation, management and staff, about HIV/AIDS.

2 Creating a conducive environment – An NGO needs to create an environment within the organisation where PLHA are accepted. Some participants in the data analysis workshop felt that this step needs to happen before it is possible to sensitise the organisation on HIV/AIDS issues, while others felt that it would not be possible to create an
accepting environment unless management and staff have been sensitised to the issues.

3 Developing policies for involvement and identifying areas of possible involvement – An NGO intending to involve PLHA needs to have concrete policies, which reflect the organisation’s commitment and give PLHA involvement a definitive status. At the same time it also needs to identify specific areas for potential future involvement of PLHA.

4 Sharing information about opportunities for PLHA involvement – After identifying potential areas of involvement, an NGO needs to ensure that PLHA are aware of these opportunities. This requires disseminating information to PLHA beneficiaries of other organisations.

5 Identifying PLHA potential and providing training – Once opportunities are available, an NGO needs to identify the skills, capacities and interests of PLHA and to provide them with appropriate training. Tokenistic training, where PLHA are trained but their skills are not used, should be avoided.

6 Providing opportunities for involvement in all areas – An NGO needs to involve PLHA according to their skills and potential, not limiting their involvement to specific areas of activity, such as care and support. For example, PLHA who have the capacity should play a role in management, policy making and strategic planning.

7 Respect for PLHA and their views – An NGO needs to respect PLHA, whatever their background, and to take the views of PLHA into account when planning and designing services.

8 Teamwork – An NGO needs to ensure that PLHA and HIV negative service provider can work as a team.

All of these conditions or steps are necessary for PLHA involvement. In addition, an NGO needs to maintain confidentiality of PLHA HIV status, since some PLHA may prefer non-visible to visible involvement.

4.6 Conclusions

The analysis of the data on individual processes of involvement for PLHA suggests that there may be a continuum of involvement in which:

- Access is an entry point for further involvement. It is when PLHA can learn how to accept the fact they are HIV positive, they also learn the basic facts of HIV/AIDS through counselling as well as how to cope with the infection. Disclosure of HIV status to a few close people – some relatives and/or friends – is essential to the process of acceptance. PLHA build some form
of support network. Through this initiation, PLHA might find the desire and the strength to help other people. For PLHA, access is characterised by the first exposure to psycho-social support and information, which have been identified as two of the major factors that enhance involvement.

- **Inclusion** is when a PLHA has reached a certain level of acceptance and feels strong enough to share his/her experience with other people, for example in support group meetings. S/he also keeps learning new skills, in particular through informal involvement in activities. These practical skills are essential to a more formal role as service provider. The support network usually grows at this stage, particularly through peer support. The efforts of PLHA can be rewarded by some material compensation that acts as an important incentive.

Some PLHA also find more material stability by being offered a job, although non-related to HIV/AIDS.

- An opportunity of formal employment in service delivery and further capacity building makes the difference for those PLHA who have shown that they have the strong desire to provide services, some basic skills and have gained experience in the field. **Participation** is a stage in which PLHA have reached a certain level of maturity in both their personal journey of living with HIV and their "professional" use of this particular expertise.

- When trying to summarise the necessary conditions for PLHA to be involved directly in the design, planning and management of programmes, NGO representatives emphasised a wide range of skills. We observed that these skills are usually the result of several years of experience in the fight against the epidemic and a lot of self-training through a large exposure in national and very often international workshops and conferences (in addition to formal education).

The data shows that in two of the NGOs who participated in the study, the organisational process of involving PLHA followed the same continuum, starting with access and moving toward participation and possibly further involvement.

In the Salvation Army Community Development Programme, the only visible HIV positive service provider was originally a support group participant (access). He then started to facilitate the meetings on a voluntary basis (inclusion) and was eventually recruited as a counsellor and formal co-ordinator of the support group (participation).

At CCDT, the initial objective of the project was to “address the immediate needs of the beneficiaries” by providing medical care, psychological support as well as
economic support. Access to these services was used as an entry point to facilitate the formation of support groups.

“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”, says one of the service providers.

The continuum is partly a consequence of the difficulty for NGOs and CBOs to find PLHA who already have the appropriate skills and experience, and are willing to be visible to their patients or clients, or even to a wider public. The problem is that there are only a few of them in Maharashtra, because stigma is still widespread in spite of a high HIV prevalence. As a result, NGOs who want to encourage a visible involvement of PLHA in their services often have to mobilise HIV positive people who are their beneficiaries, train and empower them, give them opportunities to test their skills until they are ready to become service providers27. This process is time-consuming for NGOs.

Only MNP+ has been able to start at a different level, but it is worth noting that some of its founders had actually been through the continuum in other organisations and were frustrated because there were no opportunities for involvement in these organisations.

4.6.1 NGOs are not powerless

Gender and social classes influence the types of involvement. Most PLHA who act as decision-makers are educated males who work with rights-based NGOs. Although the profile of PLHA at different levels of the continuum is varied, of the PLHA who are involved in the NGOs the majority are male, 25-35 years old, urban, and middle-income with relatively high levels of education (secondary and above). This is in contrast with the profile of PLHA in the inclusion model, which may have a mixed group of men and women with a level of education that is lower than that of the level of PLHA involved.

As most of the PLHA hail from the low-middle class and poor families, they have high expectations of financial and material benefits gained from their involvement in NGOs, in particular through paid employment.

Obviously, social factors and individual circumstances of PLHA linked to their social environment cannot be ignored, but they should not be used as an excuse by NGOs to do nothing. The list of factors identified by the study shows that many obstacles to involvement are strictly organisational and

27 This is similar to what has been observed in many companies who cannot find the skilled workers they are looking for and have to include the whole training process in their management of human resources.
structural, which can be tackled by the organisations themselves. We observed that, to some extent, the types of involvement vary with the type of NGO. In the welfare model, in particular in health care settings, there is less likely to be a conducive environment for PLHA involvement. PLHA are seen as being at risk or a risk to others and hence have a limited role to play. Also, the only organisation with involvement developed from PLHA self-help groups. In other types of organisations, there might be less flexibility and opportunity for the involvement of PLHA in policy and planning.

The main reason for identifying the factors that limit or encourage PLHA involvement and for analysing the conditions for PLHA involvement, was to enable organisations to develop strategies that addressed limiting factors and build on enhancing factors, in order to increase PLHA involvement. During the data analysis workshop, the participating organisations identified a range of possible strategies for increasing PLHA involvement.

Box 4.3
Some strategies for increasing PLHA involvement identified by NGOs at the end of the study

- Ensuring that service providers share information with PLHA about opportunities for involvement.
- Carrying out activities and providing opportunities for involvement closer to where people live, and especially in rural areas.
- Increasing the scope for PLHA involvement as volunteers with clearly defined roles.
- Encouraging peer support between PLHA.
- Conducting training and capacity building, to develop the PLHA skills for service delivery, advocacy, management, and strategic planning.
- Counselling families and educating communities, especially community leaders, to address misconceptions about HIV/AIDS and tackle stigma and discrimination.
- Sensitising partner organisations so that they accept PLHA service providers.
- Budgeting for monetary compensation to PLHA, and especially for reimbursement of travel expenses.
- Reviewing policies that may limit involvement, such as mandatory testing of care providers.
- Developing an organisational policy on PLHA involvement.
(see also recommendations at the end of the report)
Chapter 5
Positive and negative effects of PLHA involvement

5.1 Introduction

One of the objectives of the study was to assess the positive and negative effects of PLHA involvement in NGOs and CBOs on the following areas:

- The quality of life of PLHA involved.
- The activities and services of the organisations in which they are involved and quality of life of service beneficiaries.
- The structure and functioning of the organisations in which PLHA are involved.
- The families and communities of the PLHA.

Identifying an appropriate methodology to measure the effects of PLHA involvement was a particular challenge. Questions to be addressed included: Who evaluates the effects of involvement? When should effects of involvement be evaluated? What indicators should be used to measure these effects?

The research team and NGOs developed the following methodology:

- **Interviews** with HIV negative 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** – For example, in order to evaluate the effects of the involvement on PLHA, questions asked included: Has your life changed since you became involved with the organisation? In what way has it changed?

  **With or without the involvement of PLHA** – For example, in order to measure the effects of PLHA on activities, questions asked included: Are there activities that PLHA do differently and better than other service providers within the organisation? Do beneficiaries prefer to be seen by PLHA and, if so, why?

- **Direct observation by researchers of activities in which PLHA were involved.**

- **A survey of a small sample of users** in some organisations.

- The research team also worked with each NGO to develop **indicators to evaluate the quality and impact** of one of its services. These indicators
were a means of further assessing the impact of PHLA involvement on these specific services.

The methodology had the following limitations:

- **Inadequate time for data collection** – The main limitation was the short duration of 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 impacts. There was inadequate time to use the indicators developed by the organisations to assess the impact of involvement, and organisations were not always able to identify the beneficiaries of services provided by PHLA for interview.

- **Other factors may have an impact on PLHA and on organisations** – 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 organisation may also be the result of factors other than PLHA involvement.

- **Comparing services provided by PLHA and by HIV negative has limitations.** For example, the same service, such as counselling, provided to the same person by an HIV positive service provider and an HIV negative service provider will be provided at two different times in the client’s life and in particular at different stages of his or her life with HIV. This makes it difficult to compare the effects of counselling by PLHA and HIV negative counsellors. 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.

- **Another limitation in evaluating the effects of involvement of PLHA in NGOs is that involvement is often not visible.**

This chapter:

- Summarises the positive and negative effects of involvement on the individual PLHA who are involved, on the services and activities of the four organisations, on the functioning of the four organisations, and on the families and communities of the PLHA involved.

- Analyses the advantages and disadvantages, for NGOs and CBOs, of three types of involvement – *inclusion, participation* and *involvement.*
It is important to bear in mind that data was collected through in-depth interviews and FGD. Questions regarding effects of involvement were open questions and the researchers did not suggest any answer to the respondents. No questionnaire was administered to explore these themes. Researchers listed the effects that were the most often mentioned by respondents. However, opinions of respondents do not always reflect the reality. Only the comparison of the opinions expressed by respondents and data collected through other means such as life stories and observation can provide a serious analysis of the positive and negative effects of involvement.

5.2 Effects on PLHA

5.2.1 Positive effects

Improved health was mentioned by PLHA as a positive effect, as a result of receiving a salary for employment with one of the participating organisations, or food or reimbursement for medical treatment.

"Working here and getting salary … reimbursement of medicine and also used to get to eat … I was able to help the family and … no tension …" (PLHA beneficiary of CCDT.)
Involvement and access to information and support has enabled PLHA to live a positive life. Many also said that it had improved their psychological health – their worries had reduced as a result of their involvement.

“… We have learnt to live life … earlier we were not leading this life … the agency has helped us … informed us about HIV … regarding how to take medicines … they have given us support … we do not think much about HIV…” (PLHA beneficiary of CCDT.)

For some PLHA service providers, involvement with the organisation had made them feel useful and given them a purpose in life. One PLHA, who was initially a beneficiary and is now a service provider with one of the participating organisations, said that his involvement had led to him “helping other PLHA as mission (in) life.” And a female PLHA service provider explained, “Earlier it was that I am going to die… a little sooner than others so there was no attachment in life. But today it feels that there is purpose to life. It is like at least we can do something for others.” (A female PLHA service provider of MNP+) The same service provider also said she had noticed a change in her attitude and mood. “…My nature has undergone a change from irritable nature. Today I don’t lose my temper unnecessarily with others.”

For some it had been an important turning point in their lives. “… After joining here … That is why it turned my life actually … I choose the life with HIV…” (Male PLHA service provider of MNP+.)

PLHA reported that involvement in support groups and related activities had empowered them to fight for their rights and the rights of other PLHA. Service providers also felt that involvement will lead to PLHA getting involved in advocacy for PLHA rights.

“…. Other areas of activity for PLHA are … in human rights groups where they can tackle legal issues such as discrimination. For instance, sometimes an HIV positive person is thrown out of his work. They can take up such issues far better because they are much more concerned with that. We are there to support.” (Service provider of the Salvation Army.)

Another positive effect of involvement for individual PLHA was increased knowledge about HIV/AIDS services provided by hospitals and other agencies.

“… the benefit of associating with the agency (is) that today I know so much. If I would have sat at home, I would not have known so many things.” (PLHA service provider of MNP+.)
For some PLHA, being a service provider has increased confidence and self-esteem.

“If PLHA are involved in implementation of activities … say awareness programmes … and they run it on their own … this will boost their self-confidence … and (give) satisfaction that we can do something on our own.” (PLHA service provider of SOFOSH)

PLHA reported that they had received a lot of support from colleagues and peers. One said, “I was very comfortable over there. I got a lot of love, I got a lot of care, I got to meet a lot of people also”. Activities such as peer counselling and informal peer support provide PLHA with emotional and psychological support.

Service providers, PLHA and affected beneficiaries in some organisations also perceived that involvement has had or could have a positive effects on peer support, shared knowledge, and family support.

5.2.2 Negative effects

The most common negative effect mentioned by respondents was possible stigma and discrimination, for example rejection and loss of employment.

“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 of the Salvation Army.)

However, there were no concrete examples of stigma and discrimination resulting from visibility due to involvement, and this is more of a limiting factor (see Chapter 4) than a negative effect. As we explained before, involvement can be handled in such a way that disclosure is limited and therefore risks of stigma are lower.

Respondents also mentioned the negative consequences of the “mirror effect” on individual asymptomatic PLHA who identify with people who are ill with AIDS. Many felt that dealing with the death or hospitalisation of other positive people can be harmful to PLHA who are involved in care and support activities, and one of the organisations that participated in the study discourages PLHA from making hospital visits.

“…For example, when we go as a team to the hospital … the psychology of the person is that when he sees the person who is very
sick and weak, and (who) is lying in the bed ... (he may think) ‘I may also be like this person’. So in certain situations, positive people can be involved in hospital visits but it is a very sensitive area.” (Service provider of the Salvation Army.)

“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 of Salvation Army.)

Sometimes during support group meetings news that a friend is dead is withheld. As one PLHA service provider explain, there may be times when “one or two persons who are not strong enough to understand this ... that somebody has gone away. They say when will I be going”.

Some respondents mentioned the difficulty in maintaining confidentiality of PLHA who are involved.

“When we go to hospital I have two other (PLHA) coming with me, who come as friends. I will not introduce anyone by saying that he is HIV positive ... but I have seen that in 90% of the cases it has become necessary to break the confidentiality. The only reason is that if I disclose to my brother (referring to PLHA beneficiary) and if he feels good, then I have done a good work.” (Service provider of Salvation Army.)

5.3 Effects on the services and activities of the organisations

5.3.1 Positive effects

Involvement of PLHA in support groups has increased organisations’ awareness of PLHA perspectives and needs, which should contribute to more effective planning and delivery of services.

“The biggest benefit will be that we would come to know ... what kind of difficulties do they (PLHA) face ... what are their feelings about it ... then it would be easier for us to work with them”. (Service provider of SOFOSH.)
PLHA also reported that the psychological support they receive from others has given them to confidence to speak out and to participate in planning.

“Earlier I used to not speak to any one in the meeting ... used to feel shy ... now I interact ... we together (the service providers and beneficiaries) plan and talk ... we make errors ... but we speak ...” (PLHA beneficiary of CCDT.)

Involvement of PLHA was also reported to have improved services such as counselling, enabling clients to talk freely about their feelings and helping them to realise that they are not alone. Peer counselling of PLHA is also perceived to bring greater trust to the counselling relationship, although self-disclosure also adds to the responsibility of the counsellor.

“When a PLHA is involved it is a source of psychological support ... emotional support which a PLHA can give much more and is giving much more. When identity of HIV+ status is revealed to another PLHA that I am positive you can also be like me ... so that also gets included in support.” (Female PLHA service provider of MNP+.)

“When the other person is speaking and if he is positive ... and if he comes to us for counselling ... if I tell him that I am positive, then he becomes free ... They feel that this person is also like us (PLHA).” (Service provider of MNP+.)

“When I give my example ... I can tell what is happening in my life. So I tell to each one in counselling ... they are very happy after that and it is a great feeling in the sense of responsibility.” (PLHA service provider for MNP+.)

Another potential positive effect of PLHA visibility through peer counselling and giving testimony is that it may increase the awareness of other PLHA of their rights and give them the confidence to be visible and to fight for their rights.

“It might help others (PLHA) to open ... and bring about change.” (Service provider of CCDT)

“... Others will come to know and be aware of their rights.” (Service provider of CCDT.)

Respondents also reported that involvement of PLHA has resulted in an increase in PLHA beneficiaries accessing services. Poster and personal testimonies by PLHA have publicised services and encouraged other PLHA to seek support.
Finally, service providers noted that PLHA involvement should be seen as an indicator of the effectiveness of services, and that using involvement as an indicator will provide encouragement to other service providers by showing that services and activities are going in the right direction.

5.3.2 Negative effects

The “mirror effect”, described earlier, was also cited as having a negative impact on services and activities, because it can affect the ability of HIV positive service providers to do their job.

Service providers from one of the participating organisations mentioned that they had had concerns that the involvement of PLHA might have a negative effect on the other services of the NGO, in particular the adoption programme, and stigmatise the organisation, but that this had not happened.

“...if we say that they (the babies) are from HIV background, we thought that they (adoptive parents) might stop coming. However our experience shows that nothing like that happened.” (Service provider of SOFOSH.)

5.4 Effects on the functioning of the organisations

5.4.1 Positive effects

Two potentially positive effects of PLHA involvement were mentioned. One PLHA beneficiary felt that the involvement of PLHA could create a positive image of an NGO as one that is not a “commercial” organisation. Other respondents felt that PLHA involved in organisations could act as monitoring agents, ensuring proper utilisation of funds and that this “might reduce the corruption in agencies”.

5.4.2 Negative effects

Respondents mentioned two potentially negative effects on the functioning of an organisation. First, supervisors may have difficulties in managing PLHA staff and volunteers, since this might require more sensitivity and different supervision skills. Second, providing good quality services for PLHA might result in hospitals off-loading cases onto an NGO – the NGO might not have the resources to be able to respond effectively to an increased workload.
5.5 Effects on the family and community

5.5.1 Positive effects

The main positive effects on families reported by respondents is **improved mental health**, because families see the 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.

PLHA involvement has contributed to **more effective community interventions**. One of the participating organisations involves PLHA in home visits and sees this as an entry point into the community. Respondents suggested that the testimonies of PLHA will have a positive effect on the organisation’s interventions in the community, and that PLHA involvement will increase community receptivity towards messages about HIV/AIDS. In addition, the organisation feels that PLHA involvement will support community mobilisation and help to bring about changes in attitudes, encouraging families and communities to become more involved in care and support.

“… There can be a lot more social awareness … as such at the community level there is not much awareness. Thus when a person comes forward as an example then people will be more aware …”

(Service provider of SOFOSH.)

“If a PLHA tells the community about HIV/AIDS they will understand better.” (Service provider of CCDT.)
Involvement has also had an effect on wider civil society. For example, PLHA involvement has resulted in one organisation filing a petition against unqualified medical practitioners who claim to be able to cure HIV/AIDS.

Respondents also said that involvement of PLHA will lead to a more positive image of the organisation in civil society.

5.5.2 Negative effects

Respondents did not identify any negative effects on the family or community resulting from PLHA involvement.

5.6 Conclusions: what types of involvement are the most meaningful?

In order to answer the question “What types of involvement are the most meaningful?”, it is important to ask first of all: “Meaningful to whom? PLHA involved, NGOs and CBOs in which they are involved, their families, the communities served by the NGOs and CBOs, Zambian society in general?”

The data presented in this chapter has shown that involvement in general has both positive and negative effects for all categories, which means in other words that each type of involvement has a series of advantages and disadvantages that can be analysed at different levels.

Study participants prepared a dissemination strategy for the study report
5.6.1 Access

PLHA beneficiaries can benefit a lot from access to services, such as counselling, depending obviously on the nature and quality of these services. Counselling has proved useful for the psychological and even physical health of PLHA. By accessing these services, PLHA learn about HIV/AIDS, which can bring behaviour change. However, this depends on the objectives of the services offered to PLHA: in order to produce these positive effects, services should aim to improve the quality of life of PLHA and at the same time empower them so they can take better care of their own life. This was the basic approach of three of the four NGOs who participated in the study, as they mix welfare and development principles. The problem of a strictly welfare approach in a poor country without a proper welfare system like India, is that the positive impact of welfare services might be short-term because it is difficult to sustain their delivery.

As far as NGOs and CBOs are concerned, the table below shows that access has more disadvantages than advantages, compared to other types of involvement. When service users are only service users, they usually do not have their say on the services they use, which can affect negatively the relevance of these services. However, access can be more meaningful as a type of involvement when it is used by an organisation as an entry point to further involvement of its beneficiaries in the activities of the NGO (see Chapter 3). This does not mean that services are not worth providing to PLHA when they do not make any attempt to lead to involvement, but some of these services might actually not meet the needs of their beneficiaries.

Table 5.1
Possible advantages and disadvantages of access for NGOs and CBOs

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Requires less investment of resources, e.g. in training than other types of involvement.</td>
<td>➢ Less strong relationship with beneficiaries.</td>
</tr>
<tr>
<td></td>
<td>➢ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning.</td>
</tr>
<tr>
<td></td>
<td>➢ PLHA are a resource that the organisation is not using.</td>
</tr>
</tbody>
</table>

Positive effects of access on the family can be the consequences of the positive effects on the PLHA themselves. When the health of a PLHA improves, it can have a positive impact on the well-being of the family, as we have shown in this chapter.

5.6.2 Inclusion

Positive effects of inclusion on PLHA depend on the kind of involvement in the implementations of the activities of NGOs:
• When PLHA are employed as support staff, they received a regular salary and they usually also have access to benefits. This has a series of positive effects on their health: they can for example buy food. The fact of having a job in itself can also have a dramatic impact on their self-esteem.

• When they are involved in service delivery on a voluntary basis and irregularly, it is a different story. Material benefits are very few and therefore inclusion has only a very limited impact on access to food, drugs, etc. The positive effects are more at the psychological level and in terms of new skills. However, inclusion can be particularly harmful to PLHA when they have high expectations in terms of immediate benefits from their involvement. They might feel used by the organisation for which they volunteer, which can lead to immense frustration. There is also a risk of discrimination for those PLHA who are involved in outreach education. Hence inclusion of PLHA as volunteers can be empowering but it is not really sustainable and meaningful for PLHA who lack resources and support.

Inclusion can be seen as cost-effective because of the use of volunteers, but the negative side of using volunteers who are poorly trained and whose contribution is hardly rewarded, may be low quality of services and low fidelity of human resources. This is the reason PLHA are involved as “aides”, other formal 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 enough support, otherwise positive effects of involvement on the overall relevance and quality of services are limited.

### Table 5.2
Possible advantages and disadvantages of inclusion for NGOs and CBOs

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Volunteerism is cost-effective.</td>
<td></td>
</tr>
<tr>
<td>✓ PLHA are living examples to show that objectives are being met.</td>
<td></td>
</tr>
<tr>
<td>✓ More people are involved in service delivery.</td>
<td></td>
</tr>
<tr>
<td>✓ Potential to maximise use of human resources.</td>
<td>✓ Could lead to discontinuity of service delivery because PLHA are not formally or fully involved.</td>
</tr>
<tr>
<td></td>
<td>✓ Lower quality of services because of lack of training.</td>
</tr>
<tr>
<td></td>
<td>✓ Planning may be difficult.</td>
</tr>
<tr>
<td></td>
<td>✓ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning.</td>
</tr>
</tbody>
</table>

Positive effects of inclusion when PLHA are employed as support staff can be dramatic for their family, because improvement for the individual engenders improvement for the family.

#### 5.6.3 Participation

Positive effects of participation on PLHA combine the results of employment described in the previous section for HIV positive people employed as support staff,
although at a higher level, with a strong sense of achievement by helping other PLHA and the community. A possible difficulty for some PLHA in the participatory model is the limited involvement in decision-making that can cause frustration for those who have enough skills and experience but are not offered the opportunity to influence the policies of the organisations in which they are involved. However, the major problem is a risk of discrimination linked to a high level of visibility. Participation is thus particularly meaningful to PLHA who are happy with technical positions and do not fear discrimination.

Participation is meaningful to NGOs and CBOs who are ready to invest in the mobilisation, 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 organisation and its services.

### Table 5.3
Possible advantages and disadvantages of participation for NGOs and CBOs

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ Improved planning, ownership, better use of resources because PLHA are integral part of the organisation.</td>
<td>➢ 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.</td>
</tr>
<tr>
<td>➢ PLHA are living examples and show what the organisation does.</td>
<td>➢ Negative effect on activities and services from high turnover and loss of staff due to illness and death.</td>
</tr>
<tr>
<td>➢ Improves relevance and quality of services because of training and PLHA involvement in design and planning.</td>
<td></td>
</tr>
<tr>
<td>➢ Maximises use of available human resources.</td>
<td></td>
</tr>
</tbody>
</table>

The data reveals that families benefit from the participation of their relatives as employees of NGOs. Nevertheless, families should be prepared to face stigma in some circumstances.

Participation is also useful to the community in a way similar to inclusion, when there are PLHA involved in awareness raising.

#### 5.6.4 Involvement

Benefits of involvement for PLHA are the same as the benefits of participation. Involvement can be seen as more meaningful than participation to those PLHA who have the desire to shape the policies of their organisation. Like in the participatory model, PLHA have a high level of visibility that can expose them to discrimination, but the level of personal acceptance and support is also very high for PLHA involved. However, they have been through the continuum of involvement.
described in Chapter 3, and consequently have built stronger coping skills that they can use if they are discriminated against.

For NGOs who think that having PLHA in the organisation can improve their services, involvement is certainly more meaningful than other types because it allows PLHA to influence the design and implementation of programmes. As shown in the table below, involvement requires investment and good planning of human and financial resources.

### Table 5.4
Possible advantages and disadvantages of involvement for NGOs and CBOs

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>➢ PLHA have a stronger voice, can influence policies and decisions, and can ensure resources are allocated to services relevant to the needs of PLHA.</td>
<td>➢ Negative effect on activities and services from high turnover and loss of staff due to illness and death.</td>
</tr>
<tr>
<td>➢ May increase donor funding, if PLHA involvement is a donor priority.</td>
<td>➢ High cost, especially if the organisation provides treatment for PLHA(^28).</td>
</tr>
<tr>
<td>➢ Helps to reduce stigma and discrimination in the workplace.</td>
<td>➢ 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.</td>
</tr>
<tr>
<td>➢ PLHA can act as role models for other PLHA who are not visible or actively involved.</td>
<td>➢ Improves effect of awareness campaigns.</td>
</tr>
</tbody>
</table>

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

In conclusion, the study findings show that all types of involvement are meaningful at different levels. However, for each type to be really meaningful, there are a series of steps to take for PLHA and organisations (see Pathways to involvement, Chapter 4). If PLHA or NGOs fail to take these steps, positive effects of involvement tend to be limited and negative effects increase. We saw that for example different kinds of skills are necessary for PLHA, depending on the type of involvement. If a PLHA is involved in service delivery, for example outreach education, without the skills required for this, his/her involvement can be harmful to him/her, by exposing him/her to discrimination, and the quality of the activity can be very poor, preventing messages from reaching the community. Most factors that limit involvement of PLHA (see Chapter 4) may also limit the impact of whatever involvement PLHA have.

\(^{28}\) In India, only one of the four organisations provided treatment to its HIV positive staff who had access free of charge to the medical care facilities of the NGO.
In general it seems that the positive effects of involvement of PLHA outweigh the negative effects. Organisations do see the benefits of PLHA involvement in the delivery of services to other PLHA, with services being more user-friendly and therefore more effective. In turn, PLHA seem to favour their involvement in NGOs and CBOs as they feel more empowered and able to accept their condition more easily. However, some results remain difficult to analyse. We saw for example that involvement may lead to some forms of discrimination and we also observed that involvement can increase support from the family and the community. More research is needed to understand better in what circumstances PLHA suffer stigma and discrimination as a result of their visible involvement.

Another question that remains partly unanswered is the impact of involvement when it is not visible. We observed 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. Members of support groups may be visible only to other members; peer counsellors 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.

The issues of user involvement in health care and partnerships between health professionals and patients are not new research topics, and there is some evidence that user involvement generally has a positive impact of the lives of health service users. In other health and development fields, such as leprosy and disability, social interventions have demonstrated that empowerment and rights-based approaches – where the disempowered, marginalised and disadvantaged people themselves are the actors and not mere recipients of services – lead to greater benefits for the individuals, families, organisations, and society in general.

As far as HIV/AIDS is concerned, AIDS activists in Western countries claim that involvement of PLHA has changed both policies and the way HIV/AIDS services are delivered. The present study shows that, in a developing country like India, involvement of PLHA in NGOs and CBOs can make a difference at the local level for individuals, organisations and communities, even if it needs to be dramatically scaled up to have an impact in the fight against HIV/AIDS at the national level. Scaling up what has been observed in a few organisations can be achieved if other NGOs and CBOs, and more PLHA, take the steps that we have described in this report.

Some of these steps do not require radical changes in policies or major investment but they might call for some changes of behaviours or attitudes at different levels, starting with organisations who provide HIV/AIDS services, and a broad co-operation between various stakeholders. Behaviour change is not only about sexual behaviour and prevention of transmission of HIV and other STIs, it is also about changing attitudes toward those who are infected. Any serious

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behaviour change programme 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.
Recommendations

As shown by the study, involvement is both an individual process, for PLHA, and an organisational process, for NGOs and CBOs. In many cases the process is a continuum that starts when PLHA access the services of NGOs such as counselling, support group meetings or training programmes, before they actually implement activities (whether these are HIV-related or not), first informally (inclusion) and sometimes as employees of an organisation (participation). In India, only a few PLHA provide prevention, care and support services in a visible way or are involved at design, planning and management levels (involvement).

PLHA and organisations that have gone along the continuum access-inclusion-participation-involvement have followed common steps that we have described in the report. However, the process varies depending on individuals and organisations, in particular in terms of length. The study also reveals that there are many possible ways for PLHA to be involved, even in the same organisation. The following recommendations stress the basic principles and major steps for a meaningful involvement of PLHA in NGOs and CBOs.

We also include some recommendations for policy makers and other stakeholders involved in the fight against the HIV/AIDS epidemic in Maharashtra and India.

Specific recommendations for NGOs and CBOs

The study shows that, in order to facilitate the involvement of PLHA in their activities, NGOs have to build a conducive environment within the organisation. This includes:

- Psychological support, including non-judgmental and supportive attitudes of management and service providers of NGOs and CBOs and peer support.
- Various forms and degrees of training.
- Material support.

These components vary depending on the types of involvement.

Changing attitudes in NGOs and CBOs to facilitate the involvement of PLHA

Negative attitudes of management and service providers of NGOs and CBOs toward PLHA and possible involvement of PLHA in the delivery, design and planning of services can limit involvement of PLHA. Paternalistic attitudes are seen as discriminatory by some positive people.
• NGOs should not consider PLHA, in particular their HIV positive beneficiaries, as only passive recipients of care and support.

• When addressing internal or institutional obstacles to involvement of PLHA in their organisation, NGOs should look at the attitudes of management and service providers and provide them with sensitisation and training when necessary.

• It is true that the vast majority of PLHA do need some form of support, as well as care for those who are sick, and it is true as well that only a small number of them will be involved not only as service users but also as service providers. However, support can be provided to PLHA in a way that empowers them and does not keep them totally dependent on the NGOs that help them.

“Knowledge is involvement”
Capacity building of PLHA, through counselling and training, is essential to a greater involvement of positive people in the activities of NGOs.

• Providing accurate information about HIV/AIDS, its prevention, treatment, as well as the services available for PLHA in the organisation and in the community, is essential to betterment of the quality of life of PLHA.

• NGOs can use their counselling services as a starting point to empower their HIV positive patients. Counselling is empowering when it provides PLHA with accurate and up-to-date information and options so they can make their own choices.

• Capacity building should comprise knowledge, skills and attitudinal training (both experiential and formal) pertaining to the following:
  • Living with HIV/AIDS, e.g. coping skills.
  • Basic facts of HIV/AIDS.
  • Technical skills related to the delivery of HIV/AIDS services, including stress management for those PLHA involved in care and support.
  • Vocational issues, including generation of income.
  • Organisational development issues, e.g. communication, advocacy.
  • Information on the structure and functioning of the organisation in which PLHA are involved.

• Self-development, building or re-building self-confidence and self-esteem should be essential components of the empowerment of PLHA.
Offering psychological support, including peer support, to PLHA
Organisations involving PLHA have to be sensitive to their emotional needs.

- Counselling should be available to PLHA.

Peer support makes a difference in the way PLHA cope with HIV. It is complementary to the support provided to PLHA by other carers, in particular social workers and health professionals. Support groups can facilitate the involvement of PLHA by increasing confidence and visibility within a non-judgmental interactive atmosphere.

- NGOs should therefore give to their beneficiaries who are HIV positive the opportunity to meet other PLHA, whether through peer counselling or support group meetings. Depending on individuals, PLHA may prefer individual peer support (such as peer counselling) or group support. It is important that both options are available.

Material support is essential to the involvement of PLHA who have few resources
When NGOs try to involve PLHA who have few resources in voluntary work, involvement is not likely to be sustainable unless some material support is provided.

- Therefore NGOs should provide some form of material support (compensation and/or remuneration) depending on the amount of time spent by PLHA, the skills they use and the efforts they make when they work for the organisation.

Poor health as a result of lack of access to care is a major obstacle to the involvement of PLHA.

- Any organisation involving PLHA will need to be sensitive to their physical need and ensure that they have access to continuous health care.

Visibility and involvement: flexibility is required
Few PLHA want to disclose their HIV status when they are involved in NGOs and CBOs mainly for fear of stigma and discrimination:

- NGOs should not force PLHA involved in their activities to be visible at all levels.

- NGOs should consider in which activities visibility has the most impact. A positive counsellor can be visible only to his clients and colleagues within the
organisation. Members of support groups can disclose their HIV 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.

- Disclosure of HIV status should remain a personal decision and confidentiality about who is HIV positive should be respected.

- Coming out as HIV positive is a different process for each PLHA. It is important that NGOs help PLHA become visible where and when they want to.

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**Planning and implementing involvement: some simple steps to take**

Organisations with little experience of involvement of PLHA may wonder where to start. Involvement is a process that can be planned.

- It is important to demonstrate first to individuals and organisations the benefits and positive effects of different types of involvement for themselves and the community (see Chapter 5).

- NGOs should also decide and plan how they want PLHA to be involved in their activities (types of involvement).

- They should list the institutional factors that limit these types of involvement and analyse how they can tackle these obstacles as an organisation, especially in terms of human and financial resources.

- When NGOs decide that PLHA should be involved in their activities and how this should happen, a basic step is that management and service providers should inform the PLHA who access the services of the organisation about the opportunities to be involved and refer them to the relevant individuals and structures.

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**Networking between NGOs and referral systems are important to foster involvement of PLHA**

There are many social obstacles to involvement that NGOs cannot tackle alone. Moreover, not all NGOs can meet the requirements for greater involvement of PLHA or want to promote all types of involvement.

- NGOs should therefore be involved in networks at the community and national level and provide PLHA with accurate information about services and opportunities for involvement in other organisations.

- NGOs should set up referral systems so that PLHA have continuing support.
Taking gender issues into account
The study revealed that where there was a majority of women professionals in an organisation, the activities were oriented towards women. In male-dominated NGOs, the services were focused primarily on men and very few women participated in the activities. This reflects the cultural norms within which the Indian society functions.

- NGOs/CBOs should make efforts to ensure gender equity in their organisations.
- Women can play an important role in orienting and sensitising other women on common issues. This will require being sensitive to the peculiar problems faced by women when their spouses die or their children are also infected.
- For women to be involved, support services for the children and to compensate the lack of employment or loss of wages are essential. Similarly, for men to not merely access services or be included, but to participate and be involved, employment opportunities, support for daily wage loss, etc. are important enhancing factors.

Specific recommendations for PLHA
The research shows that involvement is a two-sided process dependent on both PLHA and the NGO providing services. PLHA cannot expect everything from NGOs. They also play a very important and active role. In particular, PLHA can facilitate their own involvement by:

- Taking the initiative and asking CBOs and NGOs where and how they can be involved in their activities.
- Attending as many meetings, workshops, conferences as possible. Exposure to new ideas and people, including other PLHA, is a good way to gain experience.

In addition, the study shows that peer support has positive effects on the quality of life of PLHA.

- PLHA may ask NGOs who provide care and support whether it is possible to meet other PLHA. This could be in group meetings, or individually (e.g. peer counselling) for those who are not comfortable in a group. Some PLHA might want to form their own support group, a process which could be supported by an NGO.
Forming networks and support groups
One of the ways for PLHA to be involved is to form their own networks and support groups, help themselves and other positive and affected people, as MNP+ did.

- Members of networks and PLHA support groups should agree common objectives and expectations. These should be communicated also to any new PLHA who join the network or group.

- All members should know the benefits and “costs” of their participation in the network or group. They should be clear about what they can do (roles) and they cannot do based on availability, health, skills, etc.

- Networks should decide whether they are networks of HIV positive individuals or PLHA groups, or both, in order to clarify their functioning and the roles of their members.

- When networks decide to be involved in service-delivery, they should mobilise PLHA at the community level, helping them form support groups, so that these groups can provide services easily accessible to fellow HIV positive people in their own community.

General recommendation

Stigma and discrimination, and the fear of being stigmatised and discriminated against continue to be the major factors constraining PLHA from coming forward and get involved in NGOs and CBOs.

- All stakeholders should sustain their advocacy efforts to ensure that PLHA are not isolated and do not suffer social, economic and political injustice. At the macro-level, efforts are required by the government and non-governmental sector to lobby with the media, to orient and sensitize health professionals, the corporate sector and others to the problems of PLHA and the need to support them to lead a positive life. This would encourage PLHA to develop a better self-image and greater self-confidence.
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