

Zambia

The involvement of people living with HIV/AIDS

in the delivery of
community-based
prevention, care and
support services
in Zambia

A diagnostic study



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Abbreviations and acronyms

CBO	Community Based Organisation
CBOH	Central Board of Health
CHEP	Copperbelt Health Education Project
CH&D	Community, Health and Development Programme
CHIN	Children in Need Network
CINDI	Children in Distress
CPT	Care and Prevention Team
CMAZ	Churches Medical Association of Zambia
DAPP	Development Aid from People to People
DFID	UK Department for International Development
DDCC	District Development Co-ordinating Committee
DHMT	District Health Management Team
DHS	Demographic and Health Survey
DRI	District Response Initiative
FGD	Focus Group Discussion
FHT	Family Health Trust
GIPA	Greater Involvement of People Living with HIV/AIDS
GRZ	Government of the Republic of Zambia
HBC	Home Based Care
IEC	Information, Education and Communication
IGA	Income Generating Activity
KAB	Knowledge, Attitudes, Behaviour
LSHTM	London School of Hygiene and Tropical Medicine
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NAP	National AIDS Programme
NASTLP	National HIV/AIDS/STD/TB and Leprosy Programme
NGO	Non-Government Organisation
NZP+	Network of Zambian People Living with HIV/AIDS
PHC	Primary Health Care
PLA	Positive Living Advocate
PLAC	Positive Living Advocacy Course
PLC	Positive Living Course
PLHA	People Living with HIV/AIDS
PPAZ	Planned Parenthood Association of Zambia
PRA	Participatory Rapid Appraisal
SAT	Southern AIDS Training programme
SBS	Sexual Behaviour Survey
STD	Sexually Transmitted Disease
SWAAZ	Society for Women and AIDS in Zambia
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific, and Cultural Organisation
UNFPA	United Nations Family Planning Association
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund

UNV	United Nations Volunteers
USAID	United States Agency for International Development
UTH	University Teaching Hospital
VCT	Voluntary Counselling and Testing
YMCA	Young Men's Christian Association
ZIHP	Zambia Integrated Health Programme

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. CBOs do not always require formal procedures, such as legal registration.

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

Discrimination toward PLHA – See stigma.

Empowerment – In this report, empowerment refers to a process 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.

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

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

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.

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, if the PLHA is 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.

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Executive summary – Zambia report

Background

Despite recognition of the critical importance of the involvement of people living with HIV/AIDS (PLHA) in the response to the epidemic, there has been little systematic 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 people infected and affected by HIV/AIDS and to preventing the transmission of HIV. To address this situation, the Horizons programme conducted a study of PLHA involvement in community-based programmes in Burkina Faso, Ecuador, India and Zambia. Horizons is a global operations research programme funded by USAID and implemented by the Population Council in collaboration with five partner organisations, including the International HIV/AIDS Alliance which coordinated the study.

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 effect of involvement on the quality of life of PLHA service providers and PLHA beneficiaries, 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 types of PLHA involvement that can have beneficial effects on the relevance, quality and effectiveness of NGO and CBO services.

This Executive Summary highlights the main findings from Zambia, which was selected as one of the African sites for the study, because it is an example of a country with a high prevalence of HIV, a long history of community involvement in the response to the epidemic, an active network of PLHA, and government commitment to an increasing role for PLHA.

HIV/AIDS in Zambia

The first AIDS case was reported in Zambia in 1984; by 1999 the cumulative number of AIDS cases was estimated to be 600,000. The Ministry of Health predicts that 1.26 million Zambians will be living with HIV/AIDS by 2014. In 1999, according to UNAIDS, the HIV prevalence rate in the sexually active population was 19.9%, with higher rates in urban centres and along major transport routes. Heterosexual transmission is responsible for 90% of HIV infection; mother-to-child transmission is also significant, with an estimated 25,000 HIV-positive infants born each year.

The government response, outlined in the National HIV/AIDS Strategic Framework (2000-2002), emphasises a multi-sectoral approach at central, district and community levels to HIV prevention, care and support for those

infected and affected. HIV/AIDS services are included in a basic package of care at district level, but many health facilities lack the capacity to treat HIV-related illnesses and opportunistic infections.

Despite high prevalence rates, HIV/AIDS is highly stigmatised and negative attitudes towards PLHA are widespread. Fear of stigma and discrimination, in addition to lack of access to information, counselling, care and support, means that few individuals are willing to find out or divulge their HIV status. Only 1% of the estimated 1 million PLHA in Zambia belong to the Network of Zambian People Living with HIV/AIDS (NZP+). The Strategic Framework highlights the impact of stigma and discrimination, in terms of increasing the suffering of PLHA and their families and delaying community responses to the epidemic. It also identifies PLHA as essential partners in the Zambian response, and acknowledges the importance of protecting the human rights of PLHA to promote openness, tolerance and involvement of the public in HIV prevention programmes.

Study methodology

In order to study the involvement of PLHA at the community-level in Zambia, four Zambian NGOs were invited to participate in the study, which was conducted by a team of local researchers. The four NGOs, two based in the Copperbelt, one in Lusaka, and one in a rural area, were:

- Copperbelt Health Education Project (CHEP).
- Hope Humana People to People (Hope).
- Kara Counselling and Training Trust (Kara).
- Salvation Army Chikankata Hospital Health Services (Chikankata).

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 Zambian context.

The study mainly used qualitative data collection methods, including in-depth one to-one and short key informant interviews, group interviews and focus group discussions. A total of 257 respondents, 50% of whom were PLHA, took part:

- 223 respondents from the four participating NGOs:
- 101 service providers (NGO management, salaried staff and volunteers).

- 115 service users (PLHA and persons affected by HIV/AIDS who are service users, and recipients of community or workplace outreach activities).
- relatives of PLHA service providers.
- 34 key informants (government, multilateral and donor agency policy makers, NGO staff, public and private sector health professionals, and 10 members of a PLHA support group 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, which was administered to 219 respondents.

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 findings, review the typology of PLHA involvement, refine the organisational profiles, and identify strategies to increase PLHA involvement.

Participating NGOs

Copperbelt Health Education Project (CHEP)

CHEP, established in 1988 to respond to the HIV/AIDS epidemic, is a secular NGO working in the Copperbelt province. CHEP has 41 salaried staff and three types of volunteers – part-time volunteers, community-based volunteers and workplace peer educators. Activities include: outreach education in schools, communities and workplaces; working with mass media; producing educational materials; supporting community mobilisation; establishing support groups for PLHA and affected people; counselling; training in peer education, life skills, positive living and income generation; advocacy and networking. CHEP was also a host organisation for the UNV Pilot Project to Support PLHA Involvement in Zambia.

Hope Humana People to People (Hope)

Hope, established as an HIV/AIDS project in 1996, is a secular NGO also based in the Copperbelt. Hope has 17 staff, two types of volunteers – community volunteers and foreign development workers – and activists who include teachers, workplace peer educators and PLHA trained by the project. Activities include: outreach education in schools and workplaces; health care services such as VCT and STD treatment; PLHA positive living courses; support groups for PLHA and affected people; training for community leaders, teachers and NGOs in peer education, home-based care, VCT, forming support groups; advocacy and networking; operational research.

Kara Counselling and Training Trust (Kara)

Kara, established in 1989 as a counselling centre, is a secular NGO based in Lusaka. Kara has 37 salaried staff, part-time service providers including counsellors and HIV-positive outreach educators who receive an allowance

for their work, and 40 volunteer community mobilisers. Kara activities include: outreach education in communities, schools, workplaces and clinics; support services such as VCT, a helpline and drop-in centre; support groups for PLHA; hospice care; training PLHA in income generation and coping skills, and training professionals in home-based care, counselling and outreach education. The first Zambian NGO to support PLHA involvement in outreach education activities, Kara has close links with NZP+.

Salvation Army Chikankata Hospital Health Services (Chikankata)

The Salvation Army, an international Christian movement, established Chikankata Hospital in 1946. The Community Health and Development Programme (CHDP), responsible for HIV/AIDS prevention and care, focuses on building community capacity to solve problems and, specifically, mobilisation of trained community volunteers in Care and Prevention Teams (CPTs). There are 24 CPTs. Members are volunteers. CHDP staff link the CPTs with Chikankata's health facilities. Activities of the CPTs include: community counselling; referral; home visits and practical support; health education; community mobilisation; AIDS care and management skills sharing; training communities in income generation.

Types of PLHA involvement

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

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

A range of criteria were used to describe the characteristics of involvement in each area. These criteria included the time PLHA spend taking part in activities, the kind of financial and material remuneration they receive, the extent to which their skills or expertise are used, their involvement in decision making, and the level of PLHA visibility within and outside the organisation. Using this framework, the study identified four types of PLHA involvement³ – *access*, *inclusion*, *participation* and *involvement*.

Access

Access is where PLHA take part in NGO activities as service users. In none of the participating NGOs in Zambia was *access* the only type of involvement, although the majority of PLHA are involved in the NGOs only as beneficiaries. However, NGO experience of providing services that aim to empower PLHA, such as counselling, life skills and positive living training, indicates that *access* can be a starting point for further 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.

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, voluntary basis. In the four participating NGOs, a few PLHA undertake non-HIV/AIDS tasks, such as gardening or cooking, or provide support for HIV/AIDS-related activities, such as offering informal peer support, giving testimony and participating in outreach education, drawing on their personal experience of living with HIV/AIDS. Only a small number of PLHA are visibly involved in support for service delivery, and formal training and remuneration for PLHA who are involved on an informal basis is limited.

Participation

Participation is where PLHA also deliver HIV/AIDS-related services on a formal, regular basis. As service providers, their expertise is officially recognised by the NGO and they receive financial compensation for their work. PLHA may be involved directly in planning the services they deliver, and may also be consulted about other services.

Three of the four NGOs employ PLHA as service providers, mostly on a part-time basis, but visible PLHA represent only a small proportion of service providers. These PLHA carry out outreach education, peer support and home visits, and encourage community members to seek HIV testing, counselling and support. No visible PLHA are involved in pre- and post-test counselling and in areas of service delivery that require a higher level of formal education and skills, such as medical care. The PLHA employed as service providers have received more training than volunteers or beneficiaries and are responsible for planning and implementing their day-to-day work, but they have limited inputs into the design of other services and into organisational decision-making.

Involvement

Involvement is where PLHA 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.

The study observed *involvement* at two of the participating NGOs. Both of these organisations employ PLHA as full-time programme co-ordinators who are not only responsible for planning and design of their own programmes, but are also involved in organisational strategic planning. A third organisation is in the process of moving from *participation* to *involvement*, and has enrolled PLHA staff and volunteers in a management course with a view to increasing their future management responsibilities. However, at present there are no visible PLHA in senior management positions in any of the four NGOs.

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 Zambia.

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

Poor health, specifically weakness and frequent illness, is perceived to limit the capacity of PLHA for active or sustained involvement in NGO service delivery and management, and also affects the sustainability of support groups. Poor health is linked to **poverty**, and to poor nutrition in particular. Poverty and the need to earn an income also mean that most PLHA cannot take part in NGO activities on a voluntary basis, i.e. without any financial or material remuneration of their time, efforts and skills.

Fear of stigma, discrimination, and rejection by family and potential marriage partners as a result of visible involvement in organisations associated with HIV/AIDS is a particular concern, especially in rural communities and among those of higher social status. Fear of stigma and discrimination limits in particular types of involvement that require a higher level of visibility, such as *participation* and *involvement*.

Inadequate education, skills and training and inadequate knowledge about HIV/AIDS contribute to lack of confidence among PLHA beneficiaries about their ability to become involved. Lack of formal educational qualifications and training are a significant barrier to PLHA involvement in professional service delivery and organisational management (*participation* and *involvement*).

Denial, in terms of difficulty in accepting their HIV status, also prevents some PLHA from getting involved. Related factors may include fear of stigma and lack of effective counselling to help PLHA cope.

Individual factors that enhance PLHA involvement

For most PLHA, the **desire to support others** who are infected and to fight the epidemic is the main reason for their involvement. Associated factors are **acceptance of HIV status**, the availability of **peer support** and **personal fulfilment**.

Since most PLHA are poor, **financial and material motivations**, i.e. the opportunity to earn an income or receive benefits, such as food and medicines, are particularly important. Other practical factors that enhance involvement include **knowledge and capacity** gained through information and training, and **previous involvement in other organisations**. As discussed above, **level of formal education** is an important determinant, in particular for *participation* in formal service delivery and *involvement* in design and planning of services.

Organisational factors that limit PLHA involvement

By far the most significant institutional limiting factor is **lack of financial resources** to support the costs of sustaining PLHA involvement, such as the costs of training to replace PLHA who become too sick to work or die, medical treatment, sick leave, funeral expenses and support to dependants. NGOs perceive the costs of involvement to be high and may fail to allocate resources to provide training, material support and other incentives that would promote greater involvement.

Lack of institutional policies for PLHA involvement, and **poor linkages and referral systems** between organisations deny PLHA information about, and opportunities for, involvement. **Judgmental, discriminatory and negative attitudes** of some management and staff are also perceived to limit the extent of PLHA involvement, particularly in activities other than outreach education and giving testimonies. Low visible involvement was also attributed to the **stigma associated with organisations delivering services to PLHA**.

Organisational factors enhancing PLHA involvement

A **conducive environment**, where PLHA are accepted and their contribution is valued, is critical to involvement. Such an environment is characterised by material and psychological support, information and skills building.

In the Zambian context, material support, in the form of **financial benefits**, free medical care and flexible sick leave for employees and material benefits, free medical care and meals for volunteers, is one of the most important factors motivating and sustaining PLHA involvement.

Factors that contribute to psychological support include the availability of **good counselling, non-judgmental and accepting attitudes among staff and management, peer support** and the existence of **positive role models**

in NGOs where PLHA are already involved. No mandatory testing for recruitment and respect for confidentiality are also important factors.

PLHA involvement also depends on the extent to which NGOs provide **information and training** to develop PLHA skills and capacity for positive living as well as for involvement, or referrals to organisations that offer opportunities for training and involvement in other activities. Training courses that aim to help PLHA to cope can be a first step in involving PLHA beneficiaries as service providers, provided they receive further training.

Other important institutional factors include the extent to which NGOs **integrate PLHA programmes** into other activities and to which organisational **structures**, such as a flat management structure, allow for PLHA involvement in decision-making.

Social factors that limit PLHA involvement

Many obstacles to PLHA involvement are related to the social context in Zambia, in particular **stigma and discrimination** associated with HIV/AIDS and negative social and community attitudes towards PLHA.

Lack of community support and appreciation for PLHA is an important disincentive to involvement, as are community perceptions that PLHA who are visible are pretending to be HIV positive for financial gain. Associated factors include **inadequate community knowledge and understanding** of HIV/AIDS, which result in misconceptions and fears, and **religious beliefs**, which contribute to the perception that PLHA are sinners and a culture of silence on HIV/AIDS and issues related to sexuality.

Other social factors that limit PLHA involvement include **poverty** and **dependence on NGOs** to provide care and support. **Gender** inequalities may make it more difficult for women to be visibly involved.

Social factors that enhance PLHA involvement

Referrals between different organisations – NGOs, NZP+ and home-based care teams for example – for counselling and testing, practical support, information and training, play an important role in promoting PLHA involvement.

Support from the family – parents, partners and children – is critical to PLHA involvement, as is **reduced stigma and increased acceptance** of PLHA among family, friends and the wider community. Reduced stigma and increased acceptance, linked to **improved community knowledge of HIV/AIDS**, contributes to community appreciation of what PLHA are doing, which in turn encourages their ongoing involvement. **Religious beliefs** can also support involvement, when churches preach compassion towards PLHA.

Support groups

Access, inclusion, participation and *involvement* describe internal involvement within organisations. Two of the participating NGOs in Zambia have also promoted external involvement by facilitating the formation of support groups of PLHA and of PLHA and affected persons.

- Factors that limit the formation and sustainability of support groups include: lack of clear common objectives and expectations; lack of clarity about the roles and responsibilities of members, support groups and NGOs; lack of effective leadership and succession planning; dependence on external organisations for support; mismanagement of resources and inappropriate and unsustainable income-generating activities.
- Factors that enhance the formation and sustainability of support groups include: common objectives and expectations; common experience; clear roles and responsibilities; a real sense of “belonging”; real community base; individual motivation and time for participation; receiving material and psychological benefits from involvement; clear decision-making process; appropriate income-generating activities; possible independence from NGO support.

The study used the analysis of limiting and enhancing factors to identify the processes or “pathways to involvement” for PLHA and for NGOs. Analysis of the experience of the participating NGOs in Zambia 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*. The steps or conditions necessary to achieve PLHA *inclusion, participation* and *involvement* are highlighted in the recommendations at the end of this report.

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

The main positive effects of involvement were **improved mental, emotional and psychological health**, for example, reduced depression and anxiety, increased self-esteem and sense of usefulness, and **improved physical health**, for example, less illness and opportunistic infection, and a healthier lifestyle. Improved psychological health is associated with other positive effects of involvement including **peer support**, inspiration and solidarity provided by visible PLHA and support groups.

Obtaining **employment, other material benefits** and **access to medical care** were also important benefits of involvement. These are linked to other positive effects on physical health and on the family, such as **increased acceptance** by the family and **better family relationships**. Other positive effects included **improvements in capacity and knowledge of HIV/AIDS** and **behaviour change**, specifically less casual sex and more condom use.

Negative effects on individual PLHA

The most frequently mentioned negative effects on individuals were **rejection** by families, friends and neighbours, **stigmatisation and discrimination**. **Questioning PLHA motives** for involvement was another negative effect reported.

Positive effects on organisations

Services and activities were perceived to have benefited from PLHA involvement in several ways, including **increased success of outreach programmes**, increased credibility of and **demand for services** such as VCT and training courses, and **increased numbers of PLHA joining support groups**. Most informants also thought that, where PLHA are involved in the design and planning of services, this has made services more professional, responsive and demand driven.

Positive effects on the structure and functioning of the participating NGOs included **improved understanding of the issues affecting PLHA** and **increasing acceptance of PLHA** by HIV negative service providers, resulting in changes in staff attitudes towards PLHA, and **integration of advocacy** for the rights of PLHA into the work of the organisation. PLHA involvement has also improved the **credibility** of the organisations with communities and donors, and catalysed **collaboration and networking** with NGOs such as NZP+.

Negative effects on organisations

Few negative effects were reported, apart from concerns that PLHA might **convey inaccurate information** to communities if they are not well trained, that **services will be disrupted** when PLHA are frequently sick, and that the **organisation and its service providers may be stigmatised**.

Positive effects on families and communities

Positive effects of PLHA involvement on families included **more acceptance of and support for PLHA**; some families have been motivated to play a **more active role** in HIV/AIDS activities and services. Families have also benefited from PLHA involvement in terms of **learning to cope** with caring for

PLHA who are sick, and of material and psychological support, resulting in **improvements in family life**.

Communities have also benefited from improved **understanding of HIV/AIDS** and increased **openness and willingness to discuss HIV/AIDS**. This has **reduced stigma**, which has increased community **demand for VCT and other services** and **willingness to become involved in service delivery**.

Negative effects on families and communities

Stigma and discrimination towards families of PLHA by the community was the most commonly reported negative effect of PLHA involvement. Children of PLHA experience negative effects such as fear, anger, anxiety and denial. No negative effects of PLHA involvement on communities were mentioned.

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. Most factors that limit involvement of PLHA (see chapter 4) also limit the impact of involvement, even when PLHA are involved. *Access* benefits service users and their families and can be an entry point for further involvement. *Inclusion* has a very positive effect on PLHA when they receive some remuneration, improving their health and self-esteem. Although there are fewer benefits when *inclusion* is irregular and voluntary, PLHA who volunteer may learn useful skills. 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. 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. *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.

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 found 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 **recommendations** at the end of the report.

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*”.⁴

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 world⁵.

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 activities in Zambia. The study was carried out in three other developing countries – Burkina Faso, Ecuador and India – between September 1998 and August 2001. In Zambia, the study was conducted between March 2000 and June 2001.

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 (NGO) that supports community action on HIV/AIDS in developing countries. It currently has ongoing programmes in 19 countries, including Zambia.

Zambia was chosen as one of two African sites for the diagnostic study, as it is an example of a country with a high prevalence of HIV and with a long history of community involvement in the response to the epidemic. Some PLHA in Zambia began to be open about their status almost ten years ago, and the Network of Zambian People Living with HIV/AIDS (NZP+) has been active for several years. Other important reasons for selecting Zambia for the

⁴ Declaration of the Paris AIDS Summit, 1994.

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’.

study are the commitment of the Central Board of Health (CBOH) to a new HIV/AIDS strategy that is open to an increasing role of PLHA, and the supportive presence of the Zambia Integrated Health Programme (ZIHP)⁶.

Study objectives

The objectives of the study were:

- To describe the current ways in which PLHA are involved in Non-Government 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 Zambia

In order to study PLHA involvement at the community level in Zambia, four NGOs – two based in the Copperbelt, one in Lusaka, and one in a rural area south of Lusaka – were invited to participate in the research:

- Copperbelt Health Education Project (CHEP)

⁶ ZIHP is supported by USAID, and the International HIV/AIDS Alliance is one of the partners of the programme (see 2.6 in this report).

- Hope Humana People to People (Hope)⁷
- Kara Counselling and Training Trust (Kara)
- Salvation Army Chikankata Hospital Health Services

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 Lusaka, which consisted of a co-ordinator and four research assistants for the initial phase of the study and data collection, and one research officer and one research assistant for data classification, analysis, and report writing. The researchers were trained and supported by the study co-ordination team based at the International HIV/AIDS Alliance in the United Kingdom and Horizons in Washington D.C. The research team also received administrative support from the Population Council office in Zambia.

The Network of Zambian People Living with HIV/AIDS (NZP+) provided advice and *assistance* before and during the implementation of the study and is closely associated to the dissemination and utilisation of the results.

The USAID Mission in Zambia provided support to the national and international research teams at various levels: logistical, methodological and psychological.

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 Zambia and the response of government and civil society.

In the third chapter, we will describe what forms of involvement of PLHA we observed in Zambian NGOs and CBOs, introducing a new general typology of

⁷ Hope is actually a project of the NGO DAPP (see chapter 3), but it will be referred to as an 'organisation' in this report.

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, organisations 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 Zambia⁸, 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 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

⁸ The study was conducted simultaneously in India and Zambia.

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.



Orientation workshop: making the research process accessible to study participants

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

What	How
Design and preparation of the study	
Discussion on the relevance of the study for the participating NGOs and Zambia	⇒ Meetings with the international study co-ordination team
Adaptation of the study methodology and data collection tools to the Zambian context	⇒ Participation in a five-day orientation workshop with the national and international researchers (Horizons and International HIV/AIDS Alliance study co-ordination team)
Presentation of the study to other stakeholders in Zambia	⇒ Participation in a one-day meeting with stakeholders ⁹
Appointment of “contact persons” within each organisation to liaise with research team	⇒ Meetings within each NGO
Definition of sample population for each organisation (categories and numbers of respondents)	⇒ Meetings between contact persons and research team
Identification and mobilisation of study respondents	⇒ Work carried out by contact persons within each NGO
Data collection	
Circulation of consent forms and monitoring of informed consent process	⇒ Work carried out by contact persons together with researchers within each NGO
Use of Photovoice ¹⁰ to collect information	⇒ Photographs taken by representatives of NGOs to illustrate PLHA involvement in their organisation
Training of researchers to help them cope with psychological effects of the repeated exposure to suffering of PLHA	⇒ Workshop facilitated by a PLHA member of NZP+
Data analysis	
Validation of data	⇒ Review by contact persons and 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

⁹ Stakeholders included representatives of: governmental bodies, bilateral donors, UN agencies, major national and international NGOs with programmes in Zambia, and the media.

¹⁰ See detailed explanation of Photovoice under 1.3.

	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 researchers¹¹, although HIV positive people had been encouraged to apply when positions were advertised. 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 Zambia was an orientation workshop held in March 2000¹². Representatives from the four participating NGOs, NZP+, the International HIV/AIDS Alliance, Horizons and the Population Council, 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 Zambian 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.
- 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 Zambian context.

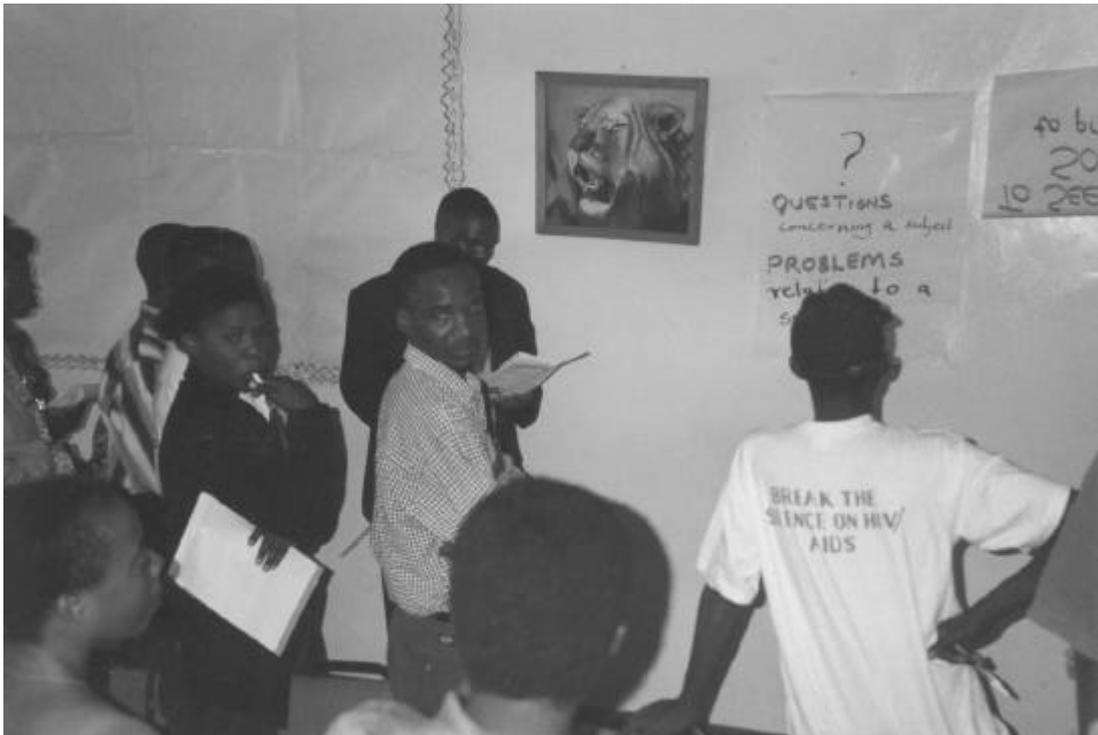
The workshop brought representatives of NGOs and researchers together in a safe and supportive learning environment so they could get to know each other before fieldwork started. It was also an opportunity to test the communication skills and attitudes toward PLHA of the applicants to the position of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

¹¹ Obviously, researchers were not requested to disclose their HIV status, whether positive or negative, to their colleagues and supervisor.

¹² The full report of the orientation workshop is available.

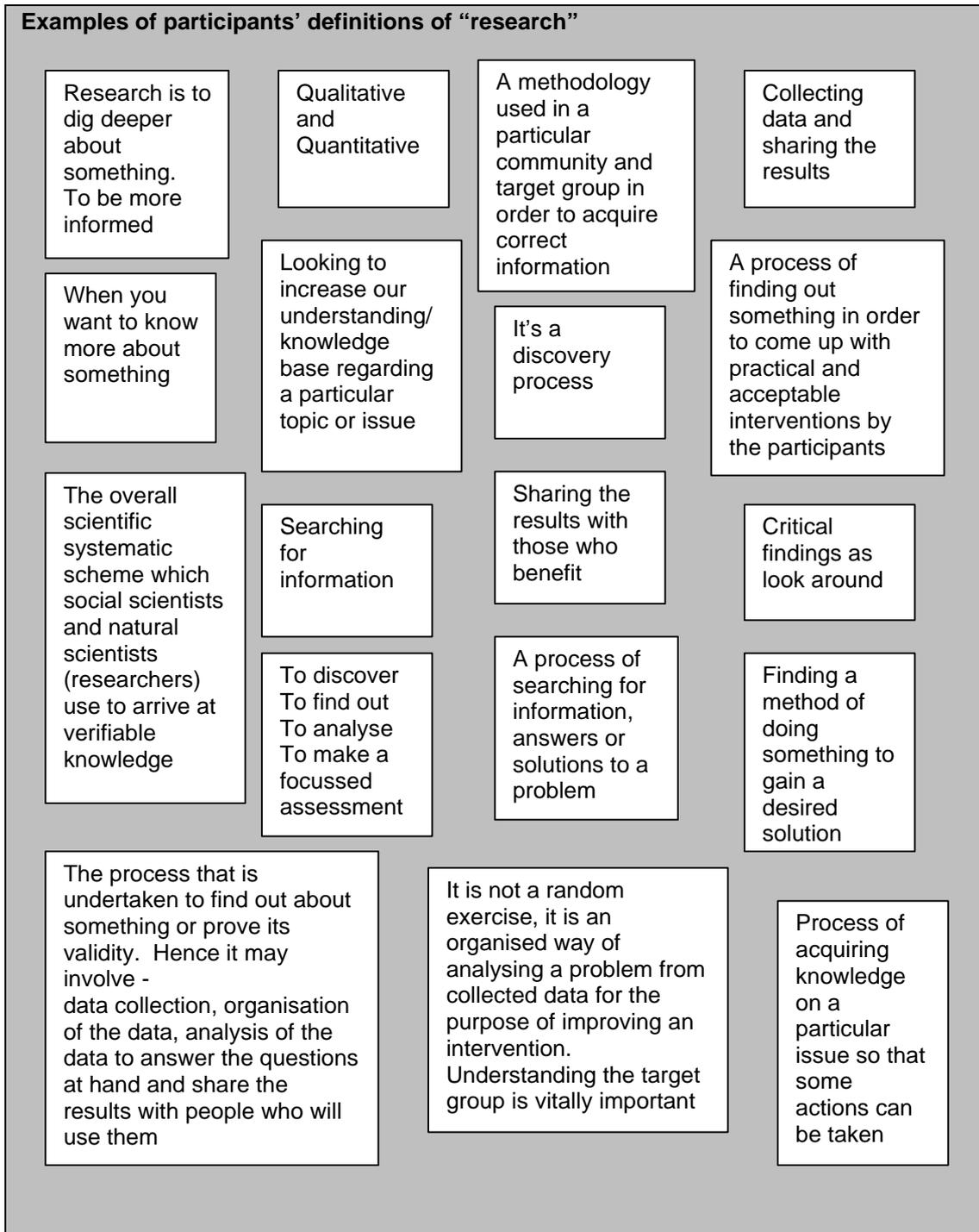
during the workshop, the study co-ordination team finalised the selection only at the end of the workshop.

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 and reviewing some data collection tools.



Orientation workshop: researchers and study participants discussing research together

Box 1.1
Results of a brainstorm during the orientation workshop:
What is research?



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 interviews¹³. 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.



The research team in Zambia: the research officer with one of the research assistants

¹³ Number of interviews and Focus Group Discussions is presented in table 1.2.

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.

Table 1.2
Discussion with study participants on advantages and disadvantages of several data collection techniques during the Orientation workshop¹⁴

One-to-one in-depth interview	
Advantages	Disadvantages
<ul style="list-style-type: none"> • Opportunity for probing • Generates a lot of information in a short time • Confidentiality • Personal, allows for rapport to be established 	<ul style="list-style-type: none"> • Expensive • Time-consuming • Could be biased • Can be awkward – too intimate • Can be intimidating • Danger of coercion • May limit response
Focus Group Discussion	
Advantages	Disadvantages
<ul style="list-style-type: none"> • Group dynamic can encourage exchange of views • Larger number of people reached than in one-to-one interview 	<ul style="list-style-type: none"> • Some people find it hard to open up in a group • Danger of domination by one/some participants • Some topics may be too sensitive for a group discussion –e.g. condoms, marriage and sexual partners • Some participants may feel intimidated by note taker – use of tape recorder cited as a way of avoiding this • Findings cannot be generalised to rest of population

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 (see Table 1.3 on page 25 for socio-demographic profile of respondents).

¹⁴ Report of the Orientation Workshop.

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, outreach and peer educators, Home Based Care (HBC) providers, community nurses, Voluntary Counselling and Testing (VCT) providers and counsellors, supervisors, trainers and managers, and other care and prevention workers).
- PLHA and persons affected by HIV/AIDS who are beneficiaries of the services delivered by these NGOs (including support group members, participants in skills training and positive living courses, HBC patients).
- Other beneficiaries (for example, recipients of community or workplace outreach activities).
- 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 1.2

Selection of study respondents from NGOs

In order to choose 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:

- **CHEP** – Outreach education, support to groups of PLHA and affected people
- **Hope Humana** – Positive Living Advocacy Course, support to groups of PLHA and affected people, counselling
- **Kara Counselling** – Skills Life Training Programme, outreach education, counselling
- **Salvation Army** – Activities of Care and Prevention Teams (CPTs) in the community

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, or volunteers of CPTs for Salvation Army.
- 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.

For one of the organisations, Salvation Army, we focused on the involvement of PLHA at the community level and therefore the vast majority of the respondents came from CPTs. Two CPTs were part of the sample (from a total of 24): one as an example of a community where there is some active and visible PLHA involvement, and the other as an example of a very rural community where until now there has not been any such involvement.

A total of 257 participants – 223 respondents from the 4 participating NGOs (see Table 1.1) and 34 key informants – were involved in the study. Participants and key informants were involved in one-to-one interviews, group interviews and/or focus group discussions as shown in Table 1.2.

Table 1.3
Study participants from NGOs

NGO	Service providers	Service users	Relatives of PLHA service providers	Total
CHEP	15	50	1	66
Hope	14	29	3	46
Kara	15	30	1	46
Salvation Army	57	6	2	65
Total	101	115	7	223

The sample of service providers represented at least 20% of staff members in all NGOs and up to 41% (Hope Humana), except for Salvation Army where the percentage of staff was lower (7%) because we gave priority to volunteers of CPTs who were the core population. The totality of the volunteers of the two CPTs selected participated in the study.

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

Fifty percent of the study participants were PLHA, whether service providers or users of the four NGOs.

The four NGOs are not representative of all NGOs working on HIV/AIDS in Zambia, but they are definitely very good examples of organisations who provide a wide range of innovative HIV/AIDS services to a relatively large number of beneficiaries.

Table 1.4
Data collection techniques

Category	N°. of one-to-one interviews	No. of group interviews	No. of focus group discussions
Service providers	13	11	3
PLHA service providers	11	2	-
Relatives of PLHA service providers	7	-	-
PLHA beneficiaries/ support group members	10	-	8
Other beneficiaries	30	2	-
Key informants	24 ¹		1 ²
Total	95	15	12

1. Key informants interviews with representatives of government including CBOH, MOH, Ministry of Defence, National AIDS Council; multilateral and donor agencies including USAID, UNAIDS, United Nations Development Programme (UNDP), United Nations Volunteers (UNV); NGOs including NZP+, Family Health Trust (FHT), Catholic Diocese Ndola; health professionals including those working for DHMTs, University Teaching Hospital (UTH); and private sector companies.
2. Focus group discussion was held with a support group of PLHA who are not involved in any NGO and are not beneficiaries of the services provided by any of the participating NGOs.

The following table presents the profile of the respondents¹⁵. Other tables included in annex 1 present in more detail the profile of the service providers and service users of the four participating NGOs.

Table 1.5
Profile of respondents

Variable	Men		Women		All	
	Frequency	%	Frequency	%	Frequency	%
Age						
15 - 24	7	6%	14	12%	21	9%
25 - 34	32	29%	53	46%	85	38%
35 - 44	39	35%	28	25%	67	30%
45 - 54	25	23%	12	11%	37	17%
55 and over	7	6%	7	6%	14	6%
Total	110	100%	114	100%	224	100%
Marital status						
Never married	19	17%	11	10%	30	13%
Married	69	63%	43	38%	112	50%
Living together	2	2%	0	0%	2	1%
Widowed	12	11%	39	34%	51	23%

¹⁵ This table is based on data collected through a questionnaire administered to 219 respondents: 209 service providers and service users from the four participating NGOs, and 10 PLHA who belong to a small self-help group which does not have any link with the NGOs. However, the total of respondents is 224 because of five duplicates that could not be identified for technical reasons.

Divorced	8	7%	19	17%	27	12%
Not living together	0	0%	2	2%	2	1%
Total	110	100%	114	100%	224	100%
Church						
Catholic	2	2%	13	11%	15	7%
Protestant	35	32%	48	42%	83	37%
Muslim	49	45%	40	35%	89	40%
Other	24	22%	13	11%	37	17%
Total	110	100%	114	100%	224	100%
School						
No education	2	2%	13	11%	15	7%
Primary	35	32%	48	42%	83	37%
Secondary	49	45%	40	35%	89	40%
Higher	24	22%	13	11%	37	17%
Don't know	0	0%	0	0%	0	0%
Total	110	100%	114	100%	224	100%
Ethnic group						
Bemba	39	35%	44	39%	83	37%
Tonga	34	31%	24	21%	58	26%
Northwestern	3	3%	3	3%	6	3%
Nyanja	18	16%	28	25%	46	21%
Barotse	5	5%	2	2%	7	3%
Mambwe	2	2%	7	6%	9	4%
Other	9	8%	6	5%	15	7%
Total	110	100%	114	100%	224	100%
Occupation						
Housework	1	1%	3	3%	4	2%
Public employee	15	14%	13	11%	28	13%
NGO and private sector employee	28	25%	13	11%	41	18%
Farmer	24	22%	16	14%	40	18%
Student	4	4%	6	5%	10	4%
Self-employed	17	15%	22	19%	39	17%
Unemployed	18	16%	27	24%	45	20%
Other	3	3%	5	4%	8	4%
No response	0	0%	9	8%	9	4%
Total	110	100%	114	100%	224	100%
Profession						
Clinical officer	4	4%	0	0%	4	2%
Nurse/midwife	1	1%	7	6%	8	4%
Psychologist	0	0%	1	1%	1	0%
Social worker	1	1%	0	0%	1	0%
Clergy	5	5%	4	4%	9	4%
Teacher	23	21%	10	9%	33	15%
Other	75	68%	91	80%	167	75%
No response	1	1%	1	1%	2	1%
Total	110	100%	114	100%	224	100%

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 Zambia.

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. This was followed by a 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.

Box 1.3 **The data analysis workshop**

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

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.

Analysis of the data at the general level

Researchers presented general trends in a participatory and accessible way, which allowed representatives from NGOs to discuss and refine the analysis. Participants also validated the typology of involvement (see chapter 3).

The profiles were further refined and finally transformed into summaries of findings¹⁶.

Box 1.4**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 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.

“When the workshop started and I heard about Ecuador and India, I was worried and thought I wouldn’t be able to cope... but now I feel that I understand the study and feel like a researcher.” (Feedback from a participant during the orientation workshop)

¹⁶ The four Summaries of findings are available.

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.

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.¹⁷ They were recruited by the participating NGOs and agreed to disclose their HIV status to the research team.



Data analysis workshop: researchers and a representative of the Salvation Army discussing the analysis of the findings

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.

¹⁷ These are people who are HIV positive or have AIDS who receive care and support from NGOs without knowing their status.

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 easy to identify and mobilise the right categories of respondents. For example, researchers wanted to have focus group discussions with people who had been reached by HIV positive outreach educators but some organisations could not mobilise this category of respondents because they could not trace them.
- 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.
- As a result, the data collected to measure impact of involvement of PLHA on some services, such as outreach education, is limited (see also chapter five).

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.

Efforts made to ensure that the research findings will be translated into action more widely include:

- Providing follow-up technical support for implementation of the strategies identified by NGOs during the study.

- Promoting links between participating NGOs, NZP+, ZIHP and the Government of the Republic of Zambia (GRZ).
- Disseminating the national report synthesising lessons learned at country level and key findings to policy makers, donors, other NGOs and CBOs, District Health Management Teams (DHMTs), church organisations, and the media.
- Exploring the potential to incorporate strategies to increase PLHA involvement within the ZIHP framework.
- Developing strategies to promote PLHA involvement in partnership with NZP+.

Box 1.5
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 record number of PLHA (50% of the study population) were identified and mobilised by NGOs and agreed to participate in interviews and focus groups 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 Zambia

2.1 Introduction

Zambia has a population of almost 9 million, 46.5% aged under 15 years (UNDP 1999) and 43% living in urban areas. Poverty is widespread, with a GNP per capita in 1997 of US\$370. An estimated 70% of households lived below the poverty line in 1996, with rural and female-headed households disproportionately poor. Total adult literacy rate is estimated at 78%. The male and female secondary school enrolment is respectively 35.1 and 22.2% (UNESCO 2000). Health services are under-resourced and health status is poor, with maternal and infant mortality rates of 940/100,000 and 80/1,000 live births respectively and life expectancy at birth of 40 years (UN data 1998). HIV/AIDS has had a devastating impact on all sectors and at all levels (see examples in Box).

Box 2.1 Impact of HIV/AIDS in Zambia

Macroeconomic:

- Annual loss in GDP growth per capita as a result of AIDS is predicted to be 1.15% by 2010 (Bonnell R, 2000, *What makes an economy HIV-resistant?* Draft report presented to International AIDS Economic Network Symposium, Durban, 7-8 July).

Household:

- AIDS-affected households in Kafue reported annual income levels of 30-35% less than unaffected households (Mutangadura G and Webb D, 1998-9, *The socio-economic impact of adult mortality and morbidity on urban households in Zambia*, AIDS Analysis Africa 9:4).
- 60% of families of AIDS patients in Mansa district perceived malnutrition to be a major risk (Kasawa, 1993, Unpublished report), and analysis of 49 case studies of families of AIDS patients found half facing food shortages (Haworth A, Kalumba K et al, 1991, Paper presented at VII International Conference on AIDS, Florence).

Private sector:

- The costs to IDENI petroleum for AIDS-related medical and funeral expenses in the early 1990s exceeded their profits of US\$24,500 (ILO, 1995, *The impact of HIV/AIDS on the productive labour force in Zambia*, EAMAT Working Paper no. 5, Addis Ababa).

Education:

- 56,000 primary school children lost a teacher to AIDS in 1999 (UNICEF, 2000, *The progress of nations 2000*, Background Paper, New York), and the number of teacher deaths in 1998 was equivalent to two thirds of the annual output of trained teachers (Kelly M, 1999, *The impact of HIV/AIDS on schooling in Zambia*, Paper presented at XI International Conference on AIDS and STDs in Africa).

- 55% of AIDS-affected households in Mansa were unable to meet the costs of children's education (Kasawa, 1993, Unpublished report), and analysis of 49 case studies of families affected by AIDS throughout Zambia found that 56 of 215 children had been forced to leave school (Haworth A, Kalumba K et al, 1991, Paper presented at VII International Conference on AIDS, Florence).

Health services:

- Health care worker mortality in two hospitals increased 13-fold between 1980 and 1990, largely due to HIV (Buve A et al, 1994, *Mortality among female nurses in the face of the AIDS epidemic: a pilot study in Zambia*, AIDS 8(3):396).
- In 1993, at Monze and Choma hospitals, 43% and 47% respectively of bed days were taken up by HIV-related disease (Foster S, 1993, *Cost and burden of AIDS on the Zambia health care system: policies to mitigate the impact on health services*, Lusaka, USAID, London School of Hygiene and Tropical Medicine (LSHTM)).
- AIDS care expenditures are projected to rise from US\$12.9 million in 1995 to US\$21 million in 2005 (Ministry of Health and Central Board of Health, 1997, *HIV/AIDS in Zambia: Background projections, impacts and interventions*).

2.2 Epidemiology of HIV/AIDS in Zambia

2.2.1 AIDS cases, HIV prevalence and incidence

The first AIDS case was reported in Zambia in 1984. The national epidemiological surveillance and research system, established by the National AIDS Surveillance Committee in 1986, includes sentinel surveillance in 22 antenatal clinics, local population-based surveys, and hospital notification of AIDS cases. While case reports come from surveillance systems of varying quality, antenatal data is considered to be reliable and antenatal care attendance is high (the 1998 Zambia Sexual Behaviour Survey (SBS) found that 92.3% of women respondents who had given birth in the two preceding years had used an antenatal clinic). The demographic impact of HIV/AIDS in Zambia is summarised in Table 2.1.

Table 2.1
Demographic impact of HIV/AIDS in Zambia (1999)

Estimated AIDS deaths (during 1999)	99,000
Estimated AIDS orphans (number of children who have lost a mother or both parents due to HIV/AIDS at age 15 years or less since the beginning of the epidemic) cumulative	650,000
Estimated orphans alive	447,114
Projected AIDS orphans (by 2010)	>1,000,000

Source: UNAIDS/WHO, June 2000

The number of reported AIDS cases to 1997 was 44,942.

However, there is significant under-reporting of AIDS cases for a variety of reasons. People may not seek hospital care, a diagnosis of AIDS may not be recorded due to the stigma attached to the disease, rural hospital and health facilities do not have the capacity to test for HIV infection, and a low proportion of the population has been tested. As of 1999, the Ministry of Health estimated the number of cumulative AIDS cases to be 600,000 and the number of Zambians infected with HIV to be 1,009,000 (923,000 adults and 87,000 children). According to UNAIDS' figures, the prevalence is slightly lower at 830,000 adults and 40,000 children. Based on these figures, the prevalence rate is 19.9% (in the sexually active population).

Table 2.2
Estimated number of PLHA in Zambia (December 1999)

Adults and children	Adults (15-49 years)	Adult rate (%)	Women (15-49 years)	Children (0-14 years)
870,000	830,000	19.95	450,000	40,000

Source: UNAIDS/WHO, June 2000

However, the national HIV prevalence masks differences between urban and rural prevalence – estimated to be 33% and 12% respectively – and different populations. For example, in 1998, HIV prevalence among women tested at 18 antenatal clinics ranged from 5% to 31%. Rates tend to be higher in STD¹⁸ patients: for example, in 1991, 60% of male STD patients and 69% of female STD patients tested in Lusaka were HIV positive. Outside Lusaka, 41% of female STD patients tested were HIV positive (UNAIDS, *AIDS in Africa Country by Country: Zambia*, October 2000).

Trends show a rapid rise in HIV prevalence among women attending antenatal clinics between the mid-1980s and early 1990s. In women attending antenatal clinics in Lusaka and Ndola, the main urban centres in Zambia, prevalence increased from 5% in 1985 to 27% in 1992, but remained stable at this rate until 1998. Although overall HIV prevalence rates remained the same between 1992 and 1998, rates declined among the youngest age group. In 1993 in Lusaka, 28% of tested antenatal clinic attendees aged less than 20 years were HIV positive, but this fell to 15% by 1998, and in Ndola the rate fell from 21% to 16% between 1994 and 1998. In women attending antenatal clinics outside the major urban centres, prevalence remained stable at 14% between 1994 and 1998, but the rate among those aged less than 20 years declined from 14% to 6% (Ministry of Health/Central Board of Health). With a slow decline in prevalence, the Ministry of Health projects an annual incidence of approximately 100,000, and that there will be 1.26 million people with HIV and a cumulative total of 2.26 million deaths by 2014.

¹⁸ Sexually Transmitted Disease.

2.2.2 Age and sex data

About 84% of AIDS cases are in adults aged 20-49. Peak ages for women are 20-29 years and for men are 30-39 years. Women aged 15-19 years are five times more likely to be infected than men in the same age group.

2.2.3 HIV transmission

Based on available information, heterosexual transmission is responsible for approximately 90% of cases. Related to this, mother-to-child transmission is also significant, and there are an estimated 25,000 new infections in infants born to HIV positive mothers each year. Factors contributing to heterosexual transmission in Zambia include prevalence of other STDs, multiple sexual relationships, low condom use, poverty, low status of women, high levels of urbanisation and population mobility, early sexual activity, and cultural practices, such as dry sex.

2.2.4 Geographical distribution

HIV/AIDS has spread throughout Zambia, and cases have been reported in all 72 districts. Prevalence rates are significantly higher in urban areas, with the highest rates in Lusaka and Copperbelt provinces (see Table 2.3).

Table 2.3
HIV prevalence by province (1998)

Province	Prevalence (%)
Lusaka	27.3
Copperbelt	26.3
Western	18.9
Central	18.7
Eastern	16.5
Luapula	16.2
Southern	15.7
Northern	13.5
North-western	11.7

Source: HIV/AIDS in Zambia, CBOH/MOH, September 1999

Rates are also high in areas with a concentration of migrant workers, border areas with significant cross-border trade and population movement, refugee camps, and along major communication and transport routes. For example, high rates of HIV infection are found in Chipata, near the Malawi border and Livingstone near the Zimbabwe border, both of which are transport and trading centres in Chirundu and Nakonde, the two largest border checkpoints in Zambia and among migrant fishermen and fish traders in Luapula province.

2.3 Knowledge, attitudes and behaviour

2.3.1 HIV/AIDS

Self-reported data on sexual behaviour and condom use are available from the 1991 prevention indicator survey, 1996 Demographic and Health Survey (DHS) and 1998. The SBS provides information about preventive practices and attitudes towards HIV/STD; condom knowledge, access and use; sexual behaviour; and attitudes towards gender, sex, STD and AIDS, based on a national representative sample of men and women aged 15-49 years (sample size: 1,943 households, 1,655 interviews with men and 2,040 with women).

Knowledge

In the SBS, virtually all respondents in urban and rural areas had heard of AIDS, 86% of men and 78% of women thought HIV could be avoided, and 88% of men and 82% of women knew that a healthy person could have HIV. However, misconceptions remain. For example, 29% of respondents thought HIV could be transmitted by mosquitoes and 30% by witchcraft.

When asked about ways to prevent HIV/AIDS, 67% of men and 57% of women mentioned condom use, an increase since the 1996 DHS when figures were 49% and 38% respectively. In addition, 35% men and 30% women mentioned having one faithful partner. However, 25% of respondents reported that there was no way to avoid HIV and more than 50% did not think that condoms protect fully against HIV. Most men and women (96% and 92%) had heard of the male condom and 87% and 69% respectively knew where to obtain condoms. Adolescents aged 15-19 years had lower levels of knowledge than adults about how to prevent HIV and where to obtain condoms.

Attitudes

The majority of SBS respondents disapproved of extramarital sex. However, while only 7% thought it was acceptable for a married man to have extramarital relations, 19% of men and 29% of women thought a man could not be sexually satisfied with one partner. More men (57%) than women (42%) considered it acceptable for an unmarried woman to buy condoms. Only 25% of men and 30% of women agreed that a married woman could protect herself against HIV/STD if she suspects her husband is infected.

Behaviour

In the 1998 SBS, the proportion of sexually active adults who reported having a non-regular partner in last 12 months was 39% for men and 17% for women, with almost no rural-urban difference and little change since the 1996 DHS. The only change in behaviour since the DHS was an increase in the proportion of men reporting themselves as married or cohabiting and a decrease in the proportion of unmarried men reporting two or more sexual partners in the last year. However, data on partnership characteristics from the SBS show that a

quarter of non-marital partnerships reported by men lasted less than one week, and that transactions in cash or kind are common.

Table 2.4
Behavioural indicators (1998)

Behavioural indicators	Age group	Male (%)	Female (%)
Reported condom use during most recent intercourse with a non-regular partner	15-49 years	33	24
Reported non-regular sexual partnership over a 12-month period	15-49 years	39.3	16.8

Source: UNAIDS, October 2000

In 1998, reported condom use was higher in urban areas (37% and 27% in urban men and women, 27% and 17% in rural men and women). Table 2.5 shows reported condom use with non-regular partners. However, a commercial sex worker survey in Ndola found that only one in four sex workers used a condom with their last client, and less than one in seven use a condom with all clients. Reported condom use within marriage was low – 6% of male and 4% of female respondents reported condom use during the last sexual intercourse.

Although the majority of adolescent respondents to the SBS were sexually active (62% males and 59% females reported that they had had sex) condom use in this age group is low. For example, of 210 adolescent girls and boys, 60% did not use condoms, 33% sometimes use condoms, and only 7% had used a condom consistently in the previous four weeks. High rates of sexual activity among adolescents are supported by data about adolescent pregnancy.

2.3.2 PLHA

The National HIV/AIDS Strategic Framework 2000-2002 reports that, in many districts of Zambia, PLHA and their families and friends are stigmatised and experience some form of discrimination, due to beliefs that AIDS is associated with illicit sex and is the result of sin, and misconceptions about how HIV is acquired. The Framework also highlights the impact of stigma and discrimination, in terms of increasing suffering among PLHAs and delaying community responses to HIV/AIDS.

Lack of access to appropriate information, voluntary counselling and testing, and to other medical and support services, in addition to fear of stigma and discrimination, means that few individuals are willing to find out their HIV status, while those that have done so are unwilling to divulge their status. When an individual is ill, although it is often suspected to be due to HIV, this may not be acknowledged until after death. Even then, HIV/AIDS is often denied as a cause of death and a less stigmatising reason, such as pneumonia or malaria, is given.

The SBS asked respondents about their exposure to HIV and about issues of stigma. Although 70% knew someone who had died of AIDS, only 42% reported that they knew someone living with HIV, despite the fact that an estimated one in five of the adult population is infected. Only 8% (9% of men, 7% of women) said they had been tested for HIV and only 6% (7% of men, 5% of women) knew their HIV status. The majority (85%) said they would be willing to care for a family member with AIDS, but 54% said that a nurse with HIV infection should not be allowed to continue working. Among adolescents the figure for HIV testing and knowledge of HIV status was lower. Only 3% of adolescent men and 6% of adolescent women had had a test, and only 2% and 4% respectively knew their status. Fewer adolescents than older respondents were willing to care for a family member with AIDS.

The District Response Initiative (UNAIDS/NAP) carried out an assessment in four districts in March 1998, which included asking workers in private sector organisations whether they agreed or disagreed with various statements about HIV/AIDS. Despite the fact that the majority knew someone with HIV, many had negative attitudes. For example, 34% felt that people with HIV had led immoral lives and 39% felt that PLHA should be isolated to stop the spread of the disease. And despite workplace education initiatives, 18% did not like the idea of working with HIV-infected people and 46% did not like the idea of sharing cups and plates with other infected employees.

“One of the difficulties we face in this country despite having the HIV epidemic now for the last 15-16 years, we still have an extremely high level of stigma. In our communities, people hardly talk about HIV/AIDS. Even as a family inside the house ... if there is someone suffering from HIV/AIDS, clearly no one will say they are suffering from HIV/AIDS ... they will say something else because of fear of discrimination and social costs” explains a representative of the CBOH interviewed during the study.

2.4 Government policies on HIV/AIDS in Zambia

2.4.1 Government structures dealing with HIV/AIDS

The National HIV/AIDS/STD/TB Council, launched in 2000, is intended to coordinate the national response to HIV/AIDS, STD and TB. Technical guidance and implementation of the National HIV/AIDS Strategic Framework (2000-2002) is the responsibility of the Secretariat, and sector ministries – each of which has an HIV/AIDS focal point – are being encouraged to integrate HIV/AIDS into their programmes. The Council includes nine technical working groups, which focus on issues including Mother to Child Transmission (MTCT) and home-based care and support. The Council and Secretariat are supervised by a Committee of Ministers, which includes representatives from Ministries of Mines and Minerals Development, Health, Education, Communications and Transport, Presidential Affairs, and Information and Broadcasting Services.

Table 2.5
Government structures and plans to address HIV/AIDS 1986-1998

1986	National AIDS Surveillance Committee, Intersectoral AIDS Health Education Committee, National AIDS Prevention and Control Programme (NAPCP) established, and AIDS co-ordinators appointed at provincial and district levels.
1987	Short Term Plan launched, prioritising blood safety.
1987	1 st Medium Term Plan (1988-1992) launched, prioritising TB and leprosy, IEC, counselling, laboratory support, epidemiology and research, STD and clinical care, programme management, and HBC.
1992	NAPCP restructured, combining with other programmes to become National AIDS, STD, TB and Leprosy Programme (NASTLP).
1993	2 nd Medium Term Plan (1994-1998) launched, prioritising the need for an intersectoral approach, involving government ministries, civil society and the private sector and PLHA, and prioritising increased access to STD care, strengthening condom promotion and distribution, TB control, and developing effective AIDS impact mitigation strategies.
2000	National HIV/AIDS/STD/TB Council and Secretariat launched, to catalyse and facilitate the implementation of the National HIV/AIDS Strategic Framework (2000-2002), and advocate for effective multisectoral approaches to prevention of HIV/AIDS transmission, care and social support, and impact mitigation for those infected and affected.

National level implementation is the responsibility of 14 ministries, with the Central Board of Health responsible for health service delivery. District Health Management Teams play a key role in district and community level implementation, with the Ministry of Health and Ministry of Local Government and Housing taking the lead in co-ordinating a multisectoral response at district and community levels. District Development Co-ordinating Committees (DDCCs), responsible for district development, are to establish committees to promote collaboration and involvement of NGOs, CBOs and the private sector in planning and implementing a multisectoral response.

Box 2.2

National HIV/AIDS Strategic Framework: Priorities

Geographic – Lusaka, Copperbelt Province, districts along the main trucking routes, districts with well-defined fishing areas in Luapula Province and Southern Province, districts with seasonal workers in rural areas, districts with refugee populations, and towns with frequent cross-border traders.

Sub-populations – People living with HIV/AIDS, orphans, commercial sex workers, public sector workers, private sector workers.

Interventions – Promotion of a multisectoral response, promotion of behaviour change, STD control, destigmatisation of HIV/AIDS, voluntary counselling and testing, reducing mother-to-child transmission, home-based care and support for people living with HIV/AIDS, community-based support for orphans and vulnerable children, and improved hospital care.

Source: UNAIDS Zambia, June 2000

The annual cost of scaling up HIV/AIDS programmes in Zambia is estimated at between US\$35-55 million (World Bank and UNAIDS, 2000, *Costs of scaling up HIV programmes to a national level for sub-Saharan Africa*, Draft report). In the second half of 2000, GRZ took steps to cost the second phase of the Strategic Framework for presentation to a donors' pledge meeting. More recently, GRZ has also proposed an accelerated response to HIV/AIDS supported by a multidonor debt swap¹⁹.

Government prevention, care and support efforts have focused on interventions to reduce HIV/STD transmission, to reduce the socio-economic impact of HIV/AIDS on individuals and families at the household, workplace and societal level, and to mobilise local and external resources.

2.4.2 Prevention policies in Zambia

Interventions to reduce HIV/STD transmission have included Information, Education and Communication (IEC), condom promotion and distribution, life skills programmes, workplace programmes, and efforts to strengthen STD control and ensure blood safety.

IEC programmes have focused on use of mass media to inform the general public about HIV/AIDS, using television, radio, billboards and pamphlets. Messages have focused on promotion of condom use, delayed sexual activity, and mutual faithfulness.

Social marketing has been the main strategy for increasing the acceptability, availability and use of condoms, since the launch of a condom social marketing programme in 1992. Male condoms are distributed through health centre pharmacies and drug stores, and non-traditional outlets such as bars and provisions stores. More recently, female condoms have been introduced and are sold through various outlets. The District Response Initiative (DRI) study of four districts highlighted the need to improve condom availability in rural areas, where demand exceeds supply.

The Ministry of Education has introduced a range of HIV/AIDS/STD and reproductive health teaching materials into the school curriculum from primary to tertiary levels. The Ministry of Sport, Youth and Child Development has developed the National Programme of Action for Youth to address general problems faced by youth, in collaboration with the Ministry of Health and Ministry of Information and Broadcasting Services. Efforts have been made, through training of health workers, to make health centres more youth-friendly.

¹⁹ It involves the following initiatives: Zambian HIV/AIDS Council and Secretariat; Ministry of Health Strategic Plan; Inter-ministerial Orphans Response Strategic Plan; Ministry of Education Basic Education Sub-sector Investment Programme; Ministry of Education Training Sub-sector Investment Programme; National Food and Nutrition Commission Plan of Action; and Strategic Plan for Strengthening the NGO Response to HIV/AIDS.

Workplace programmes have been implemented by the National AIDS, STD, TB and Leprosy Programme (NASTLP) in the public sector and through the Zambia Federation of Employers in the private sector, and companies such as Barclays Bank and Nakambala Sugar Estates have HIV/AIDS prevention programmes. The military has developed its own programme, the Zambia Defence Forces HIV/AIDS Prevention, Care and Support Programme, implemented by the Defence Forces Medical Services since 1993. The Ministry of Home Affairs, together with United Nations High Commissioner for Refugees (UNHCR), Young Men's Christian Association (YMCA) and United Nations Children's Fund (UNICEF), is implementing programmes with refugees.

STD diagnosis and treatment is provided through a network 62 STD clinics in central, provincial and district hospitals. Since 1990, the government has focused on improved training and provision of diagnostic equipment and supplies at these clinics, and, in principle, more than 80% of health centres now use the syndromic management approach. All blood products used in district, provincial and central hospitals are screened, as are prospective donors.

Regarding prevention of mother-to-child transmission, Voluntary Counselling and Testing (VCT) is not widely available and only 5% women have been tested and know their HIV status. Alternatives to breastfeeding for HIV positive women are the subject of ongoing debate, and there is currently no policy on using antiretrovirals for prevention of MTCT, although consideration is being given to introduction of nevirapine. However, programmes supported by UNAIDS, its co-sponsors and bilateral partners, include prevention of mother-to-child transmission in three sites, and planned expansion of VCT to all districts.

There is limited information about the impact of prevention interventions implemented by government, NGOs or the private sector. The DRI, for example, has highlighted difficulties in evaluating impact due to a lack of baseline data, untargeted programmes, and inadequate monitoring systems.

2.4.3 Care and support for PLHA in Zambia

Health sector reforms and decentralisation, with many responsibilities delegated to District Health Management Teams (DHMTs), aim *"to improve the quality of life of all Zambians through the development of health care systems which provide equity of access to cost-effective, quality health care as close to the family as possible"*. HIV/AIDS services are included in a basic package of health care at district level. Data on access to health care (see Table 2.6) provide some indication of health service capacity to respond to HIV/AIDS.

Table 2.6
Access to health care in Zambia (1996)

Population with access to health services	Estimated %
Urban	34
Rural	14

Source: ZDHS, 1996

Despite health reforms and decentralisation, many health centres, especially in rural areas, do not have sufficient trained staff or drugs to manage HIV-related illnesses and opportunistic infections. As a result, many people seek care from secondary and tertiary health facilities, especially for treatment of opportunistic infections. Access to appropriate information, voluntary counselling and testing, and other medical and support services, is also limited and the majority cannot afford the cost of HIV testing. There is no public sector access to antiretroviral therapy. Church health facilities – mission hospitals and clinics – as well as traditional healers, provide a substantial proportion of health care, particularly in rural areas. There is a small private health sector, mainly in urban areas.

The Strategic Framework identifies improved hospital-based and home-based care (HBC) for PLHA, and improved support and care for PLHA, widows and orphans, among its priority areas. The government has encouraged the development of HBC programmes, most of which have been implemented by church-based NGOs. However, the Strategic Framework estimates that less than 20% of PLHA are in contact with HBC programmes, and care and support remain largely the responsibility of communities and individual households.

The government, under the leadership of the Ministry of Health and Central Board of Health, is also prioritising the care and support of orphans and widows. Limited support provided by the government's Public Welfare Assistance Scheme only reaches an estimated 2% of orphans. The government is therefore encouraging initiatives to support community capacity to develop local solutions, and recently established a Task Force on Orphans to co-ordinate NGO responses.

2.4.4 Legal framework for HIV/AIDS in Zambia

Zambia does not have any HIV/AIDS-specific legislation to protect PLHA against discrimination on the grounds of HIV (UNAIDS, June 2000). However, the National HIV/AIDS Strategic Framework identifies PLHA as a priority group and as essential partners in the Zambian response to HIV/AIDS, and also acknowledges the importance of protecting the human rights of PLHAs, to promote openness, tolerance and involvement of the public in HIV prevention programmes.

The Strategic Framework specifically states that *“in collaboration with civil society and legal affairs institutions, attention is now being focused on the rights of vulnerable groups such as women and children with the intent of*

mitigating the discriminatory aspects of HIV/AIDS. Much work remains to be done to address the society-imposed stigma associated with the condition”.

2.5 Civil society response

2.5.1 Social mobilisation

Zambia has many civil society organisations, including local branches of international NGOs, such as the Zambian Red Cross; indigenous NGOs, such as CHEP; CBOs; church organisations, such as the Christian Medical Association of Zambia with more than 50 organisational members; women’s and youth groups; co-operatives, such as the Zambian Women’s Finance Co-operative; trades unions and professional associations; and private sector associations, such as the Zambia Federation of Employers. Many civil society organisations in Zambia complement or supplement government services, for example Churches Medical Association of Zambia (CMAZ) mission hospitals, Zambia Open Community Schools. (*See How citizens associate in Zambia: A guide to NGOs and CBOs for parliamentarians*).

Civil society organisations are identified as a key partner in the intersectoral response outlined in the Strategic Framework. Different civil society organisations have responded to a greater or lesser extent to the HIV/AIDS epidemic.

The private sector has played a limited role, with the exception of companies such as Barclays Bank, which has set up a prevention and counselling programme for its staff. However, a business coalition on AIDS has recently been established and there is a forum for private sector interaction with government on HIV/AIDS-related issues.

NGOs have played a significant role in the response through a wide range of prevention, care and support initiatives, including prevention education, welfare and income-generating activities. In addition, there are NGOs working on a range of specific issues, gender, law, or with specific groups, such as: Tasintha targets sex workers and also provides education to miners and truck drivers. Church organisations have made an especially important contribution to provision of care and support, and national and district interfaith working groups have recently been established. NGOs, such as Children in Distress (CINDI) and Children in Need Network (CHIN), and church groups have been instrumental in programmes for orphans and widows, such as the Kwasha Mukweni project in Lusaka where women “caretakers” visit and monitor progress of orphans in their catchment area. However, NGO and CBO coverage is inadequate with most concentrated in Lusaka and other urban areas, and many are dependent on external funding.

The extent of civil society mobilisation and collaboration varies depending on the setting, and again is largely focused in urban areas. In Ndola, there is an Urban District AIDS Task Force, an informal network of organisations that aims to promote intersectoral collaboration, networking and community

participation. The Task Force involves over 50 stakeholders, including the DHMT, central hospital, NGOs such as CHEP, Hope Humana, Society for Women and AIDS in Zambia (SWAAZ) and NZP+, church organisations such as the Catholic Diocese, Zambian Red Cross, and representatives of the police, defence forces, prisons and city council. To date the Task Force has focused on training, strengthening and building the capacity of task force members, and developing a strategic plan for Ndola Urban district. Examples of activities have included condom distribution in workplaces, training employees as peer educators, training volunteers in HBC, and establishing a collection point for donated materials. The SEPO and Livingstone District Task Force has implemented a project, with funding from Project Concern International, targeting high-risk groups, such as cross-border traders. But in Lusaka, while there are many NGOs and CBOs working on HIV/AIDS – for example of the 48 organisations nationally working on youth, 38 work in the Lusaka area – there is no co-ordinating mechanism.

In 1999, 11 of the larger, more experienced NGOs – including CHEP, Kara, NZP+, CMAZ, Planned Parenthood Association of Zambia (PPAZ), SWAAZ, Children in Need Network (CHIN) – developed a collective proposal for accelerating and co-ordinating their HIV/AIDS work, in the context of the government's proposed multidonor debt swap scheme. The proposal emphasises NGO experience and strengths in community education, participation and mobilisation, and capacity to reach smaller NGOs and CBOs. However, there is neither an official forum through which government can interact with NGOs and CBOs nor a co-ordinating body for NGOs and CBOs. There also appears to be scope for expanding the contribution of NGOs and CBOs in the response to the epidemic. For example, the DRI study noted that less than 10% of 53 organisations assessed in four districts had integrated HIV/AIDS education into their developmental programmes and suggests that there is a need for increased community involvement and social mobilisation.

2.5.2 Background to PLHA involvement in NGOs in Zambia

The involvement of PLHA in Zambia, as in many other countries, is a phenomenon that has benefited from the external influence of donors and activists from countries in the North where involvement of PLHA happened very early in the history of the HIV/AIDS epidemic. Efforts to promote national policies to increase PLHA involvement are still largely driven by international donors.

Visible involvement of PLHA in service delivery started in 1990 when the Kara Counselling and Training Trust introduced “group outreach counselling”, mainly in workplaces. An outreach group of PLHA involved with Kara founded the Positive Living Squad in the early 1990s. A member of the Positive Living Squad and co-founder of NZP+, David Chipanta, attended a meeting sponsored by UNDP, which led to the formation of the Network for African People with HIV/AIDS (NAP+). Recognition that a regional network would not work without national networks led to the creation of the Network of Zambian

People Living with HIV/AIDS (NZP+), which was established in 1996. Another co-founder of NZP+, Winston Zulu, also became a board member of the Global Network of Positive People (GNP+), and was one of only two African members to attend to Paris Summit in 1994 that promoted the concept of GIPA. The UNV Pilot Project for Support of PLHA was initiated in 1998. Despite these initiatives, visible involvement remains limited and, of the estimated one million people living with HIV/AIDS in Zambia, only about 1,000 belong to NZP+.

NZP+, a national non-profit NGO, is based in Lusaka, and has affiliated support groups in the Copperbelt, Southern, Central, North Western, Northern and Lusaka provinces. It is currently funded by UNDP, and its collaborating partners include UNAIDS, United Nations Family Planning Association (UNFPA), Southern AIDS Training Programme (SAT), Project Concern International, and the NASTLP. NZP+ was established to improve the quality of life of PLHA and with a mandate to: protect and promote the rights, interests and responsibilities of PLHA; help reduce stigma attached to HIV/AIDS through narration of personal experience; form and strengthen support groups of PLHA; contribute to HIV/AIDS prevention and mitigation efforts; and facilitate the involvement and representation of PLHA in issues affecting them. NZP+ activities include:

- Organising conferences and workshops for PLHA to strengthen solidarity and encourage PLHA to participate in efforts against HIV/AIDS. NZP+ recently organised the first annual conference for PLHA and nine provincial capacity building workshops. It has also held a series of monthly AIDS debates in Lusaka, with funding from UNICEF, targeting opinion formers from government, sport, NGOs, the media and the church, to debate the impact of AIDS, reduce stigma and encourage action.
- Exchange visits within and outside Zambia to share knowledge.
- Production and promotion of information for PLHA about nutrition, human rights, positive living, drugs and therapies, topical issues through workshops, occasional publications and a quarterly newsletter, and to normalise attitudes towards PLHA.
- Formation and strengthening of support groups.
- Facilitating access to basic medical services.
- Representing the needs and interests of PLHA in issues affecting them, advocacy and lobbying for the rights of PLHA.
- Outreach AIDS Awareness Programme, so far covering over 200 workplaces in Lusaka alone. PLHA also share personal experiences in schools and health centres.
- Radio programmes where PLHA share experiences.

The Strategic Framework notes that, while NZP+ has developed a national presence, its programmes are less well developed in the provinces, and that there has been no systematic evaluation of PLHA programmes.

“NZP+ ... must be strengthened. In my opinion, I think it is still quite weak in terms of its capacity to organise the national membership. You know that there is membership in all the nine provinces and yet

you do not see much activity out there, apart from Lusaka where the national secretariat of the NZP+ is. You do not have a lot of activities taking place in Kasama, Solwezi, Mongu, Livingstone It shows that the capacity of the NZP+ to organise other people around the country ... how they can build their own capacity first of all, and secondly the extent to which they can mobilise resources is still very limited", according to a representative of the CBOH.

As part of the UNV Support to PLHA Pilot Project, a partnership between UNDP, UNV, UNAIDS and NZP+, NZP+ members have been posted in the Ministries of Education, Community Development and Social Services, Youth and Sport, in the defence forces, Interfaith Network, DHMT in Kasama, SEPO Centre in Livingstone, CHEP, and Kara. PLHA posted as volunteers received training in HIV and development, public speaking, counselling, communication skills, starting and maintaining support groups. The Pilot Project was intended to strengthen PLHA networks, increase the self-esteem and well being of PLHA, create opportunities for PLHA to contribute, and increase community capacity to respond and national programme effectiveness.

The Strategic Plan emphasises the importance of active involvement of PLHA, and NZP+ in particular, in shaping the national response to the epidemic and as partners in the design, development and implementation of policies and programmes. However, while NZP+ has been a partner in dialogue, PLHA are not represented on national bodies and no PLHA was invited to attend the launch of National HIV/AIDS/STD/TB Council. NZP+ is seeking greater involvement of PLHA in national structures and in the demonstration districts of the Zambia Integrated Health Programme (ZIHP) through representation on district committees.

2.6 Other stakeholders: international co-operation

There are a large number of multilateral and bilateral agencies operating in Zambia. Key multilateral stakeholders include UNAIDS, UNICEF, UNDP, UNHCR, and the World Bank. Key bilateral stakeholders include USAID and UK Department for International Development (DFID). As noted earlier, UNICEF is supporting initiatives related to children and women, and together with UNHCR, refugees and displaced communities. UNDP has, together with UNAIDS, provided support for the UNV PLHA Pilot Project.

UNAIDS is also funding the Zambian HIV/AIDS District Response Initiative (DRI). Based on a study in 1998 in four districts (Lusaka, Ndola, Chipata and Mazabuka), to review policies and experiences and develop a district framework for capacity building, the DRI proposes to establish high transmission area project sites, which involve community sensitisation and social mobilisation. The Initiative aims to shift HIV/AIDS activities from a vertical, health sector-oriented approach to one focusing on:

- A stronger intersectoral approach.

- The involvement of the private sector in delivery of services.
- A more defined role for the public sector.
- Supportive district structures for Primary Health Care (PHC) and integration of HIV/AIDS into PHC in the context of health reform and decentralisation.
- Recognition that prevention activities should be integrated into sectors dealing with community development, women and youth.

USAIDS is supporting the Zambia Integrated Health Programme (ZIHP), in partnership with the government and the Central Board of Health, which aims to address the main health problems of the people of Zambia and continue the process of health reform. ZIHP provides technical assistance for:

- Communication and behaviour change.
- Community partnerships.
- Improved health worker performance.
- NGO strengthening.
- Private sector partnerships.
- Systems support.

It aims to increase quality coverage of health interventions, in 12 demonstration districts initially, through implementation of an essential health care package that emphasises HIV/AIDS, malaria, integrated reproductive health, child health and nutrition.

A wide range of international NGOs are also active in Zambia. For example, CARE International is working in partnership with the CBOH, DHMTs, Neighbourhood Health Committees and NGOs in the Partnership for Adolescent Sexual and Reproductive Health, and World Vision has implemented projects targeting truck drivers and sex workers.

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 Zambia 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 Zambia²⁰.

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).

Representatives of NGOs explained during the data analysis workshop in Zambia that a typology of involvement is a useful tool for an assessment of involvement in their organisations (what they are doing in terms of involvement of PLHA) and for strategic planning (what they would like to do).

²⁰ Examples from the four research sites are presented in the final international study report, available in 2002.

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.



The Positive Living Advocacy Course of Hope Humana: PLHA learn gardening with a HIV positive teacher (Hope Humana)

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 Zambian NGOs who participated in the study.

3.2 Characteristics of the four participating organisations

3.2.1 Copperbelt Health Education Project (CHEP)

CHEP, established in Kitwe in 1988 in response to the HIV/AIDS epidemic, is a secular NGO which covers all eight urban and rural districts in the Copperbelt province. It is one of the largest non-governmental development organisations operating in the province.

CHEP's **objectives** include:

- To help people to develop values, life and social skills to foster positive, responsible healthy lifestyles.
- To understand and deal with health problems, fears and anxieties, especially about relationships and sexuality.
- To challenge prejudices and fears related to HIV/AIDS and help people to develop understanding and a sense of community responsibility.
- To promote responsible behaviour.
- To ensure appropriate knowledge and understanding of AIDS issues and related problems.
- To help develop care and support systems for those infected and/or affected and reduce the personal and social impact of chronic illness.

CHEP's **services and activities** focus on providing technical support to community-based organisations, support groups and other organisations through:

Information, education and communication – outreach education in communities, schools, workplaces and other locations, and production of materials and information.

- Working with the mass media – TV, radio, and press.
- Support services – community mobilisation, support group formation, promoting better care for PLHA in health facilities and at home, counselling.
- Training – peer education, income-generating activities, life and social skills and positive living.
- Advocacy and networking.

CHEP's has programmes for out-of-school and in-school youth, peer education, women, workplace, psychosocial counselling, and also carries out research. Specific PLHA programme activities include support groups for PLHA and affected people, income generating through these support groups, outreach programmes, and training workshops and seminars.

CHEP has 41 **staff**, including management and support staff, and three types of **volunteers** – part-time volunteer workers, community-based volunteers, and outreach and workplace peer educators. Only part-time volunteers receive an honorarium, transport allowance and other benefits such as health

insurance. The management structure is relatively flat and participation in the decision-making process is encouraged.

Funding is received from international UN and bilateral agencies and NGOs.

CHEP was one of the host organisations for the UNV Pilot Project to Support PLHA involvement.



Members of a support group meet with the staff of CHEP to review their activities

3.2.2 Hope Humana People to People (Hope)

Hope, established as an HIV/AIDS project in Zambia in 1996 by Development Aid from People to People (DAPP), is based in Ndola in the Copperbelt province. DAPP is a secular NGO and one of 28 member associations of the Federation Humana People to People, with headquarters in Zimbabwe, which runs 156 community development, education, health and childcare projects worldwide and which started working in Zambia in 1986.

Hope's **objectives** include:

- To prevent the spread of HIV/AIDS by educating both the infected and affected.
- To provide hope and support for positive living, with PLHA as active partners in solving their own problems and participating in stopping the spread of HIV.
- To mobilise communities and change negative attitudes.

The Hope centre, which was officially opened in 1997, houses training facilities and a clinic that provides general health services as well as VCT. Hope's prevention, care and support **services and activities** include:

- Outreach – outreach education in schools and workplaces, action programme with sex workers.
- Health care services – VCT, infant feeding counselling, consultations, basic diagnostic tests, and STD treatment.
- Support – positive living (behaviour change, nutrition, health and fitness, skills training) courses for PLHA, and support groups for PLHA and affected people.
- Training – for community leaders, teachers, NGOs in peer education, VCT, HBC, organisational capacity building, forming school clubs and support groups.
- Advocacy and networking – opinion forming, production of publications, provision of contact information.
- Operational research – e.g. pilot project on mother-to-child transmission and alternatives to breastfeeding.

Hope employs 17 **staff**, including management and support staff. Hope also has two categories of **volunteers**, short-term foreign development instructors and community volunteers. The latter are young people selected by the community who participate in outreach programmes or professionals who participate in health services. Hope also has “activists”, e.g. teachers, workplace peer educators or PLHA who have been trained by the Project. Activists carry out activities with support from Hope but these activities are not initiated and supervised by the Project staff. Volunteers and activists do not receive remuneration but transport expenses are reimbursed and they receive a meal if they participate in an activity that lasts a full day.

Funding is provided by Development Aid from People to People and other member associations of the Federation.

3.2.3 Kara Counselling and Training Trust (Kara)

Kara Counselling and Training Trust, established in 1989 in Lusaka as a counselling centre and legally registered as an organisation in 1991, is now a large, secular NGO with offices in Lusaka and Choma.

The organisation aims to “*promote integrated human development by providing counselling, training and other related services which respond to current psycho-social needs in Zambia*”. The specific **objectives** of Kara are:

- To provide counselling services, including VCT.
- To provide professional training in counselling skills and training of trainers.
- To provide HIV/AIDS outreach education services.
- To offer training skills to PLHA who are economically disadvantaged.
- To promote and provide training in community home-based care and support.
- To support formation of self-help and support groups for PLHA.
- To promote gender consciousness and equity.

- To promote research into the psycho-social aspects of health and human behaviour in Zambia, especially regarding HIV/AIDS.

Kara's prevention, care and support **services and activities** include:

- Prevention – outreach education in communities, schools, workplaces and clinics (ante-natal care).
- Support services – voluntary HIV testing and counselling, counselling on other psychosocial issues, helpline, drop-in centre, support groups (post-test clubs), and medical, emotional and spiritual care for terminally ill patients who have limited resources at the Jon Hospice.
- Training – coping skills, HIV/AIDS and health education as well as income-generating activities for vulnerable PLHA; and in outreach, counselling and HBC for professionals.



The work of HIV positive outreach educators at Kara Counselling: HIV/AIDS educators with mothers receiving antenatal care at a local clinic

Kara has 37 salaried **full-time staff** including management and support staff. There are also **part-time service providers** who work with the organisation on a regular basis and receive allowances for the work they do. They include counsellors and HIV positive outreach educators. Approximately 40 “community mobilisers” mobilise clients in areas where Kara provides VCT services.

Funding is provided by international donors.

Kara was the first NGO in Zambia to support the involvement of PLHA in outreach education activities. The first Zambian HIV positive people who went public received training and counselling at Kara. They formed a group called Positive and Living Squad. Kara also has close links with many members of NZP+.

3.2.4 Salvation Army

The Salvation Army is an international Christian movement, founded in 1865, which now works in more than 100 countries. The Salvation Army's **objectives** 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 established Chikankata Health Services, situated in Mazabuka, a rural setting 120km south of Lusaka, in 1946. Chikankata consists of a 150-bed general hospital serving a population of 53,000, and four rural health centres. It also runs training for nurses, midwives and laboratory students, and a Community Health and Development Programme, and has been carrying out integrated HIV/AIDS prevention and care programmes for more than 13 years. The AIDS Management Training Services provide technical assistance to community HIV/AIDS programmes in Zambia and other African countries.

The Salvation Army Chikankata Health Services have mobilised the community in Care and Prevention Teams (CPTs), which were the focus of the diagnostic study because it seemed interesting to study the characteristics of the involvement of PLHA in community-based groups in rural settings, in particular the specific obstacles to visible PLHA involvement in these communities. CPTs developed out of what was formerly home-based care. With the home-based care approach, communities had become heavily dependent on Chikankata hospital. The Salvation Army, recognising that this was not sustainable, developed the concept of CPTs, whose purpose is to provide support for the infected and affected, combining home-based care and community counselling to community capacity building and development. The objective of this mobilisation is to maximise participation of trained volunteers in identifying and finding solutions to problems that affect their own communities.

The activities of the CPTs include community counselling, referral, home visits, practical support, health education, community mobilisation, AIDS care and management skills sharing, and training communities for income generating.

At present there are 24 CPTs under the Community, Health and Development (CH&D) Programme, which integrates all outreach programmes. CH&D workers are the link between CPTs and Chikankata's health facilities. All the members of the CPTs are volunteers who do not receive any remuneration but are reimbursed for travel expenses and receive a meal if they participate in activities organised by the Salvation Army that last a full day.

There are very few visible PLHA involved in the CPTs. The only CPT where there are a couple of PLHA who are open about their HIV status in their community participated in the study.

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 point²¹ (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 Zambia, India and to some extent Ecuador²². In Zambia and India the participating NGOs were also able to reflect on the relevance of the definitions of types and terminology and contributed to refining them during the data analysis workshops held in these two countries²³.

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.

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

²¹ The general definition is ‘the various ways for PLHA to **take part in the activities** of NGOs and CBOs’ (see Terminology).

²² The involvement of the research team in the analysis of the data was limited in Burkina Faso where the study was piloted.

²³ In Burkina Faso and Ecuador, the data analysis workshops were scheduled too early and did not allow NGOs and researchers to discuss these issues.

- **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 3.1
Areas of involvement of PLHA in NGOs and CBOs

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

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 (see 3.4.3, box Voluntary *versus* professional: What do organisations mean by Volunteers?).

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:

- Experience 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-visible²⁴. 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:

²⁴ A definition of visibility is also included in the general terminology.

- 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, the PLHA is where 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.

Box 3.1
Visibility in the study²⁵

Respondents selected as PLHA

- 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.
- 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.

²⁵ See 1.6 Ethics of research.

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 Zambia 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) Specially, 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

TYPES OF PLHA INVOLVEMENT	AREAS OF INVOLVEMENT FOR PLHA				
	PLHA use the services of the NGO	PLHA support activities and services of the organisation	PLHA deliver HIV/AIDS services	PLHA plan and design services	PLHA manage the organisation, run or influence the policy making and strategic planning process
Access	Yes	No	No	No	No
Inclusion	Yes	Yes, for non-HIV-related tasks	Yes, informally and occasionally e.g. as volunteers.	No	No
Participation	Yes	Yes	Yes, formally and regularly e.g. as part-time or full-time service providers.	Yes, they usually plan the services they deliver, and may also be consulted on other services.	No
Involvement	Yes	Yes	Yes, formally and regularly, e.g. as part-time or full-time service providers.	Yes, they plan the services they deliver. They may also contribute directly to planning of other services.	Yes, e.g. as programme or project co-ordinators, directors, trustees.

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.

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 Zambia, are described in more detail below.

3.4.3 Access

Table 3.3
Definition of Access: Areas of involvement of PLHA

Definition of Access: Areas of involvement of PLHA	
PLHA utilise services of the NGO	Yes
PLHA support activities and services	No
PLHA take part in the delivery of services	No
PLHA take part in the planning and design of programmes	No
PLHA take part in management, policy making and strategic planning	No

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 (Table 3.3 summarises these services), 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 used by PLHA

Service	Kara	CHEP	Salvation Army	Hope
Counselling:				
VCT	✓		✓	✓
Other forms of counselling	✓	✓	✓	✓
Care:				
Home-based care	✓		✓	
Referral	✓	✓	✓	✓
Medical treatment			✓	✓
Hospice care	✓			
Hospital care			✓	
Training:				
Positive living and health education	✓	✓	✓	✓
Skills training	✓			✓
Income-generating activity (IGA)	✓	✓	✓	✓
Support group formation:	✓	✓		✓

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 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 on 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. It can also be the opportunity to build skills in a series of fields through training. Two of the NGOs who participated in the study offer courses that cover a large range of areas. Hope runs a Positive Living Advocacy Course and Kara has been training PLHA in a Life Skills Training Programme for several years.

Box 3.2
The Positive Living Advocacy Course of Hope Humana

The Positive Living Advocacy Course (PLAC) started as a nutrition course in 1998, then became a Positive Living Course and the “Advocacy” component was included in 2000. Besides advocacy and lobbying, the components of the course are: fitness activities, nutrition, cooking, general health and hygiene, behavioural change, gardening, entrepreneurial skills for Income-Generating Activities (IGAs) and psychological well-being.

There are two courses every year, which run for six months each. Participants meet at the Hope centre twice a week, for a half day. The course is free and participants receive meals and some money to reimburse their transport costs from their residence to the centre.

There are on average 20 PLHA per intake. They are both women and men, between 16 and 60 years old, including some couples. Most of them are unemployed, retired or self-employed in the informal sector. They have usually completed secondary education. They come from different areas. The rule is that they should be asymptomatic to be able to attend the course on a regular basis and carry out the activities they are expected to carry out in their community once they graduate as “Positive Living Advocates”. Examinations are held at the end of each course. They are called “People’s Examinations” because all participants present what they have learned from the course and they evaluate each other.

The objectives of the course are to empower PLHA by offering “*lessons in how to live a long and positive life with HIV*”²⁶ and also make sure that they mobilise other people in the community for HIV testing and teach them about Positive Living. The latter is what Hope means by “advocacy” in this context.

Hope uses the course as a process to mobilise PLHA and facilitate their involvement in activities at Hope and in the community.

²⁶ Hope Humana, Positive Living Course: An inspiration for People Living with HIV, 1999.

Box 3.3
The Life Skills Training programme of Kara Counselling

The main objective of the Life Skills Training programme at Hope House is to help PLHA to come to terms personally with their HIV+ status, support themselves and live positively.

“The main essence of skills training is more or less like a mental therapy for somebody who has been tested positive to accept the situation”, says an HIV positive outreach educator.

However, another objective is to give HIV/AIDS a human face by encouraging trainees to be open about their HIV status in the community:

“As part of the curriculum, we do include outreach education on their syllabus as they are doing skills training that helps them to come out.”

“We can’t just talk about HIV without the people that are infected ... so what happens is that we try to make them realise that it’s only by talking about it that they would help people in different communities to come and talk about the stigma they face”, explain two of the service providers of Kara.

Based on these two objectives, the training consists of vocational courses (see above, presentation of Kara) and outreach training, which includes HIV/AIDS information, communication and presentation skills, and peer counselling.

The course targets economically disadvantaged PLHA. It is free of charge and scheduled to take three months but due to financial constraints faced by Kara it is usually longer.

The experiences of Hope Humana and Kara Counselling show that training empowers PLHA by providing them with information and skills that enable them to gain control over the decision-making process that affects them (see definition of empowerment in the Terminology).

When an NGO deliberately uses training with this aim, access can be the starting point for further involvement of PLHA in the organisation.

Another characteristic of access is the low level of visibility of PLHA. Many skills trainees at Kara do not tell their family and friends that they attend the Life Skills Training programme because they have not disclosed their HIV status. Similarly, many participants of the PLAC are reluctant to carry out “advocacy” in their own community because they do not want friends and family to know that they are HIV positive.

Box 3.4
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*.

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

Inclusion: Areas of involvement of PLHA	
PLHA utilise services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Informally Occasionally
PLHA take part in the planning and design of programmes	No
PLHA take part in management, policy making and strategic planning	No

In the four NGOs who participated in the study in Zambia, 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.

PLHA support non HIV/AIDS-related activities

At Hope, the gardener is HIV positive. He is a full-time employee of the Project and was recruited after he completed the Positive Living Advocacy Course (PLAC). He is visible inside the organisation, with colleagues and service users, and also outside Hope.

Another former participant of the PLAC has volunteered to help in the kitchen of the Project as a house-keeper. She does not receive a salary but she can take her meals at Hope when she is there.

PLHA deliver HIV/AIDS services informally and occasionally

Although the involvement of both the gardener and the housekeeper in the activities of Hope is unrelated to HIV/AIDS, they contribute from time to time to other activities which are directly linked to HIV/AIDS. The gardener occasionally teaches gardening to the participants of the PLAC. He shares his own experience of living with HIV/AIDS with the participants through informal peer support. The housekeeper also shares her experience informally in outreach activities when requested to do so by Hope. They both do it without receiving a specific remuneration for the HIV work they do: the gardener receives his salary, and the housekeeper is a volunteer.

On a different level, other PLHA who are graduates of the PLAC occasionally give testimonies during outreach activities when requested to do so by Hope. This is also on a voluntary basis, although they receive money to reimburse their transport expenses and a meal when the activity they are involved in lasts a full day.

At Kara Counselling, participants in the Life Skills Training programme (skills trainees) and members of Post Test Clubs have the opportunity to conduct outreach education. Those who decide to disclose their HIV status and take part in outreach activities usually start to be involved on a very irregular basis, assisting the outreach educators employed by the organisation. They are not considered part of the Kara outreach team. As far as the skills trainees are concerned, this form of inclusion in the outreach programme is seen by Kara as part of their training. One of the Post Test Clubs has formed a drama group and a choir that is used to deliver their messages to the public in workplaces, schools and clinics, depending on demand. The main activities include information on HIV/AIDS and positive living. They also conduct condom demonstrations and distribution in the community. If possible, they do peer counselling, but make referrals to Kara whenever they are not able to respond appropriately. The skills trainees do not receive compensation but benefit from free training and group counselling. Post-club members receive reimbursement of transport expenses.

Some of the HIV positive community-based volunteers involved in PLHA groups supported by CHEP (support group leaders) are also requested to give testimonies from time to time. Similarly to other organisations, this contribution is voluntary and they do not receive any financial compensation except the reimbursement of their expenses when they are involved in meetings directly organised by CHEP.

In the Care and Prevention Teams (CPTs) of Salvation Army, there are few visible PLHA. Like other members of the CPTs they conduct home visits to the sick, provide counselling to the families of other PLHA and are involved in health education talks. They also take part in community projects such as digging pit latrines, building roads and building shelter for the aged. All CPT members occasionally work on a voluntary basis, and do not receive any financial compensation. The few visible PLHA share their experiences in their communities and in this way give a "human face" to the epidemic. They give testimony in other communities and on request at the AIDS Management

Training Services approximately every two months. For this they receive transport costs and a per diem.

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 service-delivery 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 are usually requested to use **their own experience of living with HIV/AIDS**, by either giving testimonies or sharing their experience with other PLHA. However **they do not use other levels of technical and theoretical expertise on HIV/AIDS**, because they do not have this expertise and/or they are not requested to use it. This can explain why the level of remuneration is low: **“empirical expertise” is generally less valued than technical and theoretical expertise**.
- The kind of expertise used by PLHA does not depend only on the kind of training provided by the NGO. We found that in the *inclusive* model of involvement, many PLHA who gave testimonies **had already received some training** in the following areas: basic information on HIV/AIDS, living with HIV/AIDS (coping skills), vocational training and to some extent outreach education. Some of them were in the process of being trained and *inclusion* was used as part of the training (Kara). **However, they had not received specific and intensive training to deliver HIV/AIDS services**.
- While 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*.
- PLHA are usually **visible within the organisation**, to service providers; and **outside the organisation, when they give testimonies**. 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 3.5
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 outreach activities at the request of the organisation. 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
Participation: Areas of involvement of PLHA

<i>Participation: Areas of involvement of PLHA</i>	
PLHA utilise services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Formally Regularly
PLHA take part in the planning and design of programmes	Yes
PLHA take part in management, policy making and strategic planning	No

In three NGOs – CHEP, Hope and Kara –, we found that besides HIV positive service users or volunteers, there are also some PLHA who are **employed by the organisation as service providers** and are visible inside and outside their organisation.

Delivery of services

At CHEP, three of the 13 “part-time volunteers/workers” are visible PLHA. They are involved in school, workplace and church programmes. They give testimonies on positive living, carry out peer counselling and home visits and encourage community members to seek VCT. These part-time volunteers receive an honorarium for their work, as well as other benefits.

In the Hope project, there was one full-time, salaried HIV positive service provider, employed by the outreach programme at the time of data collection. Since the end of the study, a second PLHA has been recruited. Both hold positions of Positive Living Advocates (PLA), who share their experiences with others, encourage people to come for HIV testing, and mobilise people who are HIV positive to enrol in the PLAC. The first PLHA was originally employed as a housekeeper. After disclosing her status and participating in the PLAC, she was offered the opportunity of working full-time in the outreach programme.

At Kara, six visible PLHA outreach educators (four men and two women) work on a regular, part-time basis. They receive an allowance and free medication.

Design and planning of services

All these PLHA who deliver services also plan their own work, in terms of day-to-day activities. At Hope, for example, the Positive Living Advocate prepares her own schedule in consultation with the Programme Leader. She is also responsible for her own budget within the limits set by the Project. She is accountable to the Project for the way she manages the funds allocated to her activities. Finally, she can raise funds.

Most of them are also consulted on the activities of their programme. At Hope, for example, the full-time Positive Living Advocate is consulted about other activities of the outreach programme. However, their input is limited and they do not take part in the planning and design of other services.

Box 3.6

Voluntary *versus* professional involvement: What do organisations mean by “Volunteers”?

At **CHEP** there are three categories of volunteers:

- Thirteen “**part-time volunteers**” who are also called “part-time workers”. They provide training and are involved in workplace, church and school programmes. Although they are referred to as volunteers, they actually receive what CHEP calls honoraria, which is very much like a salary. They also have access to the health insurance scheme of the NGO and receive a transport allowance on a weekly basis. They report for work daily. **Three of the “part-time volunteers” are PLHA**, whose **involvement is formal** according to our definition (see *participation*).
- **Community-based volunteers** are involved in care and support activities, such as home and hospital visits and peer counselling. Most of them are members of support groups. They also conduct some prevention activities, by giving testimonies. They do not receive material or financial compensation from CHEP unless they attend meetings organised by the NGO, in which case their transport expenses are reimbursed. **Many of them are PLHA**, in particular the leaders of the support groups. Their **involvement in the activities of CHEP is informal** (see *inclusion*) but they do carry out **activities on a regular basis within support groups** (see **external involvement, support groups**).
- Other volunteers are peer educators who have been trained by CHEP. They

conduct outreach education in the community or in their workplace. Like community-based volunteers, they do not receive material or financial compensation from CHEP unless they attend meetings organised by the NGO, in which case their transport expenses are reimbursed. There are no visible PLHA in this category.

At **Hope Humana** there are three categories of volunteers:

- **Community volunteers** are young people who participate in the outreach activities of the project after they have been trained by Hope. They are also called Active Hope Advocates. Other volunteers are professionals with qualifications in care and support who are involved in the Health Services Programme.
- Hope calls “**Activists**” people trained by the Project, such as workplace peer educators or the HIV positive graduates of the PLAC. They can carry out activities with some support from the Project; however, they have to initiate them, which is the main difference with the community volunteers.

Neither community volunteers nor activists receive any money for their contribution. Their transport expenses are reimbursed and they receive a meal when they participate in an activity that lasts a full day, and only when the activity is organised by Hope as far as activists are concerned. **Visible PLHA fall into the category of activists** (see **inclusion**) but some PLHA activists also belong to support groups (see **external involvement, support groups**).

- **Development instructors** are young foreigners trained in development and HIV/AIDS work who stay with the project for six months. They receive an allowance for their work. There are no PLHA in this category.

At **Kara Counselling**, there are only two medical doctors helping at the Jon Hospice centre who are called volunteers. However there are also **part-time service providers** who do not belong to the staff. They include:

- Part-time counsellors
- **Part-time outreach educators who are HIV positive** (see **participation**)
- Community-mobilisers

All of them receive allowances for the work they do. It is important to stress that although they work part-time, HIV positive peer educators spend almost every morning carrying out outreach education (up to four days a week at the time of data collection).

In the **CPTs** working with the **Salvation Army Chikankata Health Services**, **all members are volunteers**, which means that they do not receive any money for their contribution. Transport expenses may be reimbursed when they are asked to participate in specific activities organised by the CHS. Regularity of involvement depends on the level of activities of the CPTs, some of them being active and some dormant²⁷. Visible PLHA who participated in the study belong to a CPT considered as active, their involvement is therefore rather regular (see **inclusion**).

In brief ...

²⁷ Designated as such by CH&D.

The term “volunteer” refers to different situations in which formality of involvement of PLHA varies depending on the organisations:

- In one case (CHEP) HIV positive “volunteers” are formally involved, which means that they carry out activities on a regular basis and their work is financially and materially rewarded (**participation**).
- Otherwise, HIV positive “volunteers” in the other organisations carry out unpaid activities. However, they often receive a material compensation that can be an important incentive for their involvement, as we will discuss in the following chapter. Their involvement can be on a regular basis but it is usually very occasional (**inclusion**).

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. The data shows that most PLHA in this category are actually part-time employees, with a **contractual status** which is **not always very clear**, such as “part-time volunteers”. 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 **outreach education** or awareness raising. The researchers did not come across any visible PLHA employed as doctors, nurses, lab technicians, or professional counsellors²⁸. 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 without any training or with minimum training than to be a doctor. In outreach education, 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 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. At Hope and Kara, all PLHA involved in

²⁸ In two organisations, there are PLHA who are supposed to carry out counselling, but it is actually more informal peer support than, for example, pre-test and post-test counselling or even peer counselling.

outreach education and “advocacy” went through the specific courses organised by the two NGOs, the PLAC and the Life Skills Training respectively. Therefore they were trained formally in the following areas: basic facts on HIV/AIDS, life with HIV/AIDS. Outreach educators of Kara are also specifically trained to conduct outreach education, including communication. At Hope, the Positive Living Advocate was enrolled in a six-month Basic Management Course. CHEP provides its part-time workers with information on HIV/AIDS and counselling training. Finally, employees usually have a better knowledge of the organisation and its services than do 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. At Kara, part-time HIV positive outreach educators actually mentor skills trainees.
- The **level of visibility** of PLHA who *participate* in NGOs is usually **high**, both within and outside the organisation, to other service providers and to beneficiaries.
- 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 may be consulted about other services.

Box 3.7

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 these PLHA about other services, but always on a consultative mode, since the final decisions lie with the management of the programmes and the organisation.

3.4.6 Involvement

Table 3.7
Involvement: Areas of involvement of PLHA

Involvement : Areas of involvement of PLHA	
PLHA utilise services of the NGO	Yes
PLHA support activities and services	Yes
PLHA take part in the delivery of services	Formally Regularly
PLHA take part in the planning and design of programmes	Yes
PLHA take part in management, policy making and strategic planning	Yes

Involvement was observed in two organisations, CHEP and Kara, while some PLHA at Hope Humana were also moving from *participation* to *involvement* at the time of data collection.

At CHEP, there is a PLHA Programme and its co-ordinator is HIV positive himself. He is a full-time employee of the organisation. Besides his position of co-ordinator, he is directly involved in service delivery as a counsellor, outreach educator, and trainer. The assistant of the programme is also HIV positive; she is employed on a six-month renewable contract. They are responsible for planning and design of the activities of this Programme and, in addition, provide inputs to design and planning of other CHEP services. They take part, for example, in the organisation's annual participatory strategic review.



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

At Kara, the co-ordinator of the outreach programme is HIV positive. He is the only visible PLHA who is working full-time. As any other co-ordinator in the organisation, he recruits and supervises staff under him and plans and designs the programme for which he is responsible. Although he is not part of senior management, his opinion may be requested regarding other programmes. He is involved in the organisation's strategic planning. It is worth noting that since the end of the study, Kara has decided to institute a board of directors, one of whom will be a PLHA.

At Hope, PLHA did not play a role in management, policy making or strategic planning at the time of data collection. However several HIV positive staff members and volunteers, including the full-time Positive Living Advocate (PLA), had been enrolled in a six-month basic management course organised by DAPP in Zimbabwe. After this training it was anticipated that they would take on greater management responsibilities within Hope and other DAPP projects in Zambia.

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**. However most PLHA *involved* are actually **full-time** employees, in contrast to what was observed for *participation*. The nature of the **link** between the organisation and PLHA involved is **very clear**, usually written in a **contract** of employment. 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.
- 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. Their families are generally aware of their HIV status. 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 inside and outside the organisation** in which they are involved and have been exposed to a vast amount of information on HIV/AIDS in workshops and conferences.
- 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. However,

we have not observed any visible PLHA in the senior management of the participating NGOs, or represented on the board of trustees.

Box 3.8
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.

3.5 Support groups: self-help as a way to externalise involvement

The four types of involvement that were presented thus far are types of **internal involvement**, since they describe how PLHA can take part in organisations as staff members, volunteers or beneficiaries in the activities and services of the NGOs that participated in the study. However, some of the NGOs have also promoted the involvement of PLHA at another level, by facilitating the formation of support groups of PLHA or PLHA and people affected by HIV/AIDS, which we have termed as **external involvement**.

Box 3.9
Definition of Support groups

Support groups, defined as groups of people who share common interests or goals and who come together to address common problems, can be differentiated by their membership or by their beneficiaries:

- Support groups can consist of PLHA only, PLHA and affected people, or PLHA, affected people and other members of the community.
- Support groups can benefit their members only, provide services to the community, or provide self-help and services to those who do not belong to the group.

Support groups observed during the study were either groups of PLHA only or mixed groups of HIV positive and affected people.

Members usually support each other but they may also support other HIV positive people who do not belong to the group, and many of the groups try to raise the awareness of the community.

Rules regarding membership are usually extremely flexible or non-existent.

3.5.1 The experience of CHEP

Community mobilisation to confront HIV/AIDS has been an important element of CHEP's work for a long time. As part of this CHEP had supported the formation of a number of support groups for PLHA and affected people at the community level. In 1997 CHEP decided to participate in the national United Nations Volunteer (UNV) Placement Programme initiated by the United Nations Development Programme (UNDP). The main expectation of the placement of an HIV+ UNV at CHEP was to scale up the mobilisation of communities, especially of infected people, against HIV/AIDS through the formation of more support groups.

According to CHEP, by 2000 there were around 125 members in 12 community-based support groups. Sixty per cent of the members were visible PLHA. A number of them, including most of the support group leaders or co-ordinators, were designated community-based volunteers of CHEP.

The support groups have developed their own objectives, which on the whole fit with the objectives of CHEP. The main activities of the groups are generally the following:

- Mutual emotional and spiritual support, through meetings and home and hospital visits.
- Income-Generating Activities, such as knitting and gardening, for material support of the members.
- Raising HIV/AIDS awareness in the community.

3.5.2 The experience of Hope Humana

Support groups are part of the vision of Hope of creating "*a movement of people that are infected and/or affected by HIV and AIDS*" in which "*being a member*" means that "*you do something to stop the spread of HIV/AIDS or provide services and care*".

The idea of Hope Humana has always been to empower PLHA, in particular in the PLAC, in order for them "*to form support groups and conduct Positive Living courses for people living with HIV*"²⁹ in the community. Support groups are seen therefore as a way to reach out more people in the community.

According to Hope, in 2000 there were 40 PLHA who were members of Positive Living Clubs, or PLHA support groups, supported by the Project. Members are usually graduates of the PLAC, current participants in the course or PLHA on the waiting list to enrol in the course.

The main activities of the groups are generally the following:

- Mutual emotional and spiritual support

²⁹ Humana People to People, Job Description, July 1999.

- Income Generating Activities, such as knitting, sewing, batik, gardening, for material support of the members
- Raising HIV/AIDS awareness in the community

3.5.3 Self-help or “assisted self-help”?

In the groups supported by CHEP and Hope Humana, PLHA are supposed to be fully *involved* by designing, planning and implementing their activities. They also manage their own resources when resources are available. However, the study found that it is difficult for the support groups to remain active and sustainable without the assistance of CHEP, Hope and/or other organisations. This is why we call this form of self-help “assisted self-help”, emphasising the contradiction between the supposed nature of the groups and the actual links between them and the NGOs that support them.

The nature of the relationship between support groups and the organisations that assist them can vary. The data shows that a challenge for both is to agree about the links that unite them and their respective expectations. CHEP believes, for example, that support group members should carry out activities which are autonomous from the NGO. Support group members feel that CHEP should provide them with more material and financial support and medication. At Hope, staff members call support group members Hope “Activists” because they have been trained by the Project, but these Activists are supposed to carry out activities which are autonomous from the Project. Even members of support groups can identify themselves as service providers of Hope, although on a voluntary basis, which creates high expectations. Like members of groups supported by CHEP, they think that Hope should provide them with more support and they are frustrated when they do not receive this support. On the other hand, service providers at Hope feel sometimes that Activists are too dependent on the Project. We will explore further the obstacles to the sustainability of support groups and the factors that can make them more sustainable in the following chapter.

Table 3.8
Summary of the types of involvement in the four participating NGOs

		CHEP	Hope	Kara	Salvation Army (CPTs)
Internal Involvement	<i>Access</i>	✓	✓	✓	✓
	<i>Inclusion</i>	✓	✓	✓	✓
	<i>Participation</i>	✓	✓	✓	
	<i>Involvement</i>	✓		✓	
External involvement	Support Groups	✓	✓		

3.6 *Exclusion* and tokenistic involvement

Table 3.9
Exclusion: Areas of involvement of PLHA

<i>Exclusion: Areas of involvement of PLHA</i>	
PLHA utilise services of the NGO	No
PLHA support activities and services	No
PLHA take part in the delivery of services	No
PLHA take part in the planning and design of programmes	No
PLHA take part in management, policy making and strategic planning	No

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, most NGOs and CBOs in Zambia do *exclude* PLHA, at least those who are visible. Reasons for exclusion will be analysed in the following chapter.

3.7 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.
- PLHA can also be involved in self-help groups supported by NGOs (external involvement).
- 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 outreach education, either for the whole community (awareness raising) or for their peers (positive living). They are also involved in peer support.
- The number of visible PLHA formally employed by NGOs (*participation*) is even smaller and represents only a tiny proportion of their service providers. 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, but their involvement is also curiously nonexistent in “professional” counselling, in particular pre and post-test counselling.
- No visible PLHA holds a senior management position.

The situation observed in the four NGOs who participated in the study is not exactly representative of the situation in Zambia because at least three 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 Zambia 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 Zambia should promote any one 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 CBO 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

Zambia is one of the countries with the highest HIV/AIDS prevalence in Africa and in the world. 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 Zambia? 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 PHLA 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:

- **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.

Factors that limit and enhance the formation and sustainability of **support groups**, i.e. what has been termed as **external involvement**, will be presented separately.

For each one of the three main categories of factors, we will start the presentation of the findings with a list of the factors mentioned by the respondents from NGOs and frequencies³⁰. We will also present the factors identified by key informants outside the participating NGOs.



CPT members pray with a woman who is ill. CPT members take care of the chronically ill whether they are HIV positive or not in order to avoid stigma (Salvation Army, Chikankata)

It is important to bear 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. Frequencies are a result of the thematic classification of transcripts of interviews and FGD by the research team. A computerised tabulation was not technically possible. Classification is therefore subject to the interpretation of

³⁰ Detailed tables are also presented as appendices. They include the categories of respondents and for each category the number of respondents who mentioned spontaneously each factor in interviews and Focus Group Discussions (FGD).

each researcher and the time line did not allow for cross-checking by a second researcher. Frequencies do not have a statistical value; they only express trends of opinions.

In addition, 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 what limits and encourages involvement in NGOs.

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 Zambian 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 Zambia and the huge number of people living in poverty (see second chapter). Poverty in the country itself is a social factor and the circumstances of PLHA who are poor are considered as an individual factor.

The following table summarises the individual factors limiting involvement mentioned by all categories of respondents for all four organisations, ranking them in order of frequency. An analysis of these factors follows the Table.

Table 4.1
List of individual factors that limit the involvement of PLHA
based on opinions of respondents from NGOs³¹

Individual factors	Frequency
Poor health of PLHA (morbidity and mortality)	18
Fear of stigma, rejection, blame if visibly involved in NGOs and CBOs	16
Inadequate education, skills and training	13
Low income, need to earn income	9
Denial (difficult for some PLHA to accept their HIV status and consequences on their lifestyle)	7
Lack of personal interest and motivation	4
PLHA with high social status do not want to compromise their situation	2
Little or inadequate knowledge and misconceptions of PLHA about HIV/AIDS	2
“Mirror effect” for asymptomatic PLHA who identify with PLHA who are sick and feel discouraged	1

Key informants identified similar factors:

Table 4.2
List of individual factors that limit the involvement of PLHA
based on opinions of key informants

Individual factors	Frequency
Fear of stigma, rejection, blame if visibly involved in NGOs and CBOs	6
Inadequate formal education, training and skills	6
Denial	2
Poor health of PLHA (morbidity and mortality)	2
Low income, need to earn income	2
Low self-esteem	1

Poor health of PLHA – specifically weakness and frequent illness – and death was the most frequently mentioned factor overall, and by Hope and CHEP respondents specifically. This factor was mentioned by all categories of respondents except relatives of PLHA service providers, and was more likely to be mentioned by HIV negative service providers and PLHA beneficiaries. For example, some HIV negative service providers perceive that PLHA can only be involved as beneficiaries because they are sick.

“It’s difficult to see how sick PLHA can provide Home-Based Care when he or she needs the same support.” (Says a female service provider of Kara Counselling.)

³¹ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Poor health is exacerbated by poverty, which, for example prevents PLHA buying food and putting into practice what they have learnt about the importance of a good diet. Some PLHA wait until they are very sick or dying to access services or get more involved in the organisations.

“They will only accept to register when they are completely finished and almost dead.” (Say the participants of a group of PLHA and affected people supported by CHEP.)

This does not mean that only PLHA who are asymptomatic have the capacity to take part in the activities of NGOs. The data shows that even those PLHA employed by NGOs have already suffered some opportunistic infections. These infections do not stop PLHA from being active provided they have access to treatment (see factors that enhance involvement). However, it is true that morbidity and higher rates of mortality among people with AIDS affect regular involvement of PLHA in service delivery and employment in management positions (*participation* and *involvement*), because they can cause disruption in the delivery of services and the general functioning of an organisation, not to mention additional costs for NGOs. This can limit the willingness of organisations to involve more PLHA (see Cost of involvement in following section).

Poor health also particularly affects the sustainability of support groups of PLHA, as we will see in the section devoted to obstacles to external involvement.



A member of the Mushili support group gives a lecture on nutrition to fellow members (Hope Humana)

Fear of PLHA of being stigmatised and discriminated against, if they become visibly involved in NGOs and CBOS, was the second most frequently mentioned factor overall by respondents from NGOs and it was the first factor identified by key informants. It was the most frequently mentioned factor, along with lack of knowledge, by Salvation Army respondents, perhaps because the perception is that it is even more difficult for a PLHA to disclose his or her HIV status in a rural community, such as the one served by the Salvation Army Chikankata hospital. This factor limits PLHA willingness to become involved with organisations that are known to be associated with HIV/AIDS – service providers at CHEP for example noted that some PLHA are even too scared to collect drugs from HBC teams.

“They think that when people see them associating with this group, they will know that they are HIV positive.” (Say a male/female support group supported by CHEP.)

Fear of the repercussions of visible involvement and being labelled, in particular rejection by family members and by potential marriage partners, was most frequently mentioned by HIV positive service beneficiaries, and was also frequently mentioned by HIV negative service providers.

“You cannot get married. If you are a woman, men would not propose love to you. If you are a man, women will be running away from you.” (Says a female PLHA service beneficiary of Kara Counselling.)

This factor was only mentioned by PLHA service providers at the Salvation Army and was not mentioned at all by service providers at CHEP.

“Some are shy and their families would reject them and neglect them. Their families would stop caring and supporting them if they went public.” (Say PLHA beneficiaries of Kara Counselling.)

We will explore further in this report whether involvement does cause discrimination for PLHA when visible and consequently whether the fear of discrimination is actually justified.

Linked to the fear of stigma is the particular **fear of compromising social status** by coming out into the open. If most PLHA who access the services of CBOs and NGOs and are involved in their activities are poor and insufficiently educated, it is also because those who earn a higher income, are better educated and/or have high-profile positions in the community are particularly reluctant to be visible.

“I was thinking to myself what my people were going to say about having a headman who was HIV positive. I thought to myself that it was not going to augur well with my position to be involved with a group of people who associate themselves with those that have HIV and AIDS.” (Says a member of a CPT working with the Salvation Army Chikankata Hospital.)

“When we try with the help of the initiative of the UNV to reach people who already have skills, like doctor, teacher and pilot ... because communities are not ready to accept them ... these people withdraw” explains the HIV positive co-ordinator of an organisation of PLHA.

Inadequate formal education, training and skills was also mentioned frequently, by HIV negative service providers in particular, but also by PLHA who provide services, as preventing PLHA involvement in activities other than outreach education and as a constraint on the entrepreneurial activities of support groups.

“I think for most of them it is a problem of qualifications. For counselling, they (the organisation) have to get social workers and health workers who are fit to become counsellors” says a service provider for Kara Counselling.

For PLHA who are beneficiaries, lack of education and training appears to contribute to lack of confidence about their ability to become involved.

“Unless I am sent out for further education there is no way I can take that post” says a PLHA service provider of Kara Counselling.

Inadequate formal education and training is not really an obstacle to access – in some NGOs, services even target PLHA without education and training, like the Life Skills Training Programme of Kara.

Neither 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. As far as PLHA involved informally in service-delivery, we saw that they are more “living examples” than experts on HIV/AIDS. They use mostly their own empirical experience of the infection but they are not requested to have a theoretical knowledge of HIV or particular technical skills to deliver services, since they do not deliver “highly technical” services such as care or even professional counselling. 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 much 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. Lack of educational qualifications was indeed cited by respondents as a particular barrier to involvement in management tasks, such as strategic planning, design of activities and services. The data collected through questionnaires shows that more than 78% of the service providers of the four participating NGOs have completed higher education (95% of men and 61% of women). Only one person had completed only primary education.

As stressed in chapter two, poverty is widespread in Zambia. It is therefore not surprising that, although HIV/AIDS affects all categories of population, many PLHA come from a **low-income group**. Because they are poor, **they need to earn an income**, which stops them being involved on a voluntary basis. Poverty was mentioned by respondents at all four organisations. While some organisations provide some incentives or allowances to PLHA involved in outreach, they do not offer a job. The reality is that PLHA need to earn an income to support their families. Many PHLA have lost jobs or breadwinners and those who do work earn little. When expectations of material support provided by NGOs are not met this can discourage sustained involvement. In addition, one respondent mentioned that people cannot devote much time to voluntary activities because they are busy with their occupations, for example during harvest time in rural areas.

“There is no food, there is nobody working, so what do they do? This limits their input because they have to look after their own families at the same time ...” (Male service providers of CHEP.)

“People would come out when they know there is a benefit.”
(Male/female service providers of the Salvation Army.)

“A lot of our members were coming from very far and most of them were unemployed ... they were hoping to benefit in some way or another but there was nothing to take back home.” (PHLA service provider of Hope.)

In one organisation, for example, those trained as counsellors are not offered a job and so some PLHA drop out of training when they realise they will not be employed.

As mentioned above, lack of training is an issue for many PLHA but when training is available, its cost is too high in some instances. Inability to afford fees was mentioned by PLHA and non-PHLA service providers at Kara:

“Training ... is not cheap ... This is the major constraint.”
(Service provider of Kara Counselling.)

The director of a major Zambian NGO confirms this point:

“The major problem that I see in the organisation that I work with, most of the people that come forward tend to be socio-economically disadvantaged. So they don’t have the resources to, for example, do the training. I am working with a support group but many of them could not do specific training, for example, counselling. They haven’t got that type of resources.”

Denial was mentioned by HIV negative service providers and PLHA service beneficiaries as a reason for not getting involved, because it is often difficult for PLHA to accept their HIV status and the possible consequences of the HIV

infection in terms of changes in their lifestyle. Social factors such as stigma are likely to be responsible for this, and lack of effective counselling services to help PLHA accept and cope with their HIV status may also be a factor.

In relation to denial, there is a risk for asymptomatic PLHA involved in care and support to identify with PLHA who are sick and feel depressed and discouraged. This is what we call the “mirror effect”:

“It has been difficult ... you may set out to visit someone and when you reach that person’s home they tell you about their problems, which makes you think about yourself and what will happen to you as well. So this really discourages someone.” (PLHA service provider Positive Living Advocate for Hope.)

Lack of personal interest and motivation to be involved was cited as a factor by service providers and beneficiaries at Hope and by one service provider at Kara. Not every person, whether HIV positive or not, is ready to join an organisation and deliver services.

When involved, some PLHA might prefer some activities to others, like outreach as opposed to counselling. This was put forward to explain why there are no PLHA counsellors. However, this may be more a function of lack of skills, training and confidence.

Little or inadequate knowledge of HIV/AIDS, resulting in misconceptions, was mentioned by PLHA service beneficiaries and HIV negative service providers at the Salvation Army and beneficiaries at CHEP. PLHA do not feel equipped to go public or become involved in certain activities that require a specific knowledge of HIV/AIDS, even of basic facts.

“They have not yet been taught all the facts about HIV/AIDS.” (Male service provider CPT, the Salvation Army.)

Something that respondents did not mention, perhaps because it is too obvious, is that most HIV positive people in Zambia do not know that they are living with HIV and/or AIDS (see chapter two), whereas the awareness of one’s HIV status is indisputably the first “practical” condition to be involved as a person with HIV.

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.

Table 4.3 summarises the institutional factors limiting involvement mentioned by all categories of respondent for all four organisations, ranking them in order of frequency.

Table 4.3
List of institutional factors that limit the involvement of PLHA based on opinions of respondents from NGOs³²

Institutional factors	Frequency
Inadequate resources to support PLHA involvement due to lack of NGO resources and NGO failure to allocate resources to offer material support and incentives (e.g. money, food, medicines)	30
Poor linkages, referral system between organisations denies PLHA information about opportunities for involvement	7
Attitudes of management and staff can be judgmental and discriminatory	5
Sometimes stigma is associated with organisations delivering services to PLHA	4
Lack of institutional policies to promote PLHA involvement	3
High cost of training because of high mortality of PLHA	3
NGOs do not give training opportunities to PLHA	1

Table 4.4
List of institutional factors that limit the involvement of PLHA based on opinions of key informants

Institutional factors	Frequency
Negative attitude of staff	5
Scarce resources	4
In-fighting	1
Poor co-ordination	1
Inaccessibility to NGOs	1

Overall, the institutional factor by far most frequently mentioned by the respondents from NGOs was the **lack of financial resources** needed to cover the cost incurred by the involvement of PLHA in an organisation. The data reveals that involvement of PLHA does have a cost for the organisations in which they are involved. Based on what we observed in the four participating NGOs and the analysis of service providers and managers of the NGOs, we have tried to summarise below the various inputs in the cost resulting of involving PLHA in an NGO.

³² Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Box 4.1**What is the potential cost of internal involvement of PLHA for NGOs?****Cost to initiate and promote involvement**

- Initial training: salaries of trainers, administration costs, reimbursement of transport expenses for participants, meals for participants, input for technical vocational training.

Cost to sustain involvement

- Further training of PLHA involved, including salaries of trainers, administration costs.
- Training of new HIV positive recruits to replace those who become too sick to work or die prematurely.
- Reimbursement of transport expenses.
- Salaries of HIV positive staff and allowances of other HIV positive service providers employed by the organisation for specific tasks related to PLHA involvement.
- Provision of medication to treat opportunistic infections and possibly anti-retroviral therapy for HIV positive staff.
- Repeated and/or prolonged sick leave of HIV positive staff.
- Funeral expenses.
- Financial and material support to dependants of HIV positive staff.

It is important to note that some of these costs are not entirely specific to the involvement of PLHA. Most organisations, for example, reimburse the transport expenses of their volunteers, whether they are HIV positive or not. Staff have to be paid, whatever their HIV status.

The additional costs are in reality linked to the amount of training required for people (human resources) who are not already trained and the consequences of employing people with a chronic disease in a context where adequate treatment is hardly available.

As we saw in the description of involvement in the four participating NGOs (chapter 3), all the organisations have some level of spending linked to the involvement of PLHA, although it varies from one organisation to another. Organisations who spend more are actually those where we observed *participation* and *involvement*, or a mix of types ranging from *access to involvement*, in particular because of the cost related to formal employment. However, many respondents explained that NGOs and CBOs either lack the resources or do not allocate the adequate resources they have for the promotion of involvement of PLHA.

“They don’t get a salary. It is just a small allowance to enable them to travel here and there and buy lunch ... there are no finances right now.” (Service provider of Kara Counselling.)

As far as NGOs are concerned, costs of involvement perceived as high, together with limited resources, are seen as an obstacle to further

involvement. For PLHA, low spending on the items listed in the table above result in a lack of incentives to be involved, especially when they need to earn an income (see individual factors).

“Those who graduated have not been supported, so they stopped because they found coming for meetings a waste of time ... time that could be used for other businesses.” (Female PLHA service provider of Hope.)

The purpose of the study was not to audit the level of spending of NGOs on the involvement of PLHA, so it is difficult to analyse whether they actually lack the financial resources or whether they have the resources but do not allocate them to encourage more involvement. However, it is important to note that the four participating NGOs (including DAPP) are rather large organisations and have high capacities to develop projects and raise funds.

Other factors mentioned included the lack of **training opportunities for PLHA**, which might be linked to the cost of training PLHA resulting from a high level of mortality among PLHA who have been trained. Some HIV positive service providers noted that they were less likely to be sent on training courses or were only offered short courses.

“The problem is I am not trained and people do not think about taking someone who is HIV positive for training. They will only send you for a simple workshop.” (PLHA service provider of Kara Counselling.)

“The other thing that makes some members not to be active is because they have not had any opportunity of attending any workshops or seminars so that they can be exposed and have a chance to meet other PLHA from different areas of the country and the world at large. If only the seminars could be held at local level, so everyone is involved.” (Support group of CHEP.)

The lack of training does not prevent PLHA from taking part in the activities of NGOs in an *inclusive* way, but it limits particularly *participation* and *involvement* since we saw that these two types require the use of specific skills that most PLHA who approach NGOs do not have.



A HIV positive outreach educator facilitates a discussion on Positive Living with HIV positive trainees at the skills training centre of Kara Counselling

Attitudes of management and service providers, which can be judgmental and discriminatory, were cited by service providers at Kara and Hope as well as by key informants. Some have the perception that management is unwilling to engage PLHA, including those PLHA that have education and skills, other than for outreach education. Even in one of the organisations some HIV positive beneficiaries who have been trained as outreach educators have not been given a chance to do outreach education as often as they would like.

“The bosses do not want to involve PLHA ... like in giving us responsibilities or jobs.” (Male PLHA service beneficiary of Kara Counselling.)

“There is a young woman who has nice grades ... but she is just doing outreach programme. She is just giving personal experience. Our certificates need to be considered. We need to be asked what we think we can do in future.” (PLHA service provider of Kara Counselling.)

One group of counsellors also felt that lack of PLHA involvement could be due to negative attitudes by counsellors towards PLHA in their organisation.

“Counsellors are part of society. If something is stigmatised and a counsellor lives in that situation, they are part of the stigma. Maybe we don’t know it yet as counsellors. Maybe we are part of this force that puts them off” says a counsellor from Kara.

A key informant who is HIV positive himself explains that he has noticed that in NGOs, like in the rest of society, some people fear direct contact with PLHA:

“Some people are not comfortable, they would rather deal with papers, publish AIDS books and AIDS magazines ... but not get in touch or too close with people who have AIDS.”

Although most participating NGOs have actively promoted PLHA involvement, they **lack institutional policies for the involvement of PLHA** that spell out clearly and in a systematic way:

- What they wish to achieve in terms of involvement as an organisation.
- How they propose to achieve it, including for example a workplace policy that lists specific benefits for HIV positive employees.

In some organisations, involvement and/or empowerment of PLHA stand as objectives but they are rather vague ideas without proper strategic planning.

“What incentives can be given to them? It has never been defined properly ... I am talking about things like transport ..., taking them for various courses like psycho-social counselling and being afforded free medical services for opportunistic infections” explains a governmental official at the district level.

Poor linkages and referral systems between organisations, which deny PLHA information about opportunities for involvement, were the second most frequently mentioned overall, and most frequently at the Salvation Army and by HIV negative service providers.

HIV negative service providers at Kara and Hope also attributed low visible involvement to the **stigma that is sometimes associated with organisations delivering services to PLHA**, since both were established specifically as HIV/AIDS organisations. However, representatives from both organisations explained during the data analysis workshop that they had overcome this obstacle quite easily by diversifying their services. The Hope Centre is now used as an “open community centre” that houses not only a clinic but also training facilities and offices.

“The organisation is associated with HIV. For example when I joined, some people thought I was HIV positive. In essence people believe that everybody associated is HIV positive.” (Male service provider of Kara Counselling.)

A key informant mentioned as an obstacle to involvement the **relative scarcity of NGOs who provide services for PLHA** and also the **inaccessibility of many NGOs** and their services for a vast number of PLHA, in particular in some rural areas:

“The other thing which limits these people with HIV is the access to the organisations which are involved in the provision of services. For example, in some places, you find that the NGOs which are there are very few which are critically dealing with actual delivery of services. They are very few and people may not find access to these organisations” explains an official of the DHMT.

Despite the lack of up-to-date and accurate data on the number of NGOs and CBOs providing HIV/AIDS services and the kind of services they provide, it is easy to observe that many organisations in Zambia are still involved only in primary prevention that targets the non-infected part of the population and almost totally excludes those who are already infected with HIV. This traditional hygienist model of prevention of the epidemic does not encourage the recognition of the role of PLHA as actors of prevention.

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 Zambia.

The following table summarises the social factors limiting involvement mentioned by all categories of respondent for all four organisations, ranking them in order of frequency.

Table 4.5
List of social factors that limit the involvement of PLHA
based on opinions of respondents from NGOs³³

Social factors	Frequency
Stigma and discrimination	41
Lack of community support and appreciation, and disbelief	13
Inadequate knowledge of HIV/AIDS in the community	6
Culture of silence on HIV/AIDS and issues related to sexuality	5
Social expectations	4
Poverty	3
Religious beliefs	2
Community dependency on institutions providing care and support	1

The social factor limiting involvement, and visibility, mentioned most frequently by all categories of respondents from all four organisations was **stigma and discrimination**, including finger pointing, name calling and labelling. Individual fear of stigma and discrimination is linked to the negative social and community attitudes associated with HIV/AIDS and PLHA, still widespread in Zambia as explained in the second chapter of this report.

“We need to realise the perception of people out there. We have our own culture, which does not sanction certain behaviour such as coming out to disclose your HIV+ status” explains the director of a Zambian NGO.

³³ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

PLHA do not become involved because they fear these negative attitudes, and so stay isolated. Some PLHA beneficiaries reported rejection, neglect, failure to find a marriage partner and assumptions that men with HIV are promiscuous and that women with HIV are prostitutes, as common manifestations of stigma and discrimination. PLHA who are involved reported their experiences of stigma and discrimination, but also noted that discriminatory attitudes can change over time. It took, for example, several years for the father of a PLHA very actively and visibly involved to accept his son.

“We have a lot of stigma attached to HIV. You find that some people regret after going out to do their work as outreach educators ... except in cases where people have not gone public, there is a problem of stigma.” (Male service provider of Kara Counselling.)

“After a seminar we went to teach others. Some people became violent. We were scared. They didn’t want to be talked to about HIV/AIDS.” (Female PLHA service provider of Hope.)

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

The fear of discrimination that was identified as an individual factor is therefore based on reality: visible involvement can lead to stigma and discrimination. However, we observed that in some cases involvement can also contribute to a decrease in stigma and discrimination toward PLHA, as we will explained in the analysis of the negative and positive effects in chapter Five.

Stigma and discrimination can affect any person living with HIV but it was noted that people of **higher social status** do not feel free to disclose that they are HIV positive because of **social pressure** on them to perform as “models of morality”, HIV infection being seen as immoral.

The second most frequently mentioned social factor was **lack of community support and appreciation** for the efforts of PLHA, and perceptions that PLHA are idle beneficiaries of services. PLHA views are ignored by families and many have experienced negative reactions when trying to do outreach and other community work – including mocking and disbelief. This is demotivating and discourages others from becoming involved.

“We do experience a lot of problems. Some do not even want to listen to what we have to say, they just start insulting us.” (Male/female support group of CHEP.)

Some people perceive that those PLHA who are involved and visible are not really infected but are pretending to be HIV positive for financial reasons, especially if they are still healthy.

“Some people were telling me that I should not have gone public as it was disgraceful. Others were saying that many people who are infected have not gone public ... maybe you are being paid by Hope Humana for going public.” (Female PLHA service provider of Hope.)

“It’s not easy because people think that you are lying, people think that it’s not real that you are sick.” (Female support group of CHEP.)

Stigma, discrimination and lack of support are linked to the third most frequently mentioned factor, **inadequate knowledge** in the community about HIV/AIDS. Despite efforts there are still misconceptions and fears about HIV/AIDS and its transmission (see chapter two, 2.3 – Knowledge, attitudes and behaviour).

Religious beliefs are also important. The perception that PLHA are “sinners” was cited as a limiting social factor by HIV negative service providers and relatives of PLHA service providers as well as by key informants.

“How can an infected person come out into the open and decide to get involved in the delivery of services to those who consider him or her an immoral person?” (Male service provider of Kara Counselling.)

“We are a Christian nation³⁴ and if one went to disclose to the churches or pastors, that would really shock everybody. It is like HIV/AIDS is equated to sin: that one has evil spirits tormenting him ... In some churches HIV/AIDS is still being looked at as a punishment from God. That is limiting PLHA to come out in the open” explains a representative from a DHMT.

It was also noted that PLHA who belong to some churches find it difficult to promote messages about using condoms to prevent the spread of HIV, because this goes against the teaching of their church.

“Because they think that as a Christian you are not supposed to encourage people to use condoms.” (Female PLHA service beneficiary of Kara Counselling.)

Some religious beliefs and/or the way they have been interpreted by some Churches have led to a **culture of silence** – people in urban and rural

³⁴ The President of the Republic of Zambia, Dr Frederic Chiluba, officially declared that Zambia is a Christian nation. It seems that actually between 24 and 49% of the Zambian population is Muslim and Hindu (CIA, *The World Factbook 2001*).

communities do not discuss openly sexual matters or HIV/AIDS, and those who do are considered to be shameful.

It is worth noting that 99% of the respondents from NGOs were Christian (77% Protestant and 22% Roman Catholic). Fifty seven percent said they belong to a religious group, including more than 70% of the service providers of the four NGOs.

Dependency on NGOs to provide care and support was cited as a factor in community non-involvement by one HIV negative service provider at the Salvation Army.

Donor influence on programmes that set unrealistic frameworks for the promotion of PLHA involvement (including specifically the short duration of the GIPA programme) was mentioned by HIV negative and positive service providers at CHEP.

Other factors mentioned included **poverty**, which can affect the involvement of communities in the fight against HIV in many ways:

- Many Zambians do not have enough money to pay for the HIV test and therefore have no possibility of knowing whether they are infected or not (see chapter 2).
- The capacity of infected and affected people for being engaged in voluntary and non-remunerated work is limited by the necessity of earning an income (see individual factors that limit involvement).
- The vast majority of PLHA and their families have no spare resources to spend on care, particularly drugs.
- The public health system also lacks resources and does not provide quality care to those who cannot afford to be treated in the private sector.
- As a result, levels of morbidity and mortality of PLHA are very high.

Although specific questions were asked to respondents regarding the situation of HIV positive women *versus* men, none of them except a representative from the Zambia Integrated Health Programme noted that **gender** could make it more difficult for women to be visibly involved:

“In some rural areas when some women discover their HIV+ status, they may not necessarily come out. For men it is easier. Women are usually expected to get permission from their husbands.”

4.3.4 Factors that limit the formation and sustainability of support groups

As mentioned earlier in this report, two of the participating NGOs (CHEP and Hope Humana) have promoted the involvement of PLHA in community-based prevention, care and support activities by mobilising PLHA and affected people and facilitating the formation of support groups on a self-help model. NGOs have faced a series of challenges in their efforts to support self-help

groups of infected and affected people, and the groups have faced obstacles to being sustainable. Both these challenges and obstacles were discussed during the data analysis workshop. They are presented below. The reasons support groups usually succeed will be presented further on in the report.

Box 4.2
Why support groups fail

Profile of participants in Support Groups

- Data collected through questionnaires from 74 participants in groups supported by CHEP and Hope Humana reveals that their profile is the following: 66% of participants are women; 80% of women have no education or only primary education (40% of men); 64% of men and 35% of women are self-employed mostly in the informal sector; 33% of women are unemployed; 53% of women are widows; 51% of them have more than 3 children (40% of men); 88% of men and 70% of women found out that they were HIV positive after being tested because of an opportunistic infection. This suggests that PLHA involved in support groups belong to a very vulnerable part of the population, where women are breadwinners living in unstable economic conditions.

Group Dynamics

- **Lack of common objectives and expectations among members**
In self-help groups, members usually provide support to each other. However, it was observed that most groups are actually a mix of self-help and service provision to people who do not belong to the group or the broader community, services including for example home visits and awareness raising. A major problem is that very often members have very different objectives and expectations. These are not discussed properly when groups are formed, or they are not transparent to new members.
- Some **members just want to receive material benefits** (which is easily understandable given the profile of members) but they are not aware of their obligations.
- Confusion of objectives often results in a **lack of clarity about roles and responsibilities of members**.
- There are too many leaders or lack of **leadership** skills or leaders lack legitimacy.
- **Mixed membership** of HIV positive and HIV negative people can make it more difficult for PLHA to share experiences.
- Exclusively PLHA membership can result in **stigmatisation in** the community.
- Instead of providing services in their local community, some groups try to carry out activities in other areas. This implies additional costs, such as transport, that the groups cannot pay for.
- **Too large** a group prevents members from participating fully.
- Only a few members participate in training opportunities or conferences, and fail to share outcomes with the rest of the group.

- The data shows that many PLHA join support groups when they are already ill (see profile of participants above) and the majority of them do not have access to treatment. Therefore they are **often sick** and many of them **die prematurely**. There is usually **no succession planning** when leaders die (and when they leave a group). Sometimes there are **no mechanisms to cope with the death** of members.
- Income-generating activities are inappropriate and unsustainable because members do not have skills or interest in the activities, or there is no market for the products. Our sample shows that many women have a low level of formal education; many of them do not work and have never worked outside the house before.
- Funds can be mismanaged.
- There is **competition** between members to access resources.

Relationship between Support groups and NGO(s) that support(s) them

- NGOs influence or impose objectives on the groups, for example by trying to convert genuine self-help groups into providers of services for the community.
- Groups depend on financial and technical resources of NGO (“assisted self-help”).
- NGOs use support group as a strategy to raise funds.
- Groups formed with support from NGO lack clarity about NGO’s role. Members have high expectations. They think for example that NGOs should provide them with more financial support.

Respondents from support groups were resentful that organisations did not allocate resources to enable them to offer material support e.g. money, food, medicines, for members and other PLHA they are taking care of.

“There are some people with urgent needs that we need to help. But we cannot do all these things without any means.” (Female PLHA service beneficiary of hope).

4.4 Factors that enhance the involvement of PLHA in NGOs

4.4.1 Individual factors

Table 4.6 summarises the individual factors encouraging involvement mentioned by all categories of respondent for all four organisations, ranking them in order of frequency.

Table 4.6
List of individual factors that encourage the involvement of PLHA based on opinions of respondents from NGOs³⁵

Individual factors	Frequency
Desire to support those who are infected and fight the epidemic by educating others	17
Financial and material motivation because of economic hardship	11
Increased knowledge of HIV/AIDS and improved capacity through information and training	6
Peer support	4
Personal acceptance of HIV status, desire to be free from burden of secrecy	4
Personal fulfilment	2
Desire to live longer	1
Experience from previous involvement in other organisations	1

The most frequently mentioned individual factor that has encouraged PLHA involvement is the **desire to support others who are infected and to fight the epidemic by educating others**, to prevent them going through the same experience, and/or because of religious beliefs and a sense of community responsibility, and/or to fight the epidemic. In some cases this desire to raise awareness means that some PLHA are doing outreach education as volunteers. Some PLHA stated a desire to challenge stigma as a motivating factor.

“I want to tell those who do not know anything about it and those who just want to ignore it.” (Female PLHA service beneficiary of Kara Counselling.)

“My wife and my sister died of AIDS. I thought my enlightenment on the dangers of HIV would reduce the spread of the disease.” (Male PLHA service provider of Kara Counselling.)

“They don’t want other people to go through what they have gone through”. (Male service provider of Kara Counselling.)

“I encourage them to also know their serostatus before they can continue with their fingerpointing.” (Female PLHA service provider of Hope.)

³⁵ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

As explained earlier, most PLHA are very poor and are therefore motivated by an opportunity to earn an income. **Financial and material motivation**, including the possibility of receiving incentives such as food and medicines, was the second most frequently cited individual factor encouraging involvement. Some PLHA report that allowances provide an incentive for going public and doing outreach work.

“The vast majority of people who we work with are from extremely impoverished backgrounds ... so for them the primary motivation is financial”. (Female service provider of Kara Counselling.)

“You can easily solicit help when you are visible.” (Male/female support group of CHEP.)

The desire to help others, and personal benefits, in terms of financial and other incentives and increased knowledge and skills, were notably the most important factors for PLHA beneficiaries.

Increased knowledge of HIV/AIDS and improved capacity through information and training was cited as a factor enabling individuals to become involved (and wanting to share this knowledge with others).

PLHA who are *involved* in the design and planning of services have gained experience from **previous involvement in other organisations**.

The data from questionnaires also shows that the **level of education** is a determinant in the involvement of PLHA, although it was not mentioned clearly by respondents. According to the socio-demographic profile of the PLHA involved as regular service providers and managers, all of them had at least completed secondary education. Co-ordinators had reached college level. This is in contrast with participants in support groups (see above): 66% of the respondents in this category had primary education or no education at all (80% of women in support groups).

Personal acceptance of HIV status and the desire to be free from the burden of secrecy were also important individual factors. Acceptance of status was cited by HIV negative service providers, whereas freedom from worry was cited by PLHA support group members.

“One is free when he or she becomes visible. The fact that you are not visible means that you are not at peace with yourself ... you will always be worried about your situation and scared that somebody may come to know about your status.” (Male/female support group of CHEP.)

A less frequently mentioned individual factor motivating involvement was **personal fulfilment**. Other factors mentioned included the **desire to live longer, peer support**.

4.4.2 Institutional factors

This section describes what NGOs have done or could do to encourage involvement of PLHA, building what is generally called a **conducive environment**. We have distinguished three major components of this environment:

- Material support.
- Psychological support.
- Information and skills building.

We will try to analyse the specific characteristics of these three components, in order to help in particular other organisations identify what concrete steps they may need to take to facilitate the involvement of PLHA.

Table 4.7 summarises the institutional factors encouraging involvement mentioned by all categories of respondent for all four organisations, ranking them in order of frequency.

Table 4.7
List of institutional factors that encourage the involvement of PLHA based on opinions of respondents from NGOs³⁶

Institutional factors	Frequency
Conducive environment – practical support to PLHA (financial benefits, material benefits, access to medical care)	18
Training (outreach, positive living etc)	15
Referrals within the organisation	10
Conducive environment – psychological support, attitudes of staff and management	10
Effective pre- and post-test counselling	4
Organisational structure, integration of PLHA involvement	5
Positive role models	3

Material support for the involvement of PLHA can include remuneration and/or material benefits, depending on the type of involvement.

Employment brings a regular income to PLHA who are working with the organisation. They can take care of their family, in particular their children. Employment also brings other benefits, such as access to medical insurance or free care and treatment, which is extremely important for PLHA. In at least one confirmed case, the organisation had decided to pay for antiretroviral drugs for one of its HIV positive employees. Employment also means that HIV positive employees can take time off for medical consultations and treatment without worrying about losing income. Only a few visible PLHA were employed by the organisations who participated in the study and therefore had access to this range of material benefits, and even fewer were employed full-time and with full benefits.

³⁶ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers. This table does not include the Salvation Army, as no factors were identified during data collection and responses focused on factors that would encourage involvement. This is because involvement of PLHA in activities of the CPTs is still very limited.

Obviously, the capacity of NGOs to employ PLHA is limited anyway because organisations cannot increase their human resources without programmatic and strategic reasons and without the corresponding financial resources. However, PLHA can be employed in a wide range of positions, from support staff (*inclusion*) to service providers (*participation*) and managers (*involvement*). Whatever the position and level of salary, employment results in a level of stability always welcomed by PLHA.

“The advantage is that CHEP has helped me to look after my children.” (Female PLHA service provider of CHEP.)

“When you talk in terms of medication it is also free of charge ... so such kind of things encourages people.” (Male PLHA service provider of Kara Counselling.)

We saw that other PLHA also take part in the delivery of services as non-regular service providers (*inclusion*) without being full-time or even part-time employees of the NGOs. They work on a voluntary basis, although the notion of “volunteerism” needs to be qualified. Organisations mobilise and retain HIV positive volunteers by giving them incentives such as some money for “transport” and/or meals.

Even organisations who organise skills-building courses for PLHA (*access*), like Hope Humana and Kara Counselling, have realised that the training not only should be free but it should include as well some kind of material support, whether it is again money for transport and meals. Participants in the Positive Living Advocacy Course of Hope Humana for example have a meal at the centre twice a week when they attend the course at the Hope centre. They also receive some money to pay for their transport from their residence to the centre. Most of them prefer to walk and keep this money to buy food that they will use during the rest of the week.

Practical support is therefore particularly essential to the mobilisation and sustainable involvement of PLHA in NGOs and CBOs in Zambia because of poverty and its consequences on most PLHA and their families. This does not mean that all PLHA should or could be employed by NGOs and CBOs, many PLHA can be volunteers but the concept of volunteerism has to be adapted to the local context.

Psychological support

Psychological support within NGOs and CBOs includes **non-judgmental and accepting attitudes of staff and management**. This was particularly important in NGOs where there are visible PLHA among employees (*inclusion*, *participation* and *involvement*). This means that staff and management do not stigmatise PLHA but they are also able to value them as active contributors to the activities of the organisation.

“When they are here they are accepted unlike when they are in the compounds where people look down on them ... we do not consider them as sick people.” (Service provider of Hope.)

“They consider every problem that I have and help me. It may be financial, health, they really stand by me. Management makes it a point that at least every day they speak to me, how are you, how are your programmes? Just that motivates me.” (Female PLHA service provider of CHEP.)

Positive attitudes of staff toward PLHA can be more or less spontaneous. They can be reinforced by sensitisation programmes. CHEP used for example the placement of a seropositive UNV in the organisation (GIPA initiative supported by UNDP) to sensitise its staff through training.

“They considered me to be part and parcel of their organisation.” (Male PLHA service provider of CHEP.)

It is worth noting that our sample shows that the vast majority of service providers from the four participating NGOs took an HIV test (79% of men and 67% of women) and for 54% of them it was voluntary testing. At CHEP, service providers were even encouraged to take a test as part of the sensitisation programme after the HIV positive UN volunteer was placed in the organisation. However, in the two CPTs of the Chikankata hospital who were involved in the study, only 26% of members and 13% of women took a test. The main reason is that they do not think they have been at risk of being infected with HIV. This perception of self-invulnerability often creates a gap and a tension between those who are supposedly HIV negative and PLHA. Under these circumstances it is not completely surprising that there are so few HIV positive people who are open about their status in the CPTs.

Peer support is also an important element in organisations where there are already PLHA involved. PLHA can share experiences and support each other. PLHA who hold positions of co-ordinators and/or service providers (*involvement* and *participation*) act as **role models** for other HIV positive people who are volunteers and beneficiaries (*inclusion* and *access*). Some PLHA have been inspired to become outreach educators by those who are already doing this work. At Kara, the HIV positive outreach co-ordinator and educators actually take part in the empowerment process of the PLHA who participate in the Life Skills Training Programme, by training them in outreach education or supervising them when they take their first steps in outreach education.

“They see them [the outreach educators] as people who have passed through the stages of being HIV positive. This helps them to see what they can do as people living with HIV. In fact we have had people joining the outreach education after observing what the others do in the outreach teaching” says a service provider of Kara.

“People in the community started seeing that if these people who are HIV positive can be open about their status ... this made people

realise that if these people can talk about their situation freely, how about us.?’ (Male PLHA service provider.)

In some organisations (Hope Humana, Kara Counselling) the first kind of psychological support many active PLHA received was counselling. The availability of good **counselling** was one factor mentioned by both HIV positive and negative service providers at Kara and Hope. Counsellors at Kara felt that individual and group counselling helped PLHA to be visible and part of the effort against the epidemic.

“During the counselling ... they discover their personal value in society and the community where they come from. The things they learn during counselling, education they acquire and their own life experiences tend to make them come out in the open to help the community. We see the desire in them to go out to the community.”
(Service provider of Kara Counselling.)

Some PLHA mentioned good counselling as one of the reasons for becoming involved in activities.

“We became involved with Hope Humana because when we first went there the counselling sessions were very good and encouraging ... this has built us emotionally and eventually we became involved in other activities.” (Female PLHA service provider of Hope.)

During counselling sessions, PLHA can learn about positive living and start to change their misconceptions about HIV/AIDS.

Information and skills building

Counsellors are also in a good position to refer PLHA to courses and training programmes in which they can learn more about Positive Living and also learn new skills. This kind of **referral** is crucial to access to other services provided by NGOs.

Two of the participating organisations, Hope Humana and Kara Counselling, have developed original **training programmes** for PLHA (see chapter 3, Access): the Positive Living Advocacy Course (PLAC) and the Life Skills Training Programme. Both programmes have some similar objectives and contents that aim to help PLHA:

- “Accept” their HIV status.
- Live positively by providing them with accurate and up-to-date information on the HIV infection and how to cope better with it psychologically and physically.
- Improve their material situation (vocational training, entrepreneurial skills, IGAs).
- Change risky behaviours for themselves and the community.
- Mobilise, support and educate their peers, i.e. other PLHA.
- Mobilise and educate the whole community (outreach education).

These training programmes have been a way to recruit PLHA among service users and turn some of them into service providers for the organisations themselves, as a kind of in-house training, and for other organisations. As explained before, all the HIV positive outreach educators working with Kara went through this training. Others are now working with NZP+. PLHA employed by Hope as Positive Living Advocates started as participants of the PLAC. It seems therefore that this kind of training is a good way to enhance the involvement of PLHA in service delivery, whether it is informal or formal (*inclusion and participation*).

“I was trained in skills training. Then I started training on basic facts of HIV/AIDS. That was when I gathered the courage to tell anybody. So I did it through the press. And when my relatives came, I just convinced them that this is that.” (Male PLHA service provider of Kara Counselling.)

“When we graduated, it was easy because they said whoever was willing to go public, would be fused into the outreach team. So it was easy for us” explains a seropositive outreach educator of Kara Counselling.

However, this is only a step to enhance *involvement*. The data reveals that NGOs have usually provided further training to those PLHA who are involved in planning, design and/or co-ordination of programmes. Several Positive Living Advocates of Hope went, for example, on a Basic Management Course in order for them to have greater responsibilities within the organisation.

For NGOs who employ PLHA, training opportunities also depend very much on the overall management of human resources within the organisations. The three participating organisations in which we observed *participation* and *involvement* of PLHA certainly saw training of their staff as a priority.

HIV positive respondents also mentioned **exposure through workshops** and seminars and meeting with other PLHA as an important factor in learning and enabling PLHA to be involved and visible.

Box 4.3

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:
 - Money for transport
 - Meals
 - Referral for care free of charge

Psychological support and non-discrimination

- No mandatory testing for recruitment
- Availability of counselling
- PLHA are not forced to disclose their HIV status
- HIV status of HIV positive staff is confidential when they do not want to come out in the open
- Non-judgmental attitudes of staff, through sensitisation when necessary
- Positive attitudes of staff and management toward active involvement of PLHA as service providers
- Peer support available inside or outside the organisation

Information and training

- Information for HIV positive service users on training opportunities and referral to activities in which they can be involved
- Pro-active training in the following fields:
 - Coping with HIV status and Positive Living
 - Basic facts of HIV/AIDS
 - Delivery of services, e.g. communication skills for outreach education
 - Specific skills relevant to the positions held by PLHA, e.g. management for existing or future co-ordinators

It is important to note that none of the NGOs who participated in the study has at this stage a written workplace policy specific to the involvement of PLHA in the organisation.

Other less frequently mentioned factors included the way the **organisation is structured**: team work and flat management structure facilitate involvement of PLHA in the decision-making process (*participation* and *involvement*).

At CHEP, service providers stressed that although the organisation created a PLHA programme to follow up the placement of a positive UN Volunteer to promote GIPA, this programme is **completely integrated with other activities** of the organisation at programmatic and financial level.

4.4.3 Social factors

Table 4.8 summarises the social factors encouraging involvement mentioned by all categories of respondent for all four organisations, ranking them in order of frequency. A brief analysis of these factors follows the Table.

Table 4.8
List of social factors that encourage the involvement of PLHA
based on opinions of respondents from NGOs³⁷

Social factors	Frequency
Referrals between organisations, HBC teams, NZP+	9
Support of family	7
Reduced community stigma, increased acceptance of PLHA	6
Improved community knowledge of HIV/AIDS	4
Religious beliefs and compassion	4

Most frequently mentioned, especially by PLHA beneficiaries and support group members, at Hope and CHEP, was **referrals between different organisations**. HBC teams of the Ndola Catholic Diocese, for example, work closely with support groups of PLHA who are also trained by Hope Humana. HBC team support includes practical items such as free food rations and medicines, which is particularly important in the Zambian context. The HBC teams have also been important in helping people to be open about their status and encouraging PLHA to join support groups.

“When the volunteer from the HBC team came to visit me, they informed me that those who had been tested had formed a group. I decided to join them.” (Female PLHA service beneficiary of hope.)

Kara Counselling has always had close links with NZP+. Referrals between the two organisations enhance involvement of PLHA in two ways: NZP+ can refer people to Kara for testing and counselling; skills trainees and HIV positive outreach educators from Kara later on often become service providers of NZP+ and other support group affiliates of the network.

Family support and influence was the second most frequently mentioned social factor encouraging PLHA involvement, by all categories of respondent in all organisations.

“I have support from my child. She is always behind me.” (Female PLHA service provider of CHEP.)

“My parents made it easier for me when they accepted my HIV positive status.” (PLHA service beneficiary of Kara Counselling.)

“I knew because my husband used to come here. That is what encouraged me to join the group.” (Female PLHA service beneficiary of Hope.)

Reduced stigma and increased acceptance of PLHA in the community, including by family and friends, was the third most frequently mentioned factor,

³⁷ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

enabling some PLHA to participate in service delivery or to become involved in other ways. When PLHA are accepted, people begin to appreciate what they do and encourage them to continue delivering services. This also allows PLHA in the community to act as role models.

“What motivates us is that though there is some discouragement from some places, sometimes when you go to other places you get encouragement from other people for the education and testimonies we give. That encouragement makes us want to continue.” (PLHA service provider of Kara Counselling.)

Increased acceptance in the community is linked to the fourth most frequently mentioned social factor, **more adequate and accurate community knowledge of HIV/AIDS**.

Although in some cases religion has led to the stigmatisation of PLHA, as explained earlier, it was also noted that **religious beliefs**, such as the compassion toward PLHA that some Churches have preached, have been an important social factor encouraging the involvement of some PLHA, according to some respondents. The Catholic Diocese has been instrumental in the formation of support groups in Ndola, and some PLHA give testimonies in church.

Access to testing was mentioned at the data analysis workshop as a social factor that could motivate PLHA involvement. It is important to note that some PLHA emphasised that they decided to take an HIV test and be counselled because HIV testing was offered free of charge by the NGO:

“Lots of us did the free HIV test and were happy because we didn’t have the money to pay for the test.” (Female PLHA service provider of Hope.)

Influence and support of donors can also enhance involvement. In the case of CHEP, the placement of the positive UN volunteer supported by UNDP within the GIPA initiative has boosted the involvement of PLHA in the organisation and the formation of support groups.

4.4.4 Factors that enhance the formation and sustainability of support groups

Box 4.4 Why support groups succeed
<ul style="list-style-type: none"> ➤ Members have clear common objectives and expectations. ➤ They know the benefits and costs of their participation in the group from the start. ➤ They have a common experience and background.

- They have a real sense of “belonging”.
- They have an individual interest and motivation in participating.
- Members obtain material and psychological benefits from involvement in support groups.
- Members are clear about what is expected from them.
- Members have enough time to devote to the group to allow it to function effectively.
- There is a strong leadership and/or a clear decision-making process within the group.
- Income-generating activities are well planned and managed, based on members’ skills and interests, appropriate training and technical support, and are sustainable and meet members’ basic needs.
- The group is based in a community and if it provides services, these services are limited to the local area.
- Community acceptance and referrals.

Relationship between support groups and NGO(s) that support(s) them

- The group receives technical support and training from NGO, e.g. in group formation, planning, group management, leadership skills.
- The role of, and links with, NGO are clear from the start.
- NGO responds to support group needs rather than directing the group.
- The group is able to continue independently of NGO support.

4.5 Conclusions

4.5.1 From *access to involvement*: a continuum for PLHA and NGOs

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 she would like to lead an outreach programme 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).

Table 4.9
Summary of conditions and steps for involvement of PLHA in NGOs

Individual processes	Organisational processes
‘Pathway to involvement’ for PLHA	‘Pathway to involvement’ for NGOs
<p>For PLHA, steps or conditions for <i>inclusion of PLHA in NGO service delivery</i> are:</p> <ul style="list-style-type: none"> • Undergo VCT • Have the desire and drive to help others and to contribute to the fight against HIV/AIDS • Have basic knowledge about HIV/AIDS • Take the initiative • Have informal and/or formal training, including in life skills • Disclose to family and/or friends and/or work colleagues – the ‘right’ person or persons to disclose status to initially depends on trust – the right person in the right place at the right time – this may not necessarily always be a family member • Have material and emotional support • Undergo training for service delivery 	<p>Steps or conditions for NGOs to have <i>inclusion of PLHA in service delivery</i> are:</p> <ul style="list-style-type: none"> • Create opportunities for PLHA beneficiaries to deliver services • Provide basic training on HIV/AIDS, e.g. positive living • Sensitise staff and management • Provide HIV/AIDS information to PLHA • Allocate budget for reimbursement of expenses related to <i>inclusion</i> in service delivery
<p>For PLHA, additional steps or conditions for <i>participation of PLHA</i> in NGO are:</p> <ul style="list-style-type: none"> • Formal contract as a service provider • Undergo formal training for service delivery • Use the experience of being a service provider in design and planning • Have emotional support • Capacity building 	<p>Additional steps or conditions for NGOs to have <i>participation of PLHA</i> in the organisation are:</p> <ul style="list-style-type: none"> • Identification of PLHA who can become service providers • Provision for specific positions for PLHA • Recruit PLHA • Allocate training budget • Design specific training programmes and put in place a structure • Provision for training on e.g. delivery of HIV/AIDS services • Provision for training on e.g. design and planning • Accompany by monitoring and evaluation

<p>For PLHA, additional steps or conditions for involvement in NGOs are:</p> <ul style="list-style-type: none"> • Capacity building on organisational issues • Literacy and numeracy³⁸ • Have managerial skills • Be responsible • Have programmatic experience • Strong communication and representation skills • Strong advocacy skills • Build an in-depth knowledge of the organisation • Be creative 	<p>Additional steps or conditions for NGOs to have involvement of PLHA in the organisation are:</p> <ul style="list-style-type: none"> • Extension of non-discriminatory employment policies to management and decision-making positions • Provision for management positions to be held by PLHA • Provision for management training • Allocation/decentralisation of budgets for specific activities to be managed by PLHA • Measures for accountability of PLHA • Open competition for jobs but include a clause in advertisements stating that PLHA are encouraged to apply for positions
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The analysis of the pathways to 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, learn the basic facts of HIV/AIDS through counselling and/or courses (PLAC, Life Skills Training) as well as learn 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. They 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 a time when a PLHA has reached a certain level of acceptance and feels strong enough to share his/her experience with other people, whether inside or outside an organisation, fulfilling the desire to help others. S/he also keeps learning new skills, in particular through informal involvement in activities such as outreach education. 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 are in general 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.

³⁸ This does not mean that literacy and numeracy are not important for *participation* or even *inclusion*, but they are not essential, whereas they are absolutely necessary skills for PLHA to be *involved*.

- 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, have 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 of range of skills. We observed that these skills are usually the result of several years of experience in the fight against the epidemic, some training provided by the organisation(s) PLHA have been working with and a lot of self-training through a large exposure in national and very often international workshops and conferences (in addition to formal education). Although various forms of support have helped PLHA who are *involved*, overcoming obstacles has been a motivation as well. They are usually passionate fighters.



Data analysis workshop: building the “pathway to involvement”

The data shows that in at least 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 involvement**.

Hope Humana started its activities by offering services to PLHA, such as testing, counselling and medical care. PLHA were only service users (*access*). Afterwards, Hope started a nutrition course for PLHA. Relatively quickly, the nutrition course became the Positive Living Advocacy Course, which was a way to encourage PLHA to take part informally in outreach activities, by giving testimonies, and helped provide positive people with skills useful for outreach education and community mobilisation. Some of them have become volunteers (*inclusion*) and others have been recruited after some time to be service providers (*participation*). Further training in project management has led to greater *involvement*, some former positive volunteers and employees taking programmatic responsibilities. The PLAC has also been used to catalyse the formation of support groups and encourage external involvement of PLHA.



Data analysis workshop: some organisational steps on the pathway to involvement

At Kara, the history of involvement has been similar. Positive people were originally clients of the counselling services. PLHA approach the organisation not to be involved but to seek some kind of support (*access*). Then Kara created the Life Skills Training Programme and PLHA could be referred to the course. Like the PLAC, this training programme has been key to the empowerment of positive people. During the course PLHA learn a series of useful skills that they can use to conduct outreach education. They can test their skills by helping the staff (*inclusion*) and some of them have been given the opportunity to become outreach educators who work with the organisation (*participation*). Kara actually supported the first group of positive outreach educators in Zambia, the Positive Living Squad; one of the founders of the group is now the co-ordinator of the outreach programme (*involvement*).

The continuum is partly a consequence of the difficulty for NGOs and CBOs in finding 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 Zambia, because of the paradoxes of a society where stigma is still widespread in spite of a prevalence of HIV of 20%. 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 and give them opportunities to test their skills until they are ready to become service providers³⁹. This process is time-consuming for NGOs and it also has a financial cost.

Only CHEP was able to identify a PLHA who already had a wide range of skills through the UNV-GIPA programme, although the organisation also invested time and money in training and supervising the positive UN volunteer.

Another cost of involving visible PLHA as service providers is linked to the health problems of people with AIDS. The risk when investing in training people who are chronically sick is that they will be too sick to be able to work and do what they have been trained for, or will even die prematurely. One solution is to make sure that PLHA have access to good quality care and treatment to avoid opportunistic infections. Since the public health system in Zambia does not provide it free of charge and most PLHA do not have the financial resources to afford private care, NGOs involved in the study have chosen to ensure access to care and treatment, at least for their employees, and to some extent for their volunteers through referrals.

These costs can be seen as an investment worth making, because of the benefits for the organisation and the community it serves, as we will show in the following chapter.

4.5.2 NGOs are not powerless

The list of factors identified by the study shows that **many obstacles to involvement are strictly organisational and structural, which can be tackled by the organisations themselves.**

Obviously social factors cannot be ignored, but NGOs should not use them as an excuse to do nothing. Obviously, a single NGO cannot reduce stigma in Zambia, but it can change the attitudes of its staff and management toward PLHA and their involvement in the organisation. NGOs cannot educate all unskilled HIV positive people in the country but they can create innovative training programmes for PLHA like the existing ones at Hope and Kara Counselling.

³⁹ 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.

NGOs involved in the study felt nevertheless that they should try to network with other stakeholders in order to overcome some of the social factors that limit the involvement of PLHA.

One organisation said that they would advocate for better access to treatment, particularly by empowering PLHA and supporting NZP+ to lobby for access to drugs, including antiretrovirals. Another organisation said it was important to lobby the government to encourage provision of quality health care, and to empower communities to demand effective service delivery by the public sector.

One NGO wanted to emphasise the importance of funding for food provision to PLHA in its discussions with donors.

Two of the NGOs wanted to strengthen links with other organisations and agencies providing complementary services and improve referrals.

4.5.3 Scaling up involvement through support groups: learning the lessons from the study

Capacities for *inclusion*, *participation* and *involvement* in NGOs that provide HIV/AIDS services are limited because each organisation has a restricted number of employees and volunteers, and not all of them can be HIV positive (unless the organisation becomes a network, or a self-help group of PLHA).

Three of the organisations involved in the study have tried to scale up involvement by encouraging the formation of support groups of PLHA and affected people and post-test clubs. Some of these initiatives have been successful and others not, for the reasons we have listed in this chapter.

A contradiction of these groups is that they need to be sustainable, and therefore they should not depend on NGOs forever, but at the same time they need a lot of technical support, in particular at the formation stage.

NGOs have realised that more technical support is needed on issues of sustainability of financial resources, including fund-raising, budgeting, management of funds, how to start and sustain income-generating activities and financial reporting. One NGO has decided to work in partnership with an organisation specialised in micro-finance. Another is looking at models of micro-credit schemes. The basic idea is that NGOs who provide HIV/AIDS services, even with a background in development, do not always have the expertise in these issues and they should learn from other organisations and other sectors.

After a dramatic increase in the number of groups it supports, CHEP has also decided to stop the formation of more groups and focus on quality more than quantity.

Hope will also completely review the kind of technical support it provides to existing or “dormant” groups, with on-going training on how to form and run a support group on the one hand and on how to generate and manage resources on the other hand.

Another important lesson of the study is that links between support groups and NGOs and mutual expectations should always been discussed in a transparent way. The same applies to relations between organisations and individuals who are HIV positive, whether they are beneficiaries or already involved in the delivery of services.

Chapter 5

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 non-PLHA and PLHA service providers, and service users, to evaluate effects of involvement in terms of comparison and changes:

Before and after the involvement of PLHA – 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 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- and longer-term effects.

- **Inadequate time and capacities to develop indicators.** We had planned to develop indicators to measure effects of involvement with the participating NGOs but there was **inadequate time and capacities** among researchers and NGO members **to develop** these **indicators**.
- **Other factors 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 in addition to PLHA involvement.
- **Comparing services provided by PLHA and by non-PLHA 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 non-PLHA 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*.

As for the previous chapter on limiting and enhancing factors, for each category of effects, (where possible) we will start the presentation of the findings with a table that lists a number of positive and negative effects mentioned by the respondents from NGOs and how many times they were mentioned (frequency)⁴⁰. We will also present the effects identified by key informants outside the participating NGOs.

⁴⁰ Detailed tables that also include the categories of respondents and the number of respondents of each category who mentioned spontaneously each effect in interviews and Focus Group Discussions (FGD) are presented as appendices.

It is important to remember 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. Frequencies are a result of the thematic classification of transcripts of interviews and FGD by the research team. A computerised tabulation was not technically possible. Classification is therefore subject to the interpretation of each researcher and the timeline did not allow for cross-checking by a second researcher. Frequencies do not have a statistical value; they only express trends of opinions.

In addition, 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 what limits and encourages involvement in NGOs.



In one of the CPTs HIV negative members and PLHA work as a team to repair the house of a member of the community who is chronically ill (Salvation Army)

5.2 Effects of involvement on PLHA

5.2.1 Positive effects

Table 5.1 summarises positive effects on PLHA as a result of their involvement, reported by different categories of respondent, for all four organisations. The table is followed by a brief analysis of the main effects identified.

Table 5.1
List of positive effects of PLHA involvement on PLHA
based on opinions of respondents from NGOs⁴¹

Positive effects on PLHA	Frequency
Improved mental and psychological health	11
Improved physical health	9
Behaviour change	8
Increased knowledge of HIV/AIDS	8
Peer support	8
Employment and/or material benefits	4
Access to medical care	3
Increased acceptance by family	2
Less stigma	1

The positive effect mentioned most frequently overall was **improved mental, emotional and psychological health**, including less depression, feeling freer and less worried, increased self-worth and self-esteem, greater sense of usefulness and responsibility, and recognition that PLHA are worthy of respect. This was mentioned in particular by PLHA service providers and their relatives and by PLHA beneficiaries.

“When I was hiding my status I used to be worried but now I am open and not worried.” (Female PLHA service provider of Hope.)

“She has put on weight and has become more open especially to us children. She seems to have peace of mind despite her illness. Something has changed.” (Son of female PLHA service provider of Hope.)

“We have really gained self-esteem.” (Male/female support group of CHEP.)

“She became a better person and her smile came back to her face.” (Daughter of female PLHA service provider of Hope.)

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

“Involving them in the delivery of services will give them a sense of self-worth and will boost their ego because they will have something to do in the way of helping others..” (Male service provider of the Salvation Army.)

⁴¹ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

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

The second most frequently mentioned positive effect was **improved physical health**, including rarely getting sick, getting fewer opportunistic infections and living a healthier lifestyle, for example eating a more healthy diet.

“I used to get sick almost every week but now it takes a long time for me to get sick.” (Male PLHA service provider of the Salvation Army .)

“My health has really improved because I have now learnt how to look after myself properly. I used to be sickly, I was in and out of hospital ... but now my health has really improved such that I even have the energy to cultivate. I know how to prevent some of these opportunistic diseases”. (Male/female support group of CHEP).

“I have become healthier and people sometimes wonder whether I am really HIV positive and this encourages me a lot.” (Male support group of CHEP.)

Hope specifically evaluated the impact on PLHA of participation in the Positive Living Courses (PLC) and PLAC. Participants reported positive effects in terms of their knowledge about good nutrition – learning about a healthy balanced diet using local, affordable foods, hygiene and fitness. This has made an important difference to their quality of life. One man reported that his weight had increased dramatically during the course as a result of good nutrition and exercise. However, some participants reported that they were unable to put what they had learnt about a nutritious diet into practice because they could not afford to buy good food.

“I try to prepare what I learnt during the course. The only problem is that I do not have the money to buy what I learnt to cook. I find it very difficult to have balanced meals because I do not have enough money... sometimes the whole week elapses without having any proteins.” (Participant in the Positive Living Course run by Hope.)

“I try to ensure that my surroundings are clean, the utensils I use are clean, I myself am clean as well as my children...It helps to defeat illnesses. Where there is cleanliness even flies don't frequent.” (Participant in a PLAC run by Hope.)

“I never used to do exercise, but now I do them three times a day.” (Participant in a PLAC run by Hope.)

“When I wake up in the morning and feel weak, I do the exercises and they help me to feel better and all body pains go away through exercises.” (Participant in a PLAC run by Hope.)

Other areas where positive effects were reported were **behaviour change**, specifically less casual sex and more condom use, **increased knowledge of HIV/AIDS**, and **peer support**.

“You can’t teach people when you are doing bad things yourself.” (Service provider of Kara Counselling.)

“You would not sleep around to infect those who are not sick” (says an HIV positive participant of a group supported by CHEP).

“I stopped ... endangering my life.” (Concerns of another participant.)

“I have stopped sleeping around. I have changed in the way I used to behave.” (says a participant of a group supported by CHEP.)

“Training has empowered PLHA in the eyes of the community ...and given them a status.” (Male service providers of CHEP.)

“We have discovered our hidden talents. We have started doing some businesses.” (Male/female support group of CHEP.)

Behaviour change and increased knowledge and capacity were the highest ranked positive effects by respondents at Kara and CHEP. However, at the data analysis workshop, it was noted that, in some cases, involvement can result in negative behaviour change, for example, having money may lead to drinking more alcohol.

Evaluation of the effects of the Hope PLC and PLAC on participants showed that some of those who had participated had subsequently been active in their community, encouraging people to go for HIV testing, sharing information with their family and neighbours, and visiting the sick.

“I have been active and I have taken many people to Hope for testing.” (Participant in a PLAC run by Hope.)

“When I go to play Nsolo and somebody talks on HIV, I take the opportunity to talk about it ... Some people also come to my house to seek advice on HIV issues.” (Participant in the Positive Living Course run by Hope.)

However, while respondents to the evaluation of the Hope PLC and PLAC noted that the courses had given them entrepreneurship and budgeting training, it appears that they were not provided with adequate skills or support to put their income-generating plans into practice.

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

Group support and solidarity, and new friends who provide psychological support, boost self-esteem and lighten the burden of HIV, were mentioned by respondents for all four organisations, and in particular by PLHA service providers and PLHA beneficiaries and support group members. Support groups and PLHA who are visibly involved have been an inspiration for other PLHA – encourages them to become visibly involved themselves – and involvement has in itself empowered and increased the capacity of PLHA to educate others. Some PLHA cited exposure to new experiences, people and places and becoming a public figure as a positive effect of their involvement.

“I became interested a lot after seeing fellow PLHA looking very fine and healthy ... then I realised these things were possible even for me.” (Female PLHA service provider of Hope.)

“The sharing of people who belong to the same group ... the same kind of problem that you have is a remedy somehow.” (Female PLHA service provider of CHEP.)

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

“Through the group we supported each other psychologically and this gave us a lot of strength to carry on.” (Service providers of Hope.)

Some PLHA also reported that after developing the skills and the courage to be visible they had also become involved in NZP+ and its activities.

Not surprisingly, given the limiting and enhancing factors identified in Chapter 4, obtaining **employment and other material benefits**, such as allowances, meals and housing, was also mentioned as a positive effect of involvement, by service providers and the relatives of PLHA service providers. Kara HIV negative service providers, for example, noted that some PLHA have had the opportunity to get employment in institutions where the positive role they can play has been recognised. And PLHA beneficiaries at CHEP noted that they had developed enterprise skills. Employment and other financial and material benefits are also linked to other positive effects on physical health, on the family and on the relationship with the family.

“Due to this programme about six people have found formal employment and there are about 150 PLHA in support groups

involved in income-generating activities. I am able to look after myself and my family ... I am now leading a very productive life because I have an income." (Male PLHA service provider of CHEP.)

"Another benefit is that of being able to buy foodstuffs from the HBC at cheaper prices." (Male support group of CHEP.)

These positive effects are obviously linked to the type of involvement. *Participation* and *involvement* bring more material benefits, as well as *inclusion* when it describes employment as support staff.

Other less frequently mentioned positive effects of involvement included: **access to medical care** (either direct care provided by the organisation or expenses of care met by the organisation or referral to other care providers), of particular importance to PLHA beneficiaries and the relatives of PLHA service providers; **increased motivation to be visibly involved**; in some cases **increased acceptance by family**, of particular importance to PLHA service providers and beneficiaries; **paying more attention to the family**, whereas previously the family had been neglected; and, in some cases **less stigma**.

"When he gets sick he receives treatment at the hospital." (Male relative of PLHA service provider of the Salvation Army.)

"There is a change in his life. He may get sick and receive treatment at the hospital. For example, he had dysentery and they healed him." (Female relation of PLHA service provider of the Salvation Army.)

"My children are my priority and I always make sure I look after them well so that they are fed properly." (Male support group of CHEP.)

"The most encouraging thing nowadays is that they have stopped mocking me or insinuating that I got the virus due to sleeping around." (Male PLHA service provider of the Salvation Army.)

5.2.2 Negative effects

The most frequently mentioned negative effects on individuals were **rejection** by families, friends and neighbours, **stigmatisation** and **discrimination**, in particular during the period shortly after disclosure. Some PLHA reported that their families and friends had rejected them. In one case this was perceived to have contributed to suicide. Another respondent linked this to social status.

"Most of the problems I faced were from the family." (Male PLHA service provider of Kara Counselling.)

“There is a case of a young man who after going public had a serious quarrel with his father and he was disowned ... he committed suicide.” (Male service provider of Kara Counselling.)

“They reacted very badly and I was chased away from home and even my own father completely rejected me saying I had brought a lot of shame to the family ... he said it would have been better for the family if we had kept it secret ... this was a very serious situation for me now, you can imagine no family to support you at the time when you need them most. I couldn’t touch my relatives’ plates, I couldn’t visit them because they were all trying to avoid me as much as possible, I couldn’t go to wherever my friends were because I was not welcome anywhere when they heard I was HIV positive.” (Male PLHA service provider of CHEP.)

“I have lost all my old friends because of this illness ... my relatives have ignored me completely.” (Male/female support group of CHEP.)

“People will avoid you. Even the cups he uses, they don’t even touch it.” (Female support group of CHEP.)

“Most of my friends used to laugh at me and point fingers... others used to say I would not live long, but I used to tell them that only time would tell.” (Support group of CHEP.)

“There are some people after knowing Mum is positive are not as close as they used to be before... most of her friends were of high status before she was positive and the time when my father was still around.” (Son of female PLHA service provider of Hope.)

Questioning PLHA motives for involvement, as discussed in Chapter 4, was another negative effect reported.

“The only thing is that people usually tease me that it’s not true that I have the virus, that I just want to use the situation to woo money from donors.” (Female PLHA service provider of Hope.)

5.3 Effects on the services and activities of the organisations

5.3.1 Positive effects

Respondents identified the following positive effects of PLHA involvement on the services and activities of the organisations:

- Increased success of outreach programmes.
- Publicity and increased demand for services (VCT, training, and Positive Living Courses).

- Increased number of PLHA joining support groups.
- Increased skills for support group formation.
- Increased credibility of services with service users.
- Improved understanding of issues affecting PLHA among non-PLHA service providers and increased acceptance of PLHA.
- Changes in staff attitudes towards PLHA leading to a more conducive environment for PLHA.
- Integration of advocacy for the rights of PLHA into the work of the organisation.
- Improved credibility of the organisation and its services with donors and other stakeholders.

Increased success of outreach and mobilisation activities and **credibility** as a result of PLHA involvement was mentioned by respondents at Kara, Hope and CHEP. However, although respondents mentioned a dramatic effect of PLHA involvement on the success of outreach programmes, the study found limited evidence to support this, and some of the data is contradictory.

HIV positive outreach educators were also perceived to be role models, encouraging others to carry out services and activities in the community.

“Like the outreach programme it has been successful at Kara because people living with HIV/AIDS have been coming out.” (Male service provider of Kara Counselling.)

“What we have seen is that the outreach educators are like role models for our (skills) trainees. They see them as people who have passed through the stages of being HIV positive. This helps them to see what they can do as PLHA. We have had people joining the outreach education after observing what the others do in the outreach teaching.” (Male service provider of Kara Counselling.)

“Other organisations have now recognised CHEP as one organisation which is in a position to help people who are HIV positive.” (Male PLHA service provider of CHEP.)

CHEP evaluated the effect of workplace outreach education conducted by PLHA with a small sample of workplace peer educators who had been trained by a PLHA employed by the organisation, and beneficiaries reported changes in attitudes towards PLHA as a result.

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

Kara also specifically evaluated the effect of workplace outreach education conducted by PLHA. Respondents particularly recalled messages about going for an HIV test and avoiding unprotected sex by being abstinent, faithful or using condoms. Specific positive outcomes cited by those who had attended the education sessions included deciding to use condoms with girlfriends, more positive attitudes towards PLHA, and starting to talk about HIV/AIDS in their family and community. One of the respondents had started to talk about sex with her children for the first time and encouraged them to have safer sex.

“I do have a girlfriend but ... I do use some form of protection.”
(Beneficiary of outreach education supported by Kara Counselling.)

“When I attended the seminar I had some feelings that those are human beings. They are like anybody else.” (Beneficiary of outreach education supported by Kara Counselling.)

“It is not their fault. They were just unfortunate to get it.”
(Beneficiary of outreach education supported by Kara Counselling.)

“I never used to talk about these things ... I used to be shy. From that time I just had the courage to call them and discuss ... I tell them that please play with safe sex.” (Beneficiary of outreach education supported by Kara Counselling.)

PLHA involvement was also cited, by respondents at Kara, Hope and CHEP, as having publicised services and **increased demand** for and uptake of HIV testing, skills training and Positive Living Courses, and workplace outreach programmes, as well as increasing membership of support groups.

“The other effect is that a lot of people do come to Kara for HIV testing because of what we do (outreach education). They get encouraged.” (PLHA service provider of Kara Counselling.)

“While the course is in progress, there is always another group enrolled for the following intake.” (Service provider of Hope.)

“On the reception of companies, it has improved tremendously because companies do write to us now requesting services we offer.” (Male service provider of CHEP.)

“There are about 150 PLHA in support groups who are very much involved in income-generating activities.” (Male PLHA service provider of CHEP.)

However, as with outreach programmes, the findings of the study regarding effect on uptake of services, in particular of VCT, are somewhat contradictory. An evaluation carried out with a small sample of employees of two companies visited a few months before the study by the team of positive outreach educators, shows that only one of them went for an HIV test after the outreach session and then never picked up the results because of fear.

For CHEP respondents in particular, the involvement of the UNV PLHA and the creation of a PLHA programme had **increased the number of support groups**, the organisation's **skills in establishing and supporting these groups**, and had also creating valuable **collaboration on advocacy and networking**, for example with NZP+.

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

"We are still networking... we added a lot of activities on HIV and a lot of people who are HIV positive and other organisations have now recognised CHEP as one organisation which is in a position to help people who are HIV positive." (Male PLHA service provider of CHEP.)

"Collaboration between NZP+ with the Copperbelt NGOs would certainly increase." (Male service provider of CHEP.)

Respondents from CHEP mentioned that involvement of PLHA – including in design and planning – had helped to make **services** provided to clients **more professional, responsive and demand-driven**. Because service providers have a better understanding of the needs of PLHA, so PLHA are getting **better care and support at the community level**.

In addition, involvement of PLHA in CHEP outreach education has led to increased demand from companies for workplace programmes.

Service providers at CHEP noted that involvement of PLHA had **increased social legitimacy**, with recognition by the community that the organisation could help PLHA.

"The community seems to have confidence more in the HBC as the provider, as the helper." (Male service provider of CHEP.)

Hope respondents mentioned that the main effect on services and activities for the organisation as a result of PLHA involvement was the **inclusion of an advocacy component in the Positive Living Course**.



A PLHA shares his experience with outpatients at a local clinic (Kara Counselling)

5.3.2 Negative effects

Few negative effects on services and activities were mentioned. Specific concerns about potential negative effects mentioned included:

- Conveying inaccurate information to communities if PLHA are not well trained.
- Disruption of service delivery when PLHA are sick very often.

Respondents also noted that there is a risk of PLHA imposing solutions based on their own experience, and of HIV positive client dependency or over-identification with other PLHA.

5.4 Effects on the functioning of the organisations

5.4.1 Positive effects

Respondents identified the following positive effects of PLHA involvement on the functioning of the organisations:

- Improved understanding of issues affecting PLHA among non-PLHA service providers and increased acceptance of PLHA.
- Changes in staff attitudes towards PLHA leading to a more conducive environment for PLHA.
- Integration of advocacy for the rights of PLHA into the work of the organisation.
- Improved credibility of the organisation and its services with donors.

Involvement of PLHA has had a positive effect on organisations in several ways. Most importantly it has **improved the understanding and changed**

the attitudes of non-PLHA service providers towards PLHA and resulted in a recognition that they need to, and can benefit from, working together. Changes in the attitudes of staff as a result of PHLA involvement, in particular at CHEP, have in turn contributed towards a **more conducive environment** for PHLA. Respondents largely attributed this to the presence of the UNV PLHA.

“I walked with them and interacted with them and that’s why I came to realise that they were normal people just like any other human being. I could eat with them and share plates with them. Now I think I understand HIV much more than I did.” (Male service provider of Kara Counselling.)

“The effect that the involvement of PLHA has had on the service providers is that they have realised the need to join forces with PLHA in the delivery of services.” (Male service provider of the Salvation Army.)

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

Another positive effect noted by some service providers at CHEP was that PHLA involvement had encouraged them to **integrate advocacy for the rights of PLHA** into their work. Non-PLHA service providers felt that they could argue against stigma and discrimination with more confidence.

“... it has encouraged staff that what they can talk about is actually possible ... that a person can live positively with HIV/AIDS. Staff have been inspired... so they are able to argue confidently about HIV/AIDS issues.” (Male service provider of CHEP.)

With regard to the organisations overall, Kara respondents noted, for example, that the involvement of PLHA has played an important role in publicising the organisation and what it does.

“People get to know that Kara is doing something great whereby people are able to come out in the open.” (PLHA service provider of Kara Counselling.)

Similarly, some Salvation Army service providers reported that PLHA involvement has led to acceptance of the role of CPTs by the community.

“The other change is that after PLHA joined the CPT, there are times when the headman could hold meetings with PLHA. This helped to accept the disease and accommodate them.” (Male/female service providers of the Salvation Army.)

“They have come to accept them in the CPT and have understood their roles fully.” (Female service provider of the Salvation Army.)

A member of a DHMT confirms that involvement of PLHA bring extra credibility to the organisations in which they are involved:

“The mixture of PLHA and non-PLHA gives credibility to NGOs for support, care giving and so on.”

5.4.2 Negative effects

Risk of **stigmatising the organisation and its service providers** was the only negative effect mentioned, by a non-PLHA service provider at Kara. It was suggested that people would not be interested in being involved with or using an organisation with visible PLHA, and the example of a leprosy hospital was given to illustrate the potential negative effect.

“When a place is stigmatised... few people will be getting there and that is what has happened to all places that have been stigmatised. Look at Chainama hospital, Liteta (leprosy hospital).” (Service provider of Kara Counselling.)

As mentioned in the previous chapter, representatives from the participating NGOs explained during the data analysis workshop that this negative effect could be addressed by diversifying the activities of the organisation.

The cost of involvement for the organisation (see previous chapter) can be seen as a negative effect but it is actually an investment that should be measured by analysing the short-term and long-term benefits of involving PLHA in the organisation.

5.5 Effects on the family and community

5.5.1 Positive effects

Table 5.2 summarises positive effects on families and communities as a result of PLHA involvement, reported by different categories of respondent, for Hope, Salvation Army and CHEP. The Table is followed by a brief analysis of the main effects identified.

Table 5.2
List of positive effects of PLHA involvement on families and communities based on opinions of respondents from NGOs⁴²

Positive effects on families and communities	Frequency
Family	
Relatives accept and support PLHA	6
Families taking an active role	3
Families learning to cope	2
Family life improved	1
Community	
Improved understanding of HIV/AIDS	10
Increased acceptance and support of PLHA, reduced stigma	8
Increased openness and willingness to discuss HIV/AIDS	8
People joining in service delivery	2
Increased demand for VCT and other services	2

The most frequently mentioned positive effect on families of PLHA involvement was that, in some cases, **relatives accept and support PLHA**. Increased acceptance and support was mentioned by PLHA service providers, their relatives, and PLHA beneficiaries. Some service providers noted that families saw the benefits of PLHA involvement in terms of educating younger family members.

“The family wish that I help the young ones especially, so that they grow well and not in the manner in which I grew up... so the family is very happy for me coming out into the open ... because it is a lesson to the young ones.” (Male PLHA service provider of CHEP.)

“Our parents ... find it difficult to accept our situation but after seeing how positive we have been about it they slowly start accepting the situation and take care of us.” (Female PLHA service provider of Hope.)

“It was hard to tell them but I was so confident. They accepted and from then onwards started giving me support.” (PLHA service provider of Kara Counselling.)

“Maybe it is because we have accepted her, we are very free with her and she is free with us” explains a relative of one of CHEP’s HIV positive service providers.

⁴² Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

“Sometimes we can even go with her at Hope... I helped her to start the task force.” (Son of female PLHA service provider of Hope.)

These changes have also led to more positive attitudes towards other PLHA outside the family. And some families have started to seek support from PLHAs.

“I have an uncle who died some three months ago. The family asked for my assistance because they suspected that he was infected.” (PLHA service provider of Kara Counselling.)

Related to this, respondents noted that, in some cases, other positive effects included **families take a more active role**. Two CHEP respondents (one non-PLHA service provider, one PLHA beneficiary) mentioned that PLHA involvement has helped their **families learn to cope** with demands of caring for PLHA who are sick. One relative of a PLHA service provider also reported that **family life had improved**, because PLHA pay more attention to their family and transfer the material and psychological benefits they receive to their family.

“I think I have come to love her more...we have become very close, she tells me everything.” (Son of female PLHA service provider of Hope.)



The Positive Living Advocacy Course of Hope Humana: PLHA learn how to improve their diet

At community level, the most frequently mentioned effect of PLHA involvement was **improved community understanding** of HIV/AIDS – with a reduction in misconceptions and demystification of HIV/AIDS. PLHA involvement and personal testimony give messages greater credibility and effect, and some communities are reported to be more attentive when PLHA discuss the issue. Seeing PLHA living positively and healthily reduces people’s fears, gives HIV/AIDS a human face, and challenges people to live positively.

“People have a lot of questions. When you explain to people how you got infected and how your life was, they will understand.” (PLHA service beneficiary of Kara Counselling.)

“The involvement of PLHA has had an effect on the members of Ngangula community in the sense that people nowadays do not have the fear that they used to have. People had a lot of misconceptions about HIV/AIDS with the majority thinking that one could die within two to four weeks of testing positive.” (Male service provider of the Salvation Army.)

“It encourages other people too especially when you look very healthy. People say ‘If someone can do it why can’t I?’” (Male service provider of Kara Counselling.)

“When someone comes out into the open, you put a human face to this disease. And so the message carries a greater effect than when you are just discussing it from without.” (Male/female service providers of the Salvation Army.)

Respondents mentioned that communities have started to appreciate that HIV can affect everyone, and to acknowledge the need to change their behaviour to prevent HIV. Seeing PLHA who look healthy has also made communities appreciate that it is not possible to discern HIV status from a person’s appearance. For example, a PLHA service provider at CHEP noted that PLHA involvement has led to community sensitisation, because people recognise that there are people with HIV in their community. A CHEP respondent also noted that people are acknowledging the need to change because of the increasing number of deaths from AIDS.

The second most frequently mentioned effect was **increased acceptance and support of PLHA and reduced stigma**, although this is changing slowly. Some respondents noted that there was less stigma due to better understanding of how HIV is transmitted and not transmitted. Some PLHA mentioned that members of the community other than relatives are seeking support from them.

“People have started accepting members from various support groups who are going round communities doing door-to-door campaigns, counselling.” (Male PLHA service provider of CHEP.)

“Even the community seek assistance from me. They come to my place. They have come to know me and what I do.” (PLHA service provider of Kara Counselling.)

An official of the Ministry of Defence points out:

“If we have PLHA in service delivery points, basically the community that is there will truly see that anyone who is HIV positive can still be productive and help the community. That will even help us to de-stigmatise people that are living with the virus.”

The third most frequently mentioned effect was increased community **openness and willingness to talk about HIV/AIDS**. Respondents noted that the involvement of PLHA helps people to start to talk about HIV/AIDS and to demystify the issue.

“It helps people because most of them don’t want to talk about it. So when they see some people talk about it that is when they start talking about it as well.” (Relative of PLHA service provider of Kara Counselling.)

“...previously in the communities people never thought that within the community people who are HIV positive can be found... it helped the community to start various sensitisation programmes to help understand what being HIV positive means.” (Male PLHA service provider of CHEP.)

“A lot of people are now benefiting in the community because they understand that HIV/AIDS is a disease that can affect them as well but that they can live positive lives too.” (Male service provider of the Salvation Army.)

“Effect on the youth in particular... they can convince the youth and other people in the community who still think that HIV/AIDS is not real but a myth.” (Female service providers of the Salvation Army.)

Again it is worth noting that involvement of PLHA in NGOs and CBOs can also have an impact on those in the community who are HIV positive or suspect they could be:

“The impact on the community has been positive, for example in Chipata Compound ... a lot of PLHA who used to sit in the background have come out in the open due to their friends⁴³” explains a member of a DHMT.

Also mentioned were an increase in the number of **people joining in service delivery**, although the numbers are still small, and an increase in demand for

⁴³ PLHA have formed a supported group called the Bwafano support group.

VCT and other services. The latter is attributed, for example by respondents at Kara, to PLHA outreach education.

“After the outreach education some people came and wanted to take the test.” (Female PLHA service provider of Kara Counselling.)

“Because now people come to us and say voluntarily that you should be visiting me or our son is sick ... this is a step forward in HBC activities.” (Service providers of CHEP.)

5.5.2 Negative effects

In some cases, negative effects of PLHA involvement have included **stigma and discrimination** towards the family in the community. For example, responses from children of PLHA service providers regarding the negative effect of parental involvement included negative psychological effect – fear, anger and worry, and denial – and stigmatisation – fear of friends knowing their parent’s HIV status.

“At first I didn’t like it because I was scared that even my friends would know that my mother is HIV positive.” (Daughter of PLHA service provider of Hope.)

“The only worry I have is how I am going to look after my brother and sister when my parents die.” (Son of PLHA service provider of Hope.)

“I did not believe that my parents had AIDS. In short I did not want to face the truth.” (Son of female PLHA service provider of Hope.)

PLHA beneficiaries belonging to CHEP support groups mentioned that their families were stigmatised and mocked: *“Even our children are teased.”*

No negative effects on communities were mentioned, but negative reactions from communities towards PLHA were reported. For example, interviewees in one CHEP support group in Mufulira noted that PLHA are still highly stigmatised in their community – PLHA are looked down on, laughed at and told that they will soon die. This has made it difficult for the support group to achieve very much. And, as noted earlier, some communities question the veracity of PLHA HIV status and do not believe that PLHA service providers are infected.

“But some people do not believe if I tell them that I am infected.” (Female service provider of Kara Counselling.)

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.

During the data analysis workshop, representatives from participating NGOs and researchers used the data to compare for example the relative advantages and disadvantages of *access*, *inclusion*, *participation* and *involvement* for the organisations in which PLHA are involved. We will present this analysis (tables 5.3 to 5.6) together with a broader analysis of positive effects/advantages and negative effects/disadvantages of each type on the categories mentioned above.

5.6.1 Access

PLHA beneficiaries can benefit a lot from access to services, depending obviously on the nature and quality of these services. Counselling, participation in courses such as the PLAC of Hope or the Life Skills Training Programme have proved useful for the psychological and even physical health of PLHA. By accessing these services, PLHA learn a lot about HIV/AIDS and it can bring behaviour change. However, this depends a lot 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 actually take better care of their own life. It is basically the approach of the four NGOs who participated in the study, who mix welfare and development principles. The problem of a strictly welfare approach in a poor country without a proper welfare system like Zambia, 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 meaningful in terms 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).

Table 5.3
Advantages and disadvantages of access for NGOs and CBOs

Advantages	Disadvantages
<ul style="list-style-type: none"> ➤ Requires less investment of resources, e.g. in training than other types of involvement. 	<ul style="list-style-type: none"> ➤ Less strong relationship with beneficiaries. ➤ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning. ➤ PLHA are a resource that the organisation is not using.

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 wellbeing 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 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. The data reveals that it is particularly important that NGOs and CBOs have a good follow-up system for positive people who have been trained in positive living courses, otherwise all the short-term positive impact of the courses can vanish quickly, especially when PLHA have little support in their family or community. 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.

The perspective of participating NGOs was that *inclusion* is 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 5.4
Advantages and disadvantages of *inclusion* for NGOs and CBOs

Advantages	Disadvantages
<ul style="list-style-type: none"> ➤ Volunteerism is cost-effective. ➤ PLHA are living examples to show that objectives are being met. ➤ More people are involved in service delivery. ➤ Potential to maximise use of human resources. 	<ul style="list-style-type: none"> ➤ Could lead to discontinuity of service delivery because PLHA are not formally or fully involved. ➤ Lower quality of services because of lack of training. ➤ Planning may be difficult. ➤ Risk that services could fail to be relevant or to meet PLHA needs because PLHA not involved in design or planning.

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.

Unlike *access*, *inclusion* can also be more meaningful to the community, through the involvement of PLHA in outreach education.

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 5.5
Advantages and disadvantages of *participation* for NGOs and CBOs

Advantages	Disadvantages
<ul style="list-style-type: none"> ➤ Improved planning, ownership, better use of resources because PLHA are integral part of the organisation. ➤ PLHA are living examples and show what the organisation does. ➤ Improves relevance and quality of services because of training and PLHA involvement in design and planning. ➤ Maximises use of available human resources. 	<ul style="list-style-type: none"> ➤ Greater investment of resources, e.g. in training PLHA to support their participation, and higher costs of training to replace staff who become sick or die. ➤ Negative effect on activities and services from high turnover and loss of staff due to illness and death.

The data reveals that families benefit from the *participation* of their relatives 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 very strong 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 5.6
Advantages and disadvantages of *involvement* for NGOs and CBOs

Advantages	Disadvantages
<ul style="list-style-type: none"> ➤ PLHA have a stronger voice, can influence policies and decisions, and can ensure resources are allocated to services relevant to the needs of PLHA. ➤ May increase donor funding, if PLHA involvement is a donor priority. ➤ Helps to reduce stigma and discrimination in the workplace. ➤ PLHA can act as role models for other PLHA who are not visible or actively involved. ➤ Improves effect of awareness campaigns. 	<ul style="list-style-type: none"> ➤ Negative effect on activities and services from high turnover and loss of staff due to illness and death. ➤ High cost, especially if the organisation provides treatment for PLHA. ➤ High investment of resources and time, e.g. in training PLHA to support their involvement, and higher costs of training to replace staff who become sick or die.

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.

In general it seems that the positive effects of involvement of PLHA outweigh the negative effects, although it is difficult to analyse some of the results. We saw for example that whole involvement may lead to some forms of discrimination, 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, at least in rich countries, and there is some evidence that user involvement generally has a positive impact on the lives of health service users⁴⁴. 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 poor country like Zambia, 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 STDs, but also about changing attitudes toward those who are infected. Any serious 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.

⁴⁴ Hogg C, *Patients, Power and Politics – From Patients to Citizens*, SAGE Publications, 1999.

Recommendations

For NGOs, CBOs and PLHA based on the diagnostic study in Zambia

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 Zambia, 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.

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.

- 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.
- NGOs can offer to HIV positive people training programmes that mix psychological support with practical information on HIV/AIDS and skills useful for the delivery of services such as outreach education and counselling. These programmes are particularly important to re-build the self-esteem of PLHA.
- Providing PLHA with training through courses and workshops is not enough. When NGOs offer training programmes to PLHA, they should make sure that they plan an individual follow-up for each one of the participants, otherwise training may have only very short-term benefits.
- Positive people who provide and/or design and plan services, or manage programmes and organisations, need to receive the training relevant to their activities like any other staff member or volunteer.

Offering peer support 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.

- 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.

- Specific training programmes for PLHA are also a good way for them to meet other positive people and initiate peer support.

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. Moreover poor health as a result of lack of access to care is a major obstacle to the involvement of PLHA.

- 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.
- AIDS NGOs who promote income generating activities and micro-credit schemes for PLHA and are not familiar with these issues should seek guidance from other organisations with experience in this field.
- NGOs should make sure that PLHA involved in their activities can be treated at least for opportunistic infections, otherwise their involvement cannot be sustainable. NGOs and CBOs can do this in different ways: they can include health insurance as part of the benefits of PLHA who work for them, they can ensure access free of charge or at low cost to their own care facilities when available, or they can refer PLHA to other organisations or public services who provide care.

Assisting the formation of support groups of PLHA to scale up involvement

The study shows that one of the ways to promote and scale up involvement of PLHA is for NGOs to assist the formation and functioning of support groups of PLHA (and PLHA and affected people).

- When NGOs decide to form or help the formation of support groups of PLHA (and in some cases affected people), they should focus on building the capacities of group members in the following areas: planning (definition of objectives, basic time line for activities), management of human resources (e.g. group dynamics, leadership skills) and financial resources (fund-raising, budgeting, basic accounting and reporting, micro-credit, etc.) depending on the needs of each group.
- When NGOs provide technical support to members of support groups, they should try to train as many people as possible and avoid selecting only a few individuals. Otherwise capacity building may have limited positive effects because PLHA who have been trained can be sick or die prematurely, and they do not always have the skills or will to share their knowledge with their peers.

- When an NGO helps support groups, the role of the NGO, and links with support groups, should be clear from the start. The NGO should try to meet the needs of support group members rather than use them for other purposes (e.g. asking PLHA to give testimonies and do outreach education when their immediate need is for psychosocial support). NGOs should always keep in mind that the first objective of a support group is the well being of its members.
-

Visibility and involvement

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.
-

Planning and implementation

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 involvement for themselves and the community (see chapter 5).
- NGOs should decide 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 people and structures.

Networking and referral

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.
-

Specific recommendations for PLHA

The research shows that involvement is a two-sided process dependent on both PLHAs 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 ask 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 support groups

One of the ways for PLHA to be involved is to form their own support groups, help themselves and other positive and affected people.

- PLHA should agree about common objectives and expectations of members. These should be communicated clearly to any new PLHA who join the group.

- All members should know the benefits and costs of their participation in the group. They should be clear about what they can do and they cannot do based on availability, health, skills, etc.
- Members should agree on a decision-making process at an early stage of the formation of the group.
- Members should plan what may happen if group leaders are sick or die prematurely.
- When a group decides to provide services to beneficiaries who are not members, these services should be provided in a community, which is accessible in order to avoid transport costs, excessive fatigue for members and disruption of services.
- Support groups may benefit from technical and financial support from local, national and international NGOs. However expectations, roles and levels of commitment of the partners should always be very clear to the group, its members and the organisation(s) that support them.
- Groups should work with other partners, in particular at the community level, in order to organise referrals for their members and beneficiaries when necessary.

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Annex 1.

Profile of respondents from NGOs: service providers and service beneficiaries

Table A1.1
Categories of respondents

Categories of respondents	Total	%
PLHA service providers	3	1.5%
Service providers, including PLHA who are not in the first category	37	18%
Service providers CPT Salvation Army	42	20%
Total service providers	82	39%
PLHA beneficiaries - members of support groups	74	35%
Service beneficiaries (CHEP: peer educators; HOPE: participants PLC/PLAC; KARA: 10 skills trainees; Salvation Army: CPT beneficiaries)	24	11.5%
Outreach beneficiaries	29	14%
Total beneficiaries	127	61%
Total respondents	209	100%

Although only three respondents were classified in the category “PLHA service providers”, there were actually more HIV positive service providers who were classified by mistake in the general category “service providers”. The total is estimated to eight.

The following tables present data collected through questionnaires. It includes some key socio-demographic characteristics of service providers and service users such as:

- Age.
- Marital status.
- Religion.
- Education.
- Ethnic group.
- Occupation.
- Number of children.

We also paid attention to the following elements:

- Membership in other associations or groups, which can be analysed as an indicator of the experience that PLHA service providers in particular can have prior to their current involvement.
- Service providers have taken an HIV test or not. The reasons for taking the test or not have also been explored but they are not presented in this table. Some of them are analysed in the report.
- Respondents have received support or not and the kind of support they have received.

Table A1.2
Profile of the respondents from the four participating NGOs

Variable	Service providers		PLHA service providers		CPT service providers		Participants support groups		Service beneficiaries		Outreach beneficiaries		All	%
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female		
Age														
15 - 24	1	2	1	0	0	0	2	7	0	0	1	3	17	8%
25 - 34	7	10	0	0	2	6	11	23	3	4	6	8	80	38%
35 - 44	7	2	0	2	11	6	4	7	6	8	8	1	62	30%
45 - 54	4	3	0	0	8	2	4	7	3	0	2	0	33	16%
55 and over	0	1	0	0	6	1	7	5	0	0	0	0	20	10%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Marital Status														
Never married	2	4	0	0	10	1	1	4	1	0	3	2	28	13%
Married	17	11	1	2	15	7	10	9	9	6	12	5	104	50%
Living together	0	0	0	0	1	0	1	0	0	0	0	0	2	1%
Widowed	0	2	0	0	1	3	8	26	1	4	1	2	48	23%
Divorced	0	1	0	0	0	4	5	9	1	1	1	3	25	12%
Not living together	0	0	0	0	0	0	0	1	0	1	0	0	2	1%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Religion														
Catholic	5	1	0	1	0	0	9	16	4	4	3	2	45	22%
Protestant	14	16	1	1	27	15	16	33	7	8	14	9	161	77%
None	0	1	0	0	0	0	0	0	1	0	0	1	3	1%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%

Variable	Service providers		PLHA service providers		CPT service providers		Participants support groups		Service beneficiaries		Outreach beneficiaries		All	%
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female		
Education														
No education	0	0	0	0	1	2	1	9	0	1	0	0	14	7%
Primary	1	0	0	0	16	8	9	30	2	3	4	4	77	37%
Secondary	0	7	1	2	10	5	14	10	7	7	11	7	81	39%
Higher	18	11	0	0	0	0	1	0	3	1	2	1	37	18%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Ethnic group														
Bemba	8	4	0	2	3	0	13	28	2	4	7	4	75	36%
Tonga	4	4	0	0	24	15	1	3	4	2	0	0	57	27%
Northwestern	0	0	0	0	0	0	1	3	0	0	2	0	6	3%
Nyanja	5	5	1	0	0	0	3	11	3	4	4	7	43	21%
Barotse	1	1	0	0	0	0	1	0	2	0	1	1	7	3%
Mambwe	0	1	0	0	0	0	2	6	0	0	0	0	9	4%
Other	1	3	0	0	0	0	4	1	1	2	3	0	15	7%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Occupation														
Housework	0	0	0	0	0	1	1	1	0	0	0	0	3	1%
Public employee	5	6	0	0	2	1	1	1	4	3	3	2	28	13%
NGO/private employee	13	9	0	1	1	0	4	1	4	2	3	0	0	0%
Farmer	0	0	0	0	23	11	0	4	1	1	0	0	40	19%
Student	0	0	0	0	0	0	0	1	0	0	3	5	9	4%
Self-employed	0	0	0	1	0	1	16	17	0	1	1	1	38	18%
Unemployed	1	0	0	0	0	1	3	16	3	5	6	4	39	19%
Other	0	2	1	0	1	0	0	8	0	0	1	0	13	6%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%

Variable	Service providers		PLHA service providers		CPT service providers		Participants support groups		Service beneficiaries		Outreach beneficiaries		All	%
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female		
Number of Children														
None	2	7	0	0	1	0	5	9	1	0	3	3	31	15%
One	6	0	0	0	0	1	3	9	1	3	6	1	30	14%
Between 2 & 3	6	2	1	1	5	6	7	6	4	4	5	4	51	24%
More than 3	5	9	0	1	21	8	10	25	6	5	3	4	97	46%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Association														
Youth group	2	4	1	0	0	0	3	3	0	1	2	1	17	8%
Women's group	0	6	0	0	0	7	0	7	0	3	1	4	28	13%
Neighbourhood security	2	0	0	0	0	0	0	0	1	0	0	0	3	1%
Health committee	3	1	0	0	3	0	1	3	1	0	2	2	16	8%
Religious group	14	12	1	1	12	9	8	25	9	12	9	8	120	57%
Trade union	2	2	0	0	0	0	1	0	2	0	3	0	10	5%
Professional body	14	3	0	0	0	0	0	0	0	1	1	0	19	9%
Political party	3	1	0	0	2	0	4	6	2	4	2	1	25	12%
HIV/AIDS organisation	10	7	1	0	9	7	14	23	2	2	6	4	85	41%
Sports club	1	1	0	0	0	0	2	0	1	2	0	0	7	3%
Other	1	0	0	1	3	3	0	0	0	1	0	2	11	5%
None	0	0	0	1	2	1	7	3	1	0	0	0	15	7%

Variable	Service providers		PLHA service providers		CPT service providers		Participants support groups		Service beneficiaries		Outreach beneficiaries		All	%
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female		
Took an HIV test														
Yes	15	12	1	2	7	2	22	41	4	6	11	10	133	64%
No	4	5	0	0	20	13	3	7	8	6	6	2	74	35%
Declines to respond	0	1	0	0	0	0	0	0	0	0	0	0	1	0%
No response	0	0	0	0	0	0	0	1	0	0	0	0	1	0%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Received support														
Yes	1	4	1	2	1	0	20	26	3	5	7	8	78	37%
No	0	0	0	0	0	0	0	8	0	0	2	1	11	5%
Not applicable	18	13	0	0	25	15	5	15	9	7	8	3	118	56%
No response	0	1	0	0	1	0	0	0	0	0	0	0	2	1%
Total	19	18	1	2	27	15	25	49	12	12	17	12	209	100%
Type of support received (*)														
Moral support	0	2	1	0	0	0	5	11	0	2	1	1	23	29%
Spiritual support	0	0	1	0	0	0	9	11	0	0	0	2	23	29%
Economic/material	0	2	0	1	0	0	18	21	3	5	4	1	55	71%
Medical examination	1	2	0	0	1	0	17	22	0	1	8	3	55	71%
Prescription for drugs	0	1	1	1	0	0	4	2	0	1	0	0	10	13%
Information	1	0	1	1	0	0	10	5	0	2	0	0	20	26%
Other	1	0	1	0	1	0	1	1	0	0	1	5	11	14%

(*) N= 78 as the total of those respondents who answered “yes” to the question “Did you receive support?”

Annex 2.

Factors that limit and enhance the involvement of PLHA – frequencies by categories of respondents

For each factor, we present separately the frequency in individual interviews and FGD. The frequency for individual interviews equals the number of interviewees who mentioned the factor at least once during their interview (one person per interview). The frequency for FGD indicates that the factor was cited once during the discussion, whatever the number of people in the group. The rationale for this is that the dynamics of FGD do not allow the counting of opinions. When one participant mentions a factor in a discussion, other participants might agree only because they are influenced by the first participant who mentioned it. We therefore present in the tables the frequency followed by “FGD” in brackets, only to differentiate it from the frequency for interviews.

Table A2.1
List of individual factors that limit the involvement of PLHA
based on opinions of respondents from NGOs⁴⁵

Individual factors	Service providers (non PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Total
Poor health of PLHA (morbidity and mortality)	8 1 (FGD)	2		2 5 (FGD)	12 6 (FGD) 18
Fear of stigma, rejection, blame if visibly involved in NGOs and CBOs	2 3 (FGD)	1	1 (FGD)	3 6 (FGD)	6 10 (FGD) 16
Inadequate education, skills and training	5 1 (FGD)	2	2 (FGD)	3 (FGD)	7 6 (FGD) 13
Low income, need to earn income	3 1 (FGD)	2		3 (FGD)	5 4 (FGD) 9
Denial (difficulty for some PLHA to accept their HIV status and consequences on their lifestyle)	2 2 (FGD)			1 2 (FGD)	3 4 (FGD) 7
Lack of personal interest and motivation	2	1		1 (FGD)	3 1 (FGD) 4
PLHA with high		1		1	2

⁴⁵ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

social status do not want to compromise their situation					
Little or inadequate knowledge and misconceptions of PLHA about HIV/AIDS	1			1	2
“Mirror effect” for asymptomatic PLHA who identify with PLHA who are sick and feel discouraged				1 (FGD)	1 (FGD) 1

Table A2.2
List of individual factors that limit the involvement of PLHA based on opinions of key informants

Individual factors	Policy makers at national Level	Policy makers at district level	National NGOs	PLHA	Total
Fear of stigma, rejection, blame if visibly involved in NGOs and CBOs	3	1	1	1	6
Inadequate formal education, training and skills	1		2	3	6
Denial		2			2
Poor health of PLHA (morbidity and mortality)	1		1		2
Low income, need to earn income		1	1		2
Low self-esteem	1				1

Table A2.3
List of institutional factors that limit the involvement of PLHA
based on opinions of respondents from NGOs⁴⁶

Institutional factors	Service providers (non PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Inadequate resources to support PLHA involvement due to lack of NGO resources and NGO failure to allocate resources to offer material support and incentives (e.g. money, food, medicines)	11 1 (FGD)	5		1 11 (FGD)	1	18 12 (FGD) 30
Poor linkages, referral system between organisations denies PLHA information about opportunities for involvement	2	1	2 1 (FGD)	1		6 1 (FGD) 7
Attitudes of management and staff can be judgmental and discriminatory	3	1		1		5
Sometimes stigma is associated with organisations delivering services to PLHA	4					4
Lack of institutional policies to promote PLHA involvement	1 1 (FGD)	1				2 1 (FGD) 3
High cost of training because of high mortality of PLHA	2			1 (FGD)		2 1 (FGD) 3
NGOs do not give training opportunities to PLHA	1					1

Annex 2. Factors that limit and enhance the involvement of PLHA

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⁴⁶ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Table A2.4
List of institutional factors that limit the involvement of PLHA
based on opinions of key informants

Institutional factors	Govt policy makers at national Level	Govt policy makers at district level	National NGOs	SG	PLHA	Total
Negative attitude of staff		2	1		2	5
Scarce resources	1	2			1	4
In-fighting	1					1
Poor co-ordination	1					1
Inaccessibility to NGOs		1				1

Table A2.5
List of social factors that limit the involvement of PLHA
based on opinions of respondents from NGOs⁴⁷

Social factors	Service providers (non PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Stigma and discrimination	12	8	1 2 (FGD)	6 12 (FGD)		27 14 (FGD) 41
Lack of community support and appreciation, and disbelief	7			3 3 (FGD)		10 3 (FGD) 13
Inadequate knowledge of HIV/AIDS in the community	1		2 1 (FGD)	2 (FGD)		3 3 (FGD) 6
Culture of silence on HIV/AIDS and issues related to sexuality, and denial		1		2 1 (FGD)	1	4 1 (FGD) 5
Social expectations		1		3 (FGD)		1 3 (FGD) 4
Poverty	3					3
Religious beliefs	1 (FGD)				1 (FGD)	2 (FGD)
Community dependency on institutions providing care and support	1					1

⁴⁷ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Table A2.6
List of individual factors that encourage the involvement of PLHA
based on opinions of respondents from NGOs⁴⁸

Individual factors	Service providers (non PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Desire to support those who are infected and fight the epidemic by educating others	6	5	1	4 3 (FGD)	1	14 3 (FGD) 17
Financial and material motivation because of economic hardship	3	2		2 2 (FGD)	2	9 2 (FGD) 11
Increased knowledge of HIV/AIDS and improved capacity through information and training	1		2 1 (FGD)	2 (FGD)		3 3 (FGD) 6
Peer support	3	1				4
Personal acceptance of HIV status, desire to be free from burden of secrecy	3 1 (FGD)					3 1 (FGD) 4
Personal fulfilment	1 1 (FGD)					1 1 (FGD) 2
Desire to live longer		1				1
Experience from previous involvement in other organisations				1		1

⁴⁸ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Table A2.7
List of institutional factors that encourage the involvement of PLHA
based on opinions of respondents from NGOs⁴⁹

Institutional factors	Service providers (non-PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Conducive environment – practical support to PLHA (financial benefits, material benefits, access to medical care)	5	7		2 3 (FGD)	1	15 3 (FGD) 18
Training (outreach, positive living etc)	6 2 (FGD)	4		2 (FGD)	1 (FGD)	10 5 (FGD) 15
Referrals within the organisation	2 2 (FGD)	1		2 3 (FGD)	1 (FGD)	5 5 (FGD) 10
Conducive environment –psychological support, attitudes of staff and management	5 1 (FGD)	4				9 1 (FGD) 10
Effective pre- and post-test counselling	2	2				4
Organisation structure, integration of PLHA involvement	3	2				5
Positive role models	1 (FGD)	2				2 1 (FGD) 3

⁴⁹ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of service HIV positive providers. This table does not include the Salvation Army, as no factors were identified during data collection and responses focused on factors that would encourage involvement. This is because involvement of PLHA in activities of the CPTs is still very limited.

Table A2.8
List of social factors that encourage the involvement of PLHA
based on opinions of respondents from NGOs⁵⁰

Social factors	Service providers (non PLHA)	PLHA service providers	CPT service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Referrals between organisations, HBC teams, NZP+	1 1 (FGD)			2 4 (FGD)		1 5 (FGD) 9
Support of family	1 2 (FGD)	1		2	1	5 2 (FGD) 7
Reduced community stigma, increased acceptance of PLHA	1			2 1 (FGD)	2	5 1 (FGD) 6
Improved community knowledge of HIV/AIDS	1		1 (FGD)	2		3 1 (FGD) 4
Religious beliefs and compassion	1			1 1 (FGD)	1	3 1 (FGD) 4

Annex 2. Factors that limit and enhance the involvement of PLHA

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⁵⁰ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of service HIV positive providers

Annex 3.

Positive and negative effects of the involvement of PLHA – frequencies by categories of respondents

For each positive or negative effect, we present separately the frequency in individual interviews and FGD. The frequency for individual interviews equals the number of interviewees who mentioned the effect at least once during their interview (one person per interview). The frequency for FGD indicates that the effect was cited once during the discussion, whatever the number of people in the group. The rationale for this is that the dynamics of FGD do not allow the counting of opinions. When one participant mentions a positive or negative effect in a discussion, other participants might agree only because they are influenced by the first participant who mentioned it. We therefore present in the tables the frequency followed by “FGD” in brackets, only to differentiate it from the frequency for interviews.

Table A3.1
List of positive effects of PLHA involvement on PLHA
based on opinions of respondents from NGOs⁵¹

Positive impact on PLHA	Service providers (non-PLHA)	PLHA service providers	PLHA service beneficiaries	Relatives of PLHA service providers	Total
Improved mental and psychological health		6	1 2 (FGD)	2	9 2 (FGD) 11
Improved physical health	1 1 (FGD)	2	1 2 (FGD)	2	6 3 (FGD) 9
Behaviour change	1	3	4		8
Increased knowledge of HIV/AIDS	2	4	2 (FGD)		6 2 (FGD) 8
Peer support	1	4	3 (FGD)		5 3 (FGD) 8
Employment and/or material benefits	2	2		1	4
Access to medical care			1	2	3
Increased acceptance by family		1	1		2
Less stigma	1				1

⁵¹ Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.

Table A3.2
List of positive effects of PLHA involvement on families and communities based on opinions of respondents from NGOs⁵²

Positive effect on families and communities	Service providers (non-PLHA)	PLHA service providers	PLHA service beneficiaries/ support group/ CPT service providers	Relatives of PLHA service providers	Total
Family Relatives accept and support PLHA		1	2 (FGD)	3	4 2 (FGD) 6
Families taking an active role		1	1 (FGD)	1	2 1 (FGD) 3
Families learning to cope	1		1		2
Family life improved				1	1
Community Improved understanding of HIV/AIDS	5 1 (FGD)	1	2 1 (FGD)		8 2 (FGD) 10
Increased acceptance and support of PLHA, reduced stigma	6	2			8
Increased openness and willingness to discuss HIV/AIDS	2 1 (FGD)	1	1 3 (FGD)		4 4 (FGD) 8
People joining in service delivery	2				2
Increased demand for VCT and other services	2				2

⁵² Service providers of the four NGOs (HIV positive or not), service users (infected and affected) and relatives of HIV positive service providers.