Enhancing the Greater Involvement of People Living with HIV (GIPA) in NGOs/CBOs in India

A Handbook of Information and Tools for NGOs/CBOs
The International HIV/AIDS Alliance greatly acknowledges all the people and organisations that contributed to this handbook.

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The handbook was field-tested during a workshop with several NGOs in India in September 2004 by a team comprised of Anandi Yuvaraj, Maheswari Boopathi, Satheesh Chandran, Christophe Cornu and Pam Decho.

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The contents and ideas expressed in this handbook do not necessarily reflect the views of the International HIV/AIDS Alliance and UNAIDS.

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Introduction to the toolkit
The International HIV AIDS Alliance envisions a world in which people do not die of AIDS. In such a world, communities will have brought HIV/AIDS under control and all people, regardless of their gender, religion, class, race, ethnicity or sexual orientation, will have access to easy, affordable and appropriate prevention, care and support and treatment services, backed up by an unbiased system of justice.

The Alliance is committed to supporting and working through a system of national linking organisations (or intermediary organisations) who, in turn, work through NGOs/CBOs that reach out to communities where people are most vulnerable to HIV. Working in this way means that NGOs/CBOs work closest to those who are most affected and are at the forefront in responding to the challenges of the epidemic, and most importantly are best placed to deliver evidence of ‘what works’.

In India, the HIV/AIDS scenario is changing rapidly and as the epidemic progresses, the care of those affected with HIV/AIDS is becoming a key priority for the country. Increased national and international political commitment is needed to make drugs more widely available to those who are most in need the historically treatment-shy Government of India has now announced the provision of free antiretroviral drugs (ART) but, in the process, has drawn attention to the need for a correct and strategic approach to greater involvement of people living with HIV (GIPA), recognising the fact that care and support is not only a human rights issue but can be a mechanism for preventing further spread of the virus. GIPA has emerged as crucial strategic tool.

The GIPA Principle - the Greater Involvement of People Living with HIV is the backbone of many interventions worldwide and is critical to ethical and effective national responses to the epidemic. It can support organisations in their work to monitor and promote the greater involvement and active participation of people living with HIV. Their participation gives a personal power and immediacy to AIDS efforts that drives and inspires others into action and they also understand each other’s situation better than anyone and are often best placed to advise one another, and to represent their needs in decision- and policy-making forums. For organisations with people living with HIV, capacity building can include assistance to building organisational, managerial and financial capacity within the organisation, strategic planning and emotional and moral support. Most importantly, tackling stigma and discrimination is fundamental to creating the kind of environment where people living with HIV can flourish and contribute in a meaningful way.

In India, the overwhelming involvement of civil society in the development process of the National AIDS Control Programme Third Phase (NACP-III) demonstrated that the concept of GIPA has been grossly misunderstood and under-utilised. With a growing recognition across the world that GIPA is crucial for the delivery of just, equitable, and appropriate HIV
services, it would be hard for the Indian experience to speak differently from other countries. Furthermore, with growing numbers of people living with HIV in India who are realising that they have rights and a powerful vehicle that can be utilised to create a safe and just environment, in the form of GIPA, now is a key moment in time to upscale efforts to make this a principle in practice.

This handbook sets out to inform readers about the different dimensions of GIPA in practice and provides tried and tested tools for use by NGOs and other institutions. We hope that the handbook makes a significant contribution to capacity building of individuals and organisations in GIPA, and in doing so, contribute to mainstreaming GIPA and ensuring the meaningful involvement of people living with HIV.

August 2006
Contents

Introduction 5

1. What is this handbook? 5
2. Why was this handbook developed? 5
3. Who is this handbook for? 6
4. How to use the handbook? 7
5. What is in the handbook? 10
6. How long does the handbook take to use? 11
7. Suggestions for an introductory session to a sensitisation workshop on the involvement of people living with HIV in an NGO 14

Module 1: Understanding the involvement of people living with HIV in NGOs 17

Contents and Summary of Key Messages 17-18

Introduction 19

Activity 1.1 Roles for people living with HIV in NGOs 21
Activity 1.2 Disclosure of HIV status and visibility of involvement of people living with HIV in NGOs 26
Information Sheet 1.A Areas of involvement and roles for people living with HIV in NGOs 29
Information Sheet 1.B Disclosure of HIV status 30
Information Sheet 1.C 'Visibility' of involvement of people living with HIV 32
Information Sheet 1.D Criteria to assess the involvement of people living with HIV in NGOs 34
Module 2: Understanding why people living with HIV should be involved in NGOs working on HIV/AIDS

Contents and Summary of Key Messages

Introduction

Activity 2.1 Exploring reasons why people living with HIV should be involved in NGOs

Activity 2.2 How involving people living with HIV can improve the work of NGOs and enhance the quality of life of PLHA

Activity 2.3 Possible risks of involving people living with HIV in NGOs if not planned for adequately

Information Sheet 2.A Potential Benefits for NGOs of involving people living with HIV

Information Sheet 2.B Potential benefits of involvement for people living with HIV involved in NGOs

Information Sheet 2.C Possible risks for NGOs of involving of people living with HIV if not planned for adequately

Information Sheet 2.D Possible risks of involvement for people living with HIV involved in NGOs if not planned for adequately

Module 3: Planning for the involvement of people living with HIV in NGOs

Contents and Summary of Key Messages

Introduction

Activity 3.1 Assessing the involvement of people living with HIV in our organisation

Activity 3.2 What kind of involvement of people living with HIV for our organisation?

Activity 3.3 Pathways to the involvement of people living with HIV

Activity 3.4 Identifying gaps for the involvement of people living with HIV in our organisation

Information Sheet 3.A Organisational obstacles to involvement of people living with HIV in NGOs
Contents

Information Sheet 3.B  Social obstacles to involvement of people living with HIV in NGOs 69

Module 4: Creating a supportive environment for the involvement of people living with HIV in NGOs 71

Contents and Summary of Key Messages 71-72

Introduction 74

Activity 4.1  Realising opportunities for the involvement of people living with HIV in NGOs 76

Activity 4.2  Understanding stigma 78

Activity 4.3  Exploring stigma and discrimination (attitudes and behaviours) 79

Activity 4.4  Exploring discriminatory policies 81

Activity 4.5  This can happen: the experience of stigma and discrimination 83

Activity 4.6  Understanding the links between discrimination and confidentiality 86

Activity 4.7  Understanding what information is confidential 88

Annex  Case Studies 90

Activity 4.8  Enforcing the rules on confidentiality 92

Annex  Written commitment to confidentiality 93

Activity 4.9  Psychosocial support for people living with HIV involved in the organisation (identification of needs) 94

Annex  Case Studies 96

Activity 4.10  How to provide psychosocial support to people living with HIV involved in the organisation? 97

Activity 4.11  What is an HIV workplace policy? 99

Annex  Example of an HIV workplace policy 102

Information Sheet 4.A  Rights of people living with HIV 110

Resources 113
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>APN+</td>
<td>Asia Pacific Network of People Living with HIV</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy or treatment</td>
</tr>
<tr>
<td>ARVs</td>
<td>Antiretrovirals</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS Service organisation</td>
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<tr>
<td>CBO</td>
<td>Community-Based Organisation</td>
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<tr>
<td>FBO</td>
<td>Faith-Based Organisation</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People Living with HIV/AIDS</td>
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<tr>
<td>GNP+</td>
<td>Global Network of People Living with HIV/AIDS</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting Drug User</td>
</tr>
<tr>
<td>INP+</td>
<td>Indian Network of People Living with HIV/AIDS</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>NACO</td>
<td>National AIDS Control Organisation</td>
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<tr>
<td>NGO</td>
<td>Non Governmental Organisation</td>
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<tr>
<td>OI</td>
<td>Opportunistic Infection</td>
</tr>
<tr>
<td>PLHA</td>
<td>People or Person Living with HIV/AIDS</td>
</tr>
<tr>
<td>SACS</td>
<td>State AIDS Control Society</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>United Nations Joint Program on AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
</tbody>
</table>
Introduction

Contents:

1. What is this handbook?
2. Why was this handbook developed?
3. Who is this handbook for?
4. How to use the handbook?
5. What is in the handbook?
6. How long does the handbook take to use?

1. What is this handbook?

The handbook is a resource collection of information sheets and participatory activities for NGOs working on HIV/AIDS who want to work towards a greater involvement of people living with HIV (GIPA) in their work. It aims at sensitising NGOs, building individual skills and organisational capacities so that NGO management, staff and volunteers can discuss and plan together in a participatory way how to meaningfully involve people living with HIV in their organisation.

2. Why was this handbook developed?

This handbook has been developed because research-based evidence shows that NGOs in India may have a limited understanding of what GIPA is and of how to plan and implement it, even if they are aware of the need to involve PLHA.

An operations research on the involvement of people living with HIV in the delivery of community-based prevention, care and support services conducted in India (State of Maharashtra) between 2000 and 2001 reached the conclusion that "involvement is a process that can be planned. It is important to demonstrate first to individuals and organisations the benefits and positive effects of different types of involvement for themselves and the community. NGOs should decide and plan how they want people living with HIV to be involved in their activities (…). They should list the institutional factors that limit these types of involvement and analyse how they can tackle these obstacles as an organisation."  

Another study carried out in three states of India in 2003 made the following recommendations: “Increased training and awareness raising regarding GIPA has to be

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provided for NGOs and other organisations working with the national and state programmes and “more structured capacity building modules and programmes with a strong GIPA content are required for PLHA, programme managers and the other organisations (including NGOs) managing and implementing HIV/AIDS programmes.”

Many people in India still see GIPA as “an idea based on adopting western inspired approaches (…) with little value and limited use in the context of the epidemic in India.” This is why the handbook has been developed and tested with the participation of Indian NGOs so that it is adapted to the Indian context. Limited involvement of PLHAs in AIDS projects in India has been due to a mix of different reasons primary among them is the fact that the Positive People’s movements are still growing at the local levels, though the National Network of Positive People was formed in 1997. Currently, most States where the Positive People’s networks have been formed either at state or district levels have been able to involve them at different levels. This is in keeping with the long tradition of social activism in India which has witnessed strategic involvement of ‘beneficiary groups’.

3. Who is this handbook for?

- **What kind of organisations can this handbook be used by?**

  The handbook is for all the Indian civil society organisations that work on HIV/AIDS, whether it is prevention, care, treatment and support, or advocacy. They may be NGOs or CBOs, and represent different organisational models: developmental model, secular welfare model, religious welfare model (FBOs) or rights-based model. They may have an exclusive focus on HIV/AIDS - AIDS Service Organisations (ASOs) - or HIV/AIDS may be just one part of their activities. They also include international NGOs working on HIV/AIDS in India.

  Although the handbook is designed primarily for NGOs and CBOs working on HIV/AIDS, some information, guidelines or participatory training activities may be used also within the public sector by organisations such as the National AIDS Control Organisation (NACO) and the State AIDS Control Organisations (SACS) at national and state level as well as by organisations who do not work on HIV/AIDS.

  The handbook is not aimed at groups and networks of people living with HIV as resources have already been developed for them by GNP+ and APN+ (see List of Resources at the end of the handbook). However, they may find some materials presented in this handbook useful by adapting them to their needs.

- **Organisations at which level of involvement of PLHA will find this handbook useful?**

  The handbook is for organisations where people living with HIV are already involved or where there is no involvement of people living with HIV at all. Whatever the kind of

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current types and levels of involvement of people living with HIV, the handbook is for those organisations who would like to understand what they could do so that people living with HIV are more involved and their involvement is more meaningful.

- **Within organisations, what kind of people in NGOs and CBOs can this handbook be useful for?**

The handbook is designed to be used by NGO management, board members, staff and volunteers. Vement of people living with HIV, the handbook is for those organisations who would like to understand what they could do so that people living with HIV are more involved and their involvement is more meaningful.

4. **How to use the handbook?**

The handbook includes two kinds of resources:

- **Participatory activities**

- **Information sheets**

These resources can be used in different ways:

- **Participatory activities** are training tools that can be used by internal or external facilitators in training workshops with staff and volunteers of NGOs. These tools are designed to involve participants in discussing and exploring the issues themselves, rather than being “taught”.

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**Description of participatory activities** includes the following sections to help facilitators:

- **Objectives** - this section describes & lists out what the participants will learn at the end of the activity.

- **Preparation for facilitators** - this section indicates what facilitators can do in preparation for running this particular participatory activity.

- **Materials needed for the activity** - all the activities can be used with a small number of simple resources available locally.

- **Estimated time needed for the activity** - this gives an indication of how much time to allow for each activity and is based on the Alliance's experience of using these activities in workshops with 25-30 participants. In practice facilitators can make the activities shorter or longer, depending on the time available and the level of skills and interest of the participants.
**Instructions & Methodology** - outlining the steps to take to complete the activity and the key questions to consider.

**Facilitators' notes** - sharing 'useful tips' about how to successfully guide participants through the activities.

The vast majority of participatory activities presented in this handbook were field-tested during a workshop with three NGOs held in India (Trivandrum, Kerala, in September 2004). However, activities can be adapted and they do not have to be implemented exactly as written and laid out.

It is also recommended that facilitators include plenty of energisers in their workshops. For more information on participatory training methodologies, pls visit [http://www.aidsalliance.org/sw7442.asp](http://www.aidsalliance.org/sw7442.asp)

**Information sheets** summarise and highlight key issues related to a specific theme.

Facilitators should read the information sheets included in each module as a preparation for the workshops. Copies of the information sheets can be made and handed out to participants in workshops. They can be read also by NGO staff and volunteers outside of training workshops.

Remember the following important tips:

- It is recommended to use the participatory activities with an individual NGO rather than a group of NGOs as it is more valuable for participants to work with colleagues from their own organisation because discussing and planning involvement of people living with HIV needs to be specific to each NGO.

- Also it is important that all the staff members, and volunteers (where applicable) are involved in the training process, either in one group if the NGO is small or in several groups in large organisations.

- The number of participants should be limited to 30 people in each training workshop.

- It is particularly important that each staff member and volunteer is sensitised / trained so that they have the same level of understanding and interest when it comes to implementing GIPA in the organisation, otherwise people who have not been sensitised may have attitudes that block the involvement of people living with HIV.

- Also implementing GIPA successfully requires commitment and buy-in from all levels of staff in the organisation.

When it is not possible to form one group for a training workshop, several groups can be formed for a series of workshops. It is preferable that groups mix representatives from different categories of staff and volunteers, such as:

- Board members,
- Executive Management,
• Intermediate Management,
• Programme Staff,
• Finance and Administration Staff,
• Support Staff other than Finance and Administration Staff, e.g. drivers, cleaners, etc.,
• Volunteers

Mixed groups are recommended for the following reasons:

• People who play different roles in the NGO may have different perceptions about the involvement of people living with HIV. Confronting their opinions will make the discussions more interesting and productive.

• Involvement of people living with HIV is not limited to service delivery. Like anyone else, HIV positive people can play many roles in NGOs depending on their skills and interest. It is therefore important that management, finance and administration staff, and support staff are sensitised on issues related to the involvement of people living with HIV.

When there are participants from several NGOs at a training workshop, it is important to have a minimum number of representatives from each NGO so that they can use the participatory activities in a satisfactory way. The minimum number or participants per NGO should be around 8-10 people in order to organise NGO groups during the workshop. This means that no more than three NGOs can be represented in the same workshop. Representation from each NGO should include the categories of staff and volunteers already mentioned above.

When there are people living with HIV already involved in the NGO and facilitators know who is HIV positive, they should not give any information about NGO members’ HIV status unless those who are HIV positive have already disclosed their status to colleagues. In general facilitators should keep all confidential information gathered about NGO staff and volunteers to themselves. Facilitators should also make clear to participants at the beginning of each workshop that it is not an opportunity to discuss other people’s HIV status. All activities have been designed to avoid situations where HIV positive participants feel exposed. There are also specific comments in the facilitators’ notes included at the end of the description of some activities to help facilitators handle issues of confidentiality during the workshop.

Facilitators should be familiar with participatory training techniques (if they are not, they can refer to the Alliance’s A Facilitators’ Guide to Participatory Workshops with NGOs/CBOs Responding to HIV/AIDS) and they should be able to sensitively handle discussions on personal matters as some of the activities suggested in the handbook will lead participants to express their own feelings on sensitive issues such as discrimination. It is recommended that skilled HIV positive facilitators are involved in the facilitation team because their experience will help to demystify many issues related to the involvement of people living with HIV. They may also bring concrete examples from their personal experience.
Some participatory activities use written materials such as handouts or flip-charts. However, all activities can be adapted so that participants with low literacy levels can take part in the activities.

**Note:** The terminology used in this handbook should always be adapted to the level of understanding of the people with whom this handbook is being used. Difficult terminology should be explained in accessible terms.

**5. What is in the handbook?**

The handbook is divided into the following modules:

- **Module 1:** Understanding what is Involvement of people living with HIV in NGOs
- **Module 2:** Understanding why people living with HIV should be involved in NGOs working on HIV/AIDS
- **Module 3:** Planning for the involvement of people living with HIV in NGOs
- **Module 4:** Creating a supportive environment for the involvement of people living with HIV in NGOs

**Module 1** introduces a framework to help understand what involvement is, exploring levels of involvement for people living with HIV in NGOs, as staff members or volunteers. The module pays particular attention to issues of disclosure of HIV status and “visible” involvement of people living with HIV versus “invisible” involvement. It also presents a list of criteria that organisations can use when they want to assess the current types and levels of involvement of people living with HIV in their activities.

**Module 2** explores the reasons why people living with HIV should be directly involved in NGOs that work on HIV/AIDS. The module provides NGO management, staff and volunteers the important opportunity to discuss and understand why the involvement of people living with HIV is beneficial for their organisation, as involvement of people living with HIV is often perceived as something that should be done to please donors and/or activists. This module aims at building group adhesion to GIPA and ownership of the decision to enhance a greater involvement of people living with HIV in the organisation.

**Module 3** takes staff members and volunteers through a series of practical activities to plan a greater involvement of people living with HIV in their organisation once they agree it is beneficial for both the NGO and HIV positive people. The assumption is that the involvement of people living with HIV is an organisational process that can be planned.
Module 4 presents all the concrete steps that an organisation needs to take in order to make the involvement of people living with HIV happen. It looks at ways to mobilise people living with HIV, ways to build a supportive environment for them to be involved, particularly through the development and implementation of a workplace policy on HIV/AIDS. The module includes activities to help the organisation overcome one of the major obstacles to involvement of people living with HIV: stigma and discrimination inside and outside the NGO. It provides guidelines on how to manage confidentiality in the NGO, how to provide for psychological support; care, including medical benefits; material support; and orientation and training.

Each module also includes a set of important messages that facilitators are strongly encouraged to use.

6. How long does the handbook take to use?

If organisations run a single workshop using all participatory activities from all four modules, they can be covered in five days (assuming that each day is seven hours of training).

However, facilitators can choose the participatory activities they want to use depending on the needs of the organisation who receives the training. However, it is important to note that the modules are presented in chronological order in the handbook and the sequence is designed according to a learning process. It is therefore recommended to train organisations starting with activities from Modules 1, 2 and 3. These three modules form a sort of ‘package’ that is a prerequisite to fully understand activities included in Module 4, in particular when the involvement of people living with HIV is seen as an organisational process that needs to be properly owned by NGO members before it is planned and implemented.

It is also important to note that this entire handbook need not be implemented in one single training workshop. Organisation can decide to have a series of short workshops instead of a longer workshop.

The following time table offers suggestions on how the sensitisation process could be implemented with an NGO:

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4These are only suggestions as the process as a whole has not been tested.
### Suggested time table for the GIPA sensitisation process with NGOs/CBOs

<table>
<thead>
<tr>
<th>Phase</th>
<th>What this would consist of</th>
<th>Who would be involved</th>
<th>When this would happen and how long it would take</th>
</tr>
</thead>
</table>
| Preparatory meeting with representatives from the management team of the NGO | • Discuss the objectives and expected outcomes of the training  
• Assessment of current involvement of people living with HIV in the organisation  
• Discuss the draft time table | • Representatives from the management team  
• External facilitators | • This should happen after the NGO has either requested for this workshop or after the NGO buys into the need for this workshop. Also after a base assessment on the existing levels of HIV related knowledge and attitudes of the NGOs has been ascertained.  
• A few hours |
| First sensitisation workshop                    | • Introduction to the sensitisation process  
• Refresher on basics of HIV/AIDS information and myths  
• Module 1: Understanding what is involvement of people living with HIV in NGOs  
• Module 2: Understanding why people living with HIV should be involved in NGOs working on HIV/AIDS  
• Module 3: Planning for the involvement of people living with HIV in NGOs | • Management,  
• All staff and volunteers  
• External facilitators | • 2 days  
• Some time after the preparatory meeting |
| Evaluation of first sensitisation workshop      | • Meeting | • Management  
• External facilitators | • A couple of hours  
• Immediately after the first sensitisation workshop |
| Second sensitisation workshop | • Module 4: Creating a supportive environment for the involvement of people living with HIV in the NGO | • Management  
• All staff and volunteers  
• External facilitators  
• (all the above should be the same people who attended workshop 1) | • 2 days  
• Not too much time should pass between the first and the second workshop. |
| Planning | • Meeting to develop an action plan for creating a supportive environment in the NGO (including the development of policies) and realising opportunities for the involvement of people living with HIV in the organisation | • Management using outputs from workshops  
• This phase may require some external technical support depending on the NGO | This should happen immediately after the second workshop |
| Development of policies | • Meetings, development and review of draft policies | • Management using outputs from workshops  
• This phase may require some external technical support depending on the NGO | Over a few weeks |

It is important to make use of the dynamics created during the two workshops to inform the subsequent phases. Therefore, the whole process should happen over a period of no more than a few months.
Suggestions for an introductory session to sensitisation workshops on the involvement of people living with HIV in an NGO/CBO

1. Make sure you present the objectives and expected outcomes of the entire sensitisation process clearly to NGO staff and volunteers.

Example:

**Objectives** = by the end of the entire process participants will be expected to be able to:

✓ Explain what involving people living with HIV in NGOs actually means
✓ Explain the positive impact of involving people living with HIV in NGOs
✓ Explain how to plan for the involvement of people living with HIV in an NGO
✓ Explain how to create a supportive environment in the NGO to implement the greater involvement of people living with HIV
✓ Analyse the strengths, challenges and opportunities for the involvement of people living with HIV in their own organisation.

**Outcomes** = by the end of the sensitisation process participants will be able to:

✓ Contribute to the development of an action plan for a greater involvement of people living with HIV in their organisation
✓ Contribute to the creation of a supportive environment in their NGO for a greater involvement of people living with HIV
✓ Contribute to enhancing the involvement of people living with HIV in their organisation

1. If the sensitisation process comprises of several workshops, make sure that you present the whole process at the beginning and stress the objectives of each phase of the process. If you had a chance to prepare the sensitisation process with representatives of the management, involve them in the presentation of the objectives and expected outcomes. Their involvement will be good evidence that it is an important process for the NGO and will help motivate staff and volunteers.

2. Always emphasise that even if global best practice shows that the involvement of people living with HIV is crucial to an effective fight against the AIDS epidemic, GIPA may not effective when it is merely imposed on NGOs from outside. **It is most effective when each organisation itself decides how people living with HIV should be involved in the NGO.** The sensitisation process helps NGOs to make informed decisions about how to plan and implement GIPA in their organisation.
3. Acknowledge that HIV/AIDS, the involvement of people living with HIV and issues related to the disclosure of HIV status are still very sensitive issues in India. Stress that the activities conducted with the NGO do not require anybody to disclose their HIV status. Emphasise the respect of confidentiality during the process.

4. Explain that all activities conducted with staff and volunteers will be participatory, using concrete examples and avoiding theoretical discussions. Invite all staff members and volunteers to participate actively in all the activities. Stress that all questions are welcome and that there are no “stupid” questions.

5. Reassure people who may have problems reading documents. Stress that all handouts will be read aloud during the workshop(s).

6. Make sure you give participants the opportunity to express their own expectations and concerns about the process, its objectives and expected outcomes.

7. As many staff members and volunteers who do not work in programmes may have a limited knowledge about HIV/AIDS, it is recommended to organise an introductory session on the basics of HIV/AIDS (ways of transmission, prevention, treatments, etc.)
Understanding involvement of people living with HIV in NGOs
Module 1 introduces a framework to help understand what the involvement of people living with HIV is, exploring areas of involvement in NGOs and the roles HIV positive people can play in each area, as staff members or volunteers. The module pays particular attention to issues of disclosure of HIV status and “visible” involvement of people living with HIV versus “invisible” involvement. It also presents a list of criteria that organisations can use when they want to assess the current types and levels of involvement of people living with HIV in their programmes.

The module includes two participatory activities. Facilitators should read the various information sheets presented in the module before they adapt and use the activities.
Understanding involvement of people living with HIV in NGOs

NGO staff and participants should be urged to consider the following key messages of Module 1:

People living with HIV are not only beneficiaries of the services provided by NGOs. The starting point is that, depending on skills, interests and state of health at a given time, people living with HIV - like all other people - can do any and all jobs within an NGO.

People living with HIV have equal rights and should have equal opportunities to work in any organisation like any one else whose HIV status is sero-anonymous.

The more technical and organisational expertise people living with HIV have, the greater their involvement in the decision-making process related to organisational, policy and strategic planning issues in NGOs.

Involvement of people living with HIV should not be equated with public disclosure of HIV status by people living with HIV involved in NGOs.

People living with HIV should never be forced to disclose their HIV status and NGOs should guarantee confidentiality for all their HIV positive staff, volunteers and service users. For those people living with HIV who decide to disclose their HIV status, there are many levels of disclosure.

Disclosing the HIV status of a colleague to a third person without the consent of the colleague who is HIV positive is a serious breach of confidentiality.

There are also different levels of ‘visibility’ of involvement of people living with HIV in NGOs. This means that the number of people within and outside the NGO who know that there are people living with HIV involved in the organisation, and who is HIV positive, may vary a lot depending on the context.

There are advantages and disadvantages of disclosure and visibility for both NGOs and people living with HIV involved in the organisations. The analysis of advantages and disadvantages should be carried out together with people living with HIV on a one to one basis in NGOs where they are involved.

Involvement of people living with HIV and the “success of a GIPA policy” do not depend on how many people living with HIV are employed or involved in the NGO, but how the organisation responds to these issues.
Introduction

What is GIPA?

GIPA stands for Greater Involvement of People Living with HIV. It is a concept born out of the recognition by programme planners and implementers, that the involvement of people living with HIV in policy formulation, service delivery and programme evaluation is an efficient method of responding to the epidemic. This recognition was also supported by the struggle of HIV positive people themselves. At the end of the Paris AIDS Summit in 1994, 42 governments, India included, issued a Declaration in which they made a commitment to support “full involvement” of people living with HIV in the “common response to the pandemic at all national, regional and global levels”. The Paris Declaration is sometimes known as the GIPA Declaration.

Since then GIPA “has been taken up as a model of best practice in the response to HIV/AIDS”.

GIPA in India

India was among the nations to endorse the principle of GIPA at the Paris AIDS Summit in 1994.

India now accounts for the highest number of people living with HIV in the world. According to NACO estimates (2005), currently 5.1million Indians are living with HIV in India.

An Indian national network of people living with HIV (INP+), set up by people living with HIV, started functioning as a formal organisation in 1997. A significant number of networks of people living with HIV have been formed by positive people at state level in recent years - some of them relatively small groups at district level.

However, the study conducted by the Policy Project in three states in 2003 shows that “Understanding of GIPA is limited for both people living with HIV and other stakeholders” and that “the practice of GIPA is also limited and there has yet to be a significant GIPA response”.

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Involvement in programme planning at national and state level

A person living with HIV was first included in the National AIDS Control Organisation, Government of India, 1999. However, the involvement of people living with HIV in programme planning varies at the State level. The involvement of people living with HIV is more visible in high prevalence states such as Tamil Nadu, Karnataka and Maharashtra than in low prevalence states. Some States even employ people living with HIV as staff in the State AIDS Control Societies. However, the involvement of PLWHAs in most situations can still be tokenistic.

'Recently GIPA related issues are being given more attention by the National AIDS Control Program (NACP) which has committed itself to supporting and implementing greater involvement".*

Involvement in NGOs

The study mentioned above and the operations research conducted by Horizons and the International HIV/AIDS Alliance in Maharashtra reveals that people living with HIV are not involved in most NGOs working on HIV/AIDS. Where they are involved, it is at the consultation level, as resource persons, or as support staff and volunteers who have a limited influence on the planning and implementation of the programmes carried out by the organisations.

Participants - NGO management, staff and volunteers

Objectives  Participants will be able to:

- Identify areas of involvement for people living with HIV in NGOs
- Identify the roles that people living with HIV can play in an NGO

Preparation for facilitators:

- Make copies of handouts for all participants.
- Read information sheets and key messages.

Materials needed for the activity:

- Handouts: ‘Generic NGO organisational chart’ or several flip-charts with the ‘Generic NGO organisational chart’ (the number of flip-charts will depend on the number of participants and small groups).
- Handouts: 'Information Sheet: Areas of involvement and roles for people living with HIV in NGOs'
- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 2 hours 15 min.

Instructions & Methodology:

1. Introduction: Explain that it is important to agree on what we mean when we talk about the involvement of people living with HIV in NGOs.

2. Divide the participants in small groups.

3. Give each group the handouts prepared for this exercise: 'Generic NGO organisational chart' or one flip-chart with the generic NGO organisational chart'.

4. Ask participants in each group to look at the organisational chart that was allocated to them and discuss what positions people living with HIV could hold in this organisation. In order to save time, give a different set of Positions to
Each group. During the discussion, participants should try to answer the following questions:

- Are there jobs in this organisation that people living with HIV can't do? For what reasons?
- Are there positions in this organisation where it would be ideal to have an HIV positive person involved? For what reasons?

Each group should choose a person who will summarise the discussions and report to the large group. The summary should focus on the following points:

- Jobs that people living with HIV can't do in the organisation according to the group and why,
- Ideal positions for people living with HIV in the organisation and why.

Facilitators can prepare in advance flip-charts with several columns where participants can summarise their analysis. Small group discussion should not last more than 30 minutes.

5. Ask participants to come back as a large group. Ask the participants chosen by each group to present their summary. After each presentation, allow participants from other groups to ask questions of clarification but keep issues to debate for the end of the exercise.

6. After all presentations and questions of clarification are over, discuss the following issues as a large group:

- Does it seem that everybody agrees on things that people living with HIV can do or cannot do in an NGO? On what do you agree as a group?
- What are the major disagreements in the group?
- Are your opinions based on your experience of what you have seen in NGOs in India or outside of India, or are they based on your own perception of PLHA?

The facilitator(s) should take advantage of the discussion to explore what real experience participants have of involvement of people living with HIV.

7. Give each participant a copy of the Information Sheet: ‘Areas of involvement and roles for people living with HIV in NGOs’ (at the end of this module) and read it loud (see below suggestions for using Information Sheets). Explain that it is a just a way to classify in categories what has been discussed previously (it is a framework to look at the involvement of people living with HIV). Ask participants whether this matches with what they discussed in their groups. What are the differences? Does that seem relevant for their organisation? Ask participants whether they have comments and questions. Answer their questions.
8. Ask participants if they have heard of GIPA and know what it means. Give some information about the background to GIPA and define the concept based on examples given during the activity and the information sheet.

9. The facilitator(s) should conclude the discussion by summarising what has been discussed and emphasise some of the key messages. Key messages can be written in advance on a chart by the facilitators. Facilitators should always ask participants whether they agree or not with the key messages and why.

Facilitators' notes:

! This exercise is a good starting point because it will reveal various elements that are crucial to community work on the involvement of people living with HIV:

! Understanding of what involvement means.

! Attitudes toward people living with HIV and their participation in NGOs: openness or hostility.

! Perceptions of what makes the involvement of people living with HIV difficult to implement.

! Facilitators can use this exercise as a way to collect 'baseline data' on the organisation and keep it in mind for the rest of the training.

! When the facilitators ask participants about their experience of the involvement of people living with HIV, they should make clear that it is not about telling who is HIV positive in their organisation if there are already people living with HIV working in their NGO.

! At this stage, the facilitator(s) should not try to convince participants who are reluctant to accept that people living with HIV can be involved in any area and hold any position provided they have the corresponding skills and enough interest in the position. Tell participants that this issue will be discussed again when it comes to analyse the obstacles to involvement of people living with HIV and how to build a safe and supportive organisational environment to overcome these obstacles.

! The discussion about GIPA and the definition of this concept should come at the very end of the activity and be based on discussions between participants during the exercises. This will help de-mystify the concept.

! If there are participants who can't read English or Hindi or other Indian language, make sure that other participants can explain or translate the contents of the handouts.
Some suggestions for using Information Sheets

The reading of the Information Sheets can become a tedious exercise. Here are some hints to make it a more dynamic activity

- Ask several participants to read the sheet. For example a first participant can read the first paragraph of the Information Sheet, afterwards a second facilitator can read a second paragraph, and so on.
- The facilitators should not read the information themselves as it may look too much like a school exercise.
- After the reading of each paragraph, facilitators should ask whether participants have questions or comments.
- When a participant asks a question, the facilitators should not immediately answer the question but ask whether other participants can answer this question. Then the facilitators can summarise and complement or correct the answers.
- When a participant makes a point, the facilitators should ask the other participants whether they agree or have a different opinion.
- The facilitators should also ask participants whether they have some examples to illustrate the contents of the information sheet.

Important warning: Information sheets are used mostly after discussions in small groups and plenary to provide participants with a framework that structures and summarises information that usually comes out of discussions. It is therefore not necessary to read completely the information sheets when all points have already been covered by the discussions. The facilitators should focus only on new information, i.e. points that did not come up during discussions.

Information Sheets are a helpful learning tool that participants can keep and refer to later during and after the workshop.
Example of generic NGO organisational chart

GENERAL BODY / BOARD OF TRUSTEES

EXECUTIVE DIRECTOR

PROGRAMS MANAGER

HIV PREVENTION CARE & SUPPORT OFFICER

SELF HELP GROUP TRAINING OFFICER

COUNSELLOR

OUTREACH WORKERS

VOLUNTEERS

PEER EDUCATORS

SELF HELP GROUP ORGANISER

ANIMATORS

FINANCE & ADMIN MANAGER

ADMIN OFFICER

OFFICE ASSISTANCE

GUARD

DRIVER

ACCOUNTANT

ACCOUNTS ASSISTANT

HR OFFICER

OUTREACH WORKERS

VOLUNTEERS

PEER EDUCATORS

ANIMATORS
Activity 1.2
Disclosure of HIV status and visibility of involvement of people living with HIV

Participants - NGO management, staff and volunteers

Objectives
Participants will be able to:

- Identify what disclosure and visibility mean
- Identify that there are different levels of disclosure and visibility

Preparation for facilitators:

- Read the Information Sheets 'Visibility of involvement' and 'Disclosure of HIV Status'
- Write A4 cards/sheets

Materials needed for the activity:

You are a counsellor and have just found out you are HIV+

Who in the organisation would you share this information with?

Who outside the organisation would you share this information with?

For what reason would you share this information with this person/these people?

If you don't want to share the information with anybody within the organisation, explain why.

- A4 sheets or cards each with one character from the positions listed on the organisational chart described in the previous activity (№1.1) (one sheet / card per participant) for example
- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 50 min.
**Instructions & Methodology:**

1. In plenary, give each participant a card with a different character from the positions listed on the organisational chart described in the previous activity (1.1). Three questions are written on each card (see materials needed above): Who in the organisation would you share this information with? Who outside the organisation would you share this information with? For what reason would you share this information with this person/these people? If you don’t want to share the information with anybody within the organisation, explain why.

2. Explain to participants that on the card/sheet there is a character who has just received some information.

3. Tell participants that they shouldn’t tell other participants what is written on the card and that they have to imagine that they are the character on the card. They should think individually about the questions and answer them on the card. Ask participants not to write their name or organisation (10 min).

4. Collect all the cards (5 min).

5. Pick up 5 or 6 cards (no more than 6 cards as the exercise may become too long and boring). Read each card and after each card, give participants the opportunity to reflect on what was written on the card asking ‘What do you think about the decision made by this person?’ No more than 5 min of discussion after each card. Emphasise the key messages on the complexity of the issue of disclosure of HIV status and the existence of various levels of disclosure to make the transition with the reading of the information sheet (40 min).

6. Read the information sheet on disclosure out loud and allow some time for questions and answers. (10 min).
7. Explain the link between disclosure and visibility and give examples (20 min)
8. Give participants the information sheet on the visibility of involvement and ask them to read it aloud (20 min). Conclude with questions such as: “Does being involved mean that you have to go public about your HIV status?” and stress key messages.

Facilitators' notes:

! At the end of the activity it should be very clear to every participant that involvement does not equal going public with one's HIV positive status. Facilitators should make sure that this key message got across to the participants.

! Disclosure is a personal decision made by the person who is HIV positive.
During a study on the involvement of people living with HIV in NGOs and CBOs conducted by the International HIV/AIDS Alliance in several countries, including India, participating NGOs and researchers identified various broad categories of activities where people living with HIV can be involved: areas of involvement. In each category or area, people living with HIV play specific roles. The table below presents the five areas of involvement identified and the roles that people living with HIV can play in each area. It also gives concrete examples of how this translates in terms of jobs, positions or titles in an organisation.

<table>
<thead>
<tr>
<th>Areas of involvement</th>
<th>Roles for PLHA</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utilisation of the services of the NGO</td>
<td>People living with HIV are service users or beneficiaries</td>
<td>Person living with HIV who is visited by home care team</td>
</tr>
<tr>
<td>Support to programmes</td>
<td>People living with HIV are staff members or volunteers</td>
<td>Accountant, cook, guard, gardener, office assistant driver, etc.</td>
</tr>
<tr>
<td>Delivery of HIV/AIDS services implementation of programmes</td>
<td>People living with HIV are service providers or programme implementers, either as staff members or volunteers</td>
<td>Counsellor, outreach educator, project officer, etc.</td>
</tr>
<tr>
<td>Planning and design of programmes and services</td>
<td>People living with HIV are programme/service designers and planners</td>
<td>Programme or project coordinator, etc.</td>
</tr>
<tr>
<td>Management, policy-making and strategic planning</td>
<td>People living with HIV are managers and policy makers within the organisation</td>
<td>Trustee, executive director, etc.</td>
</tr>
</tbody>
</table>

- The main difference between the utilisation of the services by people living with HIV and the other areas of involvement is that in the first case people living with HIV tend to be the recipients of a service provided by the NGO, while in the other areas people living with HIV play an active role.
- In some organisations, particularly in small NGOs, people living with HIV may be involved in various areas of activities and play different roles at the same time. Areas and roles are not mutually exclusive.
- Also roles that people living with HIV play in NGOs may evolve depending on opportunities. For example, an HIV positive accountant who started coming to an NGO to access its counselling services, heard about a job in the accounts department, applied and is now working as an accountant for the organisation, at the same time as also doing some voluntary peer education with the NGO.
Voluntary disclosure

- Disclosure of one’s HIV status in an organisation is sharing information related to one’s HIV status with one or various colleagues. Disclosure is made with the express or tacit condition of confidentiality.
- The prerogative and the decision to disclose or not is solely that of the HIV positive person’s.
- The person who decides to disclose their HIV status should always be the positive person themselves.
- People living with HIV involved in NGOs should also be free to choose the person or the people they want to disclose their HIV status to.
- Employment or involvement in an NGO should not/cannot be subject to disclosure to one or more persons.

Levels of disclosure for people living with HIV

- At home, with one or several relatives.
- With one or several friends.
- With sexual partner(s).
- With a doctor or other health professionals.
- At work, with one or several colleagues.
- At work, with a supervisor.
- In NGOs and CBOs, including self-help groups or networks of people living with HIV.
- In the media, at national and/or international levels.
- In other forums, such as AIDS workshops or conferences, at national and/or international level.

There is no standard combination of these various levels of disclosure. For example some people living with HIV are identified as people living with HIV in international AIDS conferences but only a few people know about their HIV status back home. Other people
living with HIV are open about their HIV status both in their community and at national and international level.

Many factors influence disclosure of HIV status, the main factor being the perception by positive people that they are safe when disclosing their status because the people they disclose their HIV status to will not stigmatise or discriminate them and will maintain confidentiality.

**'Involuntary' disclosure (breach of confidentiality)**

- Unfortunately very often the status of positive people is disclosed without their consent by other people and not by themselves.
- Some people may disclose the HIV status of a colleague who is HIV positive to other colleagues without bad intentions. For example, people may be very affected by the news of a colleague being HIV positive and need to share their feelings with somebody, or they want other people in the organisation to be more supportive for their colleague who is HIV positive. Whatever the intentions, disclosing the HIV status of a colleague to a third person without the consent of the colleague who is HIV positive is a serious breach of confidentiality (see Module 4 Managing confidentiality).
Involvement of people living with HIV is visible in an organisation when other people besides the positive people involved know that there are people living with HIV involved in the organisation.

Visibility of involvement is a result of the disclosure of the HIV status of people living with HIV working in the organisation, whether they decided to disclose their HIV status themselves and did it, or their HIV status was disclosed with or without their consent by other people in the organisation.

There can be several levels of visibility within and outside the organisation.

**Levels of visibility of involvement of people living with HIV within an NGO**

- Only one person from the organisation knows that there are one or several people living with HIV involved in the NGO and who is HIV positive, e.g. the director; the person in charge of human resources; etc.

- A few people know that there are one or several people living with HIV involved in the NGO and who are HIV positive, e.g. colleagues of people living with HIV who work in the same team; the director and the person in charge of human resources; other people living with HIV in a support group organised by the NGO; service users if the people living with HIV provide services (an HIV positive counsellor with his/her clients); etc.

- All the people working for the NGO know that there are one or several people living with HIV involved in the NGO and who is HIV positive.

**Levels of visibility of Involvement of people living with HIV outside an NGO**

- Only some beneficiaries who are in direct contact with HIV positive NGO service providers know that there are people living with HIV involved in the organisation, for example HIV positive clients counselled by a peer counsellor.

- All beneficiaries of services provided by the NGO know that there are people living with HIV involved in the organisation and who is HIV positive.

- Some health professionals know that there are one or several people living with
HIV involved in the NGO and who is HIV positive because they refer some of their patients living with HIV to the organisation in order to meet other PLHA.

- People from other NGOs and CBOs, including self-help groups of people living with HIV or people living with HIV networks know that there are one or several people living with HIV involved in the NGO and who is HIV positive.
- National and international policy makers know that there are one or several people living with HIV involved in the NGO and who is HIV positive.
- There is information in the media that there are one or several people living with HIV involved in the NGO and it is therefore public knowledge.

Involvement can be 'invisible' when nobody else besides the HIV positive person themselves know that there are people living with HIV involved in the organisation.
**Criteria to assess involvement of people living with HIV in NGOs**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Options and Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Amount of time</strong> spent by people living with HIV taking part in the activities of the organisation</td>
<td>Involvement can be <strong>regular</strong>: e.g. full-time or part-time employees</td>
</tr>
<tr>
<td><strong>Type and level of remuneration</strong> given by the NGO to people living with HIV in exchange for their time, skills and efforts</td>
<td>Remuneration can be <strong>financial</strong>: E.g. salary for fulltime or part-time employees; fees or allowances for volunteers; reimbursement of transport expenses</td>
</tr>
<tr>
<td><strong>Categories of skills or expertise</strong> used by people living with HIV when they take part in the activities of the NGO</td>
<td>Experience of living with HIV = <strong>empirical expertise</strong>: e.g. people living with HIV give testimonies on how they found out that they were infected with HIV and how they are coping</td>
</tr>
<tr>
<td>Criteria</td>
<td>Options and Examples</td>
</tr>
<tr>
<td>----------</td>
<td>----------------------</td>
</tr>
<tr>
<td>People living with HIV “voices of the epidemic”</td>
<td>People living with HIV who give testimonies or share their experience with other people living with HIV tend to talk only about their own story. They are individual voices. People living with HIV who provide services to other people living with HIV have knowledge of HIV that goes far beyond their own personal experience. They are able to formulate the problems of other people living with HIV and the solutions they have found. They are collective voices. People living with HIV involved in the management of NGOs usually speak on behalf of other PLHA, they stand for the rights of the community of PLHA. They are social voices.</td>
</tr>
<tr>
<td>People living with HIV “faces of the epidemic” - Visibility of involvement</td>
<td>See Information Sheet-Visibility of involvement of people living with HIV</td>
</tr>
<tr>
<td>Scope and autonomy of decisions that people living with HIV make</td>
<td>People living with HIV are not involved in decision-making at all. People living with HIV are indirectly involved in decision-making through a consultation process carried out by the NGO management: e.g. the NGO asks people living with HIV who participate in support groups what kind of themes they would like to discuss when they meet. People living with HIV make decisions limited to the activities in which they take part e.g. a people living with HIV who is a programme officer for prevention makes decisions in terms of planning, budget, etc. People living with HIV make decisions on organisation-wide activities, including activities they do not take part in e.g. this happens only when people living with HIV are managers or board members.</td>
</tr>
</tbody>
</table>
- When involvement is ‘formal’ or professional, e.g. people living with HIV are employed as full-time or part-time staff with a contract, they usually receive various kinds of remuneration: financial, material, and technical remuneration, including medical benefits.

- When involvement is ‘informal’, i.e. occasional, on a voluntary basis, not based on a high level of expertise, people living with HIV receive little or no financial and material remuneration.

- People living with HIV who do not have any theoretical, technical or organisational expertise are usually “used” by NGOs as “living examples” and are requested to apply mainly their personal experience of living with HIV.

- The more technical and organisational expertise people living with HIV have, the greater their involvement may be in the decision-making process related to organisational, policy and strategic planning issues.
Module 2 explores the reasons why people living with HIV should be involved in NGOs that work on HIV/AIDS, in terms of benefits for the organisation and the people living with HIV involved, and in terms of rights. It is very important that NGO management, staff and volunteers have the opportunity to discuss and understand why involvement of people living with HIV is important and beneficial for their organisation, as involvement of people living with HIV is often perceived as something that should be done to please donors and/or activists. This module aims at building group adhesion to involvement of people living with HIV and ownership of the decision to enhance a greater involvement of people living with HIV in the organisation. However, the module also considers possible challenges or risks of involvement of people living with HIV, so that participants can explore their doubts and fears about working together with people living with HIV.

The module includes two participatory activities. Facilitators should read the various information sheets presented in the module before they adapt and use the activities. 

Contents and Summary of Key Messages

Introduction

Activity 2.1 Exploring reasons why people living with HIV should be involved in NGOs

Activity 2.2 How involving people living with HIV can improve the work of NGOs and enhance the quality of life of PLHA

Activity 2.3 Possible risks of involving people living with HIV in NGOs if not planned for adequately

Information Sheet 2.A Potential Benefits for NGOs of involving people living with HIV

Information Sheet 2.B Potential benefits of involvement for people living with HIV involved in NGOs

Information Sheet 2.C Possible risks for NGOs of involving of people living with HIV if not planned for adequately

Information Sheet 2.D Possible risks of involvement for people living with HIV involved in NGOs if not planned for adequately
NGO staff and participants should be urged to consider the following key points of Module 2:

- There are many potential benefits arising from involving people living with HIV for NGOs.
- There are also many potential benefits for people living with HIV who are involved actively in NGOs.
- However the positive consequences of involvement of people living with HIV are not systematic if involvement is not carefully planned.
- Positive impact or consequences of involvement of people living with HIV in NGOs depend on various factors, the most important being a supportive environment in the NGO.
- There are also some potential challenges and possible risks related to Involvement of people living with HIV for both the positive people involved in NGOs and the organisations where they are involved. These challenges can be anticipated and prevented.
- Benefits and challenges vary a lot depending on the way people living with HIV are involved in an NGO.
- The level of visibility of involvement of people living with HIV affects both the benefits and the risks of involvement. It is obviously difficult to measure the positive consequences of involvement when it is not visible.
- People living with HIV should be involved in NGOs working on HIV/AIDS also because it is their right to influence, plan, implement and evaluate the policies that affect them and the services supposed to meet their needs and those of their families.
- Preventing people from working in an organisation because of their HIV status is also against the law in India and can be punished.
Introduction

There are many potential benefits arising from involvement of people living with HIV. They are benefits both for the positive people involved in NGOs and for the organisations themselves, as well as for the communities served by NGOs.

However benefits are not systematic, particularly if involvement is only tokenistic or poorly planned.

In some cases, consequences of involvement may be even negative for the people living with HIV involved and/or for the organisations where they are involved. This is why it is important to anticipate potential challenges or risks of involvement. These challenges or risks can be prevented if involvement is properly planned within the organisation (module 3) and implemented by creating a safe and supportive environment for people living with HIV (module 4).

This handbook explores the benefits of involvement in NGOs when it is visible, which means that at least one person knows that there are people living with HIV in the organisation as it is impossible to assess the benefits of something that is not known.

The positive consequences of involving people living with HIV for NGOs and their services is not the only reason why people living with HIV should be involved in the organisations working on HIV/AIDS. It is their right to influence, plan, implement and evaluate the policies that affect them and the services supposed to meet their needs and those of their families, as it is the right of every citizen in a democracy to have a say on decisions that affect them and to participate actively in the life of the community.

At the end of the day, benefits of Involvement of people living with HIV for NGOs are benefits for the entire community if the involvement of people living with HIV helps improve the quality of the services provided by the NGO, and its policies. This means that the meaningful Involvement of people living with HIV will help improve the quality of life of people living with HIV and their families in the community. It will also help prevent new infections, making the work of NGOs more effective in the fight against the HIV/AIDS epidemic and its disastrous consequences.
Activity 2.1 Exploring reasons why people living with HIV should be involved in NGOs

Participants - NGO management, staff and volunteers

Objectives

Participants will be able to:

- Identify the potential benefits or positive impact of involvement of people living with HIV for the NGOs they are involved in.
- Identify the potential benefits or positive impact of involvement for people living with HIV involved in NGOs.

Preparation for facilitators:

- Prepare a series of case studies and type or handwrite each case study on a piece of paper.
- Write key instructions for work in small groups on large sheets of blank paper.
- Make photocopies of Information Sheets on ‘Potential benefits of involvement for people living with HIV involved in NGOs' and on ‘Potential benefits of involvement of people living with HIV for NGOs’

Examples of case studies

A - Raju is working as an outreach educator for an NGO based in Delhi. He is 30, he is married and has one daughter. He found out he was HIV positive 5 years ago and he has been involved in the national network of people living with HIV since then. He is open about his HIV status with his colleagues. He also discloses his HIV status when he is involved in awareness raising events.

B - Usha is a social worker. She also volunteers for an NGO based in Pune. She does counselling for HIV positive people. She is HIV positive herself but she has not disclosed her HIV status to her colleagues. Only her husband knows that she is living with HIV. She does not want to share her experience with her clients either, although sometimes she hears stories of women very similar to hers. Usha is 27 and she has one child.

C - Ritu is the director of a very large development NGO based in Chennai.
She is 41. She was diagnosed with HIV only recently when she got sick. Now she is on antiretrovirals and her health is good. By coincidence her NGO started to get involved in HIV prevention work when she found out about her HIV status. She decided not to tell anybody that she has AIDS. Ritu is married and she has one son.

**D** - Sanjay is a doctor. He is 35. He works at a public hospital in Mumbai. He is also involved in two NGOs that provide people living with HIV with medical and psychosocial support. Sanjay is HIV positive. He was diagnosed three years ago. He usually tells his patients and the people he counsels about his HIV status, especially when they are very depressed.

**E** - Kusum is 25. She works with an NGO that runs a shelter for single mothers, including sex workers, and their children. Some of the mothers and children are HIV positive. Kusum takes care of the children, bathing them, dressing them, feeding them, playing with them, etc. Kusum was a sex worker herself and she is HIV positive. Only the NGO director and the program officer in charge of the shelter know her HIV status.

**Materials needed for the activity:**

- Information sheets on ‘Potential benefits of involvement in NGOs for people living with HIV’ and on ‘Potential benefits of involvement of people living with HIV for NGOs’
- A4 paper or flip-charts with one case study on each A4 paper or flip-chart
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

**Estimated time needed for the activity:** Approximately 1 hour 45 min

**Instructions & Methodology:**

1. Divide participants in small groups (up to 6 participants in each group). Give each group a piece of paper with a case study written on it. Ask one of the participants to read the case study to the other group members (5 min)

2. Ask people to brainstorm and discuss the potential benefits or positive impact of involvement of people living with HIV in the situation described by the case study (40 min). Ask participants to list separately:
✓ Potential benefits or positive impact of involvement (if any) for the person living with HIV described by the case study, including potential consequences for the family of the positive person.

✓ Potential benefits or positive impact of involvement (if any) for the organisation where this person is involved, including benefits for service users and other staff members.

3. Each group should choose a participant who will summarise discussions held in the small group and report to the large group. Potential benefits can be summarised on flip-charts.

4. Ask participants to come back as a large group and to present their work. Each group should read their case study at the very beginning of their presentation as the other participants do not know the situation analysed by other groups (maximum 45 min)

5. In plenary ask participants what may affect the impact of involvement for both the person living with HIV and the NGO in the situations described by the case studies. Explore the difference between impact of ‘visible’ and “invisible’ involvement, e.g. ask participants 'Would it make a difference if Usha disclosed her HIV status to her clients in terms of positive impact?’; 'Would it make a difference if Ritu disclosed her HIV status to her colleagues in terms of positive impact?’; 'Would it make a difference if she disclosed her HIV status on TV?'; 'Would it make a difference if Sanjay disclosed his HIV status to other health care workers in terms of positive impact?’ Make the difference between impact of ‘visible’ and ‘invisible’ involvement. (15 min)

Facilitators’ notes:

! Participants should focus only on what is positive as other activities will address the potential risks or negative impact of involvement (if not planned for) of people living with HIV and the obstacles to involvement.

! Based on comments from participants, emphasise that the benefits of disclosure will depend on various factors: environment, levels of disclosure, etc.
Activity 2.2

How involving people living with HIV can improve the work of NGOs and enhance the quality of life of PLHA.

Participants - NGO management, staff and volunteers

Objectives-
Participants will be able to:

- Identify how involving people living with HIV can improve the work of NGOs.

Preparation for facilitators:

- Write key instructions for work in pairs on large sheets of blank paper.

Estimated time needed for the activity: Approximately 1 hour

Instructions & Methodology:

1. Divide participants into pairs (people sitting down next to each other). Ask people to sit down face-to-face. Ask all participants to imagine now that they are HIV positive. Ask them to discuss the following issues within each pair. Stress that they do not need to write anything:

   - Given their current role/position in the organisation, would the fact of being HIV positive improve the work they do?' or in other words 'Would the fact of being HIV positive have some positive impact on the quality of the work they do? What kind of positive impact?'; and

   - 'By telling the management and their colleagues that they are HIV positive, would they get some personal benefits?'.

2. Back in plenary, ask who would like to share what was discussed in pairs. Write down on a flip-chart the list of potential benefits for positive people and NGOs (additional to those already listed in the previous activity 2.1).

3. Ask participants whether there are additional good reasons why people living with HIV should be involved in NGOs, besides positive consequences or benefits for them and the organisations where they are involved.

4. As a conclusion, give participants information sheets on 'Potential benefits of Involvement of people living with HIV for people living with HIV involved in NGOs' and on 'Potential benefits of Involvement of people living with HIV for NGOs'. Information sheets can either be read loud in plenary (see suggestions for using Information Sheets) or read individually by participants at the end of the day. If they are read loud in plenary, additional time will be needed.
Facilitators' notes:

! Participants should focus only on what is positive as other activities will address the negative impact of involvement of people living with HIV and the obstacles to involvement.

! In this exercise, make sure that participants speak in the first person as at this stage the approach has to be personal, unlike in the first exercise on 'positive impact' where the analysis was more general. Every time a participant expresses generalities, remind them that we are talking about their current professional situation.

! Based on comments from participants, emphasise that the benefits of disclosure will depend on various factors: environment, levels of disclosure, etc.

! In the final discussion on good reasons why people living with HIV should be involved in NGOs, facilitators should mention a rights-based approach if participants do not talk about it.
Activity 2.3
Possible risks of involvement of people living with HIV in NGOs if not planned for adequately

Participants - NGO management, staff and volunteers

Objectives- Participants will be able to:

- Identify the possible risks / challenges of involvement of people living with HIV in NGOs for the organisations where they are involved.

Preparation for facilitators:

- Make photocopies of the Information Sheets on 'Possible risks of Involvement of people living with HIV for NGOs' and 'Possible risks of involvement for people living with HIV involved in NGOs'.

Materials needed for the activity:

- Photocopies of the Information Sheets on 'Possible risks of involvement of people living with HIV for NGOs if not planned for adequately' and 'Possible risks of involvement for people living with HIV involved in NGOs if not planned for adequately'.
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 35 min

Instructions & Methodology:

1. Divide participants in 2 groups. Ask one group to brainstorm on possible risks of PLHA involvement for PLHA involved in NGOs. Ask the other group to brainstorm on possible risks of PLHA involvement for NGOs (30 min).
2. Ask participants to come back in plenary and to present their work (30 min).
3. Give the Information Sheets. There is no need to read the Information Sheets if all the points have already been mentioned by the small groups. If some points have not been mentioned by the group, the facilitators should focus only on those points (25 min).
4. Ask participants whether they can think of what could be done to prevent some of the possible risks of involvement of people living with HIV they identified (10 min).

5. The facilitators should link this with what will be discussed during the sessions on 'Supportive environment'. Facilitators should not start to discuss issues like 'stigma' in detail as it may take a lot of time. One key message is that in order to prevent any negative consequences the NGO can put in place a supportive environment, which will be explored later during the workshop.

**Facilitators' notes:**

It is important to use the word 'risks' with care and emphasise that they are possible risks, i.e. they can be prevented. However, other words such as 'challenges' may be confusing as participants will think of challenges in terms of obstacles to involvement while by 'risks' facilitators should focus only on the consequences of involvement when they are potentially negative.

This activity should be used as a transition between the first series of activities from Modules 1 and 2 and the rest of the handbook. Facilitators should stress that most possible risks of involvement of people living with HIV can be prevented, if involvement is properly planned within the organisation (Module 3) and implemented by creating a safe and supportive environment for people living with HIV (Module 4).

Example of workshop participants' outputs from the first part of the activity 'Risks when involvement is not planned for' (adapted from a workshop conducted with Alliance India partners in Trivandrum in 2004)

<table>
<thead>
<tr>
<th><strong>Possible perceived risks for person living with HIV</strong></th>
<th><strong>Possible perceived risks for NGO</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Being stigmatized by colleagues</td>
<td>- Organisation being stigmatized</td>
</tr>
<tr>
<td>- Not being considered for training opportunities because organisation may prefer to invest in people they consider to be 'healthy'</td>
<td>- Perception by other staff that HIV positive people are getting more benefits, leading to dissatisfaction and de-motivation</td>
</tr>
<tr>
<td>- Frustration at feeling that certain assignments are not given to them</td>
<td>- High staff turnover</td>
</tr>
<tr>
<td>- Fear of getting sick more often than other staff and losing job</td>
<td>- Extra 'burden' to organisation</td>
</tr>
<tr>
<td>- Not being able to access welfare schemes</td>
<td>- Impact on organisational policies</td>
</tr>
</tbody>
</table>

The facilitator used this as an opportunity to make the link to next part of the training process by stressing the importance of effective planning for involvement.
Potential benefits of involvement of people living with HIV for NGOs

Positive impact on prevention and awareness raising

Involvement of people living with HIV may increase the success of outreach education and awareness raising activities in the community because it tends to change the perceptions that people have of HIV-positive people by giving HIV/AIDS a “human face”.

↩ People understand better the difference between HIV and AIDS, and that AIDS does not mean death.

↩ They appreciate that a person with HIV can look healthy and realise that anyone can be at risk of infection, as it is not possible to identify an HIV-positive sexual partner, or HIV positive IDU with whom you may share a needle, just by the way she or he looks.

↩ People understand that people living with HIV are able to live positively and to be active like "normal "people. Attitudes towards people living with HIV may become more open and accepting.

↩ HIV-positive educators act as role models, encouraging other people living with HIV to live positively.

↩ Involvement of people living with HIV increases the willingness of people to take an HIV test because they feel encouraged when they see that people who tested positive are able to live a “normal” life.

Positive impact on care and support services

- Involvement of people living with HIV may encourage other people living with HIV to seek support.

- Involvement of people living with HIV in the planning and delivery of services helps to make these services more responsive, relevant and demand driven.

- Involvement of people living with HIV as staff with access to up to date information on emerging technologies and models may also increase the quality of services provided as they fulfil the role of advocates for people living with HIV within the organisations that they work.

- Peer counselling and peer support in general help people living with HIV in a different and complementary way compared to psychological support provided by people who are not HIV positive.

↩ People living with HIV who receive psychological support from other people living
with HIV realise that they are not alone and isolated.

- They are able to find solutions to their problems with others who are in the same situation.

- HIV-positive counsellors are less likely to have judgmental attitudes than health professionals and therefore it is easier for them to empathise with their clients.

- Involvement of people living with HIV increases people living with HIV awareness of their rights.

### Positive impact on the general functioning of NGOs

- Involvement of people living with HIV can improve understanding of the issues affecting people living with HIV and increase acceptance of people living with HIV among HIV-negative staff and volunteers. Changes in staff attitudes towards people living with HIV may help to create a more supportive organisational environment in NGOs.

- Involvement of people living with HIV increases the credibility of the organisation and its services with service users, other organisations and donors.

  - As a result of Involvement of people living with HIV, organisations tend to integrate advocacy for people living with HIV's rights into their work.

  - People living with HIV involved in NGOs have 'inside' knowledge of the needs of positive people and they have a strong motivation to stand up for their own rights.

  - HIV-negative staff and volunteers have a better understanding of the issues affecting people living with HIV because they work together and they have more confidence to argue against stigma and discrimination.
Information Sheet 2.B

Potential benefits of involvement for people living with HIV involved in NGOs

Improved psychological health

- Through their involvement in NGOs, people living with HIV often have the opportunity to meet other HIV-positive people. As a result they realise that they are not alone and that they can share problems and solutions with other PLHA. This can bring an end to isolation, in particular self-isolation and self-stigma.

- Involvement of people living with HIV also means better access to information and improved knowledge of HIV/AIDS. More accurate information helps people living with HIV change their perceptions of HIV infection, and gives hope to those who used to think that a positive test result was the end of their life. As a result there is a greater acceptance of being HIV positive.

- People living with HIV actively involved in the activities of NGOs have a greater sense of purpose and usefulness. They command greater respect and recognition from others when they contribute to the community. This leads to increased confidence and self-esteem.

- For those positive people who have received training and those involved in decision-making, being involved in the activities of NGOs is an empowering process.

Improved physical health

- People living with HIV involved in NGOs usually have better access to information regarding care. They are more aware than other people living with HIV of what options exist in terms of treatment, where they can access care and who can provide them with good quality care.

- People living with HIV involved in NGOs may also have more information about what they should and should not eat and drink, and what physical activities they should or should not undertake. As a result people living with HIV may eat a healthier diet and live a healthier lifestyle, providing they have the financial resources to afford sufficient nutritious food.

- In some cases people living with HIV have access to free medical care or reimbursement for medical treatment provided by the NGO where they are employed. NGOs can also refer people living with HIV to other organisations that provide treatments free of charge.

Material benefits

People living with HIV who are employees, and volunteers who receive some form of financial or material compensation, find that involvement provides a more or less regular income. The remuneration they receive for their work is essential to their well-being and that of their families, as they can buy medicines and food.

In many cases, involvement of people living with HIV has a therapeutic effect on PLHA.
**Impact on activities because of sickness or premature death of people living with HIV involved in the organisations when there is no treatment**

Where treatment is not available, there is a potential risk of disruption of the activities when people living with HIV who are staff members or volunteers are sick or die prematurely.

**Higher cost of training PLHA**

Where early treatment is not available, there may be a perception that the cost of training people living with HIV is higher if they die prematurely and have to be replaced by new staff members or volunteers.

**Higher cost of employing people living with HIV because of medical benefits**

NGOs who provide medical benefits to their staff and/or volunteers may have to pay more for HIV positive people as there is a greater risk of them getting sick more frequently than other people who do not have a chronic disease.

**Stigmatisation of the NGO**

Organisations where there is visible Involvement of people living with HIV may be seen as people living with HIV organisations, with a risk of stigmatisation for all staff members and volunteers, both HIV positive and HIV negative.

Some people might not wish to use the services of an organisation with visible people living with HIV because they might be identified as using these services and being HIV positive themselves.

**Conflicts between HIV-negative and HIV-positive people within the organisation**

Conflicts may arise from judgmental attitudes of HIV-negative staff and volunteers towards PLHA. People living with HIV may also be denied any participation in the decision-making process and feel used by the NGO (tokenistic involvement).

In other cases the promotion of Involvement of people living with HIV may lead to undervaluing the contribution of HIV-negative people in some areas and cause resentment.
Possible risks of involvement of people living with HIV involved in NGOs if not planned for adequately

Stigma and Discrimination

As a result of visible involvement, people living with HIV may face stigma and rejection, which is why most positive people disclose their HIV status only to the people they trust and prefer to be involved in NGOs without being open in public.

Adverse psychological impact of identifying with other people living with HIV who are ill or dying

This effect is most likely to happen when people living with HIV are involved in activities that bring them into contact with other people living with HIV who are very sick or in the terminal stages of AIDS, such as home or hospital visiting.

The death of colleagues who are HIV positive can also affect the psychological health of people living with HIV involved in NGOs.

Burn-out

There is a high risk of burn-out in organisations where there are very few positive people involved in the activities of the NGO. There are many demands on them and it can be difficult to deal with the pressure. It can be also physically tiring for people living with HIV and have an adverse impact on their health.

Feeling used by NGOs

People living with HIV who are not involved in the decision-making process and/or receive little training and compensation from the NGO with which they work may feel at some point that they are used by the NGO.

Community suspicion of motives for involvement

People living with HIV may be accused of pretending to be HIV positive to obtain financial benefits from their involvement in NGOs.
Planning for the involvement of people living with HIV in NGOs
Contents and Summary of Key Messages

Introduction

Activity 3.1 Assessing the involvement of people living with HIV in our organisation
Activity 3.2 What kind of involvement of people living with HIV for our organisation?
Activity 3.3 Pathways to involvement of people living with HIV
Activity 3.4 Identifying gaps to enhance the involvement of people living with HIV in our organisation

Information Sheet 3.A Organisational obstacles to involvement of people living with HIV in NGOs
Information Sheet 3.B Social obstacles to involvement of people living with HIV in NGOs

Module 3 takes participants through a series of practical activities to plan a greater involvement of people living with HIV in their organisation once they agree it is beneficial for both the NGO and positive people. The assumption is that the involvement of people living with HIV is an organisational process that can be planned. It is also an individual process for each HIV positive person but, as explained in the introduction, the handbook focuses more on the organisational perspective. The starting point of the planning process is an assessment of the current level of involvement of people living with HIV in the organisation carried out by a selected number of people in the organisation. Afterwards management, staff and volunteers engage in a consultation process in order to identify obstacles to the greater involvement of people living with HIV as well as strengths that will facilitate the process, and gaps to be filled.
NGO staff and participants should be urged to consider the following key points of Module 3:

- Involvement of people living with HIV is a process that can be planned by NGOs at organisational level.
- NGOs should try to identify the obstacles to Involvement of people living with HIV in their activities in order to be able to overcome those obstacles.
- There are two broad categories of obstacles: social obstacles linked to the context or environment, and organisational obstacles linked to the NGO itself.
- While it might be more difficult and slower to address social obstacles, it can be relatively easy and quick for an NGO to change the organisational obstacles to Involvement of people living with HIV. NGOs should not always use the social context to explain that it is impossible to involve people living with HIV in their activities as most obstacles to participation of people living with HIV comes from inside the organisations and not from outside.
- Not all NGOs in India need or want to involve people living with HIV in the same way. There is not one single model for the involvement of people living with HIV at community level. NGOs should be able to make decisions based on their history and current characteristics.
- Decisions about the best way to involve people living with HIV in the NGO should be guided by the interest of the beneficiaries of the services provided by the organisation: how will Involvement of people living with HIV make a positive difference in the quality of the services they receive, whether it is prevention, or care and support? How will involvement of people living with HIV improve the quality of life of people living with HIV and their families in the communities where the NGO works? How will Involvement of people living with HIV help prevent new infections?
**Introduction**

Planning involvement of people living with HIV is an exercise of introspection for NGOs. If no people living with HIV are involved in the organisation, they will have to understand why, and what are the obstacles to this lack of participation of people living with HIV in their activities. They will have to explore in particular internal obstacles to their involvement, ranging from lack of understanding of the benefits of involving positive people to widespread discriminatory attitudes towards people living with HIV in the organisation.

Organisations need to be encouraged to explore these issues without trying to elude aspects that may be seen as negative. NGOs where there is no participation of people living with HIV and who embark on the process of planning a greater involvement of positive people in their activities should never be blamed for reacting too late or too little in the history of the epidemic in India. On the contrary, their commitment should be supported and organisational strengths that can enhance the participation of positive people in the NGO should be emphasised.

No one can and should decide for NGOs what kind of Involvement of people living with HIV is good for them. The role of organisations providing technical assistance to NGOs on these issues is therefore to help them analyse:

- Where they come from and where they are in terms of involvement of people living with HIV
- Where they would like to go, taking into account internal and external obstacles and keeping in mind what benefits the involvement of people living with HIV can bring to the community where the NGO works
- What obstacles (especially internally) the NGO can easily overcome and how the organisation can anticipate potential risks of involving PLHA
- What organisational strengths will make Involvement of people living with HIV easier to implement

Only this kind of participatory process can secure the ownership by the NGO of the decision of involving people living with HIV and of the way this should happen. Otherwise NGOs may feel that it is a decision imposed to them and involvement will never happen or will be tokenistic.

It is also important that the participatory process involves all staff members and volunteers in the NGO as implementing GIPA successfully will require commitment and buy-in from all levels of staff in the organisation.
Activity 3.1 Assessing the involvement of people living with HIV in our organisation

Participants - NGO management only

Objectives - Participants will be able to:

- Assess how people living with HIV are currently involved in their organisation (visible involvement).

Preparation for facilitators:

- Make copies of the NGO’s organisational chart or draw the chart on large sheets of blank paper. This means that the facilitators should contact the management beforehand in order to have this kind of information.

Materials needed for the activity:

- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff
- Information sheet on ‘Areas of involvement and Roles for people living with HIV in NGOs’

Estimated time needed for the activity: Approximately 45 minutes

Instructions & Methodology:

1. Since this activity is the first step of the planning process, facilitators should explain the whole process and present the various steps:

   - Step 1: Assessing current visible involvement of people living with HIV in the organisation.
   - Explain that the assessment of involvement of people living with HIV in the organisation cannot be conducted with the whole staff because of issues of disclosure of their HIV status by people living with HIV already involved in the NGO and visibility of their involvement. Sharing with all staff members what positions people living with HIV hold in the organisation would be a breach of confidentiality if those people have disclosed their HIV status only to a limited number of colleagues in the organisation.
2. Step 2: Discussing what involvement is needed or desirable in the organisation (based on previous discussions on positive impact of involvement).

3. Step 3: Identifying obstacles to GIPA in the NGO (including organisational weaknesses) and organisational strengths, and gaps

Explain that steps 2 and 3 need to be carried out with the whole staff through a consultation process to ensure ownership of the decisions made regarding the involvement of people living with HIV and commitment to implement those decisions.

2. Give participants a copy of the NGO’s organisational chart. Using information sheets presented in the second module participants should answer the following questions:

   a. In what areas are there already people living with HIV involved in the organisation?
   b. What roles do they have?

3. Participants should mark the areas and positions held by people living with HIV on the chart.

4. Participants should also discuss the following characteristics of this involvement: Are they staff or volunteers? Are they paid for what they do? Do they make decisions? How do these decisions impact on the organisation?

**Facilitators’ notes:**

- This activity should not be part of a workshop organised with the management, staff and volunteers of the NGO. It should be conducted with the management only during a meeting at the beginning of the planning process.

- Facilitators should stress that information shared during the session/meeting is confidential as not all members of management are aware of who is HIV positive in the organisation.

- Some organisations may conclude that there is no involvement of people living with HIV in their organisation, in which case the activity will be extremely

- Emphasise that the next steps of the planning process need to involve all the staff and volunteers in a participatory consultation process because implementing GIPA successfully will require commitment and buy-in from all levels of staff in the organisation.
Activity 3.2
What kind of involvement of people living with HIV for our organisation?

Participants - NGO management, staff and volunteers

Objectives- Participants will be able to:

- Identify areas of involvement for people living with HIV in their NGO.
- Identify roles/positions for people living with HIV in the organisation.

Preparation for facilitators:

- Make copies of the NGO's organisational chart.
- Stick on the walls flip-charts from previous activities on positive and negative impact of involvement of people living with HIV.
- Prepare flip-charts with 'Areas of involvement' as a title and 'Roles' as a sub-title

Materials needed for the activity:

- Copies of the NGO's organisational chart used in the previous activity
- Flip-charts with 'Areas of involvement' as a title and 'Roles' as a sub-title
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour

Instructions & Methodology:

1. Explain that this activity is part of a process that comprises of various steps:
   - Step 1: Assessing current visible involvement of people living with HIV in the organisation.
   - Step 2: Discussing what involvement is needed or desirable in the organisation (based on previous discussions on positive impact of involvement).
   - Step 3: Identifying obstacles to GIPA in the NGO (including organisational
weaknesses) and organisational strengths, and gaps

2. Show the generic organisational chart on a flip-chart and explain what assessment of involvement is about: identifying in which areas there are people living with HIV involved and how many of them there are. Ask participants: 'If we do that here for your organisation, what will happen?'. Let participants answer the question and explain that the assessment of involvement of people living with HIV in the organisation cannot be conducted with the whole staff because of issues of disclosure of their HIV status by people living with HIV already involved in the NGO and visibility of their involvement. Sharing with all staff members what positions people living with HIV hold in the organisation would be a breach of confidentiality if those people have disclosed their HIV status only to a limited number of colleagues in the organisation. Emphasise issues of levels of disclosure and visibility and the link with confidentiality. Ask: ‘How can it be done to protect confidentiality?’ Explain that one solution is for an assessment to be carried out by a limited number of people within the NGO, e.g. management, person in charge of Human Resources, board members. Explain that the assessment has already been conducted by the relevant people (20 min).

3. Explain that steps 2 and 3 need to be discussed in the whole organisation through a consultation process because it is really important that all staff and volunteers understand the obstacles to a greater involvement of people living with HIV in the organisation and how they can be overcome, as every person will be part of the solution.

4. Divide participants into small groups. Make sure that each group has a copy of the NGO’s organisational chart.

5. Ask participants to discuss what type of involvement of people living with HIV they think is needed or desirable in their organisation in for example three years’ time (depending on the planning cycle in the organisation). This should be based on previous discussions on the impact of the involvement of people living with HIV on NGOs and people living with HIV involved, as well as other good reasons why people living with HIV should be involved in NGOs.

6. Facilitators should prepare in advance flip-charts with ‘Areas of involvement’ as a title and ‘Roles’ as a sub-title that participants will fill in.

7. In plenary compare the results of the discussions within each group. Stress what is in common and discuss pros and cons of suggestions made only by a minority of participants.
Example of workshop participants' outputs from the activity 'What kind of involvement for our organisation' (adapted from a workshop conducted with Alliance India partners in Trivandrum in 2004)

<table>
<thead>
<tr>
<th>Area:</th>
<th>Roles:</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS Projects</td>
<td>Accounts &amp; Administration 2</td>
</tr>
<tr>
<td></td>
<td>Programme Manager 1</td>
</tr>
<tr>
<td></td>
<td>Training Officer 1</td>
</tr>
<tr>
<td></td>
<td>Counsellor</td>
</tr>
<tr>
<td></td>
<td>Male 1</td>
</tr>
<tr>
<td></td>
<td>Female 1</td>
</tr>
<tr>
<td></td>
<td>Outreach worker 50%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area:</th>
<th>Roles:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other projects and general - staff</td>
<td>Appointment as staff based on qualification and experience,</td>
</tr>
</tbody>
</table>
Activity 3.3  Pathways to involvement of people living with HIV

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify organisational and social obstacles to Involvement of people living with HIV in their organisation.
- Identify organisational strengths that can be used to overcome obstacles and move towards Involvement of people living with HIV or enhance existing involvement.
- Set realistic objectives for GIPA in their organisation

Preparation for facilitators:

- Prepare flip-charts presenting the two categories of obstacles with brief definitions and examples.
- Make photocopies of Information Sheets on obstacles to Involvement of people living with HIV.

Materials needed for the activity:

- Flip-charts presenting the two categories of obstacles with brief definitions and examples (see Annex to this activity).
- Flip-charts with potential areas of involvement and roles for people living with HIV identified during the previous activity, e.g. Service Delivery HIV positive Peer Counsellors; Planning and Design of Services HIV positive Programme Officer for Prevention; Policy Making and Strategic Planning HIV positive Trustee.
- Photocopies of Information Sheets on obstacles to involvement of people living with HIV
- Large number of A4 sheets of paper or cards of different colours
- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff
**Estimated time needed for the activity:** Approximately 2 hours 10 min

**Instructions & Methodology:**

1. Introduction: explain that obstacles to involvement can be classified in two broad categories:
   - Organisational obstacles
   - Social obstacles
   (10 min)

2. Divide participants in several small groups. Give each group a flip-chart with one of the areas of involvement and potential roles for people living with HIV in this area identified by participants during the previous activity (3.2). There can be as many groups as potential roles for people living with HIV identified in the previous activity, or the same group can work on several areas/roles. Ask each group to brainstorm and try to identify social and organisational obstacles to this kind of involvement. They should write each obstacle with a thick pen on a sheet of A4 paper or card and put the cards in a line on the floor. The line should lead to the flip-chart presenting one area of involvement and the corresponding roles for people living with HIV in this area. Some obstacles may be specific to some of the roles, in which case they should be positioned in front of the corresponding flip-chart. All the other obstacles will be common to all the roles (30 min)

3. Ask participants to classify organisational obstacles and social obstacles. Tell them that they have to focus on organisational obstacles because it is easier and faster to address those obstacles rather than the social ones, for which NGOs need long-term strategies (10 min).

4. Using the same small groups, ask participants to analyse existing strengths in their organisation (if any) that can be used to overcome obstacles. Write them with thick pens of a different colour on sheets of A4 paper or card (or use A4 paper or card of a different colour) and position them in front of the corresponding obstacle (30 min).

5. When all the groups have finished, ask all participants to move around in the room(s) and read what other groups have produced (i.e. the lines on the floor with obstacles and corresponding strengths) comparing with the production of their own group (15 min)

6. Bring participants back together. Ask them whether they have noticed differences and which ones. Allow time for questions of clarification and answers (15 min).

7. Give copies of Information Sheets on 'Obstacles to involvement of people living with HIV' to all participants. There is no need to read all the contents of the Information Sheets if all the points have already been mentioned by the small groups. If some points have not been mentioned by the group, the facilitators should focus only on those points. Allow time for questions and answers (20 min).
Facilitators’ notes:

- Facilitators should make sure that each group has enough space to draw the lines of cards on the floor.
- It is preferable to use papers of two different colours to write down obstacles and strengths.
- Facilitators should encourage participants to focus more on organisational “weaknesses” and strengths as people could waste time discussing broad social obstacles to involvement that cannot be changed easily. The message to participants is that “organisational obstacles can be changed by the organisation”. To help participants you could use the following descriptions:

Organisational obstacles

These include characteristics of the organisation in which people living with HIV are involved or willing to be involved, such as institutional policies, structure and management.

Social obstacles

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.

These also include characteristics of people living with HIV who are or who could be involved, such as good or poor health, level of education and range of skills.
Example of workshop participants' outputs from the activity 'Pathways to involvement' (adapted from a workshop conducted with India HIV/AIDS Alliance partners in Trivandrum in 2004)

- Work continuity
- Project - time frame
- Training opportunities
- Organisation values
- Limitations in health schemes
- Financial over burden for the organisation
- Limited grant
- Geographical Location (Non-priority area)
- Health problems
- Lack of acceptance among other employees
- Lack of support from members of the family
- Appointing in honorary
- Proof of status
- Availability of qualified persons
- Trained Staff
- Infrastructure facilities
- Rapport with Government and Private
- Broad-minded
- National / International
- Organisations reach
- Organisations reach
- Health centers
- Crisis management systems
- Flexibility
- Dedicated staff
- Collecting external
Activity 3.4  Identifying gaps to enhance the involvement of people living with HIV in our organisation

**Objectives**  Participants will be able to:

- Identify what is still missing in their organisation to achieve the involvement of people living with HIV, based on the analysis of organisational obstacles and strengths

**Preparation for facilitators:**

- Summarise on flip-charts the organisational obstacles and corresponding strengths identified by the groups in the previous activity (N°3.3).

**Materials needed for the activity:**

- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

**Estimated time needed for the activity:** Approximately 1 hour

**Instructions & Methodology:**

1. Tell participants that all the obstacles and the corresponding strengths they identified in the previous activity (3.3) have been recorded on a chart.

2. Tell participants that now they will be asked to analyse what they think their organisation still needs or in other words what is missing in their organisation in order to achieve the type of involvement of people living with HIV they have identified previously (activity 3.2). Facilitators can tell participants that these things that are missing are called gaps. A gap can also be defined as an obstacle that a NGO cannot address with its existing strengths (10 min).

3. In plenary brainstorm for each obstacle and strengths, asking them what the gaps are. E.g.:
   - **Obstacle:** discrimination within the NGO
   - **Strengths:** compassion, training capacity, etc.
   - **Are these strengths sufficient to overcome that obstacle? What is still missing to address this obstacle in a satisfactory way? What are the other elements needed to overcome this obstacle?** (45 min)
4. Single out what elements are the components of a supportive environment to make the transition with the following activities (5 min).

**Facilitators' notes:**

! Activity 3.3 should be conducted at the end of the day or before a break so that facilitators have time to summarise organisational obstacles and corresponding strengths identified by the groups in the activity before they start activity 3.4.

! Describe what a gap is in very simple words as participants may find the definition confusing. In some cases it may not be necessary to use the word ‘gaps’ in the instructions given to the participants.
Social obstacles to the involvement of people living with HIV in NGOs

Difficulty in taking an HIV test

- Most HIV-positive people do not know that they are HIV positive because they either have never taken and HIV test or have not collected the results.
- In some areas there is no access to Voluntary HIV Counselling and Testing (VCT).
- The importance of taking an HIV test when there is no treatment available may no be obvious to people.

Poor health of PLHA

- Many people living with HIV find out about their HIV status when they are already sick and wait until they are very ill before they seek services from NGOs.
- Inadequate care provided by the public health system contributes to the poor health of PLHA. Access to antiretroviral therapy is still extremely limited in India.
- In a context of limited access to good quality care, poor health of people living with HIV makes their involvement more difficult as high mortality and morbidity rates among people living with HIV affect in particular the sustainability of their involvement.
- This in turn may limit the willingness of some organisations to involve or employ more PLHA.

Fear and reality of stigma and discrimination limit Involvement of people living with HIV

There is no systematic link between involvement, even when it is visible, and stigma and discrimination. However.

- Stigmatisation of HIV/AIDS and negative social attitudes towards people living with HIV are widespread in India.
- People living with HIV fear that by being involved in organisations working on HIV/AIDS, they may be identified as HIV-positive and as a result labelled and discriminated against.
- Some people living with HIV are also stigmatised because of their sexual orientation (Men who have Sex with Men - MSM) or behaviours (Injecting Drug Users IDUs).
- The degree of concern about stigma and discrimination appear to be influenced by the social status of the PLHA. HIV-positive people of a higher social status feel less free to be involved and disclose because of concerns about compromising their position in society and because of social pressure to act as role models.
Difficulty in accepting HIV status (denial)

Because of stigma and discrimination, accepting one's HIV status may be a long process and involvement requires a certain level of personal acceptance. However, many people living with HIV never accept that they are living with HIV and the consequences of this situation – this is often referred to as 'denial'.

The limitations of poverty

- People living with HIV from low-income groups need to earn an income and cannot be involved in NGOs on a voluntary basis.
- Many people living with HIV see involvement as an opportunity to have a job or receive money. When expectations of material support by NGOs are not met, this can discourage sustained involvement.
- Poverty contributes to poor health as poor people cannot afford to buy drugs, nutritious food, etc.
- Many people living with HIV lack money to cover transport costs, either to travel to the NGO or to carry out activities. People living with HIV cannot always walk long distances if their health is compromised.

Lack of education and skills is an obstacle to involvement

- People living with HIV who are poor are less likely to have had access to formal or vocational education.
- Involvement in areas such as planning and design of programmes and services, as well as management, policymaking and strategic planning, requires levels of knowledge and skills that go beyond personal experience of living with HIV.
- Limited skills and knowledge contribute to lack of confidence of people living with HIV about their ability to become involved.

It is more difficult for women to be involved because of their social status

- Sometimes women do not go outside the home, and even less without the authorisation of their husband.
- Domestic, household and childcare responsibilities limit women's opportunities for involvement.
- The vast majority of women in India do not have access to education and are therefore less likely to have the required qualifications and skills to be involved. Women are often used as volunteers for this reason.
Judgmental and discriminatory attitudes towards people living with HIV among HIV-negative management and staff

Some people still fear direct contact with people living with HIV because of a lack of clear understanding of modes of HIV transmission.

Judgmental attitudes may be even stronger towards MSM, IDUs and sex workers.

Discriminatory policies

Mandatory HIV testing is a discriminatory policy. Also some NGOs may have a policy of non-involvement of people living with HIV in some areas of activity such as childcare, because of lack of awareness of universal precautions and concerns for the health of the children.

Failure to consider potential of people living with HIV and offer opportunities for involvement

NGOs often have a limited vision of areas where people living with HIV can be involved. NGO management and staff may perceive that people living with HIV do not have the ability to contribute to services and activities because they lack education and skills.

Lack of information about opportunities for people living with HIV to be involved in programmes

For example, people living with HIV who access NGO services are not always told by service providers how they could become involved in some of the activities carried out by the organisation.

Most NGOs do not have mechanisms to inform and orient people who are willing to be involved on a voluntary basis in their activities, particularly their HIV-positive service users.

Failure to provide training and other skills development opportunities for PLHA

There is a tendency to provide people living with HIV with basic knowledge of HIV/AIDS but not with the technical skills necessary to deliver services, and even less with management skills. Health professionals may be also unconsciously reluctant to transfer their skills to people living with HIV and share their knowledge and their power.
In many cases, only a few individuals always the same ones are trained and sent to workshops and / or conferences.

**Lack of material benefits for people living with HIV involved, including medical benefits**

NGOs that employ people living with HIV as staff members do not always consider their specific needs such as flexible working hours if necessary, extended sick leave, and access to medical benefits.

NGOs that have people living with HIV working as volunteers do not always provide them with financial compensation for transport costs and meals during activities. Few NGOs offer access to care free of charge to their volunteers who are HIV positive and cannot afford to pay for medical expenses.

**NGO management may perceive the cost of involving people living with HIV to be high compared to financial resources available**

NGOs often mention lack of funds to reimburse travel expenses, to provide medical care and other forms of financial support.

**Lack of gender balance and/or sensitivity within NGOs may influence involvement of people living with HIV**

Women are less likely to be involved in organisations seen as male-dominated, or their involvement is limited to being volunteers.

Few NGOs have considered ways in which they could provide practical support to enable more HIV-positive women to be involved; for example, through provision of childcare facilities.

**Organisational stigma and secrecy**

Stigma associated with NGOs working on HIV/AIDS and organisations seen as people living with HIV organisations may deter involvement of people living with HIV who do not want to disclose their HIV status.

In order to avoid stigma, the HIV status of people living with HIV involved is confidential information shared by a limited number of people. It can have negative effect when it becomes a policy of secrecy as it prevents other HIV-positive people to meet their peers and follow their example by being active in the organisation.
Creating a supportive environment for the involvement of people living with HIV in NGOs
Module 4
Creating a supportive environment for the involvement of people living with HIV in NGOs

Contents and Summary of Key Messages

Introduction

Activity 4.1 Realising opportunities for the involvement of people living with HIV in NGOs
Activity 4.2 Understanding stigma
Activity 4.3 Exploring stigma and discrimination (attitudes and behaviours)
Activity 4.4 Exploring discriminatory policies
Activity 4.5 This can happen: the experience of stigma and discrimination
Activity 4.6 Understanding the links between discrimination and confidentiality
Activity 4.7 Understanding what information is confidential
Annex Case Studies
Activity 4.8 Enforcing the rules on confidentiality
Annex Written commitment to confidentiality
Activity 4.9 Psychosocial support for people living with HIV involved in the organisation (identification of needs)
Annex Case Studies
Activity 4.10 How to provide psychosocial support to people living with HIV involved in the organisation?
Activity 4.11 What is an HIV workplace policy?
Annex Example of an HIV workplace policy
Information Sheet 4.A Rights of people living with HIV
Module 4 presents all the concrete steps that an organisation needs to take in order to make Involvement of people living with HIV happen. It looks first at ways to mobilise PLHA. Afterwards the module describes how to build a supportive environment for people living with HIV to be involved, particularly through the development and implementation of a workplace policy on HIV/AIDS. The module includes activities to help the organisation overcome one of the major obstacles to Involvement of people living with HIV: stigma and discrimination towards people living with HIV inside and outside the NGO. It provides guidelines on how to manage confidentiality in the NGO so that people living with HIV are not discriminated against. The module also presents other components of a supportive workplace environment and policy: psychological support; care, including medical benefits; material support; and orientation and training.

**NGO staff and participants should be urged to consider the following key points of Module 4:**

- Realising opportunities for the involvement of people living with HIV in NGOs is not only about bringing people living with HIV together in support groups. There are various strategies that may be used depending on the area of involvement, the roles that people living with HIV are likely to play in the NGO and the levels of disclosure and visibility of their involvement.

- One of the major obstacles to Involvement of people living with HIV is stigma and discrimination in the community but also in the NGOs themselves. It is therefore very important to sensitize NGO management, staff and volunteers so that they understand what is discriminatory and stigmatising for people living with HIV and how to change their behaviour and attitudes.

- Confidentiality on information related to HIV is crucial to a supportive environment in NGOs as people living with HIV feel safer if they can disclose their HIV status knowing that this information will be kept confidential.

- Everybody in the NGO should know exactly what kind of HIV-related information is confidential or not.

- There should be organisational procedures in place for the protection of confidentiality. Everybody in the organisation should be aware of these procedures (including disciplinary procedures).

- Positive people may need psychosocial support because of the kind of work they do in the organisation, e.g. if they are involved in palliative care. The NGO should be able to provide this kind of support.
Appropriate orientation and training are crucial to the success of the involvement of positive people in the NGO.

Access to care and treatment is also essential to a sustainable involvement of positive people in an NGO, as otherwise people living with HIV may be often sick or even die prematurely.

When positive people are involved in NGOs on a voluntary basis, it is important to take into account their social situation and provide them with adequate material support if needed in order to ensure that their involvement can be sustainable.

The best way to ensure a supportive environment for people living with HIV in the organisation is to write all the policies related to this in a document called an HIV Workplace Policy. A written policy allows an easier dissemination of principles and rules to all the people working in the organisation. However a written policy does not prevent from organising on a regular basis training and sensitisation events on issues related to HIV in the workplace.
Introduction: Supportive Environment and HIV Workplace Policies

Creating a supportive organisational environment to enhance a greater involvement of people living with HIV in an NGO is a major step in the implementation of what has been planned by the organisation in terms of Involvement of people living with HIV. A supportive environment is about overcoming the internal and also external obstacles to involvement, using the existing organisational strengths and filling the gaps identified during the planning process.

A supportive organisational environment for a greater involvement of people living with HIV is made of the following components:

- Changing discriminatory behaviours and attitudes within the organisation;
- Ensuring a proper management of confidentiality on HIV-related information, including the definition of what kind of information should be confidential and what organisational procedures should be put in place for the protection of confidentiality;
- Making care and treatment accessible to PLHA, through a medical benefits policy for example;
- Providing adequate material support those people living with HIV involved on a voluntary basis in the activities of the NGO who need it;
- Providing adequate orientation and training to PLHA;
- Making psychological support accessible to PLHA.

The NGO can agree on a certain number of principles, guidelines and rules on these issues. These principles and rules should be included in a written document that is usually called an HIV Workplace policy and addresses all the issues related to the presence of positive people amongst the employees. This policy or set of policies is a useful tool in the promotion of GIPA. HIV workplace policies can be accompanied by other more specific documents such as a Medical Benefits Policy describing the rights and obligations of employees in terms of access to care and treatment with financial support from their organisation. In organisations where there is a large number of volunteers, the NGO can also produce ‘charters’ that list the rights and obligations of the people working with the organisation on a voluntary basis and without any contractual link.

Workplace policies that include principles, guidelines and rules related to HIV/AIDS do not have to be HIV-specific. They can be inclusive of other chronic illnesses and serious health conditions. It is up to each organisation to decide whether they prefer to have a specific HIV Workplace policy, the risk being to create resentment against people living with HIV amongst HIV negative staff members as the latter may feel that their HIV positive colleagues receive a better treatment and have more benefits than they do. However the disadvantage of a broad workplace policy may be that some characteristics specific to HIV,
such as stigma and discrimination towards HIV positive employees are not death with adequately.

Creating a supportive organisational environment to enhance a greater involvement of people living with HIV in an NGO is a task where every one can participate. However it is clearly the responsibility of the NGO management and other decision-making bodies, including the Board, catalyse and monitor the process.
Activity 4.1

Realising opportunities for the involvement of people living with HIV in NGOs

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify potential strategies to realise opportunities for the involvement of people living with HIV in the areas and roles (positions, jobs, etc.) they identified during the planning process.
- Make recommendations to NGO management about the best strategies to opportunities for the involvement of people living with HIV in the areas and roles (positions, jobs, etc.) they identified during the planning process.

Preparation for facilitators:

Prepare flip-charts summarising the different ways to realise opportunities for the involvement of people living with HIV in NGOs

Materials needed for the activity:

- Flip-charts summarising the different ways to realise opportunities for the involvement of people living with HIV in NGOs
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 10 minutes

Instructions & Methodology:

1. Explain to participants that this activity is the first step in the implementation process and present the following step: “Creating a supportive environment for the involvement of PLHA” with several components (list components).
2. Ask the following question: ‘What do you think are the various ways to realise opportunities for the involvement of people living with HIV in NGOs?
3. Facilitators should give a presentation about the different ways for NGOs to realise
opportunities for the involvement of people living with HIV using flip-charts prepared in advance:

- People living with HIV already involved in the organisation are empowered so that they can hold positions where the NGO has decided that a people living with HIV would make a difference.

- People living with HIV who are the beneficiaries of the services provided by the NGO are identified (based on their existing and potential skills) and empowered so that they can work with the organisation either as volunteers or staff.

- The NGO advertises positions stressing that candidates should be HIV positive, which implies that people who apply should be open about their HIV status.

- Some organisations invite positive people with relevant qualifications to apply and the disclosure of the HIV status is voluntary.

- NGOs can contact the people living with HIV groups or networks to recommend their members for the job opportunities they have.

- People living with HIV may contact the NGO because they would like to work with the organisation either as volunteers or staff.

- People living with HIV create their own organisations and networks.

4. Divide the participants in several small groups. Give each group a flip-chart with one of the areas of involvement and some of the potential roles for people living with HIV in this area previously identified by participants (activity 3.3). Ask them to discuss what would be the best strategy to realise opportunities for the involvement of people living with HIV for those roles/positions among the strategies presented by the facilitators. Participants should list the pros and cons of each strategy. Participants can be invited to come up with alternative strategies of they can think of any. (20 min)

5. Bring participants back together. Ask each group to present their work: the best strategy they have identified and why (the pros); why they think that the other strategies are less appropriate (the cons). Participants from other groups should be encouraged to discuss the pros and cons.

Facilitators' notes:

Facilitators should stress that realising opportunities for the involvement of people living with HIV in NGOs is not about bringing people living with HIV together in support groups. There are various strategies that may be used depending on the area of involvement, the roles that people living with HIV are likely to play in the NGO and the levels of disclosure and visibility of their involvement.
Activity 4.2  Understanding Stigma

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify which perceptions may be seen as stigmatising by people living with HIV and why.

Materials needed for the activity:

- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 45 minutes

Instructions & Methodology:

1. Give participants small pieces of paper.
2. Tell participants that they will be asked a question, their answers will be absolutely anonymous and that they should be very sincere about their thoughts or feelings. Ask them to think of the first words that come to their mind when they think of people with HIV and write them down, e.g. '(They are) victims'; '(They are) people like everybody else'; 'AIDS carriers', 'Sick'; 'Compassion'; 'Disgust'; 'Fear'; 'sinner'; 'skinny'; etc.
3. Put all the pieces of paper in a bag.
4. The facilitator should open the bag and stick the pieces of paper on flipcharts. Read the contents to all participants.
5. In plenary ask participants which perceptions (and words) may be seen as negative or pejorative by people living with HIV and why.

Facilitators' notes:

! Facilitators should be aware that words that do not seem pejorative may be perceived as such by people living with HIV, e.g. 'victims'.
Activity 4.3  
Exploring Stigma and Discrimination (behaviours and attitudes)

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:
- Identify attitudes, behaviours and policies within the NGO that can be stigmatising and discriminatory towards PLHA.

Materials needed for the activity:
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Stickies
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 40 minutes

Instructions & Methodology:

1. Intro: explain that addressing attitudes and behaviours that are stigmatising or discriminatory is part of creating a supportive environment for the involvement of people living with HIV in NGOs (5 min)

2. Ask participants to explain what they understand by stigma and discrimination. Give at least one example of S&D related to HIV (5 min)

3. Form small groups.

4. Participants will be asked to imagine that they are HIV positive. Give them stickies and ask them to write two behaviours/attitudes (e.g. something that somebody tells you, something that somebody does to you) that they would find stigmatising or discriminating in their organisation.

5. The facilitator collects post-its and sticks them on a chart. The facilitator reads them aloud. Ask participants what they think about this. Emphasise differences of perceptions of what is stigmatising or not (30 min)
Facilitators' notes:

- Facilitators should not give theoretical definitions of stigma and discrimination at the beginning of the session. Empirical definitions will come out of the discussions based on experience of participants.
- Alternatively, facilitators can conduct this activity only and drop the previous activity (4.2)
Activity 4.4
Exploring discriminatory policies

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:
- Identify policies within the NGO that can be stigmatising and discriminatory towards PLHA.

Materials needed for the activity:
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of green and red paper
- Stickies
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 40 minutes

Instructions & Methodology:
1. In the same small groups as in the previous activity (4.3) ask participants ‘Can you think of any policies within your organisation that are discriminatory whether discrimination is based on gender, caste, age? Which ones?’ Explain that sometimes policies are written but most of the time they are not written.

2. Ask participants ‘Now, can you think of policies in your organisation that are discriminatory based on the HIV status of people?’. If participants can’t think of anything, ask them ‘What about HIV testing and employment in your organisation?’ Afterwards ask participants ‘Can you think of other policies that could be discriminatory in terms of HIV status?’ (30 min.)

3. In plenary ask each group leader to summarise what they identified as discriminatory organisational policies (30 min).

4. Give each participant two small pieces of paper: a green one and a red one. Tell them that they will be asked questions during the following presentation. If their answer to the question is ‘Yes’ they should raise their green ‘card’, if their answer is ‘No’ they should raise the red ‘card’.

Alliance
Creating a supportive environment for the involvement of people living with HIV in NGOs
5. Ask participants: ‘Do you think that people living with HIV have specific rights?’ and ask them to raise one of the cards. Ask some participants to give the rationale for their answer. Ask: 'Do people living with HIV have the rights to confidentiality?'. Ask some participants to give the rationale for their answer. Ask: 'Do you think that people living with HIV are denied some of their rights?'. Ask which ones and give participants the Information Sheet on the protection of the rights of people living with HIV and comment. Ask them if they know laws that discriminate against people living with HIV? Ask them if they know laws that protect the rights of people living with HIV?

6. Discuss how the social context (at national and state level) can influence policies and behaviours within the organisation. (40 min.)

**Facilitators' notes:**

! When using Information Sheet on the protection of the rights of PLHA the facilitators should ask participants if they can think of examples for each one of the rights mentioned.
Activity 4.5

This can happen (the experience of Stigma and Discrimination)

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify emotional consequences of stigma towards people living with HIV.

Preparation for facilitators:

- Prepare small pieces of paper with either 'HIV positive' or 'HIV+', 'HIV negative' or 'HIV-'; 'HIV status unknown' or 'HIV?' written on them. There should be as many pieces of paper as there are participants. The proportion should be more or less as follows: ¼ with the 'HIV positive' sign, ¼ with the 'HIV negative' sign and ½ of pieces of paper with the 'HIV status unknown' sign.

- Prepare small pieces of Sticky tape, Blu-Tack or Sticky Stuff that will be used to stick the pieces of paper on the backs of participants.

Materials needed for the activity:

- Small pieces of paper with either 'HIV positive' or 'HIV+', 'HIV negative' or 'HIV-'; 'HIV status unknown' or 'HIV?' written on them. There should be as many pieces of paper as there are participants.

- Sticky tape, Blu-Tack or Sticky Stuff that will be used to stick the pieces of paper on the backs of participants.

Estimated time needed for the activity: Approximately 45 minutes

Instructions & Methodology:

1. Ask participants to stand side by side in a circle and to close their eyes.

2. Co-facilitators should stick on the back of each participant a sign that says either 'HIV positive' or 'HIV+', 'HIV negative' or 'HIV-'; 'HIV status unknown' or 'HIV?'. The facilitator who gives instructions has to explain what the co-facilitators are doing. (5 min)

3. Participants do not know what sign they wear and are not allowed to tell other participants what is written on their back.
4. Ask all participants to move around in the room and read what is written on other people’s backs without saying anything.

5. Ask participants how they feel at this stage.

6. Ask participants to try to avoid those who wear the HIV positive sign while they keep moving around in the room.

7. Ask them to do other things that were identified as stigmatising in the previous activities.

8. Ask participants who think they wear the HIV positive sign to stand up in the centre of the room. Ask them why they think that they wear the HIV positive sign and how they feel.

9. Ask the other participants how it feels to stigmatise this group of people.

10. Ask them whether at this stage they already know what sign they are wearing: ‘HIV negative’ or ‘HIV status unknown’. Ask them how it feels.

11. The co-facilitators take the participants who wear the sign ‘HIV?’ together with the group ‘HIV +’ already in the centre of the room. Ask them to form another group in the centre of the room, next to the group of ‘HIV positive’ people. Ask them how they feel being in this group. Do they feel different from their colleagues with the ‘HIV positive’ sign? Why?

12. Take participants who wear the HIV positive sign and are still in the outside circle in the centre, tell them that they actually wear the HIV positive sign and ask them why they did not go to the centre when participants who thought they were wearing the ‘HIV+’ sign were asked to stand in the centre of the room.

13. Explain that this exercise shows how difficult it is to feel stigmatised or even to stigmatise even this was fiction. It also shows that perceptions of stigma are very subjective. This can happen in real life (5 min).

14. Ask all participants to form a single circle again and hold hands so that they feel they belong to the same group again. Facilitators can also organise a brief exercise to relax participants such as deep breathing.
Facilitators' notes:

Facilitators do not have to include all the activities related to Stigma and Discrimination suggested in this handbook in their training. However, it is important to note that this activity is not just another way to discuss stigma. It is particularly important for people to understand 'physically' as well as psychologically how it feels to be stigmatised and to stigmatise.

Facilitators should make sure that small pieces of paper are securely stuck in the back of the participants and that they won't fall down during the exercise.

This activity can be extremely stressful for many participants. It is important for facilitators to handle it with tact and allow participants to express their feelings during the whole activity and at the end of the activity.

The activity should always be facilitated by at least two people as it is easier for two people to manage the group.

Participants may laugh at the beginning of the activity. It is usually a way to deal with their stress. Facilitators should let participants release their tension but they should ask participants to concentrate on their feelings.

Facilitators should not present the activity as a 'game' as this activity creates a lot of stress among participants and they may feel that the word 'game' is not appropriate or even pejorative for an activity that causes strong emotions and feelings.

Facilitators should give instructions and ask questions in a 'neutral' tone, i.e. without making the activity sound too serious (it is not therapy) but without laughing either as it is not a game (see above).

Because of the strong emotions it generates in most participants, it should never be conducted at the end of the training day because participants will not be able to 'digest' the stress. It is recommended to carry out this activity just before or after lunch-break. It can be followed by a good energiser.
Activity 4.6  
Understanding the links between discrimination and confidentiality

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Explain the link between stigma and discrimination, and confidentiality

Materials needed for the activity:

- Envelopes
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 30 minutes

Instructions & Methodology:

1. Divide participants in small groups. Give them a pen and a piece of paper, ask each person to think of something very personal, that they wouldn't want anyone to know about them (like a secret).

2. Ask each person to write/draw this on the piece of paper stressing that it will not be seen by anybody else. Ask participants to fold it up so that no one can see it and to put it in an envelope.

3. Ask participants to pass their envelope to the person on their left who must not open the envelope. At this stage, the facilitator may need to reassure participants and insist that envelope should not be opened.

4. Each group discusses the following questions:
   - How does it make you feel that someone is holding this information? Why?
   - How would you feel if they opened up your piece of paper & came to know something about you that you don't want them to know? Why?
   - How do you think they would treat you as a result?
   - How would you react if they stigmatized you and discriminated against you?
How do you feel holding someone else’s piece of paper? Why?

5. Ask everyone to give the envelopes unseen back to their colleague.

6. Based on group discussions stress that we should always remind ourselves of how we would feel if personal information were disclosed. We need to be cautious with information that others share with us and that we share with others. Introduce the concept of ‘confidentiality’ and ‘confidential’. Ask participants what it means.

7. Make transition with the following activity where participants will discuss how to manage confidential information related to HIV.

Facilitators' notes:

- This activity can be stressful for some participants. It is important for facilitators to handle it with tact and allow participants to express their feelings during the whole activity and at the end of the activity.

- Facilitators should give instructions and ask questions in a 'neutral' tone, i.e. without making the activity sound too serious (it is not therapy) but without laughing either as it is not a game.
**Activity 4.7**

**Understanding what information is confidential**

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**Participants - NGO management, staff and volunteers**

**Objectives** - Participants will be able to:

- Identify what kind of information related to HIV should not be shared with other people within the NGO.

**Preparation for facilitators:**

- Read the case studies (see annex) very carefully and choose those they want to use during the activity.
- Prepare three A4 signs: 'Disagree', 'Not sure', and 'Agree'

**Materials needed for the activity:**

- Photocopy of case studies for facilitators
- Three A4 signs: 'Disagree', 'Not sure', and 'Agree'
- Large sheets of blank paper (flip-chart or manila paper)
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

**Estimated time needed for the activity:** Approximately 1 hour 30 minutes

**Instructions & Methodology:**

1. Ask participants what they understand by “confidentiality “and/or “confidential”. (5 min)
2. Tell participants that this exercise is about understanding exactly what should be kept confidential or not regarding HIV in the NGO.
3. Tell participants that the facilitator is going to read several case studies that present situations where a person discloses information on a colleague who is or might be HIV positive to other people in the workplace. For each situation, participants will have to decide whether they think that the person has breached confidentiality. Identify three areas of the room which can be labelled 'disagree', 'not sure', and 'agree'. (10 min)
4. After reading each case study, ask participants to move to one of the 3 areas according to what they think. Ask participants from each group why they have made this choice. Allow enough time for discussions between participants who made different choices.

5. After each discussion give the right answer to participants and explain why there was a breach in confidentiality or not. Summarise what kind of information is confidential or not when it comes to HIV/AIDS.

**Definition of HIV-related information that must be kept confidential**

It includes information that someone:

- Has HIV/AIDS or may have HIV/AIDS;
- Has chosen to have an HIV test or have been counselled about having a test for HIV;
- Is receiving or has received treatment or counselling which suggests he or she may have HIV/AIDS;
- May have had experiences which put him or her at risk of contracting HIV; or
- Has a close association or relationship with someone with HIV

Based on Developing HIV/Workplace and Medical Benefits policies with partners in Cambodia, Burkina Faso and Senegal. Draft Summary 2003. International HIV/AIDS Alliance

**Facilitators' notes:**

! Some participants will have a hard time accepting the broad definition of what kind of HIV-related information must be kept confidential. Facilitators should be able to explain clearly for what reasons this information is confidential and what the negative consequences of disclosure may be.

! Facilitators should stress that very often in the workplace people breach confidentiality on HIV-related information because they want to help a colleague and not because they want to harm this person. However they are not always able to assess the negative consequences of disclosing such information for the person and his/her family.

! Facilitators should stress that the bottom line for the respect of confidentiality is to ask the person who is subject of the information whether they agree to disclose HIV-related information, or to keep quiet in the case this person disagrees.

! Facilitators should read the case studies very carefully before the exercise so that they do not get confused when they read them aloud to the participants.
Case Studies

1. **Meena** is the administrative assistant to the director of the Human Resources Department in a private company. One day, she opens the mail and finds a medical certificate for **Sanjit**, one of her colleagues. The medical certificate explains that **Sanjit** will have to take days off frequently because of repeated lab exams and treatment. **Meena** knows **Sanjit** quite well and she is really upset. She feels she needs to talk to somebody to open her heart. She has lunch with **Arun**, an accountant in the same company and a close friend of hers. **Meena** tells **Arun** “I just found out that **Sanjit** is very sick. He has lost so much weight lately. He is taking a treatment. You know, I am sure it's AIDS. This is so sad”. Did **Meena** breach confidentiality? **Answer**: Yes, **Meena** breached confidentiality. Participants should choose the ‘Agree’ sign.

2. **Anjali** is an employee in an NGO. She is pregnant and after a test she finds out that she is HIV positive. She is really depressed and she is on sick leave for a few weeks. She asks a colleague she knows well, **Suchitra** to come to see her. **Anjali** explains to **Suchitra** what the situation is. **Suchitra** tells **Anjali** that it would be better to talk to the director of the NGO in order to avoid problems and find work arrangements that could be more suitable to **Anjali**. **Anjali** thinks it would be a good idea to talk to the director. **Suchitra** makes an appointment with the director and tells him that **Anjali** is off sick leave because she found out that she is HIV positive. Did **Suchitra** breach confidentiality? **Answer**: **Suchitra** breached confidentiality if **Anjali** did not give her formally the authorisation to talk to the director. However she did not breach confidentiality if **Anjali** asked her to go and meet the director on her behalf. The case study is not clear (on purpose) and participants should choose the ‘Not sure’ sign.

3. **Rahul** is 30, he is a civil servant in the Ministry of health. He suddenly dies. **Rohit**, the head of the department where **Rahul** was working is upset and decides to gather the colleagues for a Memorial service after the funeral. **Rohit** tells his colleagues. “**Rahul** is a great loss for our department. He was extremely bright and a very committed civil servant. I didn't want to tell you anything before he died, but **Rahul** actually died of AIDS. I don't want other young people like H to die like that, he should be an example for us and we should protect ourselves and other people.” Did **Rohit** breach confidentiality? **Answer**: Yes, **Rohit** breached confidentiality because the death of a person...
does not mean that people can share confidential information about this person. Sharing confidential information about a person can have negative consequences on the family and loved ones of this person. Participants should choose the 'Agree' sign.

4. **Ashok** is working for a big NGO. He is providing technical support to other organisations who are trying to scale up VCT in the country (give the name of a local organisation that people know). Once, late in the afternoon, he goes to a meeting with members of an organisation who is running a VCT centre. He sees **Arjun**, one of his colleagues, who is in the waiting room where people expect the result of their test. The day after, he goes back to the office and tells **Ujwala**, another colleague: “Guess who I saw yesterday taking an HIV test? **Arjun**. Well actually, I am not too surprised, given the drug-addiction problem he has been having, it’s quite normal he wants to know if he is HIV positive or not.” Did **Ashok** breach confidentiality? **Answer:** Yes, **Ashok** breached confidentiality because breaching confidentiality is not only telling other people that this person is HIV positive, it is also implying that this person may be HIV positive because of her/his behaviour. Participants should choose the 'Agree' sign.
Activity 4.8  Enforcing rules on confidentiality

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify what policies may be put in place to protect confidentiality in their organisation.

Preparation for facilitators:

- Make photocopies of the “Commitment to Confidentiality” (Annex to this activity) for all participants.

Materials needed for the activity:

- Photocopies of the “Commitment to Confidentiality” (Annex to this activity)
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 30 min

Instructions & Methodology:

1. Divide participants in small groups (up to 6-7 participants in each group). Ask them to brainstorm on which rules/policies should be put in place in the organisation so that confidentiality on HIV-related information is protected (20 min).

2. Give photocopies of the “Commitment to Confidentiality” to all participants. Ask them to read it aloud and discuss the following issues:
   - Advantages and disadvantages of this kind of document;
   - Feasibility of using this type of document in the NGO;
   - Amendments to be made to the document.
   (30 min)

3. Bring participants back together and ask representatives from each group to summarise what their group thinks about the document and the possible changes they would suggest to this kind of document (40 min)

4. Conclude by explaining the advantages of written rules on confidentiality.
Commitment to Confidentiality

1. I have read and understand the organisation’s HIV/AIDS Workplace Policy.

2. I recognise that through my employment or association with the organisation I may learn HIV-related information of a highly personal and confidential nature.

3. I understand that such information includes information that someone
   - Has or may have HIV/AIDS;
   - Has been asked to have an HIV test or been counselled about having a test for HIV;
   - Is receiving or has received treatment or counselling which suggests he or she may have HIV/AIDS;
   - May have had experiences which put him or her at risk of contracting HIV; or
   - Has a close association or relationship with someone with HIV.

4. I will only disclose such information with the consent of the subject of the information.

5. I understand that breach of this agreement may result in disciplinary action, and depending on the law, possible legal proceedings against myself or the organisation.

Signed: __________________________ Date: __________________________
Activity 4.9
Psychological support for people living with HIV involved in the organisation (identification of needs)

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Explain the reasons why psychological support may be needed by people living with HIV involved in the NGO.

Preparation for facilitators:

- Read case studies carefully (see annex) and prepare additional case studies if needed.
- Prepare flip-charts with one case study written on each flip-chart + series of questions.

Materials needed for the activity:

- Series of flip-charts with one case study written on each flip-chart + a series of questions.
- Large sheets of blank paper (flip-chart or manila paper)
- Small pieces of blank or coloured paper
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 1 hour 30 minutes

Instructions & Methodology:

1. Introduction by facilitators: Remind participants that providing psychological support to people living with HIV involved in NGOs is another component of what is called a 'supportive component'. Explain that PLHA involved in NGOs may need psychological support for 2 main reasons (10 min.):

- There are needs related to the fact that living with a chronic illness stigmatised by society is not easy. Any person in this situation may need psychological support.
- For PLHA involved in NGOs working on HIV/AIDS, there are also some needs related to the kind of work they do in the organisation, the situations they are exposed to due to their involvement. During this activity, participants will explore the second category of needs.
2. Form small groups. Give each small group a flip-chart or a card with a case study written on it and a series of questions. Ask all participants from the same small group to imagine that they are in the situation described on the flip-chart. They should try to answer the questions written on the chart.
   - e.g. An HIV positive counsellor might find it difficult to listen to the stories of other PLHA who are the same age as their and who are very sick because it makes them think of their own situation, and sometimes they get really worried about their health, etc.
   - e.g. HIV positive women doing outreach education may find it difficult to deal with the comments of some people who tell them that they are prostitutes/immoral because they got infected.

3. After they answer the first set of questions, ask participants whether these problems would be the same for men and women. (30 min.):

4. Bring participants back together and ask them to list the difficulties specific to the job described in the case study, which were identified during the discussion (30 min)

5. Facilitators should ask participants to compare psychological difficulties for the different roles described in the case studies and identify what is specific to certain roles and what is common to all the roles. Conclude by summarising what psychological difficulties related to their participation may be common to PLHA involved in NGOs working on HIV/AIDS and stressing that some difficulties are specific to certain types of work. It is also important to stress that in some jobs all people need support, whether they are HIV + or not, e.g. all counsellors need support and supervision (20 min.)

6. Facilitators should make the transition with the following activity on how to respond to psychological difficulties that PLHA involved in NGOs may face.
**Annex: Activity 4.9**

**Case studies**

1. Imagine that you are an HIV positive person providing counselling to other people living with HIV in a VCT centre run by an NGO.
   
   **Questions:** What would be difficult for you psychologically? Would there be things in your work that would be more difficult psychologically than for a HIV negative counsellor? What kinds of things? Why?

2. Imagine that you are an HIV positive person doing outreach education with an NGO. You go to schools, private companies, government offices and you talk openly about your experience as a PLHA.
   
   **Questions:** What would be difficult for you psychologically? Why?

3. Imagine that you are an HIV positive NGO volunteer visiting other people living with HIV who are ill at the hospital and at home.
   
   **Questions:** What would be difficult for you psychologically? Would there be things in your work that would be more difficult psychologically than for a HIV negative NGO volunteer? What kinds of things? Why?

4. Imagine that you are the HIV positive director of an AIDS organisation. You haven’t disclosed your HIV status to anybody inside and outside the NGO. Your organisation has a very high profile in India and you participate in many meetings at State and national level.
   
   **Questions:** What would be difficult for you psychologically? Why?

5. Imagine that you are a medical doctor living with HIV. You are working with a large NGO specialised in care for PLHA. Only some of your colleagues know that you are HIV positive but you never talk about your HIV status to your patients.
   
   **Questions:** What would be difficult for you psychologically and would there be things in your work that would be more difficult psychologically than for a HIV negative doctor? What kinds of things? Why?
Activity 4.10  
How to provide psychological support to people living with HIV involved in the organisation

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

- Identify ways to meet the needs for psychological support identified during the previous activity.

Preparation for facilitators:

- Prepare a flip-chart entitled ‘Psychological support available inside & outside the NGO with a circle in the centre that says 'NGO'
- Prepare for each group a series of post-its with categories of psychological support written on them

Materials needed for the activity:

- Flip-chart titled ‘Psychological support available inside & outside the NGO with a circle in the centre that says 'NGO'
- Post-its with categories of psychological support written on them
- Thick pens
- Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 50 minutes

Instructions & Methodology:

1. Divide participants in small groups.
2. Give each group a flip chart titled ‘psychological support available inside & outside NGO’ with a circle in the centre that says 'NGO' + post its with categories of psychological support: peer support group, professional, peer counselling, etc. (10 min)
3. Ask participants to stick the post-its on the flipchart inside or outside the NGO describing where support is available when it is outside the NGO (e.g. hospital, name of another NGO, etc. (20 min)
5. Ask participants to look at overall picture where are the gaps, where? Is there a referral system? (10 min)

**Facilitators' notes:**

Facilitators should stress that there is not one category of psychological support that is better than other. Each category has advantages and disadvantages. The choice depends on individuals and what they need at a particular time. Some people may not feel comfortable in groups and will prefer one-to-one counselling. Other people may need to see a psychologist first and afterwards may feel like sharing their experience with other people in the same situation.

Example of workshop participants' outputs from the activity 'How to provide psychological support' (adapted from a workshop conducted with Alliance India partners in Trivandrum in 2004)
Activity 4.11 What is an HIV workplace policy?

Participants - NGO management, staff and volunteers

Objectives - Participants will be able to:

• Identify the main elements that should be included in a HIV workplace policy for the NGO

Preparation for facilitators:

• Make photocopies of an example of HIV workplace policy for NGOs (Annex to this activity)

Materials needed for the activity:

• Photocopies of an example of HIV workplace policy for NGOs (Annex to the activity)
• Copies of existing workplace policies in the participating NGOs if available
• Large sheets of blank paper (flip-chart or manila paper)
• Thick pens
• Sticky tape, Blu-Tack or Sticky Stuff

Estimated time needed for the activity: Approximately 2 hours

Instructions & Methodology:

Option 1

1. If the NGO already has an HIV workplace policy go to Option 2.

2. In plenary explain to participants that they are going to discuss what could be included in an HIV workplace policy if their organisation decided to have one. Explain that a policy is made up of several sections (use the chart to explain the sections) and items under each section. Each small group will be given the headings of a couple of sections and will have to discuss what contents could be included in these sections. Stress that at this stage participants are not requested to write the policy and they only have to discuss the contents in broad lines. Give a couple of examples to make sure that participants understand the task. E.g. Under “HIV screening, recruitment and
employment” one of the items could be that no mandatory HIV screening should be requested by the NGO; under “reasonable accommodation” one of the items could be that PLHA working for the NGO can have flexible hours for medical appointments. Stress that it is not a problem if participants cannot think of anything for some of the sections suggested by the facilitators. (15 min)

3. Divide participants in small groups and give them a few headings each (30 min).

4. Ask each group to choose one section they would like to explore in more details in plenary.

5. Bring participants back together and ask each group to present their work. Allow some time for questions by participants from other groups (45 min).

6. Give participants photocopies of the example of HIV Workplace policy (annex) and comment the sections they said they would like to explore in more details by giving concrete examples (30 min)

Example of distribution of the sections included in the HIV Workplace Policy

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Group 4</th>
<th>Group 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV screening, recruitment and employment</td>
<td>Confidentiality</td>
<td>Occupational or other exposure</td>
<td>HIV prevention</td>
<td>Reasonable accommodation</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>Duty travel and vaccination</td>
<td>Gender dimensions</td>
<td>Information and training</td>
<td>Counselling, grievance and disciplinary procedures</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Termination of employment</td>
</tr>
</tbody>
</table>
Option 2

1. If the NGO already has a general workplace policy, make sure to have copies for the workshop. Give participants copies of the policy. Divide them in small groups.

2. Ask them to analyse how they could incorporate HIV-related issues into the policy.

3. Bring participants back together and ask each group to present their work. Allow some time for questions by participants from other groups.

4. Give participants photocopies of the Alliance HIV workplace policy. Read the document in plenary and ask participants what they think of the example at different levels:
   - Relevance to the organisation
   - Feasibility for implementation
   - Gaps

Reactions of participants should be carefully written down by one of the facilitators so that the NGO can use this material if the NGO management decides to develop the HIV workplace policy after the workshop.

Facilitators’ notes:

! Facilitators should emphasise that participants are not requested to write an HIV workplace policy for their organisation during this exercise, although the outcomes of the discussions could be used if and when the NGO management decides to develop an HIV workplace policy for the organisation.

! Facilitators should stress that the document given to participants is only an example based on international best practice but it is up to each NGO to decide what should go in their HIV workplace policy.
Annex: Activity 4.11

Example of an HIV/AIDS Workplace Policy

Contents

Statement of Duty
Commitments
1. Objectives
2. Definitions
3. Responsibility for Implementation
4. HIV screening, recruitment and employment
5. Confidentiality
6. Duty travel and vaccination
7. HIV prevention
8. Occupational or other exposure
9. Information and training
10. Stigma and discrimination
11. Reasonable accommodation
12. Termination of employment
13. Gender dimensions
14. Counselling, grievance and disciplinary procedures
15. Revision
16. Commencement
**Statement of Duty**

As an organisation working in the field of HIV/AIDS prevention and control, we often tend to be outward oriented. Duty bound to provide our services to others. To date, we have focused on the expertise and actions required by partners, those affected and infected.

However, we are reminded everyday that HIV/AIDS is non-discriminating. We are not only service providers, but also directly and individually affected.

We are duty bound to practice compassion and tolerance towards all people with HIV, including our colleagues. These workplace and medical policies aspire to provide a framework for recognising the existence of HIV/AIDS in our midst as well as for providing mechanisms for providing prevention, care and support to ourselves and our colleagues.

In subscribing to these policies, we are also committing ourselves to living a healthy lifestyle, which includes good health practices and good health-seeking behaviour. The HIV/AIDS in the workplace and medical benefits policies are developed on the premise that we do not knowingly put ourselves at risk, and that we seek appropriate care and support of acceptable quality.

**Commitments**

- The organisation shall be fully committed to providing a supportive working environment for dealing with HIV in the workplace.
- The organisation shall not discriminate against staff on the basis of their HIV/AIDS status with specific regard to training, promotions and staff retention.
- The organisation shall have a zero tolerance approach towards verbal, physical, emotional or psychological abuse and discrimination of HIV positive persons by or from co-staff and management.
- The organisation shall ensure and foster a high sense of team spirit and support for HIV/AIDS infected and affected persons.
- The organisation views confidentiality as imperative when dealing with HIV and shall therefore ensure that confidentiality about HIV/AIDS status is not infringed upon. Mechanisms shall therefore be put in place to ensure that:
  - All medical and other HIV/AIDS-related information is kept confidential.
  - Shared confidentiality is respected.
  - Any other relevant personal information is not revealed without the consent of the HIV infected or affected person.
- The organisation shall not endorse/require mandatory HIV testing for whatever purposes from staff or would be staff.
- The organisation shall undertake to treat HIV infection and AIDS as any other chronic illness.
1. Objectives

The organisation HIV/AIDS Workplace Policy has the following objectives:

1) To prevent HIV infection in the organisation staff and their dependants.
2) To assure a supportive work environment for staff infected and affected by HIV/AIDS.
3) To manage and mitigate the impact of HIV/AIDS on the work of the organisation.
4) To eliminate stigma and discrimination in the workplace on the basis of real or perceived HIV status, or vulnerability to HIV infection.

Should any of the policies outlined in this document be in conflict with national law, then in every instance national law will take precedence.

2. Definitions

'Staff' includes full-time and part-time staff with contracts of employment with the organisation

'Dependent' includes both adult & child dependants meaning:

- 'Adult' is a person aged 18 years or older.
- 'Adult dependent' includes a person who is either
  - staff member's spouse
  - staff member's parent or spouse's parent who lives with the staff member and is dependent

'Child dependent' includes both

- staff member's child under the age of eighteen
- staff member's child under the age of twenty if still in school

'HIV-related information' includes information that someone:
3. **Responsibility for implementation**

3.1 The Executive Director, through the HIV/AIDS Workplace Team has responsibility for the implementation of this policy.

4. **HIV screening, recruitment and employment**

4.1. The only medical criterion for recruitment is fitness to work. HIV infection does not, in itself, constitute a lack of fitness to work.

4.2. There is no obligation on applicants or staff to inform the organisation of their HIV status.

4.3. HIV screening will not be required either as a condition of recruitment or for continuation of employment, unless required by law (e.g. for duty travel).

5. **Confidentiality**

5.1. The organisation encourages a supportive work environment in which staff can discuss HIV/AIDS openly, including their own experience living with HIV. Where staff members disclose that they or their dependents are living with HIV, the confidence will be respected with regard to the circumstances in which the information was shared. If there is any doubt, the person living with HIV should be consulted before further disclosure takes place.

5.2. HIV-related information relating to applicants for employment, staff or dependants will be kept strictly confidential, and be kept only on medical files.

5.3. Staff and volunteers working for the organisation shall sign a commitment to
confidentiality, and shall be informed that the unauthorised disclosure of HIV-related information is a disciplinary offence, that may result in a grievance procedure as per the organisation's personnel policies. Depending on the situation, it may also lead to legal proceedings against the person who disclosed the information, and the organisation.

5.4. With the voluntary and informed consent of the person concerned, HIV-related information may be disclosed strictly as necessary for the purposes of recruitment or assignment of staff living with HIV where the job description or task identifies this qualification.

6. **Duty travel and vaccination**

6.1. For duty travel to a country which requires HIV screening for entry or residence, this requirement will be made known to staff in advance of duty travel. In such cases, the staff member with HIV may choose not to travel to the country concerned.

6.2. Where HIV screening is chosen, the organisation will make available pre and post-test counselling, if it is not otherwise available free of charge.

6.3. If a staff member is unable to take up an assignment in a particular country because of that country's HIV-related requirements, depending on the situation, the organisation will take reasonable steps to find an alternative assignment.

6.4. Proof of vaccination (e.g. yellow fever) may be required for travel to some countries. In such cases, the organisation will advise staff and ensure that they have the opportunity to seek confidential medical advice on the advisability of vaccination according to their health status and to seek an exemption from vaccination.

7. **HIV prevention**

7.1. The organisation will provide staff with sensitive, accurate and up-to-date information to enable them to protect themselves from HIV and other sexually transmitted or blood-borne infections.

7.2. The organisation will provide information to staff as to where safe blood can be obtained.

7.3. The organisation will also provide information on where sterile needles and syringes can be obtained.

7.4. The organisation will ensure all the organisation vehicles are fully fitted with seat belts. Where available, seat belts must be worn by all staff when travelling on duty. The organisation will also ensure that all the organisation vehicles are regularly and properly serviced and maintained.
7.5. Helmets must be worn by the organisation staff when travelling on duty by motorcycle. Helmets shall be made available for staff travelling on duty by motorcycle.

7.6. Access to good quality condoms (male & female) shall be made available to staff. Access will be free, simple and discreet.

7.7. Access to free, voluntary and confidential HIV testing and counselling shall be made available to staff and costs reimbursed as per the medical benefits policy.

7.8. Access to free, STI diagnosis and treatment shall be made available to staff and costs reimbursed as per the medical benefits policy.

8. **Occupational or other exposure**

8.1. In the case of accidents involving the risk of exposure to human blood, universal precautions shall be used to ensure there is no risk of transmission of HIV or other blood borne infections.

8.2. The organisation shall develop procedures for the immediate referral for counselling, assessment and medical treatment (with post-exposure prophylaxis, where appropriate) staff exposed to the risk of HIV infection (e.g. through accident or sexual assault), whether in the work place or elsewhere.

8.3. Reasonable paid time off will be provided for counselling following occupational or other exposure.

8.4. The organisation shall provide insurance cover for work-related accidents and injuries for all staff.

9. **Information and training**

9.1. The organisation will provide information and training on the workplace issues raised by the epidemic, on appropriate responses, and on the general needs of people living with HIV and their carers.

9.2. Such information and training will be gender sensitive, as well as sensitive to disability, and sexual orientation.

9.3. Information will include the availability of local support organisations for people living with HIV, and other affected communities.

9.4. Staff training on HIV/AIDS will take place during paid working hours and attendance by all staff including senior staff shall be considered as part of work obligations.

10. **Stigma and discrimination**

10.1. The organisation will not discriminate on the basis of actual or perceived HIV
status, or membership of a group at increased risk of HIV infection, in the conditions of work, including opportunities for advancement.

10.2. Staff living with HIV, shall be treated no less favourably than staff with other serious illnesses.

10.3. The organisation will undertake activities to address HIV and related stigma in the workplace, including through staff training and the promotion of an open, accepting and supportive work environment for staff who chose to disclose their HIV status.

11. Reasonable accommodation

11.1. The organisation may reasonably accommodate the special needs of staff living with, or directly affected by, HIV/AIDS on a case-by-case basis, subject to the overall requirements of the organisation.

11.2. Depending on the situation, reasonable accommodation may include flexible working hours and time off for counselling and medical appointments, extended sick leave, transfer to lighter duties, part-time work, and return-to-work arrangements.

12. Termination of employment

12.1. HIV infection is not a cause for termination of employment. Staff with HIV-related illness will continue in employment as long as they are otherwise fit for available, appropriate work.

12.2. In the case of termination of employment due to extended illness, staff with HIV will be accorded the same benefits and conditions as apply to termination due to other serious illnesses.

13. Gender dimensions

13.1. The organisation acknowledges that HIV/AIDS impacts on male and female staff differently. This includes the recognition that women normally undertake the major part of caring for those with AIDS-related illnesses, and that pregnant woman with HIV have additional special needs.

13.2. Any staff and family assistance arrangements will be designed to accommodate these differing impacts, and as appropriate to redress gender inequalities, for example by encouraging and supporting men as carers.

14. Counselling, grievance and disciplinary procedures

14.1. The organisation will identify a qualified counsellor from whom staff can seek confidential advice, counselling and referral on HIV-related matters. Information
will also be provided on where such advice, counselling and referral can be found.

14.2. Staff can use grievance procedures from the organisation's personnel policies for work-related grievances, including failure by the organisation to implement any aspect of this policy.

14.3. Disciplinary proceedings, as per the organisation's personnel policy, may be commenced against any staff member who violates this policy.

15. Revision

15.1. The Executive Director, with the support of the HIV/AIDS Workplace Team, shall review this policy periodically, and revise it as necessary in consultation with the Board.

16. Commencement

This policy applies from the date that the Board formally adopts the policy.
In India, all persons have certain basic rights guaranteed by the Constitution. These “fundamental rights” include the Right to Life and Personal Liberty, the Right to Equality and Non-Discrimination, and the Right to Health and Education. Besides the Constitution, statutes too provide rights. For example, the right to receive equal pay for equal amount of work done is afforded under the Equal Remuneration Act. In addition, certain rights are recognized under common law or judge made law. The right to privacy and confidentiality is one such right. Theoretically, rights are available to all people, including people living with HIV.

In reality however, people with HIV are often denied their entitlements because of the fear, stigma and prejudice that surrounds the epidemic. Some common sites of infringement of rights of people living with HIV are hospitals, workplace and educational institutions. Here’s an overview of rights and protections available to people living with HIV:

**Right to bodily autonomy**

Every person of sound mind has a right to determine what should be done to her/his body. This principle encapsulates the right of a person not to be subjected to medical procedures including HIV testing without her/his informed consent. According to the National AIDS Control Organisation (NACO) guidelines, HIV testing must be preceded by pre-test and followed by post-test counselling. Testing without informed consent including before surgery, recruitment in a job or admission in an educational institution contravenes an individual’s right to autonomy.

**Right to confidentiality**

A person’s HIV status is private information, which cannot be revealed publicly and without her/his consent. People living with HIV have a right to have their HIV status kept confidential especially in relationships based on trust, such as, doctor patient and counsellor-client. Disclosure however, can be made, if required by law or to protect an identifiable person’s life.

**Right to health**

Denial of medical services to people living with HIV on grounds of their HIV status constitutes a violation of their fundamental right to health. While state health care institutions are obliged to provide medical treatment to all persons without

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*Lawyer’s Collective HIV/AIDS Unit, India*
discrimination, private hospitals are obligated to treat patients only in emergency situations and till the patient can get other medial assistance.

**Right to employment**

People living with HIV cannot be denied a job solely on the ground of their HIV status. **People living with HIV have a right to be considered for employment and be employed** if they are qualified, are fit to perform that job and do not pose a risk of transmission to others in the workplace. Termination from the job merely on the basis of an employee's HIV positive status is also prohibited.

People living with HIV who are medically incapacitated to fulfil the present job or pose a significant risk to other persons in employment can **seek accommodation in another job**, commensurate with their skills so long as that does not pose undue financial or administrative hardship to the employer.

**Right to Education**

There have been instances of schools refusing admissions to children living with HIV. This **constitutes an infringement of the right to equality and non-discrimination, in addition to the right to receive education.**

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**Legislation protecting rights of PLHA**

Existing legal protections against discrimination and rights violations faced by people living with HIV are inadequate. Standards for Consent and confidentiality are subject to vagaries of the common law regime. Constitutional provisions against HIV related discrimination do not apply to private entities. To fill this lacunae and ensure protection of rights of people living with HIV universally, the National AIDS control organization has committed itself to enacting a comprehensive HIV/AIDS legislation. Lawyers Collective HIV/AIDS Unit, a legal group working on Human rights in the context of HIV/AIDS, is working on draft legislation. The bill has undergone an extensive process of consultation and scrutiny by stakeholders. Some of the key measures being proposed in the draft bill include procedures for testing with informed consent, maintenance of confidentiality and permissibility of disclosure of HIV status and prohibition of discrimination in state and private institutions. The draft is likely to be submitted to Parliament before the end of the year.
Case Study

Everyone has the right to work, to free choice of employment, to just and favourable conditions of work, and to protection from unemployment: **Bombay court upholds employment rights of PLHA**

On 16 January 2004, the Bombay High Court pronounced two judgements ordering public sector companies to employ HIV positive workers. In X v State Bank of India, a worker was denied employment on grounds of his HIV positive status, despite medical experts declaring him to be asymptomatic and fit to perform the job. The court directed the respondent bank to employ the petitioner on first available vacancy an observed that “Protection an dignity of the HIV infected persons is essential to the prevention and control of HIV/AIDS. Workers with HIV related illness should be treated the same as any other worker with an illness.

This judgement is considered as landmark judgement in the South Asia region as it is establishing the right of people living with HIV to continue to work without discrimination.

Resources


UNAIDS. 1999. *Best Practice Collection. From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. UNAIDS

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