Handbook on access to HIV/AIDS-related treatment

A collection of information, tools and resources for NGOs, CBOs and PLWHA groups

Joint United Nations Programme on HIV/AIDS

UNAIDS

UNICEF • UNDP • UNFPA • UNDCP
ILO • UNESCO • WHO • WORLD BANK

World Health Organization

International HIV/AIDS Alliance

Supporting Community Action on AIDS in Developing Countries

UNAIDS Best Practice Collection

UNAIDS/03.11E (English original, May 2003)

ISBN 92-9173-161-7

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WHO Library Cataloguing-in-Publication Data

Handbook on access to HIV/AIDS-related treatment : a collection of information, tools and other resources for NGOs, CBOs and PLWHA groups / produced by UNAIDS, WHO, and the International HIV/AIDS Alliance.

(UNAIDS best practice collection. Key material)

1.HIV infections - therapy 2.Acquired immunodeficiency syndrome - therapy 3.Anti-HIV agents - supply and distribution 4.Health services accessibility 5.Needs assessment 6.Resource guides 7.Handbooks. I.UNAIDS II.World Health Organization III.International HIV/AIDS Alliance.

ISBN 92 9 173161 7 (NLM classification: WC 503.2)

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UNAIDS BEST PRACTICE COLLECTION

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International HIV/AIDS Alliance
Supporting Community Action on AIDS in Developing Countries

Produced by UNAIDS, WHO and the International HIV/AIDS Alliance

Geneva, Switzerland
May 2003

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Joint United Nations Programme on HIV/AIDS: www.unaids.org
A website about the Joint United Nations Programme on HIV/AIDS, with many useful publications.

World Health Organization: www.who.int
A website about the World Health Organization, with many useful publications.

International HIV/AIDS Alliance: www.aidsalliance.org or www.aidsmap.com
A website about the International HIV/AIDS Alliance, with many practical publications and helpful links to other useful websites.

Preface

The International HIV/AIDS Alliance, the World Health Organization (WHO) and the UNAIDS Secretariat welcome readers to this handbook.

Designed to be a useful resource for the different groups involved in treatment for HIV-related conditions, the handbook is also an implicit tribute to these groups. It is a concrete acknowledgement that, without their work, the global response to AIDS would be much smaller – and much less effective – than it is today.

Groups of people living with HIV/AIDS (PLWHA), nongovernmental organizations (NGOs) and community-based organizations (CBOs) have been at the forefront of prevention and care since the world first became aware of the epidemic two decades ago. Instead of passively leaving these tasks to the medical profession or public health authorities, they have become partners in providing HIV-related commodities and services – and, in some places, they have been the only providers. They have also courageously built roles for themselves as advocates and teachers, changing the way the world thinks about HIV/AIDS and responds to the people who live with it. In doing so, they have built hope, spread important skills and ensured better delivery of HIV/AIDS-related services and commodities.

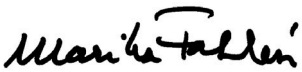
Recognizing that these groups remain a key resource in the global response, this handbook aims to widen their participation even further by providing them with a useful collection of information and tools. However, the word 'providing' implies one-way giving when, in fact, the creation of this handbook has been a two-way process: while the Alliance, WHO and UNAIDS Secretariat may be providing the finished product, the essential 'raw material' was provided by dozens of individuals and groups in Africa and Asia. Their generous and enthusiastic participation during the design and field-testing stages gave the handbook the benefit of their experience and expertise, and kept it focused on the practical needs and challenges of providing treatment to people living with HIV/AIDS.

This process echoes the creation of another book a decade ago – the *AIDS Home Care Handbook* – which was published by WHO after extensive consultation with NGOs working in HIV/AIDS care in developing countries. That pioneering book has been used all over the world, freely adapted to fit widely different conditions in a variety of places.

This new handbook proceeds in the same spirit of partnership. The Alliance has contributed its strong field experience and expertise in collaboration with local NGOs and CBOs. WHO has overseen the technical content, in particular on drug management issues. The UNAIDS Secretariat, as a global advocate for mobilizing NGOs' and CBOs' entry into the field of care, initiated the handbook's development, brought in the Alliance and many other NGOs and CBOs, and provided funding.

It is hoped that this new handbook will prove as useful as the earlier book, which it does not replace but complements. We hope that it will encourage groups already involved in HIV/AIDS care to extend the services they provide, and that it will encourage other groups (perhaps doing some other HIV-related activity, such as prevention and support, or in other fields of health, such as family planning and reproductive health) to get involved.

If the global response to HIV/AIDS can be thought of as a chain, then treatment is one of its essential links. We hope that this handbook will help groups around the world to find their own ways of reinforcing that link – and, in doing so, strengthen the entire chain.



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Acknowledgements

We wish to thank all those who have so generously given their time, energy and guidance during the development of this handbook (please see page 126). A special thanks to Calle Almedal and Salvator Niyonzima from UNAIDS, to the Alliance, and to the many people with HIV/AIDS who shared their experience and supported the development of this resource. We couldn't have done it without you!

Acronyms

AIDS	acquired immunodeficiency syndrome
ARV	antiretroviral therapy
CBO	community-based organization
DOTS	directly observed treatment – short course (for example, TB medication)
EDM	Essential Drugs and Medicines Policy Unit (of WHO)
EML	essential medicines list
HAART	highly active antiretroviral therapy
HIV	human immunodeficiency virus
INN	international non-proprietary name
MTCT	mother-to-child transmission
NGO	nongovernmental organization
PCP	*pneumocystis carinii* pneumonia
PLWHA	people living with HIV/AIDS
STI	sexually transmitted infection
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	voluntary counselling and testing
WHO	World Health Organization

Introduction
Read this first!

The *Handbook on access to HIV/AIDS-related treatment* aims to build practical skills for nongovernmental organizations (NGOs), community-based organizations (CBOs) and groups of people living with HIV/AIDS (PLWHA) that are responding to HIV/AIDS in developing countries. It is a resource designed to help NGOs, CBOs and PLWHA groups to improve the quality of their work on HIV/AIDS-related treatment.

The handbook is intended for use by organizations and trainers who support such groups. It can be used flexibly, with one or a group of NGOs, CBOs and PLWHA, and can be used in training workshops or as a resource on technical support visits.

The handbook has five chapters. These cover key definitions, concepts, assessment methods, planning steps, skills associated with effective HIV/AIDS-related treatment work and keeping track of such work.

The *Handbook on access to HIV/AIDS-related treatment* is based on the practical experiences and participatory approaches of the International HIV/AIDS Alliance.

1. What is this handbook?

This handbook aims to support NGOs, CBOs and PLWHA groups in developing countries that are providing treatment to people living with HIV/AIDS or are thinking of doing so. It is intended to help NGOs, CBOs and PLWHA groups to find practical ways to understand, plan and undertake work on HIV/AIDS-related treatment.

It is a resource that will help to:

- **build practical skills** among NGOs, CBOs and PLWHA groups by using participatory activities and sharing experiences;
- **provide a training resource** for NGO support programmes, training organizations and individuals;
- **facilitate learning** about the HIV/AIDS-related treatment work of NGOs, CBOs and PLWHA groups.

This handbook is not about the clinical management aspects of HIV/AIDS-related treatment. The handbook addresses the wider issues around HIV/AIDS-related treatment and what NGOs, CBOs and PLWHA groups will need to do if they become involved or want to become more involved. The International HIV/AIDS Alliance, the World Health Organization (WHO) and the UNAIDS websites provide details of other publications for information on clinical management.

2. Why was this handbook developed?

The experience of the Alliance, UNAIDS and WHO showed that many NGOs, CBOs and PLWHA groups already involved in HIV/AIDS care, advocacy and prevention were being challenged to do something about improving access to treatment for people living with

HIV/AIDS. Most of these groups, however, had limited experience and/or knowledge about treatment. Available resources proved difficult to adapt for small groups without medical expertise.

At the same time, the experiences of other NGOs, CBOs and PLWHA groups that were already carrying out creative and effective work on HIV/AIDS-related treatment were often not documented. This meant that they were not making full use of the lessons learned, whether to improve the quality of their own work or to help others by sharing these lessons.

As a response, the handbook that has been developed is a collection of information, tools and lessons on a range of topics related to improving access to HIV/AIDS-related treatment for people living with HIV/AIDS.

3. How was this handbook developed?

International HIV/AIDS Alliance partners and others working on HIV/AIDS and essential drugs were extensively consulted through needs assessments in Côte d'Ivoire, India and Zambia before the handbook was drafted. When the handbook was available as a working document, it was field-tested in a series of skills-building workshops in Cambodia, India and Zambia. The handbook has been amended and adapted accordingly.

This handbook has been inspired by the ideas of many organizations in many countries and has directly benefited from their varied experiences. It has drawn on the work of groups providing HIV/AIDS care and support who have seen that access to treatment is a serious problem for people living with HIV/AIDS in resource-poor settings. It has also drawn on the work of those who have worked for many years to improve access to essential drugs for all people living in resource-poor countries.

4. Who is this handbook for?

The *Handbook on access to HIV/AIDS-related treatment* is for NGOs, CBOs and PLWHA groups, and the people and organizations that support them in responding to HIV/AIDS in developing countries. These include NGO support programmes, training institutions and individual trainers.

5. How can this handbook be used?

The handbook is designed to help NGOs, CBOs and PLWHA groups to think through the various issues and the context of HIV/AIDS-related treatment before they make decisions about whether, and how, to get involved in practical work on treatment. The handbook can be used both as an information resource and as a training resource for planning and implementation of work on HIV/AIDS-related treatment.

Using the handbook as a training resource may require a certain level of facilitation skills for guiding large group discussions or small group activities. Ideally, the facilitators should also have some knowledge of HIV/AIDS-related treatment. Moreover, facilitators should have HIV/AIDS competence. A practical resource on basic facilitation skills for participatory workshops is available from the International HIV/AIDS Alliance.

The material in this handbook is designed to be used in the order in which it is presented. The handbook may also be used in a more flexible way so that facilitators can tailor the work

schedule to meet the needs of different NGOs, CBOs and PLWHA groups. For example, some groups may want to have a training workshop in which they do most of the activities, while others may want to use a selection of activities over a period of time, or to focus on one or two activities to meet a specific, urgent need. An example of a workshop schedule is included at the end of this section (see page 15).

For most of the handbook, facilitators can use the activities either with an individual NGO, CBO or PLWHA group or with several such groups. However, for Chapter 4 participants need to work with colleagues from their own organizations. This is because assessing treatment needs and resources and deciding what HIV/AIDS-related treatment work to undertake is specific to each individual NGO/CBO or PLWHA group.

This handbook can be used with NGOs, CBOs and PLWHA groups with different levels of experience in HIV/AIDS-related treatment. It is particularly suitable for those who are new to this area of work.

The contents of each chapter aim for a balance between sharing technical information in a user-friendly way and providing practical tools to develop an understanding of technical information. At the end of each chapter, there is a list of additional resources that NGOs, CBOs and PLWHA groups may find useful.

For the most part, the contents of Chapters 1-5 follow the format below.

Introductory text	*explaining the subject and the key issues involved; information can be given to participants as handouts*
↓	
Participatory group activity	
Aim	*stating what the activity is designed to achieve*
↓	
Instructions	*outlining the steps to take to complete the activity and the key questions to consider*
↓	
Facilitators' notes	*sharing useful ideas about how to successfully guide participants through the activity*
↓	
Example	*an example of a completed activity is given to show how the activity has been used*

Facilitators can read through the introductory text and aim for each point and use the information as the basis for an initial group discussion. They can then work through the instructions for the participatory group activity, using the facilitators' notes to avoid possible pitfalls. Finally, they can use the example to clarify any points that are unclear. It is important to note that, although the ideas and activities in this handbook have been tried and tested by the International HIV/AIDS Alliance and its partners, they do not try to provide 'perfect' examples of how things should be done. Therefore, the instructions should not be followed word for word but should, instead, be adapted to participants' specific needs, skills and interests. In addition, the examples should be seen as just one way that the activity can be put into action, as opposed to the only correct way.

6. What is in the chapters of this handbook?

Following this Introduction, the handbook is divided into five chapters.

Chapter 1: First questions to ask
- definitions of care and support, treatment, availability of treatment, access to treatment
- links between HIV/AIDS-related treatment and HIV prevention
- factors affecting access to HIV/AIDS-related treatment
- barriers to treatment access and opportunities to improve access to treatment

Chapter 2: Foundations of treatment
- basics of effective treatment – supportive relationships, knowledge, skills and attitudes
- ethical approach to treatment
- information about treatment
- working with others – partnerships and advocacy to improve access to HIV/AIDS-related treatment

Chapter 3: Putting treatment into practice
- resources for HIV/AIDS-related treatment work
- drugs – names, information
- choosing the right drugs
- making the best use of drugs
- getting drugs
- managing drug supplies
- donations
- storing drugs
- dispensing drugs

Chapter 4: Assessing needs and resources, and deciding what to do
- assessing the treatment needs and resources of people with HIV/AIDS and of the community
- assessing what others are doing to respond to treatment needs
- assessing your organization's capacity to respond to treatment needs
- making decisions about what to do

Chapter 5: Learning from and improving HIV/AIDS-related treatment work
- keeping records
- monitoring HIV/AIDS-related treatment work
- evaluating HIV/AIDS-related treatment work
- keeping track of change and responding to change
- sharing lessons and experiences
- scaling up or scaling down HIV/AIDS-related treatment work

7. What materials are needed to use this handbook?

All the activities in this handbook can be used with a few simple resources. These are:

- large sheets of blank paper
- small pieces of blank paper
- marker pens
- sticky tape, 'Blu-Tack' or 'Sticky Stuff'
- samples of drugs

Most of all, both facilitators and participants will need enthusiasm, energy and creativity!

8. Who developed this handbook?

The **International HIV/AIDS Alliance** is an international nongovernmental organization that supports community action on HIV/AIDS in developing countries.

The Alliance aims to:

- make a significant contribution to HIV prevention, care and support to children affected by the epidemic, by working together with communities in developing countries;
- promote the sustainability and scaling-up of effective community AIDS efforts, by building the capacity of CBOs, NGOs and NGO support programmes;
- influence and improve the HIV/AIDS policies and programmes of international agencies, donors and the international NGO sector, with particular emphasis on the role of community action.

The **World Health Organization (WHO)** is the world's leading international public health agency. The mission of WHO in essential medicines is to help save lives and to improve health by closing the huge gap between the potential that essential medicines have to offer and the reality that, for millions of people around the world, medicines are unavailable, unaffordable, unsafe or improperly used.

To achieve this mission, WHO's essential medicines strategy has the following broad objectives:

- to help countries to develop and implement national drug policies and to integrate essential medicines into national health systems;
- to work with countries to enhance access to essential medicines, particularly to medicines for priority diseases;
- to strengthen the quality, safety and efficacy of all medicines through developing and putting into practice global regulatory and quality assurance standards;
- to help to ensure that health professionals and consumers use medicines properly and provide the public with independent, unbiased information about medicines, including information on traditional medicines.

To address the many factors driving the HIV/AIDS epidemic, and help countries deal with the impact of HIV/AIDS on households, communities and local economies, the United Nations took an innovative approach in 1996, drawing six organizations together in a joint and cosponsored programme – the **Joint United Nations Programme on HIV/AIDS (UNAIDS)**. The six original cosponsors of UNAIDS – the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Educational, Scientific and Cultural Organization (UNESCO), WHO and the World Bank – were joined in April 1999 by the United Nations International Drug Control Programme (UNDCP), and in 2001 by the International Labour Organization (ILO).

As the leading advocate for worldwide action against HIV/AIDS, UNAIDS leads, strengthens and supports an expanded response to the epidemic that will:

- prevent the spread of HIV;
- provide care and support for those infected and affected by the disease;
- reduce the vulnerability of individuals and communities to HIV/AIDS; and
- alleviate the socioeconomic and human impact of the epidemic.

9. Further sources of information

Facilitators' guide for needs assessments on access to HIV/AIDS-related treatment – a resource to support the development of a practical toolkit for NGOs, CBOs and PLWHA groups. International HIV/AIDS Alliance, 1998. Assessment tools, and questionnaires for assessing treatment needs of people living with HIV/AIDS.

Needs assessment reports (Zambia, India, Côte d'Ivoire): development of a toolkit on access to HIV/AIDS-related treatment. International HIV/AIDS Alliance, November 1999–January 2000. Reports of needs assessments on issues of HIV/AIDS-related treatment access; results of these visits formed the basis for the development of the *Handbook on access to HIV/AIDS-related treatment.*

A facilitators' guide to participatory workshops with NGOs/CBOs responding to HIV/AIDS. International HIV/AIDS Alliance, December 2001. A guide to support people who facilitate participatory workshops.

This is a sample schedule based on skills-building workshops carried out by the International HIV/AIDS Alliance

References to the relevant sections of this handbook are given in brackets, where appropriate

	Day 1	*Day 2*	*Day 3*	*Day 4*	*Day 5*
1 hour 45 minutes	• Registration • Introductions • Workshop outline and objectives • Expectations and ground rules	• Recap **The foundations of treatment** • The supportive relationship (2.1.A) • Knowledge, skills and attitudes (2.1.B)	• Recap • Feedback on information needs for treatment (2.1.D)	• Recap • Sharing of experiences: managing the provision of treatment	• Recap **Assessing treatment needs and deciding what to do** • Assessing needs and resources – people living with HIV/AIDS and the community (4.1, 4.2.A)
15 minutes			BREAK		
1 hour 30 minutes	**Defining treatment** • What is care and support? (1.1.A) • What is treatment? (1.1.B)	• An ethical approach to treatment (2.1.C)	• Advocacy to improve access to treatment (2.3.B) • Working with others (2.3.A)	• Essential drugs (3.2.B) • Rational prescribing of drugs (3.2.F)	• Assessing environmental needs and resources – what others are doing (4.2.B)
45 minutes			LUNCH		
1 hour 30 minutes	• Linking treatment and prevention (1.2) • Availability and accessibility of treatment (1.3.A, 1.3.B)	• Common ailments and treatments for PLWHA (2.1.D) • Information needs for treatment (2.1.D)	**Putting treatment into practice** • Identifying resources for treatment (3.1)	• Drug donations (3.3.B)	• Assessing needs and resources – your organization (4.2.C) • Analysing results and deciding what to do (4.3)
15 minutes			BREAK		
1 hour 30 minutes	• Barriers to, and opportunities for, access to treatment (1.3.B)	• How treatments vary (2.2)	• Financial management (3.1) • People management (3.5)	• Drug ordering, storage and dispensing (3.3.D, 3.3.C, 3.4.C)	• Workshop evaluation

Chapter 1
First questions to ask

Chapter 1 of this handbook helps groups to develop an understanding about:

- care, support and treatment – including how they are defined, how they are connected, and where they can be provided;
- the links between treatment and prevention and how they can combine to reduce the impact of HIV/AIDS;
- barriers to access to treatment and how they prevent people living with HIV/AIDS from getting effective treatment; and
- how access to treatment for people living with HIV/AIDS relates to:
  – the HIV/AIDS epidemic and its context
  – other aspects of health care
  – social and economic conditions.

1.1 Care, support and treatment

1.1.A Care and support

Care and support are based on an active concern for the well-being of others and ourselves. People directly affected by HIV/AIDS need care. People living with HIV/AIDS, their families and communities are also involved. They all need support to face the challenges of illness and meet the needs that arise. The aim of HIV/AIDS care and support is to improve the quality of life of people living with HIV/AIDS, their families and communities. Care and support are important because they boost efforts to prevent the further spread of HIV.

Comprehensive care, an important part of care and support, is about responding to the needs of a person living with HIV/AIDS in a holistic (or 'whole') way. It involves a variety of information, resources and services to address a range of needs – not just medical needs.

Comprehensive care

Comprehensive care includes the following important basics:

- diagnosis
- treatment
- referral and follow-up
- nursing care
- counselling
- support to meet psychological, spiritual, economic, social and legal needs.

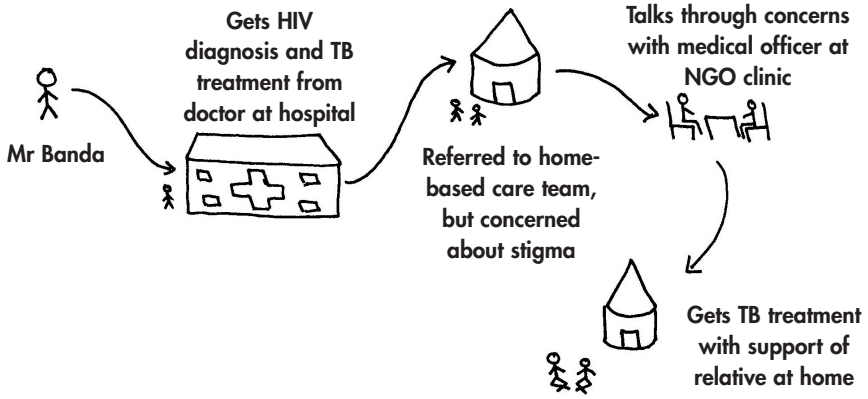
Each person living with HIV/AIDS has different needs, depending on the stage of illness and the circumstances. For example, a person living with HIV/AIDS who is not ill will have

different needs from a person living with HIV/AIDS who is very ill and confined to bed most of the time, and will require different care and support.

Comprehensive care for a person living with HIV/AIDS should happen within a continuum of care. This means responding to the full range of care and support needs in different places – such as hospital, clinic, community and home – over the course of the person's illness. Responding to these needs also requires a coordinated response from people with a variety of complementary skills – such as family members, counsellors, nurses, doctors, community health workers, people living with HIV/AIDS, pharmacists and volunteers. It is vital that all these people work together to ensure an efficient flow of information, resources and services between them, providing a continuum of good-quality care and support.

Case study – Continuum of care in Zambia

Mr Banda lives in a town in Zambia. He went to the hospital for an HIV test because he was losing weight and coughing. Due to his cough, the doctor also checked him for tuberculosis (TB). The results of both tests were positive. The doctor started Mr Banda on TB treatment while he was in hospital. But, when Mr Banda was coughing less, he was sent home and referred to the home-based care team of a local church. The team came to Mr Banda's house to support him in taking his drugs regularly, but he shouted at them not to come back. The team persuaded Mr Banda to see the Medical Officer who listened carefully and realized that Mr Banda was afraid that his neighbours would see the team visiting him, realize he had TB and reject him. So, the team helped Mr Banda to talk to a trustworthy relative who learned how to help Mr Banda take his drugs every day and go for check-ups at the hospital. Mr Banda's TB was controlled and he started to feel much happier.



Participatory group activity

Aim

To identify the elements involved in comprehensive care and support for people living with HIV/AIDS.

Instructions

1. Explain the aim of the activity.
2. Present participants with a definition of comprehensive care and support (see previous page).

3. Divide participants into small groups of four to six people.
4. Ask each group to brainstorm (based upon their own experiences) on the different elements involved in comprehensive care and support for people living with HIV/AIDS. Ask them to write them on a piece of flipchart paper.
5. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • Why is it important that care and support for people living with HIV/AIDS be comprehensive?
   • Are any of the elements of care and support more important than the others? Why?

Facilitators' notes

- Encourage participants to think about the whole range of needs of people living with HIV/AIDS, rather than just their medical symptoms.
- Ensure that participants include the everyday elements of care and support for people who are healthy and living with HIV/AIDS, as well as for those who are ill. Examples include nutrition and a loving environment.

Example

At a skills-building workshop, NGO/CBO participants shared their experiences about providing comprehensive care and support for people living with HIV/AIDS. They decided that the key elements included:

- personal and family hygiene
- spiritual support
- environmental hygiene
- education on diet
- food
- income-generating activities
- employment
- sharing experiences
- transport
- counselling
- nursing care
- clothing
- blankets
- relief of symptoms
- treatment
- medicines
- school needs
- singing.

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that effective care and support should involve responding to a variety of different elements, including physical, spiritual, psychosocial and material support.

Reference: Adapted from a workshop on access to HIV-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April 2001.

1.1.B Treatment

Treatment is a key element of care and support for people living with HIV/AIDS. It can be:

- **curative** – curing disease either temporarily or permanently;
- **preventive** – preventing disease from happening or becoming worse;
- **palliative** – reducing symptoms in order to reduce discomfort and distress.

However, treatment is not just part of a linear process of ensuring that drugs are accessible to those who need them.

For medicines to be effective, there should also be access to other forms of care and support. These can, even without drugs, provide some relief from illness and improve a person's well-being. They also encourage better use of drug treatment when it is necessary. For example, if people have support from their communities and have food and clean water, they will be better able to resist illness, but they are also likely to benefit more from medicines when they need them.

Treatment needs vary depending on the stage of illness. This affects where treatment should take place and what resources are required. The needs of people living with HIV/AIDS should be central to deciding where treatment is provided. People living with HIV/AIDS need treatment to be accessible in different locations at different times. Sometimes it can start in one place (such as a hospital) and continue in another (such as a person's home). This can be better for the person who is ill, and it may reduce the cost and complexity of the work. When treatment is being given in different locations, it is important to have effective coordination of information, resources and services between the different places (see the case study in Chapter 1.1.A on page 18).

IMPORTANT!

The focus of this handbook is HIV/AIDS-related treatment with drugs, meaning pharmaceutical drugs and medicines used in the allopathic ('western') system of medicine. However, treatment with drugs must always be linked to, and supported by, other forms of care and support (such as counselling, nutrition and traditional remedies) for them to be effective.

Participatory group activity

Aim

To develop a common understanding of what is meant by treatment for people living with HIV/AIDS.

Instructions

1. Explain the aim of the activity.
2. Present participants with a definition of treatment (see previous page).
3. Divide participants into small groups of four to six people.
4. Ask each group to brainstorm (based upon their own experiences) about the different types of treatment for people living with HIV/AIDS.
5. Ask each group to draw a diagram or picture to show how treatment with drugs relates to other elements of care and support.
6. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
7. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - Which types of treatment are 'necessary' for a person living with HIV/AIDS? Why?
   - Can any type of treatment be given in isolation?
   - How can treatment with drugs be positively affected by the other elements of care and support? How can it be negatively affected?

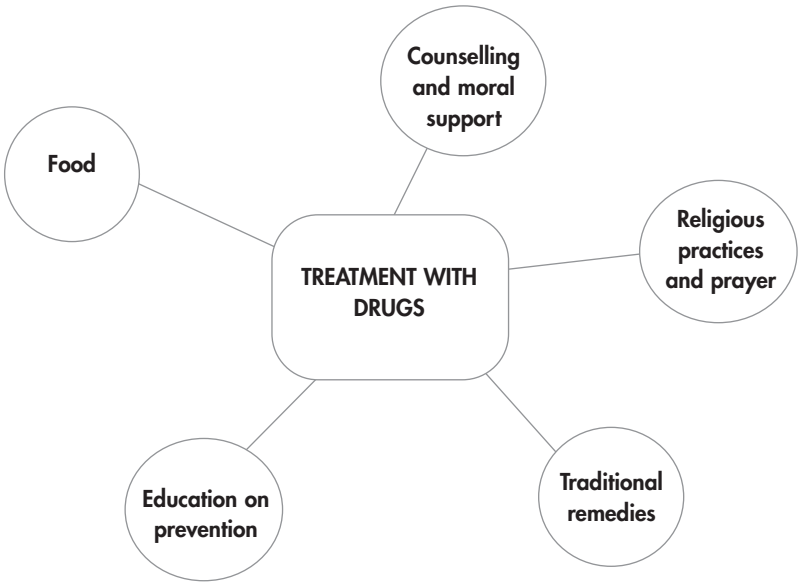
8. Emphasize that all elements of care and support are vital for people living with HIV/AIDS, but that the focus of this training work will be treatment using pharmaceutical drugs – meaning medicines used in the allopathic ('western') system of medicine (see box on previous page).

Facilitators' notes

- Ensure that participants are clear about the definition of treatment before looking at how treatment with drugs and other elements of care and support relate to each other.
- Encourage participants to include a variety of elements of care and support (such as nutrition, psychosocial support, traditional remedies and personal hygiene) alongside pharmaceutical medicines.

Example

At a skills-building workshop, NGO/CBO participants identified different types of HIV/AIDS-related treatment and drew a diagram to show how treatment with drugs related to other elements of care and support.



Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that, if treatment with drugs is to be effective, it should be combined with, and supported by, other elements of care and support, such as food and counselling.

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

1.2 Linking treatment and prevention

HIV prevention aims to prevent the transmission of HIV and reinfection. HIV/AIDS-related treatment aims to improve the quality of life of people living with HIV/AIDS. HIV prevention and HIV/AIDS-related treatment support each other in many ways.

- Well-designed HIV prevention activities can lead to increased voluntary counselling and testing (VCT), which in turn can lead to broader and quicker access to treatment for people living with HIV/AIDS.

- Well-designed HIV prevention activities can reduce fear and stigma around HIV/AIDS, which in turn improves the quality of life of people living with HIV/AIDS as they become more accepted and understood in their families and communities.

- Through VCT, people can learn about HIV prevention and, if they are HIV-positive, be given information about how to live safely with the virus and plan for the future. VCT also helps people to get assistance early on and to learn about possible treatments for health problems that may occur. For example, VCT can be helpful for preventing tuberculosis (TB) and sexually transmitted infections (STIs).

- If women learn that they have HIV/AIDS, because of prevention programmes and VCT services, they can access services which, if they become pregnant, will reduce the chance of passing on HIV to their unborn or newborn children. Women and men might also choose to increase contraceptive use.

- Access to care and support has been shown to increase condom use and other preventive behaviour among people living with HIV/AIDS. These positive changes can be reinforced when care and treatment programmes deliberately promote and distribute condoms.

- Increased availability of care and increased visibility and acceptance of people living with HIV/AIDS makes the broader population more aware of HIV/AIDS and increases safer behaviour.

Case study – Home care in Cambodia

In Cambodia, home-care teams from local organizations support a large number of families affected by HIV/AIDS. Most of the people living with HIV/AIDS found that their overall well-being improved due to the visits from the home-care teams; families spent less money on medicines and had to make fewer visits to hospital. In addition, neighbours, friends and family members came to understand more about HIV/AIDS and to be less afraid of the virus – there was less stigma around HIV/AIDS in the community, making it easier to provide education on HIV prevention.

Participatory group activity

Aim

To identify the links between HIV/AIDS-related treatment and HIV prevention.

Instructions

1. Explain the aim of the activity.
2. Present participants with a definition of HIV prevention.
3. Divide the participants into small groups of four to six people.
4. Ask each group to discuss whether they agree or disagree with the following statements:
   - *HIV/AIDS-related treatment can help to reduce the need for HIV prevention.*
   - *HIV prevention can help to reduce the need for HIV/AIDS-related treatment.*
5. Ask each group to make a diagram or drawing showing the links between HIV/AIDS-related treatment and HIV prevention.
6. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
7. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - Does everybody have a similar view of the links between HIV/AIDS-related treatment and HIV prevention? Why?
   - What is the single most important link between HIV/AIDS-related treatment and HIV prevention? Why?

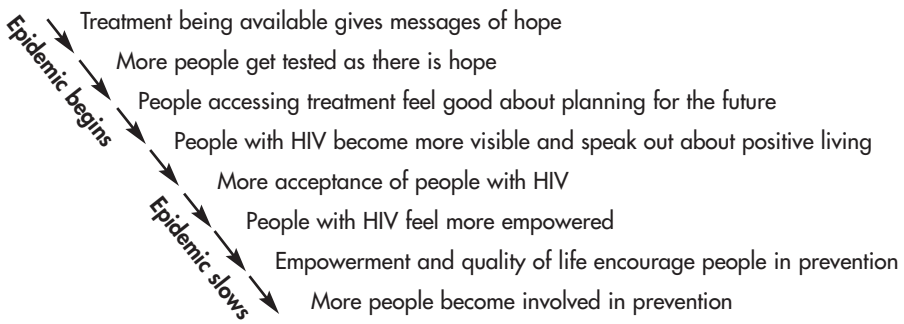
Facilitators' notes

- Ensure that participants are clear about what is meant by HIV prevention before they assess its link to HIV/AIDS-related treatment. Ensure that their definition includes prevention of other illnesses as well as prevention of HIV transmission.
- Encourage participants to focus on the practical links between HIV prevention and HIV/AIDS-related treatment, rather than the theoretical ones.
- Ensure that participants keep focused on the links between HIV/AIDS-related treatment and HIV prevention, rather than getting distracted by debates about which is more important.

Example

At a skills-building workshop, NGO/CBO participants discussed the statements: "HIV-related treatment can help to reduce the need for HIV prevention"; "HIV prevention can help to reduce the need for HIV-related treatment." They found that, based upon their experiences, they strongly agreed with the statements.

Participants then drew a diagram of how they saw the links between HIV/AIDS-related treatment and HIV prevention in practice.



Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

1.3 Access to treatment

1.3.A Availability of treatment

For people to use a treatment, it must be available – meaning that it can be found anywhere that is appropriate.

A treatment is available if the materials needed to treat a health problem can be found in the community. For example, basic drugs (such as paracetamol and simple antibiotics) are available in many countries, especially in towns. However, newer drugs (such as antiretrovirals) may not be widely available. Some reasons why a drug might not be available include the following:

- the drug is new and not yet legally allowed for general use;
- the drug is not imported into the country for commercial reasons;
- the public health system does not allocate funds to purchase the drug; and
- only specialists are allowed to give the drug.

So the first step in making certain that people have access to the drugs they need is to ensure that these drugs are available within their own countries by securing the economic, legal and technical resources that can allow this to happen. When they are available, it is important to work on ensuring that people can actually have access to drugs for treatment when and where they need them.

Access to drugs depends on four key factors:

- **rational selection** – choosing drugs that are safe, effective, valuable to public health and guaranteed to be of good quality;
- **affordable prices** – governments and individuals must be able to afford their essential medicines and maintain people's health;
- **sustainable finances** – the money to pay for treatments must continue to be available when needed and in changing circumstances;
- **reliable health systems** – access to drugs needs to be supported by systems that ensure availability whenever the drugs are required.

Participatory group activity

Aim
To identify where drugs for HIV/AIDS-related treatment are available in the community.

Instructions
1. Explain the aim of the activity.
2. Present participants with a definition of access to drugs for HIV/AIDS-related treatment (see above). Brainstorm about some examples of what it means in practice at a community level.
3. Lead a group in brainstorming about what is meant by availability of drugs for HIV/AIDS-related treatment. Share some local examples of what it means in practice.
4. Divide the participants into three groups.
5. Give each group an example of drugs for HIV/AIDS-related treatment, such as:
   Group 1: a simple treatment (such as paracetamol for pain relief);
   Group 2: a well-known but less simple treatment (such as for tuberculosis);
   Group 3: an antiretroviral drug.

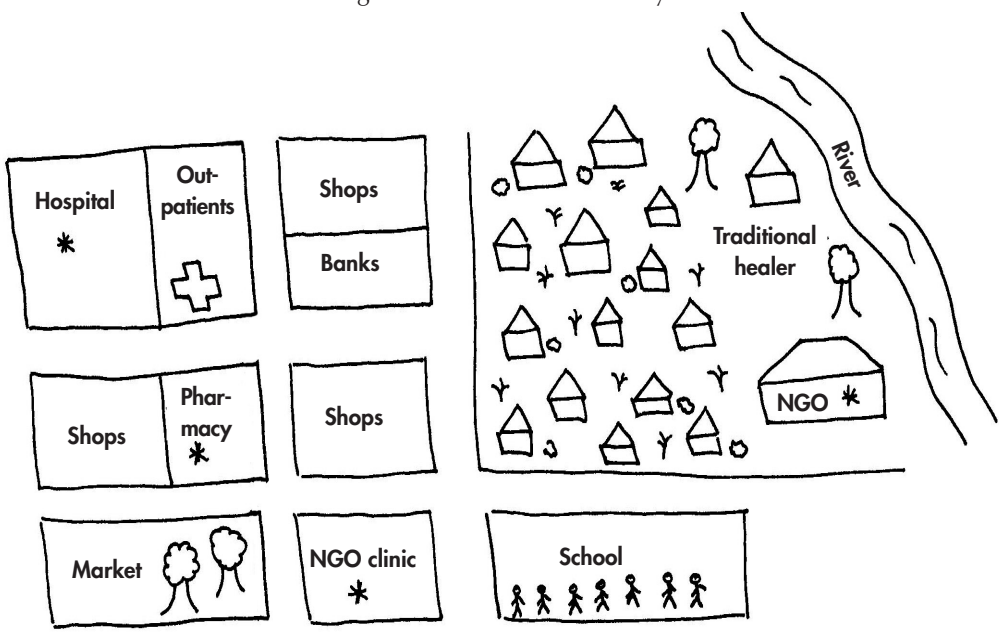
6. Ask each group to draw a simple map of their community on a large piece of flipchart paper. Ask them to include all the main local features (such as roads and buildings).
7. Ask each group to mark the places in their community where the drugs for HIV/AIDS treatment are available to people living with HIV/AIDS. These might include their homes, the clinic, hospital, pharmacy, NGO, traditional healer or marketplace.
8. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and make comments.
9. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • What do the maps show about the overall availability of drugs for HIV/AIDS-related treatment in the local community?
   • What types of drugs are more available than others? Why?
   • How might the availability of drugs vary in different types of communities, such as those in rural or urban areas?

Facilitators' notes

- Encourage participants to use the majority of their time to plot the availability of the drugs for their particular treatment rather than to develop elaborate maps of their communities.
- Encourage participants to think of informal sources of drugs (such as traditional healers and market stalls) as well as formal sources (such as doctors and pharmacies).

Example

At a skills-building workshop, NGO/CBO participants drew a map to show the different places where rifampicin (a TB drug) is available in their local community. The places marked with a star indicate where the drug is found in the community.



Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that informal sources of drugs (such as traditional healers) can play an important role in supporting people living with HIV/AIDS by helping them make better use of available drugs for treatment.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

1.3.B Accessibility of treatment

For people to use treatment, it must not only be available but also accessible. This means that the treatment should be found in the appropriate place and that it should be easy for people to obtain and use properly.

Sometimes, drugs for a treatment can be available locally but are not accessible. This might occur because:

- people cannot afford the right drug;
- the treatment provider discriminates against people living with HIV/AIDS and refuses to give them the drug;
- the treatment provider does not have the right skills to give the drug; and
- it is too difficult for people living with HIV/AIDS to get to where the drug is available.

A **barrier to access** to treatment is anything that prevents a person from getting the treatment they need. There can be many barriers for people living with HIV/AIDS. These barriers may be related to:

- **a service** – such as its location, cost, staff attitudes, skills or facilities offered. For example, a clinic might only be open during the day when many people living with HIV/AIDS are working.
- **the context** – such as the political, economic and cultural situation in which treatment is provided. For example, women might not be able to access treatment for STIs because sex is a taboo subject or because of the stigma of being seen at an STI clinic.
- **attitudes to treatment** – such as the knowledge and beliefs of community members. For example, local people might believe that HIV counselling and testing are only for members of 'high-risk' groups such as sex workers.

There are many different types of barriers to access to HIV/AIDS-related treatment. These include:

- **financial barriers** – such as the cost of drugs and the need to prioritize other general supplies, such as food;
- **organizational barriers** – such as poor administration of treatment services and lack of skilled staff;
- **physical barriers** – such as treatment facilities being distant and transport not being available; and
- **social barriers** – such as stigma being associated with a treatment and people being concerned about confidentiality.

Further information on this subject can be found in two information sheets: 'Barriers to access to treatment' and 'Factors affecting access to HIV/AIDS-related treatment'; at the end of this chapter (see pages 30-34).

Participatory group activity

Aim

To identify barriers and opportunities for access to HIV/AIDS-related treatment.

Instructions

Part 1: Identifying barriers

1. Explain the aim of the activity.
2. Present participants with a definition of access to HIV/AIDS-related treatment based on the description on the previous page.
3. Lead a group in brainstorming about what access to HIV/AIDS-related treatment means.
4. Divide the participants into small groups of four to six people.
5. Ask each group to brainstorm about the barriers to access to treatment for people living with HIV/AIDS. Ask them to write each barrier on a separate piece of folded card.
6. Bring everybody back together and ask each group to share their results by explaining their cards and placing them in a row along the floor (to represent road-blocks on the path to access to treatment). Encourage the participants to ask each other questions and to make comments.
7. Facilitate a brief group discussion about what has been learned from the activity, based upon questions such as:
   - How many major barriers are there to access to HIV/AIDS-related treatment?
   - How might barriers vary for people living with HIV/AIDS?

Part 2: Classifying barriers

8. Write the following headings at the top of separate pieces of flipchart paper:
   - Financial
   - Organizational
   - Physical
   - Social

   Present to participants what each heading means, in terms of the types of barriers to access to HIV/AIDS-related treatment (see previous page).
9. Working as a large group, classify the barriers that were presented by the small groups (see Part 1 above), by writing each one down under the heading on the flipchart that best describes it.
10. Facilitate a brief group discussion about what has been learned from the activity, based upon questions such as:
    - Is there more of one type of barrier than another? Why?
    - Which types of barriers might be easier to overcome?

Part 3: Identifying opportunities

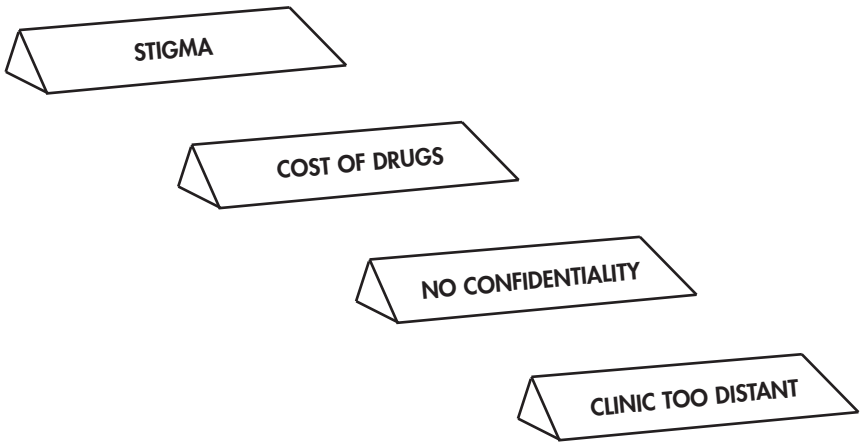
11. Divide the participants into four groups.
12. Give one of the lists of physical, organizational, financial and social barriers (see Part 2 above) to each group.
13. Ask each group to identify which barrier on their list is the most important.
14. Ask each group to write the most important barrier at the centre of a piece of flipchart paper. Then ask them to add opportunities to overcome the barrier, by putting them in circles around it. If the opportunity can be addressed easily, it should be placed near to the barrier. If it is difficult, it should be placed further away.
15. Bring everybody back together and ask the groups to share their results. Encourage participants to ask each other questions and to make comments.
16. Facilitate a brief group discussion about what has been learned from the activity, based upon questions such as:
    - To what extent can something be done about all of the barriers?
    - Which opportunities would it be suitable for NGOs/CBOs to tackle?

Facilitators' notes

- It may be useful to allow participants time to read Information Sheet 1: 'Barriers to access to treatment' before they classify the types of barriers.
- Encourage participants to be as concrete as possible when identifying barriers; that will make it easier to find solutions.
- Encourage participants to focus on simple, practical steps to overcome barriers, rather than on complex strategies that would be difficult to achieve.

Example

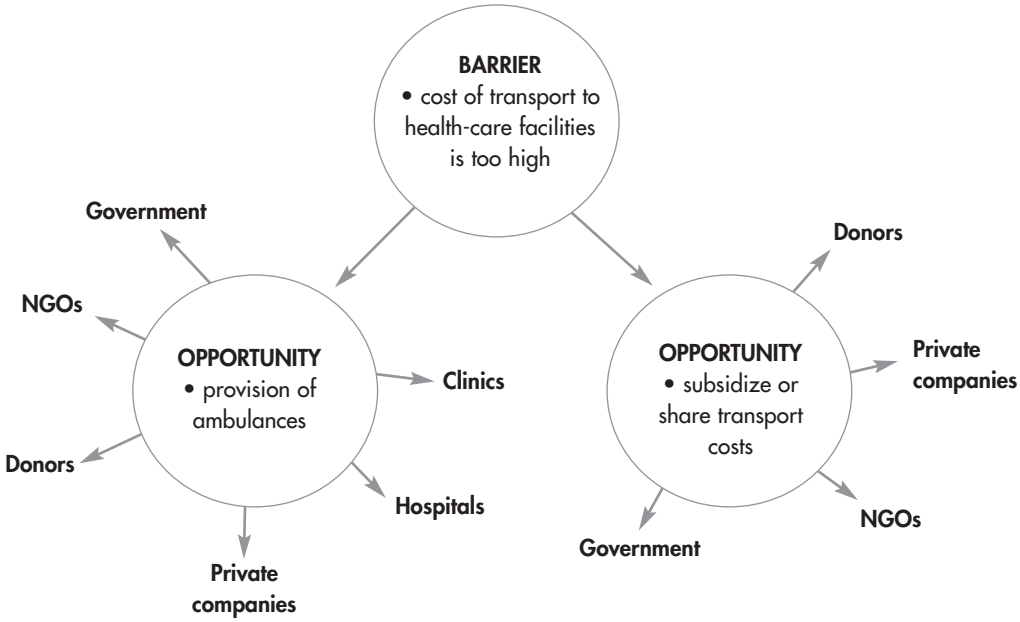
At a skills-building workshop, NGO/CBO participants brainstormed about barriers to access to treatment for people living with HIV/AIDS. They wrote the barriers on folded cards and then presented them on the floor to represent road-blocks to access to treatment.



Then, the participants classified the barriers to treatment under four headings.

Organizational	Physical	Social	Financial
• Negative attitudes of health-care workers • Lack of materials needed for treatment • Delays in treatment/health-care workers not available • Corruption in health-care facilities	• Distance to health facilities • Lack of transport	• Traditional beliefs • Stigma • Ignorance • Denial • Myths and misinformation about HIV/AIDS	• Poverty • Cost of drugs • Expense of user fees in hospitals • Cost of transport to health-care facilities • Lack of medical insurance schemes

Finally, small groups selected the most important barrier from one of the lists of financial, organizational, physical and social barriers. They then identified opportunities to overcome that barrier. For example, the group focusing on financial barriers identified the cost of transport as the barrier that causes the most difficulty for people living with HIV/AIDS. The same group identified the following opportunities to overcome the cost of transportation to health-care facilities:



Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that a variety of people and organizations needs to be involved in overcoming barriers to treatment access.

Reference: Adapted from a workshop on access to HIV-related treatment, Catholic Diocese of Ndola and the International HIV/AIDS Alliance, Zambia, April 2001.

Information Sheet 1

Barriers to access to treatment

There are many different types of barriers to access to HIV/AIDS-related treatment. They can be classified into four main groups.

1. Organizational barriers

Access to HIV/AIDS-related treatment becomes difficult if the necessary materials and skills are not available, and if services are not organized to support its proper use.

If health-care services are not fully available or accessible, access to HIV/AIDS-related treatment will be very limited. This may happen because of:

- a lack of health services near to the people who need them;
- inadequate organization and management of health services – for example, if people cannot have tests, get a diagnosis, receive counselling and get treatment in the same location at convenient times;
- lack of staff, budget or money within health services;
- unreliable supplies of drugs and other materials;
- lack of information and clear policies to support effective treatment;
- confusing procedures and poor administration within health services, such as record-keeping that is not confidential, or badly organized referral systems.

2. Physical barriers

In urban areas, where transport is more available and distances are shorter, people can usually get to health facilities or health workers can visit them in their homes. However, in rural areas and communities outside the boundaries of towns and cities, physical access to HIV/AIDS-related treatment is much more difficult. Some of the common physical barriers include the following:

- Health facilities may be far away, with people having to travel great distances with inadequate transport.
- The terrain may be difficult to cross, for example because of hills or rain.
- The journey may be dangerous, for example because of warfare or criminal activity.
- There may be few vehicles or other forms of transport available.

3. Social barriers

People may not access HIV/AIDS-related treatment because they have certain beliefs about the treatment. For example, they may think that drugs would not make a difference to them, or that unpleasant side-effects outweigh the benefits. Attitudes towards HIV/AIDS can also prevent people from accessing HIV/AIDS-related treatment.

- Secrecy about a person's HIV status can result from people being afraid to talk about HIV/AIDS in their families or communities.

- People experience stigma when they feel ashamed or are made to feel ashamed about HIV/AIDS. People may also fear that others will blame them for it.

- When people living with HIV/AIDS are treated unfairly, they suffer discrimination. People may fear that their HIV status will be obvious to others if they are seen to be having treatment. This could result in loss of work or home, or their children may be stopped from going to school. Sometimes health workers refuse to provide treatment for people living with HIV/AIDS because they fear that they may become infected. They may also believe that they do not have sufficient technical skills to provide treatment.

- Fear of stigma and discrimination can also prevent people from seeking treatment. But if people living with HIV/AIDS are included in family and community activities and involved in prevention, care, support and treatment work, this can be a very effective way of reducing stigma and discrimination.

- People may think that HIV/AIDS mostly affects people in specific groups, such as sex workers, men who have sex with men, and injecting drug users. Often these groups are already discriminated against or have poor access to health care, and HIV/AIDS adds to their difficulties. Overcoming stigma and discrimination is an important way of improving their access to HIV/AIDS-related treatment.

- Confidentiality is about sharing sensitive information (such as a person's HIV status) only with those who really need to know. The person most affected by the information – the person living with HIV/AIDS – is the 'owner' of the information. Others must respect their wishes about sharing it. Wherever possible, the person living with HIV/AIDS should be encouraged to share the information him/herself with those who really need to know. If this cannot be done, the person's consent must be obtained before passing the information to others. If people feel that their HIV status will remain confidential, they will be more likely to seek counselling, testing, treatment and support.

False 'cures'

Sometimes, people persuade those who have, or think they have, HIV/AIDS to use their services by seeming to offer acceptance and help. They give false or dangerous treatments that they claim can make people better or even 'cure' them. But there is still no known treatment – whether traditional, pharmaceutical or alternative – that can make HIV go away or guarantee that symptoms will not reappear. So, any claim of a 'cure' should be regarded with extreme caution.

4. Financial barriers

People living with HIV/AIDS, their families and communities often face difficult choices about the costs of treatment. For example, they may have to decide between paying for treatment and buying food or paying school fees for children.

Drug pricing

It is useful to understand how drug producers and suppliers make decisions about how much to charge for drugs. Factors that affect prices include:

- the costs of putting a drug on the market, including its research, production, distribution and marketing;
- the price that people are willing or able to pay for a drug;
- legal controls on drug prices;
- patents (a form of legal ownership) – giving the producers of a drug sole control of it and enabling them to set prices for a number of years without competition;
- original drugs being copied as generic drugs by other companies; generics compete with the original drugs and this can lead to prices being reduced.

Reducing the cost of drugs is an important part of improving access to HIV/AIDS-related treatment. This has been done in some parts of the world by:

- buying good-quality, cheaper, generic drugs from companies in countries where patents for the original drugs have expired;
- several buyers combining their purchase of drugs and getting cheaper prices by buying larger quantities;
- political action by people living with HIV/AIDS and advocacy groups to get companies to lower their prices;
- setting up insurance schemes or solidarity funds to buy some types of treatment;
- political action to get governments to declare HIV/AIDS a national emergency, and to use legal measures to import generics or introduce local generic manufacturing;
- advocacy for governments to provide drugs at no cost in government health schemes, to abolish taxes on essential medicines and to control mark-ups on drug prices and dispensing fees.

Information Sheet 2

Factors affecting access to treatment

Access to HIV/AIDS-related treatment is affected by many factors, including the following.

1. Types of health systems

Drugs and other forms of treatment are generally used within the various health systems of a country. Health systems can be defined as public (meaning that they are provided and funded by the government) or private (meaning that they are provided and funded by commercial means or NGOs). Traditional health systems also often function alongside other systems or, in some cases, provide an important source of care that is easily available and accessible.

Public health systems are a way that governments fulfil their duty to provide for the well-being of their people. Each country has a different method of doing this; one common way is by providing funds from the national budget to spend on health. The public health system may provide care and treatment without charge, or user fees may be charged, with the person paying all or part of the costs. Services are usually supported by national policies to control costs and to ensure safe and effective use of treatments.

Private health systems are not funded by the government and they may or may not participate in government health policies or guidelines on the use of treatments. This depends on the laws about health care in a particular country. Examples include:

- doctors, care providers, hospitals and clinics that charge for their services and drugs;
- licensed pharmacies, wholesalers and general stores that sell drugs and medical supplies;
- insurance schemes that pay for health care in return for a regular payment from the client;
- NGOs/CBOs that may or may not charge for their services;
- informal providers such as market traders and unlicensed treatment providers.

Traditional health systems involve traditional healers and the use of traditional medicines. They are common in many countries and are important because:

- in some places, they may be the main source of health care that is available locally and easily accessible;
- they provide alternatives if medical treatment causes side-effects or other problems; and
- they often provide socially or culturally acceptable ways to deal with illness.

In some countries, traditional healers also have a working relationship with medical practitioners in the public and private health systems. Where this happens, it can be possible to encourage traditional healers to:

- provide care and symptom relief for HIV/AIDS-related illness;
- teach people about harmful practices;
- dispel myths about HIV/AIDS;
- teach people about HIV prevention; and
- refer people to health facilities.

2. Economic and political factors

The economic and political situation of a country also affects access to HIV/AIDS-related treatment. The poorest countries have the heaviest burdens of illness and HIV/AIDS can make existing difficulties even worse. It is much harder for people to resist infections if they do not have adequate physical and financial security, food and education. If there is an overall lack of money – both nationally and individually – there are fewer funds for care and treatment.

Political will, which involves leaders deciding to make HIV/AIDS a priority, can drive action on access to HIV/AIDS-related treatment. This often depends on commitment from the most senior people in power – from presidents to community leaders. Political will can change official priorities for health care and is also important for reducing stigma and discrimination.

3. Stage of the epidemic

The stage of the HIV/AIDS epidemic in a country affects how many people need treatment. In turn, this affects the demands on local health systems.

Early stages of HIV/AIDS epidemic

At this stage, most people living with HIV/AIDS are not yet sick and only a small number need treatment. Therefore, the needs are likely to be:

- HIV prevention, including diagnosis and treatment of sexually transmitted infections and tuberculosis
- HIV/AIDS information, diagnosis, counselling and support to help people to cope psychologically
- preparation to help people to cope in the future when more people will become sick
- training and sensitization of health-care workers
- sensitization and education of communities

Later stages of HIV/AIDS epidemic

At this stage, more people living with HIV/AIDS are visibly sick or dying, and more need treatment. Therefore, the needs are likely to be:

- support and information for people who are living with HIV/AIDS but are not yet sick
- HIV/AIDS-related treatment and care and support for people with varying degrees of illness
- support for people who care for others in their family or community
- support for adults and children who have lost family members
- HIV prevention to reduce both the number of new infections and the extent of illness in those with HIV/AIDS
- balancing needs relating to HIV/AIDS with the community's overall health and social needs

1.4 Further sources of information

Care, involvement and action: mobilising and supporting community responses to HIV/AIDS care and support in developing countries. International HIV/AIDS Alliance, June 2000. A report sharing the lessons learned in community-based care and support in Africa, Asia and Latin America.

Care and support for people with HIV/AIDS in resource-poor settings. C Gilks et al., Department for International Development (DFID), 1998. A review of care needs for people living with HIV/AIDS, discussion of strategies, costs and impact of ways to improve quality of life.

HIV/AIDS prevention in the context of new therapies. Report of a meeting organized by UNAIDS and AIDS Research Institute of the University of California, San Francisco. A Laporte, P Aggleton. Geneva, UNAIDS, 1999 (UNAIDS/99.11E). A discussion of changing contexts of HIV prevention and care and the relevance of antiretroviral drugs to prevention and care programmes.

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Chapter 2
Foundations of treatment

Chapter 2 of this handbook helps groups to develop an understanding about:

- the basic elements of treatment, including how supportive relationships combine with knowledge, skills, attitudes and ethics for effective treatment work;
- how different treatments vary, including how technical, financial and social factors affect what NGOs, CBOs and PLWHA groups working in HIV/AIDS-related treatment can provide, and what HIV/AIDS-related treatment can be accessed by people living with HIV/AIDS;
- working with others to improve access to treatment, including partnerships with communities, donors, government and others, and advocacy at community, national and international levels.

2.1 The basic elements of treatment work

2.1.A Supportive relationships for treatment work

Supportive relationships aim to improve the quality of people's lives. They are at the core of providing effective treatment for people living with HIV/AIDS.

Supportive relationships are important in HIV/AIDS-related treatment work for the following reasons:

- they bring together someone who needs treatment and someone who can respond to those needs in a supportive and effective way;
- they are based on identifying the needs of the person seeking treatment and helping that person to live a better and longer life;
- they are two-way – with both people needing openness, cooperation and information for treatment to be effective; and
- they are based on trust and need to grow over time.

There are many kinds of supportive relationships such as that between a doctor and a patient and that between a community volunteer and someone who is ill at home.

Supportive relationships in treatment work are built and maintained in different ways.

- Making treatment available and accessible helps to build trust within supportive relationships. Supportive relationships promote good use of treatment – because even drug-based treatments need a supportive environment in order to work properly.
- People living with HIV/AIDS can both help themselves and support others affected by HIV/AIDS. Any relationship involving people living with HIV/AIDS needs to be based on a positive attitude and a belief that treatment is worthwhile.
- A health worker who prescribes HIV/AIDS-related drugs has special technical knowledge and skills that people needing treatment often do not have. The skilled

helper and the person living with HIV/AIDS should decide together what treatment is useful and what effect it might have on the person's life, not just medically but also economically and socially.

- A person living with HIV/AIDS needs to be respected as someone who can make choices about treatment. Treatment will be more effective if the helpers, with technical knowledge, encourage people living with HIV/AIDS to be actively involved in their own treatment.
- A person living with HIV/AIDS who helps her/his seronegative partner to avoid infection, and a seronegative person who supports a person living with HIV/AIDS to maintain treatment use, are also examples of supportive relationships.

Participatory group activity

Aim

To understand the different supportive relationships involved in providing treatment for people living with HIV/AIDS.

Instructions

1. Explain the aim of the activity.
2. Divide participants into small groups of four to six people.
3. Ask each group to think of a 'typical' person living with HIV/AIDS in their community. Ask the group to brainstorm about who might be involved in supportive relationships in providing treatment for that person.
4. Give each group a large piece of flipchart paper. Ask the groups to draw their typical person living with HIV/AIDS in the centre. Then ask them to write around the person the names of those they thought of while brainstorming.
5. Give each group a different coloured pen. Ask them to draw lines to show where supportive relationships occur between the people that they have drawn. This will result in a web of supportive relationships.
6. Bring everybody back together and ask the groups to present their results. Encourage the participants to ask each other questions and to make comments.
7. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - Why are supportive relationships necessary for providing effective treatment?
   - Is the person living with HIV/AIDS the only one to benefit from supportive relationships?
   - Should a supportive relationship be one-way or two-way? How can a 'receiver' help a 'provider'?
   - What sort of help can be given through a supportive relationship?

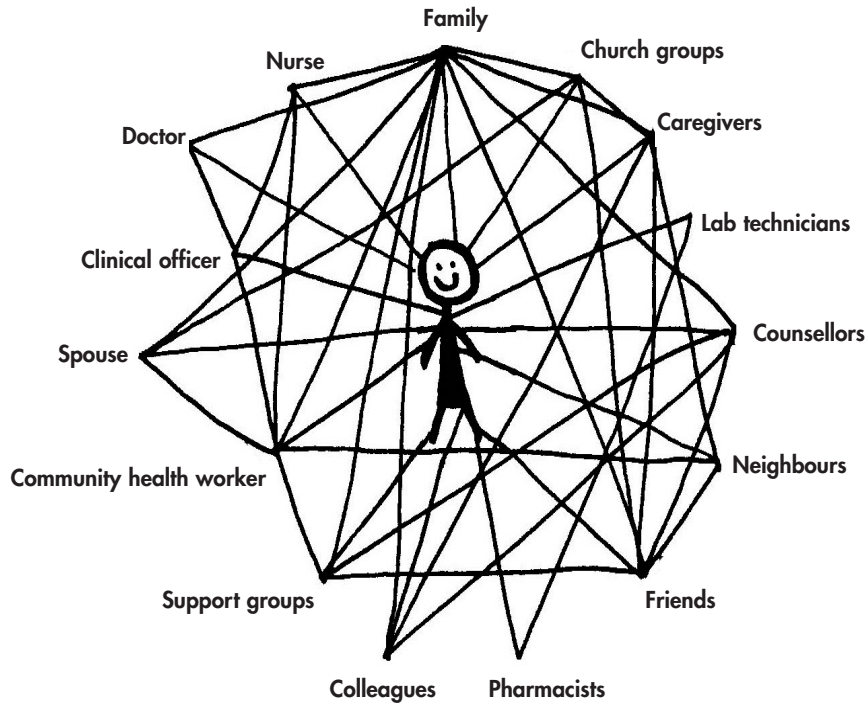
Facilitators' notes

- Participants may think of a supportive relationship as being only between a doctor and a patient. Therefore, encourage them to think as broadly as possible about all types of people that might be involved, including family, friends, colleagues, health workers, counsellors and other people living with HIV/AIDS.
- Emphasize to participants that it is important to see people living with HIV/AIDS as active providers as well as receivers within supportive relationships.
- Encourage participants to consider how providers of support might be able to help each other. For example, the family of a person living with HIV/AIDS could help health workers by sharing information about their needs and how they might be met.

Example

At a skills-building workshop, participants drew a diagram to show all the different people who could be involved in supportive relationships in providing treatment to a typical person

living with HIV/AIDS. They then drew lines to show how those people relate to the person living with HIV/AIDS and to each other, resulting in a web of supportive relationships:



Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that, for treatment to be effective, a person living with HIV/AIDS needs to be both a provider and a receiver in supportive relationships.

Reference: Adapted from a workshop on access to HIV-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April, 2001.

2.1.B Knowledge, skills and attitudes for treatment work

Knowledge, skills and attitudes are all important for establishing a supportive relationship and providing effective treatment to a person living with HIV/AIDS.

Knowledge means an understanding of information and ideas. It is important for HIV/AIDS-related treatment because it allows caregivers to understand what is going on, to reassure the person seeking help, and to suggest the most appropriate plans. It is important that knowledge is kept up to date, so that it can be the basis for providing the best possible treatment.

Having skills means knowing how to do something. The skills may relate to technical work (such as how to prescribe medicines) or 'people' work (such as how to support a person living with HIV/AIDS in communicating their treatment needs). Some of the most essential skills for providing effective treatment include:

- listening
- planning
- taking action.

Attitudes refer to how individuals view issues and other people. Appropriate attitudes are vital for people involved in HIV/AIDS-related treatment work. For example, if a person is open and genuine, rather than condemning or pitying people living with HIV/AIDS, it will encourage people to come forward for help, take care of themselves and avoid feeling overwhelmed. It is also important for people involved in treatment work to be respectful and accepting of socially marginalized people such as sex workers, prisoners, men who have sex with men, and injecting drug users.

Some examples of the knowledge, skills and attitudes needed for effective HIV/AIDS-related treatment work are set out below.

Knowledge

- HIV transmission
- Nutrition
- Health education
- Positive living
- HIV/AIDS-related treatment:
  - – symptoms and causes
  - – treatments for common problems
  - – drugs
  - – new treatments

Skills

- Communication
  - – asking questions
  - – listening
  - – checking that people understand
- Planning/managing treatment with the person living with HIV/AIDS
- Follow-up and referral
- Training
- Counselling

Attitudes

- Compassionate
- Respectful and non-judgemental
- Honest
- Based on common sense
- Equal
- Positive and encouraging

Participatory group activity

Aim

To identify the knowledge, skills and attitudes needed by an 'ideal' treatment provider.

Instructions

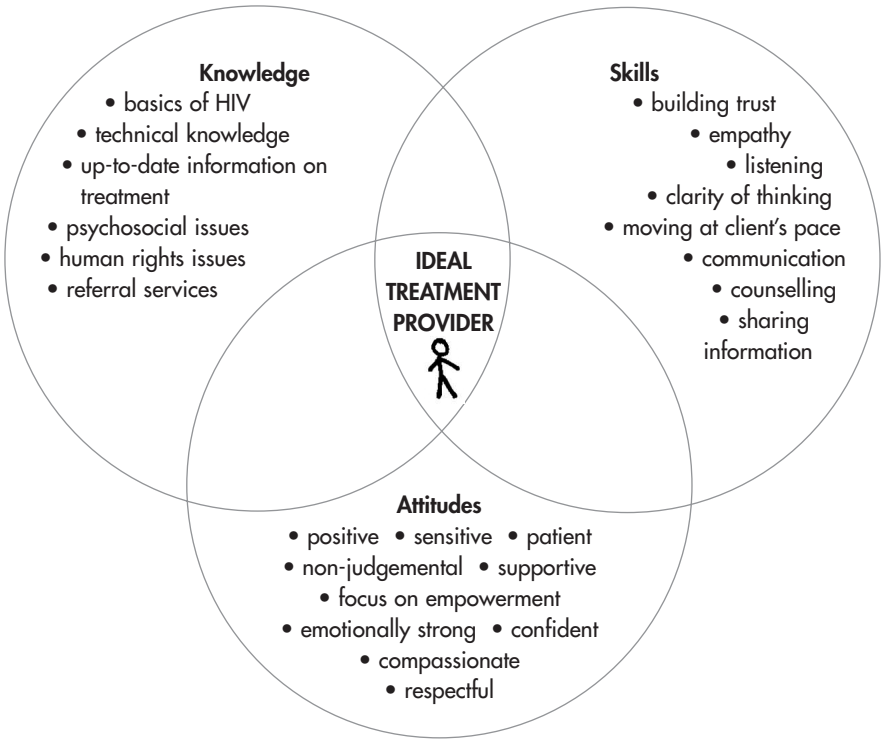
1. Explain the aim of the activity.
2. Present participants with the definitions of knowledge, skills and attitudes (see above). Provide them with an example of what each one means in practice in relation to HIV/AIDS-related treatment work.
3. On a large piece of flipchart paper, draw three interlinking circles and label them 'knowledge', 'skills' and 'attitudes'. Draw an ideal treatment provider in the centre where the circles overlap.
4. Ask participants to write the knowledge, skills and attitudes of an ideal treatment provider on small pieces of paper and to stick them in the appropriate circle on the flipchart.
5. Review what everybody has placed in the three circles. Encourage the participants to ask each other questions and to make comments.
6. Facilitate a discussion about what has been learned from the activity, based upon questions such as:
   - Did participants determine the relative importance of knowledge, skills and attitudes?
   - Which knowledge, skills and attitudes are preferable and which are necessary?
   - How does the ideal treatment provider compare with reality?
   - What practical steps can NGOs/CBOs take to close the gap?

Facilitators' notes

- Remind participants that no one is perfect and that the ideal treatment provider is simply something to aim for! Help them to focus on practical ways to make their own work as near to ideal as possible, while taking into account their context and resources.
- Encourage participants to see that a balance of knowledge, skills and attitudes is necessary for treatment work to be effective. For example, a doctor might have immense knowledge, but, without good communication skills and a positive attitude, her/his work will not be successful.

Example

At a skills-building workshop, NGO/CBO participants brainstormed about what knowledge, skills and attitudes are required to carry out effective HIV/AIDS-related treatment. They then presented them in the form of a diagram with an ideal treatment provider at the centre.



Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that the negative attitudes of doctors often arise because they lack skills and resources, and that they need moral and practical support from others to improve their provision of treatment.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

2.1.C An ethical approach to treatment work

A respect for ethics is an important part of effective HIV/AIDS-related treatment. This involves the principles or morals that shape people's personal and professional behaviour and their attitudes towards others.

An ethical approach to treatment is based on the principles of proactively doing no harm and minimizing risk. Ethics are particularly important in the context of work on HIV/AIDS as it is a highly personal and sensitive subject. In addition, work on access to HIV/AIDS-related treatment is, at times, complex and controversial, especially as it highlights issues of inequality.

Some examples of an ethical approach to HIV/AIDS-related treatment work include:

- empowering people living with HIV/AIDS and allowing them to choose for themselves;
- not discriminating against people – for example, because of their HIV status or because they use illegal drugs;
- maintaining confidentiality;
- ensuring suitable and equal participation by all those involved;
- ensuring that benefits and difficulties are shared appropriately among those involved; and
- appropriate referral.

Wherever possible, an ethical approach to HIV/AIDS-related treatment should be developed in a participatory way, involving both providers and receivers. This will help to ensure that everyone is following an agreed way of working.

Participatory group activity

Aim

To identify an ethical approach to HIV/AIDS-related treatment work.

Instructions

Before starting this activity, the facilitator needs to develop three role plays about providing treatment to people living with HIV/AIDS in the community. Each role play should highlight a key ethical issue relating to treatment work, such as:

Role play 1: a person living with HIV/AIDS being refused treatment;
Role-play 2: a person living with HIV/AIDS refusing to take treatment;
Role-play 3: a health worker testing someone for HIV without their consent, and then breaching confidentiality about the result.

The role plays should involve a variety of treatment providers (not just doctors), and should try to show people living with HIV/AIDS in different types of family or community situations.

1. Explain the aim of the activity.
2. Ask a small group of participants to act out the first role play.
3. Facilitate a group discussion about what ethical issues about HIV/AIDS-related treatment were highlighted by the role play. Ask participants how the situation could have been improved. Encourage the participants to ask each other questions and to make comments.
4. Repeat the process for the second role play.
5. Repeat the process for the third role play.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • Why might people act unethically? How can you help them to change their behaviour?
   • Is it ever appropriate to breach a person's confidentiality when providing HIV/AIDS-related treatment?
   • How can treatment providers respond if their ethics are different from other caregivers or the person living with HIV/AIDS?

Facilitators' notes

- Select enthusiastic and appropriate participants to act out the role plays and give them an outline of the story in advance so that they can prepare.
- Encourage those acting out the role plays to be creative – for example, by wearing costumes or using objects – in order to bring the situations to life.
- Encourage participants to draw the links between ethics and the other aspects of an 'ideal' treatment provider – namely, knowledge, skills and attitudes (see previous activity).
- Encourage participants to consider how their personal beliefs (for example, about religion) might affect their professional ethics when involved in treatment work.

Example

At a skills-building workshop, NGO/CBO participants acted out the following role play about a person living with HIV/AIDS being refused treatment:

> *Tilak is known in his community as a drug user. He is feeling very ill so he goes to see the doctor at the local NGO clinic. Dr Singh suspects that Tilak may have meningitis and TB.*
>
> *Dr Singh recommends that Tilak be taken to the government hospital for more specialized care. A staff member from the NGO accompanies Tilak to the hospital.*
>
> *Tilak is refused treatment in the outpatient department and denied admission to the hospital.*

After the role play the participants identified the key ethical issues highlighted by it and how the situation could be improved. The participants then followed the same process for two further role plays – the first about a person living with HIV/AIDS refusing to take treatment, and the second about a health worker testing someone for HIV without their consent and breaching their confidentiality about the result.

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that refusal to treat someone who is thought to be HIV-positive is discrimination and a violation of their right to health.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

2.1.D Information for treatment work

Good information is vital for treatment work. It enables the person who needs treatment and the person who provides treatment to make appropriate and effective decisions together about what will be effective and how to put it into practice.

Effective HIV/AIDS-related treatment work requires information in two areas: the nature of the health problem, and the treatment required.

The health problem. To provide effective treatment, a diagnosis has to be made to understand what is causing the problem. This means identifying and naming specific illnesses. It usually requires some special training, but people who may not be qualified health workers can often diagnose common conditions after some basic skills-building – for example, community health workers are often trained to recognize the signs of TB. A diagnosis can be based on symptoms, such as cough or diarrhoea, and the history of the problem (meaning what is said about how the symptoms developed). Sometimes, it may also be necessary to do a laboratory test to be certain of the diagnosis or to monitor progress during treatment.

The treatment. When a diagnosis and treatment have been decided, the relevant information needs to be:

- **objective** – it is neutral, not affected by discriminatory attitudes, and free of bias (for example from someone seeking to persuade people to use a particular type of treatment);
- **accurate** – it is up to date and gives people a clear idea of what the treatment is, when and how to use it, and how it will make a difference to particular health problems;
- **in simple language** – it is communicated in a way that those providing and receiving the treatment can easily understand.

HIV testing

People often ask for an HIV test because they have some symptoms such as continual diarrhoea. A laboratory test, to check a sample of blood, can confirm the diagnosis. Sometimes trained health workers can diagnose HIV infection without testing, because the person's pattern of illness strongly suggests that HIV is the cause. However, testing, like any form of treatment, should be carried out only with the informed consent of the person.

Early testing and diagnosis for HIV can be very helpful because, when people know their HIV status, they can act both to take care of themselves and to avoid passing the virus on to others. If the result is positive, they can get the care and support they need for living with HIV/AIDS.

This process should be accompanied by appropriate information, counselling and support to help the person to cope with the news, to seek the treatment that they need, and to plan for the future.

Participatory group activity

Aim

To identify common health problems experienced by people living with HIV/AIDS, treatments for them and the type of information needed.

Instructions

Part 1: Common health problems

1. Explain the aim of the activity.
2. Draw a line on a large flipchart to represent the lifeline of a typical person living with HIV/AIDS in the local community. For example, it might start with the person receiving a diagnosis of being HIV-positive and end with their death.
3. Ask participants to suggest common health problems that the person living with HIV/AIDS might experience during their life. Examples might include fever or TB. Write these down at appropriate points along the lifeline.
4. Facilitate a brief discussion about what has been learned from the activity, based upon questions such as:
   • What does the lifeline show about the number and types of illnesses that a person living with HIV/AIDS might experience?
   • Which of these illnesses are major and which are more minor?

Part 2: Treatment for common health problems

5. Ask participants to select the three or four most common health problems identified in Part 1 on the previous page. Ask them to write each one on a separate piece of flipchart paper.
6. Ask the participants to suggest possible treatments for each problem. List them on the appropriate sheet. Examples might include aspirin or TB drugs.
7. Clarify any points that are unclear and correct any misconceptions (for example, about which drugs are effective for which illnesses).
8. Facilitate a brief group discussion about what has been learned from the activity, based upon questions such as:
   • What do the lists show about the variety of treatments that a person living with HIV/AIDS might require during their lifetime?
   • Which treatments are available and accessible in the local community?

Part 3: Information about treatment

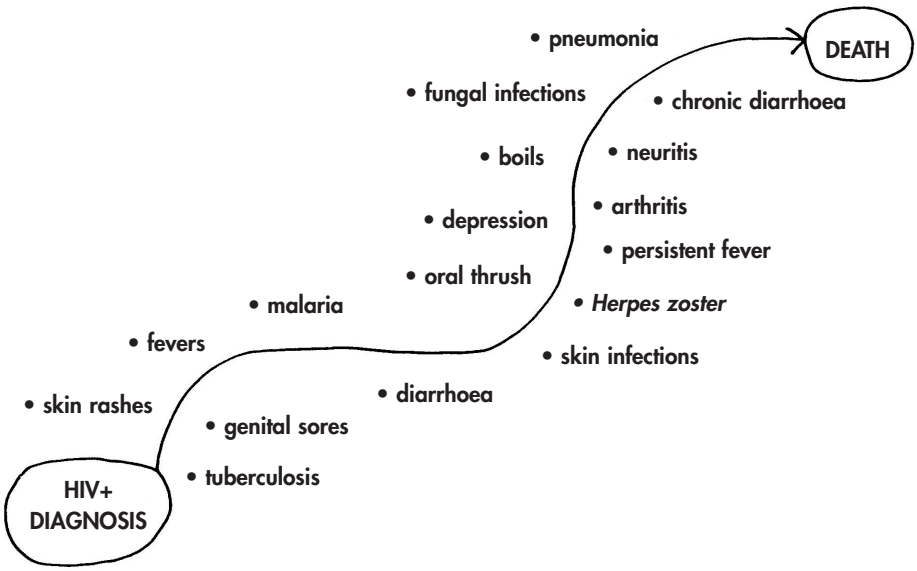
7. Ask each participant to select one of the treatments identified in Part 2 above.
8. Give the participants time (such as over a lunch break) to fill in a treatment information sheet about their selected treatment (see example at the end of this chapter).
9. Bring the participants back together to share their experiences on filling in the sheets. Encourage them to ask each other questions and to make comments.
10. Facilitate a group discussion about what has been learned from the activity, based on questions such as:
    • How easy was it to get the information?
    • Who can get this information? Who needs it?
    • Is all of the information necessary? Is more information needed?

Facilitators' notes

- The facilitators for this activity should be familiar with treatments for common HIV/AIDS-related conditions, including the range of treatments that are available locally.
- Remember that the aim of the activity is to find out what is actually happening in practice. Get participants to talk about real experiences rather than what the textbooks say about treatments.

Example

At a skills-building workshop, NGO/CBO participants drew a lifeline of a person living with HIV/AIDS, noting the common health problems that might be experienced:



The participants then identified three or four of the most common health problems and listed the possible treatments for them. For example, for chronic diarrhoea, participants identified the following treatments.

Common health problem: chronic diarrhoea

- oral rehydration salts
- guava leaves
- charcoal
- folic acid
- strong tea leaves
- rice water
- imodium (loperamide)
- intravenous fluid (for severe diarrhoea)
- flagyl (metronidazole)
- septrin (co-trimoxazole)

Then the participants selected one of the identified treatments and filled in a treatment information sheet (see end of this chapter) for it, as in the example below.

Treatment Information Sheet

Basic information	
What is the treatment called?	*Charcoal*
How does the treatment help people living with HIV/AIDS?	*Stops chronic diarrhoea*
Using the treatment	
What form does the treatment take and how is it used?	*Tablets that can be swallowed*

Afterwards, the facilitator led a group discussion about what had been learned from the activity. Participants agreed that people living with HIV/AIDS, their families, NGOs/CBOs and health workers all need clear and accurate information about treatment from people with the relevant training and experience.

Reference: Adapted from a workshop on access to HIV-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April 2001.

2.2 How different treatments vary

All effective treatments have some common elements, such as supportive relationships and respect for ethics. However, the factors that affect decisions about treatments can be very different. These include technical, financial and social factors.

Technical factors. Treatments can differ in the training, equipment and facilities needed to provide them. For example, in a home-care setting, these would vary greatly for paracetamol compared with antiretroviral drugs.

Key technical questions to consider:

- How much training is required to provide the treatment?
- Can the treatment be provided only by a qualified health worker?
- Are special equipment, facilities or services required to provide the treatment?
- Is it easy for the person receiving the treatment to use it?
- Is the treatment effective only if it is taken in combination with others?

- Does the person using the treatment need the help of a skilled worker to use it?
- Would you start the treatment without being sure that you have enough supplies for the full course?
- Can the treatment be delivered easily to a large number of people?

Financial factors. The costs of treatments vary greatly. It is important to consider whether the costs can be met for the whole time that a treatment should be given. If a treatment is not used for the correct time, people can become ill again or become resistant to certain drugs, making further treatment more difficult or even impossible. It is important to consider how much it will cost for someone to access the treatment for as long as they need it.

Key financial questions to consider:

- What is the actual cost for the full course of the treatment?
- Are there other costs involved in the treatment (such as travel, food or the necessary laboratory tests)?
- What are the costs involved in delivering the treatment to a sizeable number of people?
- Would you start providing the treatment if you did not have enough money to pay for the full course?

Social factors. Social factors play an important role in accessing treatment. For example, if those attending an HIV/AIDS clinic are stigmatized, people may not go there for treatment. Communities view different treatments in different ways. It may be acceptable for people to openly use paracetamol but stigmatizing to use TB drugs. So, even if the treatment is available, people may be afraid to access it.

Key social questions to consider:

- How does the community view the treatment?
- What are the social implications for someone who goes for/uses the treatment?
- Is the treatment sensitive to the person seeking treatment? For example, can a sex worker access the treatment?
- Do cultural beliefs or practices have an impact on the treatment?

Participatory group activity

Aim

To assess different treatments in terms of their technical, financial and social factors.

Instructions

1. Explain the aim of the activity.
2. Divide the participants into three groups. Allocate a type of treatment to each group, for example:
   Group 1: a drug for TB prophylaxis, such as isoniazid (INH);
   Group 2: an antiretroviral drug, such as zidovudine (AZT);
   Group 3: a drug for pain relief, such as paracetamol.
3. Give each group a copy of a treatment assessment sheet (see example on page 53 at the end of this chapter). Ask them to use it to assess the technical, financial and social factors that affect their type of treatment.
4. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.

5. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • To what extent do the factors vary for the different treatments?
   • How would the different factors affect the decisions that an NGO/CBO might make about what type of treatment to provide?
   • Which factors could be easily changed? Which could not?

Facilitators' notes

- Select treatments that participants are familiar with, so that they can carry out a thorough analysis.
- Encourage participants to discuss the answers to the questions in the treatment assessment sheet and to reach consensus within their group, rather than simply ticking the boxes.
- Encourage the participants to identify other key questions about technical, financial and social factors affecting treatment.

Example

At a skills-building workshop, NGO/CBO participants used a treatment assessment sheet to analyse the technical, financial and social factors affecting three types of HIV/AIDS-related treatment – paracetamol (a drug for pain relief), isoniazid (a drug for TB prophylaxis) and zidovudine (an antiretroviral drug). The results of the analysis of technical factors for paracetamol, for example, are shown in the box below.

Treatment Assessment Sheet
Paracetamol: technical factors

What level of training is required to provide the treatment?	(Low)	Medium	High
Can the treatment be provided only by a qualified health worker?	Yes	(No)	Don't know
Are special equipment, facilities or services required to provide the treatment?	Yes	(No)	Don't know
Is it easy for the person receiving the treatment to use it?	(Yes)	No	Don't know
Is the treatment effective only if it is taken in combination with others?	Yes	(No)	Don't know
Does the person using the treatment need the help of a skilled worker to use it?	Yes	(No)	Don't know
Would you start the treatment without being sure that you have enough supplies for the full course?	(Yes)	No	Don't know
Can the treatment be delivered easily to a large number of people?	(Yes)	No	Don't know

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that NGOs/CBOs need to make strategic decisions about balancing cheap general treatments (such as paracetamol) with expensive HIV/AIDS-specific ones (such as antiretroviral drugs).

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

2.3 Working with others to improve access to treatment

2.3.A Partnerships to improve access to treatment

No one person or organization on their own can address all the treatment needs of people living with HIV/AIDS. Working with others can help to improve access to new and existing treatments and resources. It can also improve the quality of the treatment that is provided and help in reaching more people.

Examples of the complementary roles of different types of organizations include the following:

- **Communities and solidarity groups** can provide personal support for people living with HIV/AIDS and keep others in touch with treatment needs.
- **NGOs/CBOs** can provide people, training, information, ideas, material support and skills (such as in counselling) for treatment work.
- **Government systems** can provide policies, leadership, human resources and material support (such as skilled health workers, drugs and medical supplies) for treatment work;
- **Businesses** can provide financial or 'in kind' sponsorship for treatment work, and encourage public support.
- **Professional associations and academic institutions** can contribute knowledge and guidance on treatment, as well as contributing research and generating new knowledge that may be helpful in improving treatment.
- **Donors** can provide funds for treatment work and facilitate learning from the experiences of other countries.
- **Religious organizations** can provide volunteers for treatment work, mobilize community support and help to reduce discrimination.
- **Media** can provide accurate information about treatment issues, help to raise awareness and reduce stigma.

Participatory group activity

Aim

To identify those with whom an NGO/CBO can work to improve access to HIV/AIDS-related treatment in their community.

Instructions

1. Explain the aim of the activity.
2. Divide participants so that they are working with colleagues from their own NGO/CBO.
3. Ask participants to write the name of their NGO/CBO in a circle in the centre of a piece of flipchart paper.
4. Ask participants to brainstorm about what people and organizations their NGO/CBO could work with to improve access to HIV/AIDS-related treatment in their community.
5. Ask participants to write the names of each of the people and organizations in a circle around their NGO/CBO. Ask them to draw a line connecting each one to their NGO/CBO.
6. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
7. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • What practical support and resources can each person or organization bring to work on access to treatment?
   • Which people or organizations are already involved in work on access to treatment?

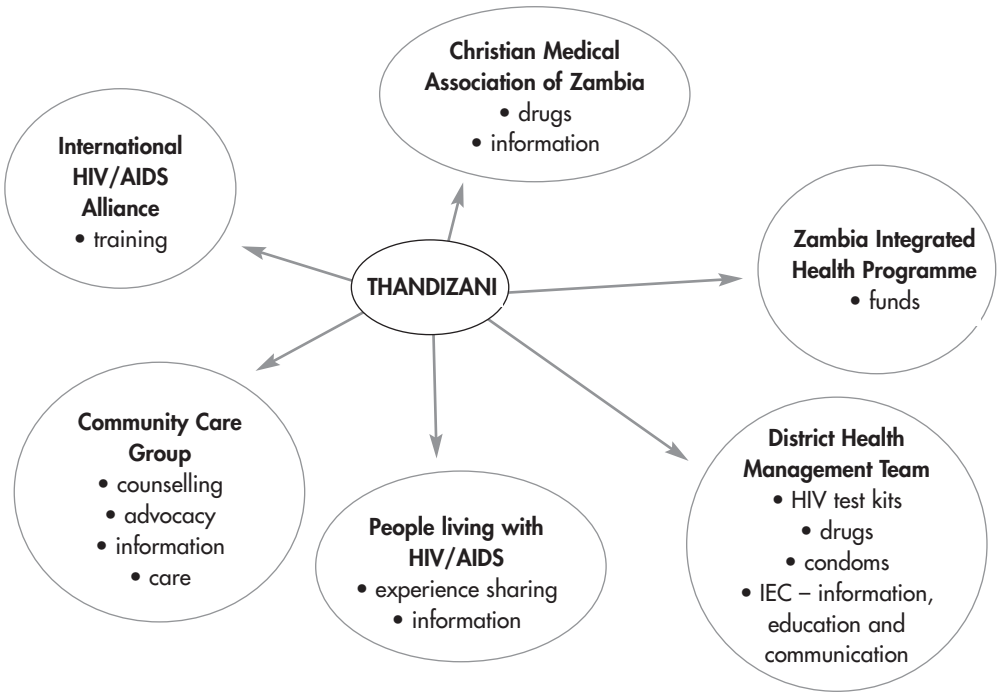
• What are they doing? What next steps should the NGO/CBO take to form a partnership with the people and organizations that they have identified?

Facilitators' notes

- Encourage participants to think broadly and creatively about who they can work with to improve access to HIV/AIDS-related treatment. For example, help them to think beyond medical professionals and also to consider groups such as religious organizations and businesses.
- Remind participants that, for drug-related treatment work to be effective, their NGOs/CBOs will also need to form partnerships with groups involved in other areas of treatment work, such as counselling and nutritional support.

Example

At a skills-building workshop, a participating NGO called Thandizani identified organizations with which it could build partnerships to improve access to HIV/AIDS-related treatment in its community.



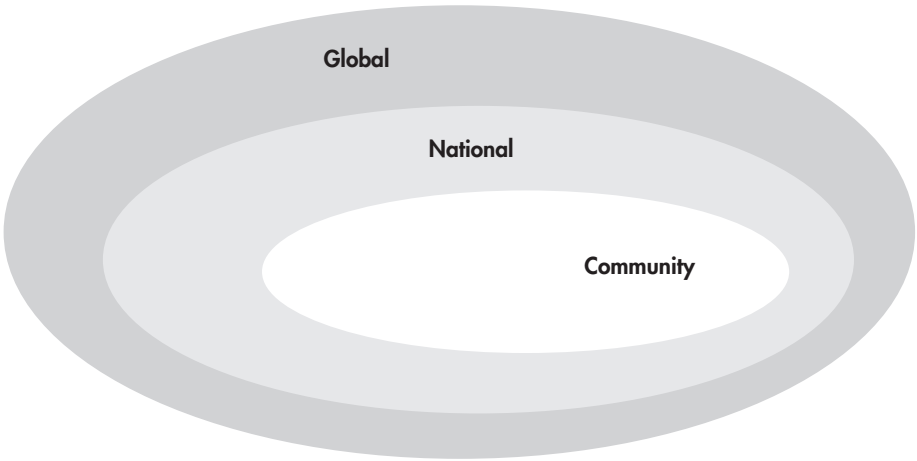
Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that working in partnership can not only increase the quantity of work on access to HIV/AIDS-related treatment, but also improve the quality, because it allows groups to share their lessons and ideas.

Reference: Adapted from a workshop on access to HIV-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April, 2001.

2.3.B Advocacy to improve access to treatment

Advocacy is a process of working towards changes in attitudes, policies and practices. It is carried out by people proposing improvements on behalf of themselves or others, and involves activities to influence decision-making individuals and institutions.

Advocacy to improve access to HIV/AIDS-related treatment requires clear strategies to bring about change on several different levels, including community, national and global. Advocacy at one level can significantly impact the other levels.



Examples of advocacy by NGOs/CBOs for improving access to treatment at different levels include:

- **Community level**
  – accompanying people living with HIV/AIDS to the hospital or clinic to ensure that they receive treatment;
  – influencing local pharmacists to stock drugs that are needed for people living with HIV/AIDS;
- **National level**
  – participating in the development of standard treatment guidelines for HIV/AIDS;
  – influencing the government to improve the supply of HIV/AIDS-related drugs in hospitals and clinics;
- **Global level**
  – lobbying international pharmaceutical companies to reduce the price of HIV/AIDS-related drugs;
  – encouraging international drug suppliers to make HIV/AIDS-related drugs widely available at low cost.

Participatory group activity

Aim

To raise awareness about how advocacy at different levels could improve access to HIV/AIDS-related treatment.

Instructions

1. Explain the aim of the activity.
2. Present participants with a definition of advocacy (see previous page). Share an example of an advocacy strategy on access to treatment at each level – community, national and global.
3. Divide the participants into three groups and ask them to brainstorm about, and list, possible advocacy strategies. Ask:

Group 1 to focus on community-level advocacy
Group 2 to focus on national-level advocacy
Group 3 on global-level advocacy.

4. Bring everybody back together and ask the groups to present their results. Encourage the participants to ask each other questions and to make comments.
5. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - How does advocacy on one level affect issues at another level?
   - What types of resources are needed for advocacy strategies at different levels?
   - What contributions can different types of organizations make to advocacy work?

Facilitators' notes

- Support participants to think creatively about advocacy strategies. Encourage them to think about what would really make a difference.
- Support participants to think realistically about advocacy strategies. Encourage them to think about what they can really achieve.

Example

At a skills-building workshop, NGO/CBO participants identified the following examples of advocacy strategies for improving access to treatment at community, national and global levels.

Community level	National level	Global level
• Advocate better collaboration between NGOs on access to HIV/AIDS-related treatment • Advocate more information about issues relating to treatment and access to HIV/AIDS-related treatment	• Advocate an improved supply of free drugs from the government • Advocate on international issues such as compulsory licensing and parallel importing of HIV/AIDS-related drugs	• Advocate more involvement of people living with HIV/AIDS in work on treatment issues • Advocate lower international prices for HIV/AIDS-related drugs

The facilitator then led a group discussion about what had been learned from the activity. For example, participants agreed that the involvement of people living with HIV/AIDS in advocacy on access to HIV/AIDS-related treatment was vital at all levels.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

Treatment Information Sheet

Basic information

What is the treatment called?
(may have more than one name …)

How does the treatment help people living with HIV/AIDS?

Using the treatment

What form does the treatment take and how is it used?
(e.g., lotion to rub on skin, tablets to swallow …)

How much of the treatment should you use at a time?
(e.g., two tablets, a teaspoon of syrup …)

How often should you use the treatment?
(e.g., whenever you feel the need, twice a day …)

How long should you use the treatment for?
(e.g., for one week, until the problem gets better, the rest of your life …)

Do you need to do anything else to go with the treatment?
(e.g., drink lots of water, take the treatment before or after food, avoid specific foods …)

Effects of the treatment

Can the treatment have harmful effects? If so, what are they?

What should you do if you suffer harmful effects from the treatment?

What do people who have used the treatment say about it – good and bad?

Obtaining the treatment

Where can you get the treatment?

How much does it cost, in cash or goods?

Are there any extra costs for using the treatment?
(e.g., fees to the health-care provider, buying other supplies such as dressings …)

What will the total costs be for a complete course of the treatment, or (for long-term treatment) per month or week?
(e.g., costs for follow-up)

What is the total when the cost of the treatment is added to any extra costs?

Is there any other information you should have about the treatment?

Treatment Assessment Sheet

Name of treatment .....

Technical factors

What level of training is required to provide the treatment?	Low	Medium	High
Can the treatment be provided only by a qualified health worker?	Yes	No	Don't know
Are special equipment, facilities or services required to provide the treatment?	Yes	No	Don't know
Is it easy for the person receiving the treatment to use it?	Yes	No	Don't know
Is the treatment effective only if it is taken in combination with others?	Yes	No	Don't know
Does the person using the treatment need the help of a skilled worker to use it?	Yes	No	Don't know
Would you start the treatment without being sure that you have enough supplies for as long as the treatment is necessary?	Yes	No	Don't know
Can the treatment be delivered easily to a large number of people?	Yes	No	Don't know

Financial factors

What is the duration of the treatment?	Short	Medium	Long
What is the actual cost of the treatment?	Low	Medium	High
What are the other costs involved in the treatment (such as travel, food and necessary laboratory tests)?	Low	Medium	High
What are the costs involved in delivering the treatment to a sizeable number of people?	Low	Medium	High
Would you start providing the treatment if you didn't have enough money to pay for the full course?	Yes	No	Don't know

Social factors

How does the community view the treatment?	Positive	Negative	Neutral
What are the social implications for someone who goes for/uses the treatment?	Positive	Negative	Neutral
Is the treatment sensitive to the person seeking treatment? For example, can a sex worker access the treatment?	Yes	No	Don't know
Do cultural beliefs or practices have an impact on the treatment?	Yes	No	Don't know

2.4 Further sources of information

Enhancing the greater involvement of people living with or affected by HIV/AIDS (GIPA) in sub-Saharan Africa. Best Practice Key Material. Geneva, UNAIDS, 2000 (UNAIDS/00.38E). A report outlining the principles and issues related to the greater involvement of people living with HIV/AIDS.

The involvement of people living with HIV/AIDS in the delivery of community-based prevention, care and support services in Ecuador – research summary. Horizons–Population Council and International HIV/AIDS Alliance, 2001. A report summarizing the research results of different aspects of the involvement of people living with HIV/AIDS.

Voluntary counselling and testing (VCT). Best Practice Technical Update. UNAIDS, May 2000. A report outlining the technical aspects, background and challenges of voluntary testing and counselling.

Building partnerships: sustaining and expanding community action on HIV/AIDS. International HIV/AIDS Alliance, March 2000. A report outlining experiences and lessons learned in helping communities and NGOs to develop and sustain partnerships for improving responses to HIV/AIDS.

Pathways to partnerships toolkit. International HIV/AIDS Alliance, May 1999. A toolkit of practical ways for NGOs and community groups involved in HIV/AIDS to plan and build effective partnerships with other organizations.

AIDS home care handbook. Geneva, World Health Organization, 1993 (WHO/GPA/IDS/HCS/93.2). A manual about care and support for people living with HIV/AIDS at home, for health workers and communities, which aims to boost confidence about people's own ability to provide safe, compassionate and helpful care to people living with HIV/AIDS.

Food for people living with HIV/AIDS. Luanne Epstein, Network of Zambian People Living with HIV/AIDS, 1995. A handbook on nutrition and positive living for people living with HIV/AIDS.

Collaboration with traditional healers in HIV/AIDS prevention and care in sub-Saharan Africa. Best Practice Key Material. Geneva, UNAIDS, October 2000 (UNAIDS/00.29E). An overview of how traditional healers can be involved alongside medical and community care for people living with HIV/AIDS, with examples from various African countries and suggestions for developing collaboration.

Chapter 3
Putting treatment into practice

Chapter 3 of this handbook helps groups develop an understanding about:

- working out what material, financial and human resources are required for treatment work;
- the role of drugs in HIV/AIDS-related treatment and how to make the best use of drugs;
- the importance of managing the different aspects of drug supply; and
- the importance of managing other aspects of work on HIV/AIDS-related treatment, including money, transport and people.

3.1 Resources for HIV/AIDS-related treatment work

When an assessment has been made and priorities have been decided, an NGO/CBO needs to consider the full range of resources that will be involved in providing HIV/AIDS-related treatment. These resources can be divided into three main areas: material, financial and human.

Reliable supplies of material resources are vital for HIV/AIDS-related treatment work. These include:

- drugs and other medical supplies, such as gloves, syringes and needles;
- laboratory and diagnostic tests, chemicals and equipment;
- support materials, such as notebooks, pens, furniture and fuel; and
- maintenance materials for buildings and equipment.

The situation and type of work will determine what specific materials are necessary. It is important to think of what will be done and how it will be done, so that you can list exactly what will be needed.

Material resources for dispensing drugs

If drugs are to be dispensed, there should be a separate area for preparing and giving them out, away from where people wait. This area should include:

- dispensing equipment, including counting aids and liquid measures;
- a dispensing bench for counting tablets and recording the items being given out;
- space for the person dispensing the drugs to explain the medicines to patients; and
- supplies of dispensing materials – plastic dispensing bags, bottles, etc.

There should also be a storage area for drugs, which should be dry, shaded from heat and secured from theft. This area should include:

- adequate shelving to make stock-keeping easy and efficient;
- a fridge for any drugs and vaccines that need to be stored below 15°C; and
- a place to lock away valuable or easily misused drugs.

The materials that are needed can be grouped under these headings:

- **consumables** – such as drugs, condoms, syringes, gloves and dressings that need to be replaced regularly because they get quickly used up or have to be discarded after use;
- **equipment** – such as scissors and blood pressure machines that need replacing when they are lost, damaged or stolen;
- **capital** – such as buildings, vehicles and large equipment that should last a long time with proper maintenance.

These headings are useful because, in budgeting and accounting, items such as consumables are dealt with differently from capital items. Often, different sources of funding have to be found for different types of items.

In terms of financial resources, groups need to work out their costs for materials and human resources in order to make a budget. A budget is an essential tool for managing money. It is a way of working out how much money will be spent over a period of time – usually one year. It includes what is spent (expenditure) and what is earned or received (income).

Preparing a budget for HIV/AIDS-related treatment work

Questions to think about include the following:

- How much money is needed to start up and continue the work?
- Where will the money come from and how will it be accessed?
- What will happen if funding is interrupted?
- Should an NGO/CBO have more than one source of money?

Remember to include all the possible items and to divide them into different headings, such as wages, transport, drugs, equipment and training. Make separate lists of one-off capital items and recurring items (meaning those that come up frequently). This will help to identify ways of keeping costs as low as possible. If you do not know the exact price of an item, you can ask suppliers to provide estimates and then compare them. Budgets must be reviewed regularly; last year's budget may not be appropriate for this year, for example, if changes in prices or currency rates have occurred or if your work is expanding.

Sample treatment budget

Budget for treatment programme
January 2002 to December 2002

Money coming in (income)		**Money going out (expenditure)**	
Grant from donor	20 000	Salaries	10 000
Grant from government	20 000	Rent of premises	6 000
Miscellaneous sales	500	Purchase of drugs	11 000
Total	**40 500**	Other medical supplies	10 500
		Electricity	1 000
		Other expenses	2 000
		Total	**40 500**

Developing a budget also helps to plan for sustainability. It helps in answering questions such as: How long can the work continue with the money that is available? When will more funding be needed and where will it come from? It is important for groups to be as self-sustaining as possible and to get funds from more than one source. It is also important to think about any costs that might be paid by local people as part of their contribution to improving access to HIV/AIDS-related treatment. For example, a family might feed home-care workers during a visit, or friends might bring food to patients in hospital.

Often, the money that a group receives will not be enough to pay for everything that is needed. In these cases, the **VEN** method (see box) can be used to show in a budget which items are vital, essential, or non-essential.

Using VEN to make a budget

V = vital – something that you can never do without
E = essential – something that you would normally always have
N = non-essential – something that is good to have, but that you can manage without

You should decide whether each item proposed for a budget is vital, essential or non-essential. It is important to make these decisions as a group, as there may be different opinions!

If money is limited, most of it should be spent on vital items. If there is still some money left over, essential items can be bought. Do not purchase non-essential items until you are sure that you can get enough vital and essential supplies and have some money left over.

A group must also have good bookkeeping and accounting systems to ensure that its money is well managed. These will provide proof to donors that the money is being managed and spent effectively and help in planning future developments. The law usually requires that an independent person audits accounts regularly on a yearly basis.

A group also needs to consider its human resources. To deliver HIV/AIDS-related treatment, a group needs people who can build and maintain helping relationships with people living with HIV/AIDS. They need to have an appropriate attitude, as well as the technical knowledge and skills to do their work effectively (see Chapter 2.1.B, page 38).

Examples of relevant technical knowledge and skills include:

- making a diagnosis;
- identifying the best drugs available and current guidelines for using them;
- monitoring the effects of drugs; and
- keeping up to date about new treatments.

In addition, the people in the group need to have organizational skills to support its treatment work. These include:

- accounting and administration;
- management and planning;
- purchasing and controlling stocks of drugs and other materials; and
- fundraising and external relations.

Technical and organizational skills can be provided by a group through:

- building the skills and knowledge of existing staff and volunteers;
- recruiting and training new staff and volunteers with the right skills and knowledge;
- finding sources of skilled help and knowledge outside the NGO/CBO.

To start with, a group will need to work out a list of the relevant skills, the time needed for each task, and any training that will be necessary. These will vary greatly according to the HIV/AIDS-related treatment to be provided. For example, a hospital providing complex services for diagnosis and treatment will have very different requirements from a home-based project using a few drugs and focusing on nursing care.

You will also need to be clear about when and where your services will be provided. Then you can recruit people who are willing to work at certain times and in certain places. For example, will you provide services only during working hours or during evenings or weekends? Will you offer services in only one place, or will people have to travel to different places?

When these issues have been worked out, you can write job descriptions that say exactly what each person in the group is required to do, when they will do it, and who will be their manager.

Participatory group activity

Aim

To identify the material, financial and people resources needed for different types of HIV/AIDS-related treatment work.

Instructions

1. Explain the aim of the activity.
2. Select three types of 'typical' treatment activities carried out by local NGOs/CBOs/PLWHA groups and the number of people that benefit from them. For example:
   - a community-based TB DOTS (directly observed treatment, short course – a TB control strategy) programme – to benefit 100 people;
   - a home-care programme – to benefit 20 people living with HIV/AIDS;
   - a family health clinic – to benefit 200 people with STIs.
3. Divide participants into three groups.
4. Give each group one of the treatment activities and the number of people it would benefit. Ask them to identify the material, financial and human resources that would be required.
5. Ask participants to identify organizations with which they would need to link to get the resources for the treatment activity.
6. Ask participants to divide their material resources according to the VEN classification (of vital, essential, non-essential).
7. Bring everybody back together, and ask the groups to present their results. Encourage the participants to ask each other questions and to make comments.
8. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - How does the type of treatment affect the resources required?
   - How is the scale of resources affected by the number of people being reached?

Facilitators' notes

- Encourage participants to decide what is vital, essential and non-essential, based upon the practical needs of their patients rather than on their own opinions.

- Encourage participants to think of ways to reduce their costs – for example, by making the best use of their existing resources rather than getting new ones.

Example

At a skills-building workshop, NGO/CBO participants identified the resources that would be needed to provide home-based care for 60 people living with HIV/AIDS. They also identified other organizations with which they should link to get the resources.

	What resources are required?	What organizations should we link with?
Material resources	• Kit of essential medicines • Food • Motorbike, helmet and fuel • Raincoat	• Other NGOs • Government • National Centre for HIV/AIDS, Dermatology and STI Control
Financial resources	• Salaries for staff • Transport costs • Administration costs • Refreshments for meetings • Patient support funds	• Other NGOs • International donors • Local donors
People resources	• Home-care staff: 3 NGO staff 2 government staff 5-10 volunteers	• Other NGOs • Health centre • Community leaders • Government

The participants then used the VEN system to classify the material resources as vital, essential or non-essential.

Classification by the VEN system

Item	Classification	Item	Classification
paracetamol 500mg tablets	E	plastic bags	E
oral rehydration salts	V	cotton wool	E
loperamide	E	plasters	E
primperan (metoclopramide)	N	micropore tape	E
nystatin suspension 25ml	V	safety pins	N
potassium permanganate 10mg sachets	E	bandages	E
		tweezers	E
iodine solution 10%, 30ml vials	E	scissors	E
		cloths	N
calamine lotion 500ml	N	gloves	V
benzyl benzoate 30ml	E	household bleach	V
promethazine 100ml	N	soap powder	E
multivitamins	N	condoms	V

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

3.2 Drugs for HIV/AIDS-related treatment

Drugs are one of the most important material resources for HIV/AIDS-related treatment work. With the right drugs, it is possible to treat diseases, reduce suffering and save lives. Without them, care can still be given, but many problems will continue or get worse, and people will have less confidence that care, support and prevention are worthwhile.

Drugs can be very useful when they are made, stored and managed correctly and when they are used in the right way. Money is often wasted on drugs that are inappropriate for the health problem in question, or of poor quality, or badly managed. Drugs are not 'magic'. Not every illness can be treated with a drug and some drugs are more effective than others. Some drugs may seem more effective because of their name or packaging, but they may be no better than others, just more expensive. Drugs can also be ineffective and dangerous if they are used in the wrong way or for the wrong disease.

This handbook focuses on drugs, but much of what is said applies to other medical supplies, such as dressings and syringes. As with drugs, adequate supplies of these items are needed for effective treatment. They must be of good quality, safe to use, and effective for the job. Many medical supplies also have expiry dates, which must be checked regularly. Medical supplies should be managed in the same way as drugs.

Some important questions to ask about drugs

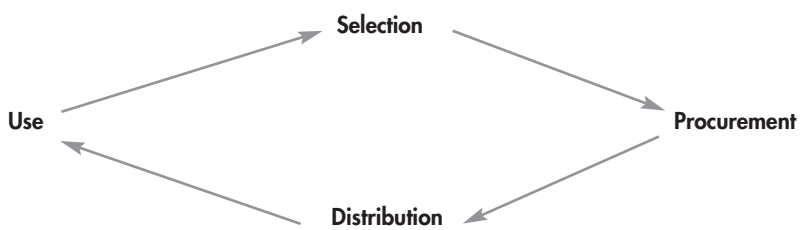
Before obtaining any drugs, you need to think about:

- Which drugs are needed for the type of treatment you want to provide?
- Where will you obtain the drugs?
- Do you have the right information to use drugs safely and effectively?
- What quantity of each drug is needed?
- Which supplier is best?
- What are the dangers and benefits of donated drugs?
- How should drugs be stored?
- What is the best way to make use of the drugs?
- How should drugs be given to the patient?

In this section, we will focus on aspects of choosing and making the best use of drugs. Section 3.3 will then look at how to ensure the best quality and practical care of drugs for HIV/AIDS-related treatment.

3.2.A Managing HIV/AIDS-related drugs

Drug management follows a well-recognized cycle of processes and events, whatever types of diseases or drugs are being considered. This is known as the drug management cycle.



Each aspect of the drug management cycle must be carried out well so as to make sure that the next stage in the cycle happens smoothly. Effective and efficient functioning of the whole cycle is necessary to ensure that access to good-quality, appropriate and affordable drugs is possible for all who need them.

Selection of drugs according to need and affordability will only succeed if the procurement process works well, providing good-quality drugs at affordable prices. When the drugs have been procured, they have to go through a distribution process to move them from the delivery point, such as a warehouse or clinic store, to the place where they can be provided directly to patients. The patients' use of the drugs then provides feedback that helps to evaluate what is needed, as well as suggestions for improving the selection. This is a continuous and ongoing process throughout the drug management cycle.

It is, of course, important to support the management cycle with good organization, information, human resources and financing so that each stage can feed smoothly into the next. The cycle will also be better supported if policies have been worked out locally and nationally about drugs and their management – for instance, by asking questions such as:

- Who decides which drugs are needed?
- What procedures are agreed for procurement?
- Who is responsible for distribution?
- Who may provide drugs to patients?
- What guidelines exist for the use of drugs?

Similarly, a good legal framework that supports the control of manufacture, importation, distribution, prescribing and use of drugs will make it easier to ensure that drugs are provided safely and effectively.

3.2.B The essential medicines concept

The essential medicines concept is an important tool for deciding which drugs are needed. It is based on the principle that a limited number of drugs (called essential medicines) will treat the majority of health problems for a given population.

An essential medicines list (EML) focuses on a small, carefully selected list of drugs. Obtaining, distributing and managing drugs can be more efficient and cost-effective when focused on a limited number of products. EMLs are usually based on treatment guidelines and local treatment needs. Prescribing can also be safer and more effective, because health workers and patients can become familiar with the effects and uses of a limited number of drugs. EMLs and treatment guidelines can be used as a basis for training health-care workers.

A *Model list of essential medicines*, developed by the World Health Organization (WHO), is arranged according to types of disease, with individual drugs listed under each disease. The model list provides an example of good practice of an EML and can be used to advocate a national EML. In some countries, the EML also shows who may prescribe each drug and where they may use them. The national EML should be available from the Ministry of Health, a pharmacist or government hospital.

New drugs are often expensive and, because they are new, there is limited experience in using them, so they may not be included in an EML. However, some new drugs prove to be life-saving or necessary for tackling serious public health problems and might be important enough to add to an EML. If prices are high, most people will not have access to them. As time passes, new drugs should become cheaper and more accessible and there will be more

experience to judge their safety and effectiveness. National EMLs should therefore be updated regularly – for instance, every year or two.

Essential medicines lists for NGOs/CBOs: Based on local treatment needs, NGOs/CBOs providing HIV/AIDS-related treatment can make their own EML, using the national EML or the *WHO Model list of essential medicines* as an example. If the NGO/CBO works mainly in the community, it should try to work in line with government guidelines and EMLs for primary health care. It should include only the drugs that are essential for the organization's specific work. In this way, NGO/CBO staff can learn more about the effects and use of the limited range of drugs and ensure that reliable supplies continue to be available.

An NGO/CBO involved in HIV/AIDS-related treatment might include the following on its EML:

- drugs for pain or fever, such as aspirin, paracetamol or morphine;
- drugs for infection, such as co-trimoxazole;
- drugs for diarrhoea, such as oral rehydration salts and charcoal tablets;
- drugs for skin problems, such as calamine lotion and promethazine tablets; and
- drugs for nutrition problems, such as vitamins and iron.

The list should be regularly monitored and formally reviewed at least once a year. Training for care and treatment should include training about the essential medicines concept and about the rational use of drugs. Systems will also be needed to record and monitor the use of drugs and ensure that adequate supplies are maintained.

Case study – Drug provision in Lusaka, Zambia

The Catholic Diocese of Lusaka developed a home-based care programme to coordinate the work of 35 community projects providing support, prevention, and pastoral and medical care to people living with HIV/AIDS. The diocese provided the necessary drugs, and training for their use, through its central office in the city.

Bulk drug supplies were distributed regularly to the projects. But this depended on using a standard list of drugs and other materials for treating common problems – an essential medicines list. This was developed by modifying government lists created for general community health care and including items that were particularly relevant to people living with HIV/AIDS. The programme manager also developed simple systems for ordering and recording the use of the drugs. She made sure that project workers understood the importance of keeping good records to get adequate quantities of the right drugs for their work.

But accurate records also allowed the managers to see how drugs were being used. They focused training sessions on needs for accurate diagnosis and rational prescribing. They were also able to highlight where something unusual was happening, such as high amounts of antibiotics being used. By coordinating the different records, they identified specific training needs and improved diagnostic and prescribing skills among the health workers. Patients benefited from these improvements in care and became more confident about dealing with their health needs.

Participatory group activity

Aim

To raise awareness about the concept and use of essential medicines lists (EMLs).

Instructions

Before starting this activity, the facilitator needs to get a copy of the national EML for each participant. If this is not available, copies of the World Health Organization's *Model list of essential medicines* can be used instead.

1. Explain the aim of the activity.
2. Present participants with the concept of essential medicines and the importance of having an EML (see previous page).
3. Ask participants to brainstorm about a list of drugs that are commonly used for HIV/AIDS-related treatment in the local community.
4. Give participants a copy of the national EML. Ask them to identify if the drugs that they have brainstormed about are on the list.
5. If some of the drugs discussed by participants are not on the EML, ask participants to assess whether that is reasonable or whether the EML should be changed. If they decide on the latter, ask them how they would ensure that the change took place.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - What factors decide whether a drug should be on an EML?
   - Why should NGOs/CBOs have their own EML?

Facilitators' notes

- Ensure that participants are clear about the concept of essential medicines right from the start of the activity before progressing to discussions of EMLs.
- Encourage participants to think critically about why some HIV/AIDS-related drugs that are essential to their work might not be on the national EML. Also encourage them to consider why some drugs on the national EML might not be essential to their own work.

Example

At a skills-building workshop, NGO/CBO participants brainstormed about a list of drugs used for HIV/AIDS-related treatment in their local community.

These included:

- co-trimoxazole
- nystatin
- fluconazole.

They then reviewed the national *Zambian Essential Medicines List* and the *WHO Model list of essential medicines*. The participants identified that fluconazole (one of the drugs they had listed) was not on the national Zambian list but was included in the WHO list.

The facilitator then led a group discussion about what had been learned from the activity. For example, participants agreed that NGOs/CBOs should advocate to their government that drugs such as fluconazole, which are included in the *WHO Model list of essential medicines*, be added to the Zambian Essential Medicines List.

Reference: Adapted from the workshop on access to HIV/AIDS-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April, 2001.

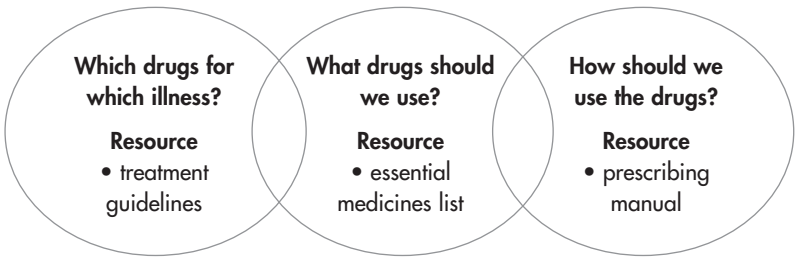
3.2.C Guidelines for treatment

Many governments have produced national treatment guidelines that are intended to improve rational drug use and encourage good practice in HIV/AIDS-related treatment work. In addition, many NGOs/CBOs have developed their own treatment guidelines.

Treatment guidelines provide information about different health problems and the necessary advice for treating them. They will tell health workers about diagnosis and management of health problems as well as what alternative treatments can be used. They do not usually give complete information about each drug, just what is necessary to use it – such as the dose and length of treatment.

A prescribing manual (sometimes called a formulary) contains detailed information about each drug that is available for different health problems. This includes the dose, side-effects, necessary precautions and other special requirements for using the drug. It is usually arranged in the same way as an essential medicines list, with the drugs listed alphabetically under the types of disease that they can treat.

These key resources – treatment guidelines and prescribing manuals, alongside essential medicines lists – can be used together to answer key questions about providing effective HIV/AIDS-related treatment.



The quality of treatment for people living with HIV/AIDS is improved if national treatment guidelines are developed with the participation of NGOs/CBOs that provide treatment on a daily basis. Their active involvement will ensure that the treatment needs of people living with HIV/AIDS are more accurately understood and are reflected in the advice given.

Realistic treatment guidelines will also provide better input for the national essential medicines list and prescribing manuals. This, in turn, will encourage improved availability and accessibility of drugs for HIV/AIDS-related treatment. WHO's *Guidelines for scaling up antiretroviral therapy in resource-limited settings* provide guidance on technical and policy aspects of ARV therapy (see 'Further sources of information' on page 93).

Participatory group activity

Aim

To raise awareness about treatment guidelines and other important sources of information for rational drug use.

Instructions

Before starting this activity, the facilitator needs to collect some examples of prescribing manuals and treatment guidelines. If possible, they should include some local, national and/or international examples.

1. Explain the aim of the activity.
2. Ask participants what information they need in order to provide effective HIV/AIDS-related treatment.
3. Ask participants to share their practical experiences in finding out this type of information.
4. Explain to participants what is meant by prescribing manuals (or formularies) and treatment guidelines (see previous page). Show them some local, national and international examples.
5. Ask participants what national prescribing manuals and treatment guidelines are available to them and whether they are appropriate for their situation. Encourage the participants to ask each other questions and to make comments.
6. Discuss how NGOs/CBOs could help to improve national prescribing manuals and treatment guidelines for HIV/AIDS-related work.
7. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • Why are national materials (such as treatment guidelines) important for NGOs/CBOs, alongside their own practical experiences?
   • How can NGOs/CBOs influence what is included in national prescribing manuals and treatment guidelines.

Facilitators' notes

- Help participants to think positively about how to improve national prescribing manuals and treatment guidelines, rather than just criticizing the current weaknesses.

Example

At a skills-building workshop, NGO/CBO participants brainstormed about what information they needed in order to provide effective HIV/AIDS-related treatment. They then shared their experiences of finding out the information.

Participants were shown examples of local, national and international prescribing manuals and treatment guidelines. They then discussed which of these resources were available to them and whether they were appropriate for their situation. Some of their comments included the following:

- *The Zambian EML gives us an idea of what drugs can be used for each type of illness, but it doesn't give us any idea of dosage.*
- *National treatment guidelines would be very helpful but they are not yet available in Zambia.*

Finally, the participants discussed how NGOs/CBOs could help to improve national prescribing manuals and guidelines. Their ideas included the following:

- *The Zambian National Formulary is a dictionary of drug treatment. This includes information on dosages and side-effects. It should be more easily available and accessible.*
- *The Zambian Government is working on developing local treatment guidelines. NGOs/CBOs involved in providing care and treatment should be involved in the process of developing the treatment guidelines.*

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that national and international guidelines are important resources, but are only truly useful when combined with local experiences.

Reference: Adapted from the workshop on access to HIV-related treatment, Catholic Dioceses of Ndola and the International HIV/AIDS Alliance, Zambia, April, 2001.

3.2.D Choosing the right drugs

It is vital to choose the right drugs for HIV/AIDS-related treatment. Answering the following questions can help in making good decisions.

Will the drug make a difference to the health problem? Some drugs are more effective than others. Additionally, some conditions cannot be treated with drugs: for example, the common cold is caused by a virus for which no drug exists.

Is the drug safe? No drug is absolutely safe to use, although most are safe if used at the correct dose and for the correct amount of time. All drugs can cause some unwanted effects. For example, aspirin is good for relieving mild pain, but can also cause indigestion or bleeding in the stomach.

Where can you get information about the drug? Reliable information about drugs is very important for safe and effective treatment, both for health workers and for the people who take the drugs.

Are patients and their helpers able to follow the treatment regime? If it is too complicated to take the right drugs at the right time, or to deal with requirements for drugs to be taken with or without food or drink, treatment will fail. This is especially important if more than one drug is being used – for example, with antiretroviral or TB combination treatments. Drug side-effects can also prevent people from following a regime or completing it. Failing to follow and complete treatment for infections is a major cause of drug-resistant illnesses.

Can you get enough supplies of the drug? This is especially important if you want to provide a complete course of treatment, or to continue treatment indefinitely for long-lasting diseases. For example, antibiotics must be taken for a short but specific number of days, but antiretroviral drugs must be taken for life. Other drugs can be used only when needed for specific symptoms, such as paracetamol for mild pain. You will need to know how much of a drug a person needs, and how many people need to be treated, in order to work out the full quantity required.

Can patients and treatment providers afford enough drugs to make treatment effective? Choosing the right drugs always involves questions about costs. If patients and their families have to pay for treatment in one way or another, they may fail to obtain enough of the right drugs. If treatment providers cannot afford the chosen drugs for the people they treat, they may have to restrict their work or lose credibility by not having drugs to offer their patients.

3.2.E Drug names

It is important to know and remember the names of drugs, even when they are long or difficult to say. Referring to a drug as 'the white tablets' or 'the pink syrup' can lead to dangerous mistakes. Drugs that look the same may contain very different chemicals, and some that look different may actually be the same.

The name of a drug must appear clearly on the label. You should never accept a drug without a name. A person who cannot read should at least know that every drug has a name and that different drugs must not be mixed together or kept without a label. All drugs have at least one or two names. These include:

- **a chemical name** – the scientific name of the drug chemical. This is mainly used by researchers, but is sometimes shortened and used by health workers instead of the generic or brand name.

- **a generic name** – the name that is adapted from the chemical name and is shorter and easier to say. This is usually decided by the World Health Organization and is also called the international non-proprietary name (INN).
- **a brand or proprietary name** – the name chosen by the producer of the drug. This is short and easy to remember, to encourage people to ask for the drug by that name. The same producer may have several different brand names for the same drug.

One way to reduce confusion about drug names is to use only generic names. For example, paracetamol is a generic name, but it also has many brand names. In addition, it is often combined with other drugs in many hundreds more brands for joint pains, fevers or coughs. A person might use two or three of these brands for different reasons and not realize that they are taking an overdose of paracetamol, which can cause serious liver damage.

Generic drugs are products that have only the generic name on the label. They are usually available if there is no valid patent (or legal ownership) on the drug. Mostly, there is little practical difference between using generic or branded versions of the same drug.

Branded or proprietary drugs are products that have a brand name. They are often advertised using this name, to encourage people to be loyal to that one company's product. This can lead to people prescribing or asking for the brand even when cheaper generic products are available.

Generic drugs are usually cheaper than brand-name drugs, often by a large amount. When a generic drug arrives on the market, there is usually competition between companies. This drives prices down and, sometimes, can even lead to the original drug becoming much cheaper.

Drug names

Generic and brand-name products contain the same active drug, but have different names. For example:

Chemical name of drug: *(12Z,14E,24E)-(2S,16S,17S,18R,19R,20R,21S,22R,23S)-1, 2-dihydro-5,6,9,17,19-pentahydroxy-23-methoxy-2,4,12,16,18,20,22-heptamethyl-8-(4-methylpiperazin-1-yliminomethyl)-1, 11, 13-trienimino) naptho (2,1-b)-furan-21-yl acetate*
Generic name of drug: *rifampicin*
Brand name of drug: *rifadin, rifampin, rimactane*

Some generic drugs are combined together in the same medicine. These combinations are often given a **compound generic name**, for example:

trimethoprim	+	*sulphamethoxazole*	=	*co-trimoxazole*
(generic name)		(generic name)		(compound generic name)

International generic names can vary slightly according to language. For example:

Generic name in English: *amoxicillin*
Generic name in French: *amoxicilline*
Generic name in Spanish: *amoxicillina*
Generic name in Latin: *amoxicillinum*

Some countries use **non-international generic** names. For example:

International generic name used by most countries: *paracetamol*
Non-international generic name used by the United States of America: *acetaminophen*

Participatory group activity

Aim

To identify the different types of drug names involved in HIV/AIDS-related treatments.

Instructions

Before starting this activity, the facilitator needs to collect together some examples of packets, containers or labels for drugs used in HIV/AIDS-related treatment. These can be obtained from a treatment project or a pharmacy. You can have more than one example of the same drug, but, as a whole, they should represent a variety of types of drugs. You will need enough packets, containers or labels to give one to each pair of participants.

1. Explain the aim of the activity.
2. Present participants with definitions of generic and brand names of drugs (see previous page).
3. Ask participants to work in pairs.
4. Give one example of a packet, container or label for a drug to each pair. Ask them to look at it, and to identify the generic and brand names of the drug.
5. Ask each pair to exchange their packet, container or label with another pair so that they have a different drug. Ask them to look at it and to identify its generic and brand names.
6. Repeat the activity one more time.
7. Bring everybody back together and ask some of the pairs to present the generic and brand names of the drugs that they looked at. Check that they have identified the names correctly. Encourage the participants to ask each other questions and to make comments.
8. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - Is it easy to identify the generic and brand names of drugs?
   - How different are the generic and brand names of drugs?
   - Who might need to know the generic and brand names of drugs? Why?

Facilitators' notes

- The facilitator for this activity should be someone who is very familiar with the differences between generic and brand names of drugs, and who can offer clear and simple explanations to participants.
- Keep repeating the activity until every participant can confidently pick up a packet, container or label and quickly identify the appropriate generic and brand names.

Example

At a skills-building workshop, NGO/CBO participants were given packets, containers and labels for drugs used in HIV/AIDS-related treatment. After examining them, they identified the generic and brand names of the drugs. For example:

Generic name: co-trimoxazole
Brand name: bactrim
Brand name: septrin

Generic name: paracetamol
Brand name: panadol
Brand name: crocin

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that many people involved in HIV/AIDS-related treatment (including people living with HIV/AIDS, home-based care workers and community volunteers) need a basic knowledge about the different names of drugs.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

3.2.F Using drugs effectively

Rational drug use is another key concept that is important for an effective HIV/AIDS-related treatment programme. It is about finding ways to make the best use of drugs, by prescribing them sensibly and taking into account all the information that you have about:

- the health problems you are treating;
- the facilities that are available;
- the people who need the treatment;
- the drugs that are available and accessible to them;
- their economic and social situations; and
- their beliefs and practices with regard to drugs and treatments.

Rational drug use is supported by answering questions such as:

- Is the drug really necessary?
- Is the drug the correct one for the condition?
- Is the drug being used according to standard treatment guidelines?
- Is the drug suitable for the person – for example, a child or pregnant woman?
- Are the dose, frequency and length of treatment correct?
- Are any other drugs being taken that might interfere with this one?
- Is the drug likely to be available?
- How expensive is the drug? Can you afford it?
- How effective is the drug for this condition?

Irrational drug use (when drugs are not provided in a sensible way) can happen when:

- a drug is used that is ineffective for the condition;
- wrong or insufficient advice is given to the patient about using the drug;
- too high or too low a dose of the drug is used;
- the drug is given for too long a time;
- the drug is given for too short a time; and
- too many drugs are given at the same time, with similar or conflicting effects or causing increased risk of side-effects.

Ways to encourage rational drug use include ensuring:

- appropriate and independent information;
- training of health workers;
- consistent drug supply; and
- understanding views and beliefs about drugs.

Appropriate and independent information. Unbiased and accessible information about drugs encourages rational drug use. The information should be written by people who do not have a financial interest in the things they are writing about, and the information should be in language that people understand. Budgets for treatment work should always include some money for buying up-to-date reference books and information about drugs, including official treatment guidelines and EMLs. Old information about drugs can be dangerous because it will not include recent updates about drug safety or about new drugs.

Training of health workers. In addition to having good information, health workers need training in providing effective treatment. All health workers need to keep up to date with the latest information on new drugs, new diseases and new ways of dealing with all kinds of health problems. Planning for HIV/AIDS-related treatment work should always include

training to keep people up to date and to refresh their understanding of good practice and the role of drugs in treatment. An NGO/CBO must ensure that sources of information are kept up to date and that time and funds are available to allow workers to access new updates.

Consistent drug supply. Rational drug use will only be possible if the necessary drugs are continuously available and accessible. If not, it is difficult to encourage rational prescribing and the use of an essential medicines list. People will seek alternative drug supplies from private doctors or pharmacies and will not always get the continuing support they need for their treatment. For example, many countries suffer from interrupted supplies of TB drugs. This affects treatment and prevention of TB and encourages the disease to become resistant to the drugs. It also discourages patients and health workers, and wastes money and medicines. If this happens, treatment is likely to fail, and expensive alternative drugs will be needed to overcome drug-resistant bacteria.

Understanding views and beliefs about drugs. What people believe about the drugs they are taking is a very important part of any treatment. If people think their drugs will not work, they are less likely to start taking them or to use them correctly. It is vital to find out what people know and think about drugs – for example, through discussions with community groups. You might have to change the way drugs are prescribed or provide education for community members to improve their understanding about drugs and the way they are used.

Participatory group activity

Aim

To build awareness about rational drug use in HIV/AIDS-related treatments.

Instructions

1. Explain the aim of the activity.
2. Read out the following case study to participants:
   A woman has had mild diarrhoea, with loose stools, but no blood or mucus, for two days. She goes to see a health worker who prescribes the following medication: co-trimoxazole, two tablets twice a day for five days; tetracycline, 250mg, one capsule daily for three days; vitamin B injection.
3. Ask participants to identify why this prescription is not an example of rational drug use. Encourage the participants to ask each other questions and to make comments.
4. Ask participants what would be a more rational prescription for the health problem. Correct any inaccurate suggestions.
5. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • What could be the consequences if drugs are prescribed irrationally?
   • Who needs to have at least basic knowledge about rational drug use? Why?

Facilitators' notes

- The facilitator for this activity should be someone who is very familiar with rational drug use and confident about information relating to the specific case study. This will help to ensure that clear and accurate information is provided to the participants. (The example on the following page provides the correct advice on the rational prescription.)
- Remember that the aim of the activity is to build awareness about rational drug use, rather than build medical knowledge. Make sure, therefore, that the activity does not become too technical or intimidating for participants who lack detailed knowledge about drugs or treatment.

Example

At a skills-building workshop, NGO/CBO participants studied the following case study:

> *A woman has had mild diarrhoea, with loose stools, but no blood or mucus, for two days. She goes to see a health worker who prescribes the following medication: co-trimoxazole, two tablets twice a day for five days; tetracycline, 250mg, one capsule daily for three days; vitamin B injection.*

They then identified why this prescription is an example of irrational drug use:

- The most important treatment for diarrhoea has been forgotten – drinking plenty of fluids and using oral rehydration solution to stop dehydration.
- The woman only has mild diarrhoea and is not passing blood or mucus, so she probably does not need an antibiotic. She definitely does not need two different types of antibiotics (co-trimoxazole and tetracycline).
- The prescription does not specify the strength of the tablets to be used. If an antibiotic were needed, co-trimoxazole would be suitable in the correct dose, but not if the woman is already taking it for long-term prevention of HIV/AIDS-related opportunistic infections.
- Tetracycline can be used for diarrhoea, but is not usually the first choice. Doxycycline is more useful. Also, the usual adult dose of tetracycline is 250-500mg three to four times a day, for at least five days. A three-day course of one 250mg tablet a day is unlikely to work and could cause the woman to build resistance to the drug.
- An injection of vitamin B is unnecessary. Injections can be dangerous, especially if unclean needles are used. Vitamin B injections should only be given if there are specific symptoms of vitamin deficiency.

Participants identified that a rational prescription would involve giving the woman the correct advice (based on a hearing a detailed history of the problem). It would focus on helping her to improve her situation rather than wasting time and money on unnecessary drugs. It would include the following advice:

- mild diarrhoea usually clears up in a few days without drugs;
- plenty of fluids and oral rehydration solution should be drunk;
- directions on how to make and use oral rehydration solution;
- how to prevent diarrhoea through better hygiene and safer water; and
- a return visit is recommended if the diarrhoea does not improve after two more days.

The facilitator then led a discussion about what had been learned from the activity. For example, participants agreed that rational drug use is vital for both the good health of the person and the reputation and resources of the NGO/CBO.

Reference: Adapted from a workshop on access to HIV-related treatment, India HIV/AIDS Alliance and the International HIV/AIDS Alliance, India, February 2001.

3.2.G Fact sheet – antiretrovirals

Drugs that directly combat HIV – antiretrovirals (ARVs) – have not been available or accessible in most resource-poor communities because of cost and technical difficulties in using them. However, prices of ARVs are coming down and easier ways are being found to use them. Everyone involved in ARV treatment needs to be well informed about the drugs, the services that are needed to support their use, and the risks and benefits of using them. Some NGOs/CBOs/PLWHA groups are already involved in providing ARVs to relatively small numbers of people. Some donors and governments are looking for ways to provide ARVs to larger numbers of people, especially in countries with high HIV/AIDS prevalence.

What are ARVs? There are three types of ARV drugs and each type of drug attacks the virus in a different way. These different types of drugs used in combination work to reduce the amount of virus (viral load) in a person's body. This combination of drugs is referred to as HAART – highly active antiretroviral therapy. Successful HAART helps a person to stay healthy and live longer. However, the drugs must be taken exactly as prescribed and for the rest of a person's life. Many ARVs cause side-effects and some strains of HIV are resistant to some of the drugs, so treatments must be carefully chosen and monitored with regular laboratory tests to ensure that they are effective and safe.

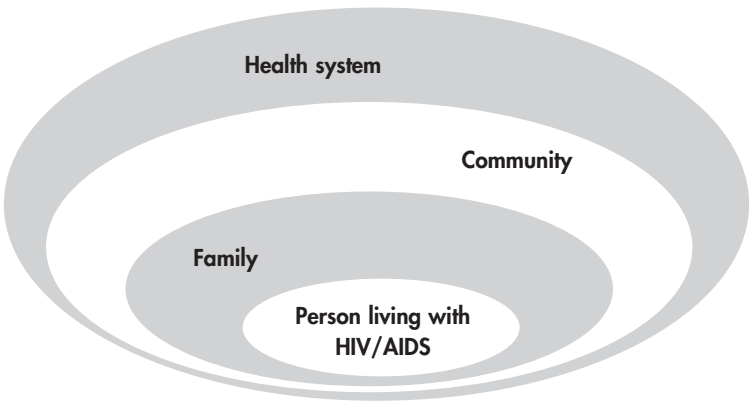
ARVs do not cure HIV/AIDS; they only reduce its effects and prolong life.

In the special case of preventing mother-to-child HIV/AIDS transmission (MTCT), just one type of drug may be used briefly, to protect a child around the time of birth from becoming infected by its HIV-positive mother. This does not change the mother's HIV status. HIV infection can also occur through breastfeeding or, if the mother is receiving HAART, the ARVs may pass on in the mother's milk with possible benefits to the child but also with the risk of side-effects. Treating mothers and babies is therefore especially challenging.

ARVs – antiretrovirals included in the *WHO Model list of essential medicines*

Types of ARVs	Generic and short chemical names
Nucleoside analogues (also called nucleoside reverse transcriptase inhibitors or NRTIs)	*zidovudine (AZT)* *didanosine (ddI)* *stavudine (d4T)* *lamivudine (3TC)* *abacavir (ABV)*
Non-nucleoside reverse transcriptase inhibitors (NNRTIs)	*efavirenz (EFV)* *nevirapine (NVP)*
Protease inhibitors (PIs)	*saquinavir* *ritonavir* *indinavir* *nelfinavir* *lopinavir*

ARV treatment should always take place within the continuum of care across the following:



The following support the safe and effective use of ARVs:

- good treatment information that is easy to understand – how it is used, the risks and benefits, maintaining and looking after drug supplies and, especially, understanding that not treating HIV/AIDS is a better option than partial treatment that leads to development of resistant viruses and shortening of life;
- strong social support to help people to adhere to the treatment regime, to maintain access to prescribed drugs and to cope with side-effects;
- prevention and reduction of stigma or discrimination so that people are not discouraged from using or helping with ARV treatment;
- integrated health systems that include treatment for TB, for opportunistic and sexually transmitted infections and for other health problems (viral load is increased by the presence of other infections);
- trained counsellors and access to facilities for voluntary counselling and testing – the first important step in making a decision about ARV treatment;
- prescribers and health workers trained in clinical management of HIV/AIDS;
- laboratory services to provide checks on the level of HIV infection, through CD4 or similar tests (viral load tests are very expensive); testing for drug side-effects (such as liver damage) is also important;
- supply services that can maintain adequate and uninterrupted supplies of ARVs and other HIV/AIDS-related drugs, HIV test kits and laboratory materials, which means adequate funding to maintain all the above so that treatments are not interrupted;
- support when ARV treatment cannot be used, and encouragement to follow the various other means of maintaining health and living with HIV/AIDS.

3.3 Sourcing and looking after good-quality drugs

People often get supplies of drugs from a number of sources. Groups use many of the same sources. These include:

- local drug sellers, shops and markets;
- local pharmacies and chemists;
- health centres and hospitals;
- friends and family (sometimes using drugs that are left over from uncompleted treatment); and
- donations from supporters.

When there are many sources, it can be difficult to be sure that all the drugs obtained are going to be safe to use. The quality and cost of drugs can vary widely, depending on their source. Even when reliable sources are available, the cost of drugs can limit where people get them. However, the quality is always more important than the cost. Low prices are attractive but, if the quality is bad, the drugs may be ineffective or even dangerous. This, in turn, means that treatment will not be successful, further illness may be caused and, in the end, the costs will be higher in both human and financial terms.

You should therefore aim to get the best quality drugs you can at the lowest possible cost. This will allow you to get more drugs for your money, or to have more money to spend on other useful things. It will also mean that, if users of your services have to pay something for treatment, you will be able to charge them less. It is extremely helpful to spend some time checking what suppliers are available, and finding out what prices they charge and whether their drugs are of good quality. You can then select which suppliers to use regularly and which suppliers to avoid.

A group can use money more effectively by buying good-quality generic drugs. Usually the packaging is simpler and the drugs are not advertised, which reduces the costs of production and may reduce the selling price. Costs can also be controlled by protecting the quality of drugs through careful storage, good stock control and drug management from the moment of purchase through to when they are handed out for the patient to use for treatment.

Case study – How an NGO used a list of approved suppliers to buy drugs

When HIV/AIDS started to become a problem in the community, the monks at the pagoda knew that they could support and educate people about prevention. Soon, they also realized that people were suffering because they could not get effective treatment. So they set up a small clinic to offer traditional remedies and recruited a trained health worker to provide drug treatments for some illnesses that responded better to modern treatments.

They used money from donations given by rich people to start a drug fund that worked as an insurance scheme. People paid a small subscription per month and were entitled to basic treatments at no further cost. A senior monk managed the fund and the health worker gathered information about which drugs were needed. Together they investigated where to get drugs.

Trader A was cheapest – he seemed to have a lot of contacts and got supplies very quickly. But drugs were often almost out of date and many were branded drugs in a variety of packages with labels in different languages. This caused a lot of confusion about the names of the drugs.

Wholesaler B charged slightly higher prices and could not always deliver quickly, but he bought generics from only a few producers. The drugs usually came in the same packages and labels, making life easier for storage and dispensing. Once, when patients had the choice of ibuprofen tablets from A or from B, they said, "Oh, but we prefer the ones from B – they are more powerful, and they smell better than the ones from A."

Sometimes, it was even cheaper to buy certain drugs from a non-profit overseas supplier. Even though import duty had to be paid, the supplier provided low-cost, good-quality generics, and its supplies could be trusted.

So they bought drugs mostly from B. Although he was more expensive, the generic drugs were still reasonably priced and drug quality was more reliable. Twice a year, they ordered a few key items with long shelf lives from overseas to reduce costs and to make sure they always had enough stock. This made the service offered by the monks reliable and people trusted that they would get what they needed.

3.3.A Drug quality

Drug quality matters – bad drugs lead to bad treatment. Good-quality drugs are safe, effective and have guaranteed amounts of the stated active substance in them. The quality of a drug depends on many stages in the production process, but also on the drug management cycle. Everybody who has responsibility for a drug at some stage helps to ensure the good quality of

the drug when it reaches the patient. Even the patients and their helpers have responsibility for properly storing and caring for their drugs so that they remain effective.

Good-quality drugs

A good-quality drug should:

- contain the correct amount of the active drug;
- contain the correct amount of other ingredients required to make the active drug usable in the form of tablets, syrup or ointment;
- be labelled clearly, showing the name and quantity of the drug, an expiry date, a batch number, and the name and address of the supplier;
- not contain any contamination, such as dirt or fungus; and
- be stored correctly so that it remains effective and safe to use until the expiry date.

The producer is expected to follow established procedures for good manufacturing practice, including testing at various stages in production. This includes the drug substances themselves, the extra ingredients (such as water or sugar), the packaging and the labels.

Quality testing of drugs requires the kind of expertise found in laboratory facilities and not easily available to NGO/CBO/PLWHA group buyers, so it is not realistic to test each drug to see if it contains the correct ingredients. However, you can set up a system of quality assurance to help you ensure that the drug supplies you provide are of good quality by:

- buying only from recognized and trusted suppliers;
- checking the labelling and the containers to:
  – make sure that labels are clear, including the drug name and strength, expiry date, batch number and manufacturer's name and address
  – make sure that the container is not broken and that the lid fits tightly;
- ensuring that drug products are not broken, discoloured or bad-smelling; and
- learning from other people about their experiences in obtaining drugs.

A Pilot Procurement Quality and Sourcing Project implemented by WHO in collaboration with other United Nations organizations (UNAIDS, UNICEF and UNFPA) provides a list of suppliers whose HIV-related medicines have been found acceptable, in principle, for procurement by UN agencies. The list is regularly updated (see 'Further sources of information' on page 93).

3.3.B Sources of drugs

Drugs in larger numbers (or bulk supplies) can be obtained from different sources. These include:

- government stores
- private pharmacies and wholesalers
- non-profit or low-cost international suppliers
- donors and supporters
- direct from drug companies
- local shops and markets.

When buying drugs, it is important to consider the following points:

Competitive price. You should compare prices of different reliable suppliers. It is important to remember that the cost of a drug is more than just the price you pay for the actual medicine. For example, there are 'hidden costs' such as transport, time, customs duty and taxes.

Good quality. Drugs should be of good quality and guaranteed to be effective and fit for use.

Continuous supply. Regular supplies of drugs are necessary, not just for long-term treatments such as TB, but also for a group's credibility, since people will not come if drugs are often unavailable. It is important to find suppliers who can guarantee regular supplies of frequently used drugs.

Delivery time. This can be anything from a few hours (if buying from a local pharmacy) to several months (if buying from overseas). If drugs are not delivered in time, it will make it much more difficult for a group to do its job, and some people's health may worsen as a result.

Long shelf life. When buying a large quantity of one drug, it is important to ensure that the drug will not expire before it is used. Always tell the supplier what shelf life you want – for example, two years. Make sure the supplier tells you the expiry date before you confirm the order. It is best never to buy drugs with a short shelf life, even in an emergency, because they may expire before they can all be used. The shelf life is the amount of time available before a drug expires.

When there are few funds available, donations of drugs and medical equipment can represent very important resources for HIV/AIDS-related treatment work, but only if they are carefully controlled and the donor clearly understands the needs of recipients. Practical experiences with donations often show that they can be inappropriate, costly and even dangerous if they are not managed properly.

When using donated drugs, it is important to think about some serious questions.

Are the drugs the ones you requested? Sometimes, drugs are sent without the donor asking first what is really needed. Recipients may have to be diplomatic and negotiate supplies of really helpful drugs instead of what the donor can get hold of or thinks might be useful.

Can further supplies be obtained? For example, if you have received a three-month supply of an antiretroviral drug, what will you do when it runs out? Interrupting treatment will increase the chances of drug resistance, which may reduce the benefits of further treatment with antiretroviral drugs.

How will the side-effects of the drugs be monitored? Most antiretroviral drugs cause side-effects that are unpleasant or even dangerous. Some of these need to be monitored with complicated tests, such as liver function tests. Many health facilities do not have the equipment or expertise to carry these out.

Which drug would be the most beneficial? If you have a choice about which drugs are donated, think about which would give your patients the greatest benefit. For example, you may think a supply of an antiretroviral drug would be the most beneficial, but there are problems with these drugs. So, you may find that a drug to treat infections (such as fluconazole) would be of greater value.

It is important to establish good two-way communication between the donor and the recipient. Recipients should let donors know what they need, and not be afraid to say 'no' if something inappropriate is offered or sent. Donors should listen carefully to what the intended recipients tell them and act accordingly.

The recipient should inform the donor about:

- which drugs and equipment they require;
- what alternatives would be acceptable if the exact drug or equipment is not available;
- what quantities are needed or how many people they are meant to help;
- what language would be most helpful on labels and instructions; and
- what, if anything, has been wrong with previous donations, and how they could be improved in the future.

The donor should bear in mind the following:

- Send drugs that are on the country's essential medicines list. If there is no national list, the WHO essential medicines list should be followed.
- If specialist drugs, such as antiretrovirals, are sent, they should be sent only to people whose doctors are skilled in treating HIV/AIDS.
- The recipient must know in advance which drugs are being sent and in what quantity.
- The drugs should have at least one year of shelf life when they are received, since donations can take several months to arrive.
- Donations should be labelled in a language that the recipient understands.
- Equipment should come with instructions and information about spare parts.

Advantages and disadvantages of drug donations

Advantages of drug donations

- Donated drugs and equipment can provide access to treatment that would otherwise not be possible, either because of lack of funds or because the drugs are unavailable in a particular country.
- Donations can free up funds to be used in other ways – for example, to buy other drugs or equipment.

Disadvantages of drug donations

- The donated drugs may not be required because you already have plenty in stock.
- The drugs are not on your essential medicines list, so you may not have enough information or experience to use them effectively and safely.
- The drugs you receive are out of date, or they only have a short shelf life and cannot be used before they expire.
- Donated equipment is often sent without instructions or spare parts.
- Donations can cause unwanted and unexpected costs to recipients, such as import duties, transport costs, disposal costs for unwanted items, and time and labour to separate useful items from the unwanted ones.
- The drugs may be labelled in a language you do not understand so you may not know what they are or how to use them.

Participatory group activity

Aim

To identify the advantages and disadvantages of donations of HIV/AIDS-related drugs.

Instructions

1. Explain the aim of the activity.
2. Divide participants into three groups.
3. Ask each group to identify the advantages and disadvantages of receiving a donation of different kinds of HIV/AIDS-related drugs. For example:
   Group 1: donation of antiretrovirals
   Group 2: donation of drugs labelled in a foreign language
   Group 3: donation of drugs close to their expiry date.
4. Ask each group to develop a list of strategies that they could use to improve the donation in future.
5. Bring everybody back together and ask the groups to present their results. Encourage the participants to ask each other questions and to make comments.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   • On the whole, are there more advantages or disadvantages to donations of HIV/AIDS-related drugs?
   • How can an NGO/CBO/PLWHA group refuse a donation while maintaining a good relationship with the donor?

Facilitators' notes

- Encourage participants to think critically about the disadvantages of donations rather than taking an 'any help is good help' approach.
- Encourage participants to focus on how they can create an active partnership with the donors of drugs, rather than being the passive recipients of support.

Example

At a skills-building workshop, NGO/CBO participants brainstormed about the advantages and disadvantages of donations of certain types of HIV/AIDS-related drugs.

Antiretrovirals

Advantages	Disadvantages	Ways to improve the donation
• We don't have to pay. • The drugs can prolong the lives of people living with HIV/AIDS. • The drugs allow the patient to continue working.	• The supply is not sustainable. • Limited amounts of the drugs are sent. • If they are new drugs, we have no guidelines for using them. • Need to have access to clinical support.	• Ask donors to give us training in using the drugs. • Ask for constant and adequate supplies. • Ensure access to clinical services.

Drugs labelled in a foreign language

Advantages	Disadvantages	Ways to improve the donation
• We don't have to pay. • It means we have some drugs to give to patients.	• We can't understand instructions. • We don't know how to use the drugs. • It takes time to find someone to translate.	• Ask for good-quality drugs with a long shelf life. • Overcome language problem by asking the donor to translate the information. • Ask donors to use English.

Drugs close to their expiry dates

Advantages	Disadvantages	Ways to improve the donation
• We get the drugs free. • We don't have to look for drugs or purchase them. • It helps us to provide treatment.	• The drugs are not of good quality or very effective. • The drugs may not be finished before their expiry date and cannot be kept for a long time. • The patient may feel unhappy and worry about using the drugs.	• Check the expiry dates before receiving the drugs. • Have an agreement with the donor to send drugs with a long shelf life. • Make arrangements to dispense the drugs as fast as we can.

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that NGOs/CBOs need to build strong two-way relationships with donors, so that they can be honest with them and get the type of drugs that are most useful.

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

3.3.C Storing drugs

Storing HIV/AIDS-related drugs correctly is important because drugs are only safe to use until their expiry date if they have been stored in the right way. If they have not, they can become ineffective or unsafe.

When organizing a drug store, all drugs should be stored in a systematic way. For example, they might be put in alphabetical order according to their generic name, such as aspirin, co-trimoxazole and paracetamol. It is good practice to keep external preparations (drugs for use on the skin) on a separate shelf, because they can be dangerous if swallowed.

When you receive a new supply of a drug, look at the expiry date and then do the following:

- If the shelf life is longer than your current stock, store the new supply behind the older stock and use the old ones first.
- If the shelf life is shorter than your current stock, put the new supply at the front. But always finish an open container before starting a new one.

- If the drug has a short shelf life, such as six months or less, use a coloured marker to remind people to use it first and to keep checking the expiry date. This also applies to any other medical supplies that have an expiry date, such as laboratory test kits, condoms, latex gloves and syringes.

Ideally, do not use a drug if it has passed its expiry date. This is because the drug may have become less effective or even dangerous. The best way to prevent problems with expired drugs is to keep them to a minimum using good stock control. Then the time, effort, cost and danger of drug disposal will be kept as low as possible.

Disposal of expired drugs should be carried out in a way that makes it impossible to use the drug and reduces the risk of harm to anyone. In some countries, expired drugs are classified as toxic waste and there are regulations for their disposal. High-temperature incineration is a very effective way of destroying drugs, but it is not always available. NGOs/CBOs with expired drugs should seek advice about safe disposal from the national drug enforcement agency, local hospital or pharmacist.

Storing HIV/AIDS-related drugs

- Keep them in as cool a place as possible – in a refrigerator, if the label says so, or if it says that you should keep them at less than 10°C (for example, "store at 2-8°C"). However, drugs can also be damaged if they are kept too cold, so do not allow them to freeze unless the label says they must be kept at temperatures below 0°C.
- Keep them away from sunlight, in a box or in a cupboard.
- Keep them away from moisture by keeping containers tightly closed and protected from water.
- Keep them in a container that keeps out insects and other animals.
- Keep them in a safe place to prevent access by children or others who might take them.

3.3.D Keeping records and ordering drugs

To carry out effective work on HIV/AIDS-related treatment, it is important that the management of drugs be well organized. Keeping records and ordering drugs are important parts of this work.

Keeping stock records is very important for tracking which drugs are being well used and knowing when to reorder. An easy way to record how much of a drug is being used is to keep stock records on cards or sheets or in a ledger. Important points to remember include the following:

- Use a different card or page for each drug and each different strength of drug. For example, if you keep co-trimoxazole 120mg tablets for children and 480mg tablets for adults, you should use a separate stock card for each one.
- Record the date and quantity of the drug and sign the stock record each time a supply is received or dispensed.
- Record the expiry date of the drug each time a supply is received and make sure the oldest supply is used up first.
- Keep a written running total of the quantity of the drug that is left. This should be the same as the actual quantity on the shelf.

- Make regular stock checks – for example, every month. This will ensure that stock records are accurate about how much is on the shelves. It will also prevent you from running out or from building up unwanted stocks.
- Keep drugs in a secure place so that people cannot take them away without permission or recording on the card.

A stock record needs to be designed in a clear and simple way, such as in the example below:

Item: ASPIRIN TABS 300mg **Unit:** 1000 tablets
Minimum stock: 10 units **Maximum stock:** 40 units
Reorder level: 20 units **Order quantity:** 20 units

Date	Received from	Issued to	Amount received	Amount issued	Balance	Remarks	Signed
1/8/02			Balance brought forward		8		MD
2/8/02	Medical stores		20		28	Expiry 8/04	CG
4/8/02		Clinic 1		2	26		CG
8/8/02		Clinic 2		4	22		MD

Important things to think about when ordering drugs include getting the next supply. Always try to obtain the next supply of a drug before the present one runs out. This is especially important for vital items such as TB drugs.

It is also important to think about calculating how much to order. Use your stock records to do your calculations, but check back over the last year's records to see if variations can be expected, such as increases in malaria during wet seasons. If buying large quantities or buying from suppliers who take a long time to deliver, the following information is needed to ensure that the correct quantity is ordered and treatments are not interrupted.

Average monthly use. This can be calculated by dividing the total amount issued by the number of months during which it was issued. For example, a stock card for 300mg aspirin tablets might show that 102 units of tablets were given out during the last six months. This means that the average monthly use is 102 divided by 6, which comes to 17 units.

Delivery time. This is the length of time between making an order and receiving it. It is also called the lead time. When buying drugs from the local town, the delivery time may be only one day. But when buying drugs from a faraway supplier or requesting a donation, the delivery time can be anything from one to six months, or more.

Minimum stock level. This is the smallest quantity that should be in stock on the shelf. The level will depend on the delivery time. As a guide, you can calculate it this way: multiply the average monthly use by the number of months required for delivery and then use your judgement to add a little extra in case delivery is delayed or you suddenly need more of the drug.

Reorder level. This is the minimum stock level plus stock used during the delivery time. Ordering when you reach this level will ensure that a drug does not run out before new supplies arrive.

Supply period. This is the amount of time between one order and the next. Smaller amounts of drugs can be ordered more often if supplies are readily available at a good price. But if supplies have to travel long distances or prices are discounted for larger quantities, it may be better to have longer supply periods and buy larger amounts at lower prices.

Order quantity. This will depend on how often an order is made. If it is every six months, then the order quantity must be a six-month supply. You should check each time an order is made to see if there is any variation in amounts used (according to the time of year or circumstances) as this may affect how much is ordered.

Maximum stock level. This is the reorder level plus the order quantity. If the stock level is higher than the maximum, drugs might expire before you can use them.

Emergency supplies. If possible, it is advisable to keep an emergency supply of drugs to use if there is a problem receiving the next supply or if demands increase. Usually, about one month's supply is sufficient. As usual, it is important to check the expiry dates regularly, and to replace any drugs with a short shelf life.

A sample calculation for reordering drugs

The stock card shows 9000 tablets of 500mg paracetamol were used over the last 6 months. An order from a supplier takes 1 month to deliver and the supply period is 6 months.

From this information, you know that:

- average monthly usage is 9000 tablets divided by 6 months = 1500 tablets
- delivery time = 1 month
- supply period = 6 months
- minimum stock level (amount used during the delivery time) is 1 month = 1500 tablets
- reorder level is minimum level plus stock used in one delivery time = 1500 tablets + 1500 tablets = 3000 tablets
- order quantity is the amount you use during a supply period, namely 1500 tablets x 6 months = 9000 tablets.
- maximum stock level is reorder level + order quantity, namely 3000 tablets + 9000 tablets = 12 000 tablets.

There are several effective ways of reducing drug costs, but they depend on knowing exactly what drugs are needed and how much of each one is required. It is important to keep accurate records about the quantities of drugs received and dispensed. Buying small quantities of something that is used a lot can be very expensive compared with buying in bulk. However, it is not useful to order a large amount of a drug if only a small amount is needed, as this can result in quantities of expired drugs that have to be disposed of.

When ordering drugs, there are eight important ways to reduce costs:

1. Buy generic drugs whenever possible.
2. Buy in large quantities when appropriate. For example, it may be possible for several small organizations to buy their drugs together.
3. Pay with cash rather than asking for credit.

4. Compare prices from different reliable suppliers.
5. Buy tablets rather than capsules, syrups or mixtures, as they are usually cheaper. For children, tablets can be crushed and added to food.
6. Only use injections when the drug cannot be given any other way; they are usually more expensive and involve the additional cost of needles, syringes and water for injection.
7. Do your planning and ordering of drug supplies in a way that reduces transport costs and visits to suppliers.
8. Use other health records, such as numbers of patients seen and what health problems have been treated, to supplement your drug-quantity calculations and to revise your essential medicines list in response to changes.

Case study – Keeping records and ordering drugs, the Catholic Diocese of Ndola

In Zambia, the Ndola Catholic Diocese Homecare Programme provides community care and treatment for people living with HIV/AIDS. Previously, people were expected to go to hospital if they got sick, but many could not afford to do this. Appropriate drugs are essential to any home-care treatment programme and, like many NGOs, the Ndola team had no specialist staff trained in pharmacy.

The first goal was to set up a central drug management system, which would prevent inefficiency and ensure that every community nurse always had basic drug supplies for her patients. At the Diocesan Office, a secure storeroom and office were set up, and simple documentation – requisition forms and stock cards – were designed to keep track of drugs in stock, expiry dates and usage. Supplementary drugs for special needs could also be stocked and used if needed when patients had to go to hospital or TB drugs ran out.

At local home-based care clinics, drug management is simple but effective. Nurses dispense drugs on a set day of the week and record any drugs received or used on stock cards. The drugs are dispensed in plastic envelopes, and labelled with the drug name and strength, and the date when it should finish, which encourages patients to finish their medicines properly. New supplies of drugs are ordered from the central store every second week, using the stock cards to know exactly what quantities of each drug/strength are required. The stock card records of each home-care programme are monitored, to check if staff are adhering to agreed protocols for treatment.

The essential drug list is a key management tool; it changes from time to time in response to changing demands. Early in the project, there were many cases of lymphadenopathy and herpes but now there are fewer, due to improved home care. Other problems have increased and supplies of TB drugs are needed when free government supplies fail. Only oral drugs are used, except benzathine penicillin injection for syphilis, given at a health centre. Cheaper drugs are used if similar drugs are available; for example indomethacin is very cheap in Zambia, so it is used instead of ibuprofen.

Drugs are procured locally or from overseas using an international non-profit supplier. Local purchase is expensive and good relationships with suppliers are essential to reduce costs. Special drugs are bought when necessary but they are not listed. Some drugs come from donations; good relationships with donors are established by reporting to them what use has been made of their drugs and making clear to them which drugs are most needed and which are not.

Participatory group activity

Aim

To build skills in how to manage HIV/AIDS-related drug supplies effectively.

Instructions

1. Explain the aim of the activity.
2. Lead a brainstorming session about the steps involved in ordering supplies of HIV/AIDS-related drugs. Ask participants to think about what needs to be done to get the right drugs, in the right quantities, at the right time, at the right price, of the right quality and in the right place.
3. Divide participants into small groups.
4. Ask each group to summarize the steps that are necessary to achieve good drug supplies. Ask them to draw a timeline to show in what order the steps need to occur.
5. Bring everybody back together and ask the groups to present their results. Encourage the participants to ask each other questions and to make comments.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - What would happen if an NGO/CBO ran out of a drug?
   - What would happen if the steps for ordering drugs were carried out in the wrong order?

Facilitators' notes

- Encourage participants to be thorough in their thinking about this activity, paying attention not only to the quantity of drugs needed, but also to issues such as quality and price.
- Encourage participants to focus on simple and practical steps to manage the supply of drugs, rather than complex systems and processes.

Example

At a skills-building workshop, NGO/CBO participants brainstormed about the steps needed to manage supplies of HIV/AIDS-related drugs effectively. They then drew a timeline to show the cycle in which the steps need to occur.

1. Analysis	2. Supply	3. Reorder
• What drugs do we need? • Do we know how to use these drugs? • What quantity of each drug do we need? • Quality • Cost • Expiry date	• Delivery time • Permission letter for buying drugs • Regular supply • Emergency supply (safety stock) • Control on how to use drugs • Quantity of use and duration of supply • Dispensing drugs to patients	• Time to reorder • Recheck the quantity (checking stock) • Get permission to reorder

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that the steps for ordering drugs need to be carried out in the right order to prevent gaps in treatment, which might physically and psychologically harm people living with HIV/AIDS.

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

3.4 Providing drugs to people living with HIV/AIDS

We need to remember at this point that ensuring that people have access to drugs is more than just making them available in the area where they live or come for treatment. People need to be able to afford the drugs that are available and they need to get them in a way that is suited to their individual needs – i.e., the drugs have to be dispensed correctly. They also need the right information about their drugs and a means of transport so that they can obtain them and use them for as long as necessary.

This key stage of treatment access therefore depends not only on the mechanical processes of moving drugs around and putting them in containers with labels and instructions. It also requires good communication by health workers and encouragement for patients to make the best of their treatment and seek advice about any problems that arise with the treatment. Once again, the importance of interaction between human, financial and material resources is clear, especially in the field of treatment for HIV/AIDS-related illness when people are faced with many social and economic challenges as well as their health problems.

3.4.A Paying for HIV/AIDS-related treatment

Since costs are a key element in whether people with low incomes can access HIV/AIDS-related treatment, it is important to think about ways in which these costs can be met. In this regard, there are two important issues to consider:

The first is cost-sharing, which is used by health-care systems in many countries. It involves people paying for some or all of the costs of their care and treatment. Most commonly, people pay either a fixed amount for treatment or a proportion of the actual cost. This can help to improve the availability of drugs, but it can also cause the following problems:

- Some people cannot afford to pay for treatment. This may mean that the poorest people have less access to treatment.
- Health workers may prescribe unnecessary or expensive drugs to increase their NGO's/CBO's income.
- Charging does not guarantee a good supply of the necessary drugs.

Cost-sharing for HIV/AIDS-related treatment

Questions to consider before starting cost-sharing for drugs include:

- What will patients think about paying for their drugs?
- How will you calculate the prices to charge patients?
- Who will not have to pay for their drugs?
- What will happen if people are unable to pay? Will treatment be refused?
- How will the money be collected and managed?

The second issue is cost counselling, which can be helpful for people who need HIV/AIDS-related treatment. It involves helping people to think through difficult choices, such as how to balance the costs of illness and treatment with other daily living costs, such as food and education. When unexpected or extra expenses arise, people may also need help to work out priorities between their short- and long-term needs. Support groups can help people to make these choices, especially if they understand people's daily living needs and the costs and

availability of treatment. NGO/CBO cost counsellors need to understand what is important to people, what their money problems are, and how this relates to needs for treatment.

Cost counselling for HIV/AIDS-related treatment

Things to think about in relation to cost counselling include the following:

- Not all illnesses require drug treatments. Simple home remedies are often enough and sometimes problems clear up without using any remedy at all.
- Some treatments are not effective unless the full amount is taken regularly. Using treatments incorrectly can be wasteful as well as dangerous.
- Often people can afford only part of the full range of treatment recommended for them. They may need advice about which items are the most important and which they can leave out.

3.4.B Drug information

NGOs/CBOs need drug-related information that is objective, accurate and in simple language. The best information about treatment comes from people who can understand technical facts, but can communicate them to others in a clear way, as this helps people to understand and to make informed decisions about drugs.

Good information about a drug should include:

Effects of the drug
- Which symptoms will disappear or diminish, and when?
- How important is it to take the drug?
- What happens if the drug is not taken?

Side-effects
- What unwanted side-effects might occur?
- How can people recognize side-effects?
- How long will side-effects last?
- How serious are the side-effects?
- What should be done if side-effects happen?

Instructions
- When should the drug be taken?
- What quantity of the drug should be taken?
- How should the drug be taken?
- How should the drug be stored?
- How long should the treatment be continued?
- What should be done in case of problems?

Warnings
- What should you not do? For example, if the drug can make you sleepy, you should not drive a vehicle or operate machinery.
- What is the maximum dose? For example, some drugs are poisonous if you take too much of them.
- Is it important to continue the treatment – for example, for anti-infective drugs (such as antibiotics and antifungals), drugs for long-term conditions (such as diabetes or heart disease) and antiretrovirals?

Getting further help
- When should you go back to the person who prescribed the drug?
- When should you go back for help earlier than arranged? For example, this might be necessary if the condition worsens/does not get better, or if there are bad side-effects.
- What should you do with leftover drugs? For example, how should you dispose of them safely?

It is important not to rely on advertising material for information about a drug as it aims to persuade people to use the drug and often does not include everything that you need to know. This is especially the case in relation to side-effects or alternatives that might cost less.

3.4.C Dispensing drugs

Drug dispensing is a very important job in HIV/AIDS-related treatment work. People must receive the correct amount of the correct drug, with the correct instructions. If a mistake is made, it can be very dangerous, as well as being a waste of resources.

Steps for dispensing HIV/AIDS-related drugs

It is important to:

- Make sure you understand the prescription. Check with the prescriber if you are unsure.
- Select the required drug from your store. Double-check the name of the drug, the strength and the form (such as whether it is a tablet, skin cream, injection or liquid medicine).
- Calculate how much of the drug is needed. For example, 10ml of antibiotic syrup three times daily for five days will be a total of 150ml.
- Count or measure the required amount. Do this on a clean surface, using clean measures or tools. Avoid touching drugs with your hands. For example, use a knife or a spoon to count tablets.
- If you have labels, write one to show the name of the drug, the strength, the directions for use, the person's name (or code number) and the date.
- Check again that you have dispensed the correct drug, the correct strength and the correct quantity.
- Hand the drugs to the person, explain how they should take the drugs and give any other information that they need. This is a very important part of dispensing. If drugs are not taken correctly, the patient and the provider have wasted time and money.

Giving the right information about the drugs is as important as dispensing the drug correctly. Information about drugs can be given verbally, but people can usually remember only two or three messages at a time. It is important to focus on the key messages for that particular drug. Ask the person receiving the drug to repeat the explanation back to you. This will show if they have understood the instructions and give you an opportunity to correct them, if necessary, or give them extra information.

Written information can also be given. It needs to be clear and in language that the user finds easy to understand. For example:

Take two tablets twice a day. It is best to take them with some food. So, take two tablets with your meal in the morning and two with your meal in the evening. You must keep taking the tablets until they are all gone. If you get a skin rash, stop taking them and come back to see us as soon as possible.

Pictures can also help, but must be clear and easy to understand. For example, 'Take two tablets twice a day – two in the morning and two at night' could be drawn as:

Information required about HIV/AIDS-related drugs

A person using or providing drugs needs to know:

- how much of the drug to use;
- how the drug should be used – swallowed, rubbed on the skin or inhaled;
- how often the drug should be used;
- for how long the drug should be used;
- whether the drug should be taken after food, before food, between meals or with water;
- what to avoid when taking the drug – such as specific foods, alcohol, milk or other drugs;
- common side-effects of taking the drug and what to do about them;
- possible effects on the child if the drug is taken by a pregnant or breastfeeding mother;
- what to do if the drug does not seem to work.

For example, both the person prescribing antiretroviral treatment and the person thinking of taking antiretroviral treatment need to know:

- accurate information about drugs;
- the cost of drugs;
- the cost of laboratory tests for monitoring treatment;
- that it is a life-long therapy;
- that it is not a cure;
- that it can mean taking many pills;
- how to take the drugs – food, diet, etc.;
- the possible side-effects;
- the interactions with other drugs – TB drugs;
- the possibility of resistance – may mean changing combination of drugs.

Participatory group activity

Aim

To build skills in giving appropriate information when dispensing HIV/AIDS-related drugs.

Instructions

Before starting this activity, the facilitator needs to develop two role plays about dispensing drugs to a person living with HIV/AIDS:

Role play 1: showing bad practice in dispensing HIV/AIDS-related drugs.
Role play 2: showing good practice in dispensing HIV/AIDS-related drugs.

The facilitator also needs to select people to act out the role plays and to make sure that they are confident about their roles before the activity begins.

1. Explain the aim of the activity.
2. Ask the first group of actors to perform their role play about bad practice in dispensing HIV/AIDS-related drugs.
3. Facilitate a group discussion about what was wrong or unhelpful about the way the drugs were prescribed in the role play. Encourage participants to ask each other questions and to make comments.
4. Ask the second group of actors to perform their role play about good practice in dispensing HIV/AIDS-related drugs.
5. Facilitate a group discussion about what was good or helpful about the way the drugs were prescribed in the role play. Encourage participants to ask each other questions and to make comments.
6. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   - What could be the results of bad practice in prescribing HIV/AIDS-related drugs?
   - What are the two or three essential points of good practice that should always be remembered, whatever the circumstances?

Facilitators' notes

- Encourage the actors not to overact in the role plays and to try to show the type of situations that might occur in real life.
- Encourage participants to identify simple and practical messages about good practice, so that they can use them in their everyday work on prescribing HIV/AIDS-related drugs.

Example

At a skills-building workshop, NGO/CBO participants acted out a role play to illustrate bad practice in dispensing drugs to people with HIV/AIDS-related health problems:

> ***Role play 1:*** *A patient has finished her drugs, but tells the doctor that she has a stomach pain. The caregiver asks the doctor about the drugs, but he refuses to talk to her. He looks through his bag and gives several more drugs to the patient, quickly telling her how often to take them, but not checking to see if she has understood. Afterwards, the patient cannot remember the information and asks her caregiver what to do. Together they decide she should take one of each kind of tablet. The patient does this and develops a headache. When the doctor comes back again, he is angry. The caregiver tells him he should have explained better, but the doctor shouts at her and tells her it's none of her business.*

The participants discussed the role play and noted that the doctor did not act responsibly, did not do his job well, and did not seem to know what to do about side-effects. They also noted that he should not only have information about drugs but training in how to dispense them well.

The NGO/CBO participants then acted out a role play to illustrate good practice in dispensing drugs to people with HIV/AIDS-related health problems:

> ***Role play 2:*** *The doctor comes to see a patient with a chest infection and cough. The doctor examines him thoroughly, and lifts him up so that he can breathe and cough more easily. He asks what medicines the patient has already taken, and if he has had any previous treatment from elsewhere. The patient says no, because other health workers are afraid to come near him in case they catch the infection. The doctor explains carefully how to take the medicines, why the patient should take them, and when he should take them. He writes the information down, and gets the patient to repeat the instructions back to him. The doctor also asks the patient's wife to repeat the instructions in case the patient does not remember them clearly. He tells them what side-effects to expect from the medicines and what to do about them. He also tells them about what other care is needed, such as sitting up when the patient needs to cough.*

The participants discussed the role play and noted that the doctor had a good relationship with patient and family, a good way of explaining, and that the patient trusted the doctor. They also noted that talking about side-effects is important, because otherwise the patient might stop taking drugs when he should not.

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that the results of bad practice vary from damaging the relationship between the treatment provider and patient to putting the patient's life in danger.

Reference: Adapted from a workshop on access to HIV-related treatment, Khmer HIV/AIDS NGO Alliance and the International HIV/AIDS Alliance, Cambodia, May 2001.

3.4.D Managing transport for HIV/AIDS-related treatment

Transport is vital for effective HIV/AIDS-related treatment work. It is necessary both to enable clients to access treatment and to move supplies and skilled help to where they are needed. Transport is also necessary to move supplies and people to the places where treatment is provided. And it is required for bringing drugs and other materials from sources of supply, whether from a local town or far away. One factor in deciding which suppliers to use will be whether they provide reliable transport for their goods.

The costs and difficulties of transport affect people's access to HIV/AIDS-related health care. For example, if people living with HIV/AIDS need trained medical help, they must go to a clinic, hospital or other place where it is provided. Alternatively, the help must come to them – for example, through a home visit. Either way, transport is required. Using transport takes time and it requires money to purchase, maintain and repair vehicles, and to provide fuel. Even walking, which seems cost-free, requires fuel in the form of food and water.

An NGO/CBO might decide that it is important to have its own transport. The budget, costs, availability of spare parts and maintenance of a vehicle will have to be considered. A method of managing the transport will have to be planned – for example, making timetables and keeping records of use and repairs. It will also be important to plan what will happen when a vehicle is worn out, damaged or needs to be replaced.

An NGO/CBO and its clients should aim to find the most cost- and time-effective transport to suit their needs and resources. Factors to consider when deciding whether to take treatment to a client, or bring the client to the treatment, may include:

- How far are the clients from the treatment services?
- Are there several clients in one area?
- Does the NGO/CBO have reliable transport?
- Is there good public transport for the clients to use?
- Is there a suitable building for a clinic where clients could come?
- If it is expensive to rent a building for a clinic, would it be better to spend the money on transport?

3.5 Training and management for treatment work

People are a key resource in HIV/AIDS-related treatment work. Managing people requires planning to make sure they have the appropriate skills, training, rewards and remuneration, management, support and supervision.

The skills and training required will depend on what tasks are to be done. Providing a service such as specialist treatment of infections will require different skills from providing basic essential medicines. However, all types of work will need people with a combination of technical and personal skills.

Training can initiate, update and develop the knowledge and skills of workers. It will help them to work more effectively and efficiently, and to be more confident. Training is beneficial for volunteers as well as paid staff. Resources for training will often be available, particularly through linkages with donors and government.

Active supervision and support are necessary to support training. Different people may need training on different things, depending on their work. Training may be needed in areas such as:

- technical skills
- personal attitudes
- team-building and participative working
- management.

Planning a training programme for HIV/AIDS-related treatment

Key issues to consider when planning a training programme:

- Who needs the training?
- What kind of training do they need?
- Who can provide the training?
- What methods of training should be used?
- What material or financial resources will be required?
- How will you monitor the effectiveness and value of the training?

In addition to providing training, it is important first to check that working conditions are acceptable and meet ethical and legal standards. For example, are the procedures for hiring, disciplining and dismissing people fair and legal? Taking care of these aspects makes good sense. Staff who are treated fairly will feel respected and supported by their employers. They will respond more readily to requirements for them to work hard and effectively.

Staff are paid a wage for their work. Volunteers are not usually paid, but might receive expenses for related costs, such as travel. Pay and rewards for all workers should be fair, but they should also take into account what people value most. Employees might value additional benefits, such as food or help with transport. Recognition and praise from a manager and colleagues can also be rewards in themselves.

Volunteers are an important group of workers for many NGOs/CBOs. Some of them may be people living with HIV/AIDS themselves or affected by HIV/AIDS in some other way. The first step in recruiting volunteers is convincing community members that there is work to do and that voluntary help is necessary.

Good management and support involves good interpersonal skills and guidance to help people to do their work. Managers should collaborate with their teams to identify needs, set objectives, and plan, implement, review and evaluate their work. If possible, anyone responsible for organizing the work or for managing other people should receive specific training in relevant areas. Clear management structures are also important, so that everyone knows to whom to report and to whom to turn if they have a problem.

Good management is not just about getting the job done. It also matters how the job is done. It includes motivating and encouraging all concerned, sharing responsibility and providing support.

Work in HIV/AIDS-related treatment can be stressful. Good supervision can help in coping with this, but it must be confidential so that people can talk freely. Supervision can involve taking an objective look at how the work is progressing – for example, asking whether drugs are being dispensed correctly. Supervision is more effective if it also takes into account what is happening to individuals. For example: Is someone having difficulty carrying out their work or do they have problems outside work?

Managers should ensure that support and supervision are adequate, whether provided by themselves or fellow workers. Regular meetings are another important way to support the management of a project and to prevent staff burnout.

Meetings for managing work on HIV/AIDS-related treatment

Examples of meetings to help in the management of treatment work:

- weekly case management meeting
- monthly meeting with people receiving treatment
- monthly staff meeting
- regular retreats or parties
- an annual review and replanning meeting.

3.6 Further sources of information

WHO model list of essential medicines, 12th edition. Geneva, WHO-EDM, April 2002. Guidelines for development of national and other essential medicines lists for local use in resource-poor settings to address the health needs of the majority of people.

Access to HIV/AIDS drugs and diagnostics of acceptable quality. Geneva, WHO, 2002. Documentation of a pilot procurement quality and sourcing project that provides a regularly updated list of suppliers of HIV/AIDS-related medicines and diagnostics. www.who.int/medicines/

Guidelines for scaling up antiretroviral therapy in resource-limited settings. Guidelines for a public health approach. Geneva, WHO, 2002. Document providing guidance on technical and policy aspects of ARV (antiretroviral) drug treatments for HIV/AIDS. www.who.int/hiv/

Improving access to care in developing countries: lessons from practice, research, resources and partnerships. Report from a meeting: 29 Nov-1 Dec 2001, Paris, France. French Ministry of Foreign Affairs with support from WHO and UNAIDS, 2002. www.unaids.org

Managing drug supply: the selection, procurement, distribution, and use of pharmaceuticals, 2nd edition, revised and expanded. Jonathan D Quick et al., Management Sciences for Health in collaboration with the World Health Organization. West Hartford, Connecticut Kumarian Press, 1997. A textbook about managing pharmaceutical systems, covering selection, procurement, distribution, use of drugs, pharmaceutical policy, financing, organization, management information systems and human resources management.

Developing HIV/AIDS treatment guidelines. Best Practice Key Material. C Chela. Geneva, UNAIDS, 1999 (UNAIDS 99.13). A resource summarizing the principles and process for developing HIV/AIDS treatment guidelines.

How to manage a health centre store. Healthlink Worldwide, 1994. A guideline for running a health centre medical store, including ordering and storing essential medicines and supplies.

Management support for primary health care – a practical guide to management for health centres and local projects. Paul Johnstone and John Ranken. FSG Communications Ltd, Cambridge, UK, 1994. Principles and practice of health-care management at local level; includes role of understanding communities and individual needs, methods and examples of management.

Basic accounting for small groups. John Cammack. Oxfam (UK and Ireland), 1992. A manual about budgets, cash control, bank accounts, reports and auditing, designed for those with no previous experience of accounts.

Primary AIDS care, 3rd edition. Dr Clive Evian. Jacana Education, Houghton, South Africa, 2000.
A treatment manual, covering history and context of epidemic, progress of illness, testing, care for different stages of HIV infection, managing HIV/AIDS-related conditions, needs of different population groups, counselling, care of pain and dying, and HIV/AIDS and health workers. Written for South Africa, but applicable to many other countries. Includes use of antiretroviral therapies.

Operational principles for good pharmaceutical procurement. Geneva, WHO, 1999 (WHO/EDM/PAR/99.5).This guide aims to improve pharmaceutical procurement practices and sets out 12 operational principles for good pharmaceutical procurement, which can be adapted by users.

Guidelines for drug donations. Geneva, WHO, 1999 (WHO/EDM/PAR/99.4). This guide describes good drug donation practices and aims to improve the quality of drug donations. It can be adapted and implemented by organizations and institutions dealing with this kind of assistance.

Guidelines for safe disposal of unwanted pharmaceuticals in and after emergencies. Geneva, WHO,1999 (WHO/EDM/PAR/99.2). These guidelines provide advice on the safe disposal of unusable pharmaceuticals in emergencies and in countries where official assistance and advice may not be available.

Chapter 4
Assessing needs and resources, and deciding what to do

Chapter 4 of this handbook helps groups to develop an understanding about:

- the importance of assessment in understanding HIV/AIDS-related treatment needs and resources in their communities;
- what forms of HIV/AIDS-related treatment are or are not already available and accessible;
- how people living with HIV/AIDS decide about treatment, where they go for it, and who helps them to use it;
- what other organizations are doing about HIV/AIDS-related treatment and how it might affect a group's decision to get involved;
- the capacity of a group to respond to HIV/AIDS-related treatment needs; and
- how to make decisions about getting involved with HIV/AIDS-related treatment, and communicate them to others.

4.1 The assessment process

Many NGOs/CBOs/PLWHA groups become involved in HIV/AIDS-related treatment work because they want to respond to the urgent needs of people living with HIV/AIDS. Groups working in HIV/AIDS-related treatment should consider certain issues. These include:

- **Sustainability**. For example, has the organization got the capacity and resources to continue responding to treatment needs for as long as help is required?
- **Coverage**. For example, how does the number of people living with HIV/AIDS that the organization can help compare with the total number who need treatment?
- **Equity**. For example, are people's health needs met in a fair and just way?
- **Quality**. For example, can the organization provide treatment services that are effective, both at the start of their work and over the longer term?
- **Acceptability**. For example, are the proposed or actual treatment services acceptable to people living with HIV/AIDS and what are the community's attitudes to the treatment?

To make good decisions about starting or increasing the scope of HIV/AIDS-related treatment work, an organization needs to begin by analysing the existing needs, resources and action in its community. This can be done through an assessment.

An assessment provides a way of understanding the context in which an organization is working and of making strategic decisions about what to do. It can involve many different people and organizations, including community members, local leaders and the organization itself. It enables people to share their 'real life' experiences, opinions and concerns, usually through a mixture of focus group discussions and participatory activities.

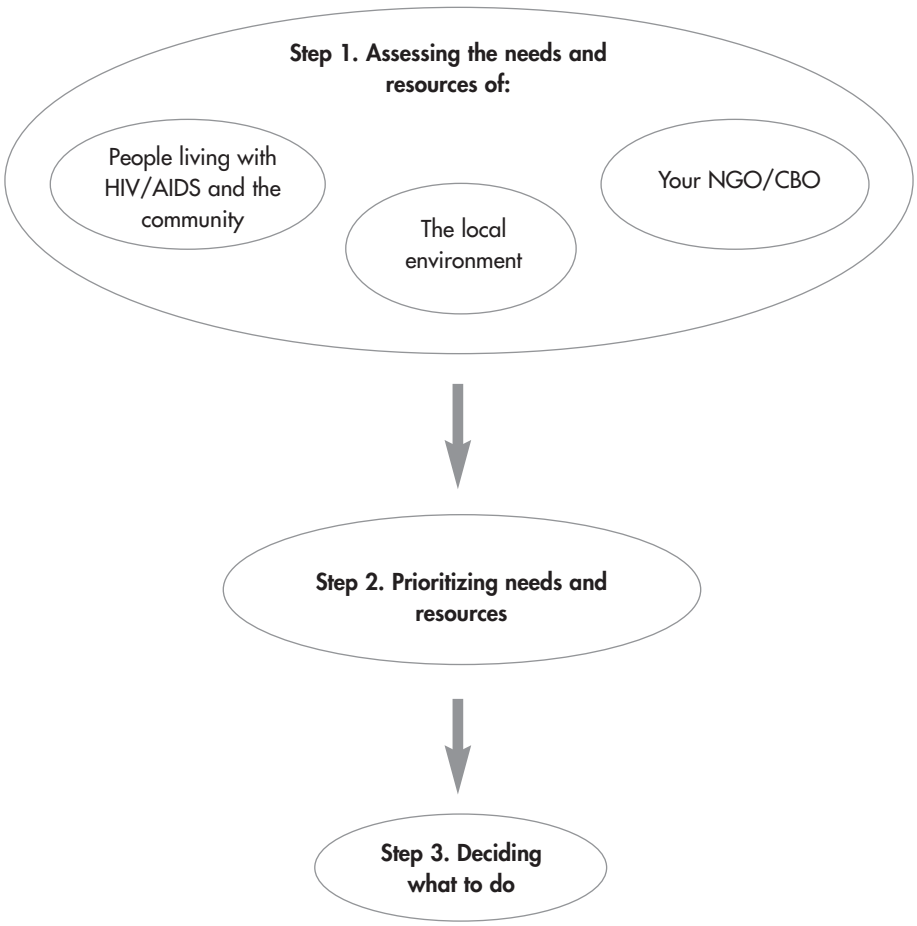
An assessment helps to ensure that action on HIV/AIDS-related treatment is based upon the real needs of the community, rather than on what people think those needs might be.

An assessment can help an organization to answer the following questions:

- What are the treatment priorities of people living with HIV/AIDS?
- What difficulties do people experience in using treatments?
- How could access to HIV/AIDS-related treatment be improved?
- How can our organization make the biggest difference possible?

The involvement of people living with HIV/AIDS is especially vital to any work aiming to meet their needs. If people living with HIV/AIDS are involved throughout – from the assessment, through the decision-making process to the implementation of the work – their ideas and experiences can contribute greatly. The involvement of people living with HIV/AIDS will also help to reduce HIV/AIDS-related stigma and discrimination.

Assessment is a participatory process involving three key steps:



This chapter includes sets of questions that can be used in the three parts of Step 1: to assess the needs and resources of people living with HIV/AIDS and of the community, the local environment and your organization. These questions can be used as the basis of focus group discussions and/or group activity sessions.

The chapter also provides help on how to prioritize needs and resources, and how to decide what your organization will and will not do.

To plan an assessment, an organization needs to decide the following:

- Who will be involved?
  – How many and what type of participants do you want?
  – Will you have separate groups of participants or mixed groups?
- How will the assessment be carried out?
  – How much time is needed?
  – When and where will you carry it out?
  – Can you talk openly about HIV/AIDS, or should you talk generally about illness?
  – How can you put people at ease about sensitive subjects?
- How will the assessment be documented?
  – How will you record your results?
  – How will you share your results with others?

4.2 Assessment frameworks

4.2.A Assessing needs and resources – people living with HIV/AIDS and the community

Any work on HIV/AIDS-related treatment must respond to the real needs of people living with HIV/AIDS and of the community. Therefore, an assessment should start by looking at the HIV/AIDS situation in the community, the impact of HIV/AIDS on the community, the type of treatment people need, what they currently do when they need treatment, and what existing resources are available.

An assessment can also look at what a person does about illness and how that is influenced by different factors and people, including family, friends and the community. Learning what happens to people on their journeys to seek treatment helps to build an understanding about the overall strengths, weaknesses and gaps of existing services in the community. It is also important to understand the community's attitudes towards illness and the community's perceptions of risk that those involved in providing treatment may face.

An assessment of the treatment needs and resources of people living with HIV/AIDS and of the community could involve some or all of the following:

- people living with HIV/AIDS
- families
- health workers
- community leaders
- caregivers
- traditional healers.

It could focus on three key questions, each of which can form the basis of both focus group discussions and participatory group activities:

- **Question A.1:** What are the treatment needs of people living with HIV/AIDS in your community?
- **Question A.2:** Where do people get HIV/AIDS-related treatment in your community?
- **Question A.3:** How do people living with HIV/AIDS seek and use treatment in your community?

Question A.1: What are the treatment needs of people living with HIV/AIDS in your community?

Questions for focus group discussions:

- What is the range of HIV/AIDS-related treatment needs in your community?
- What are the most common treatment needs of people living with HIV/AIDS in your community?
- What are the most effective treatments for people living with HIV/AIDS in your community?

Participatory group activity

Aim

To assess the HIV/AIDS-related treatment needs of people living with HIV/AIDS in your community.

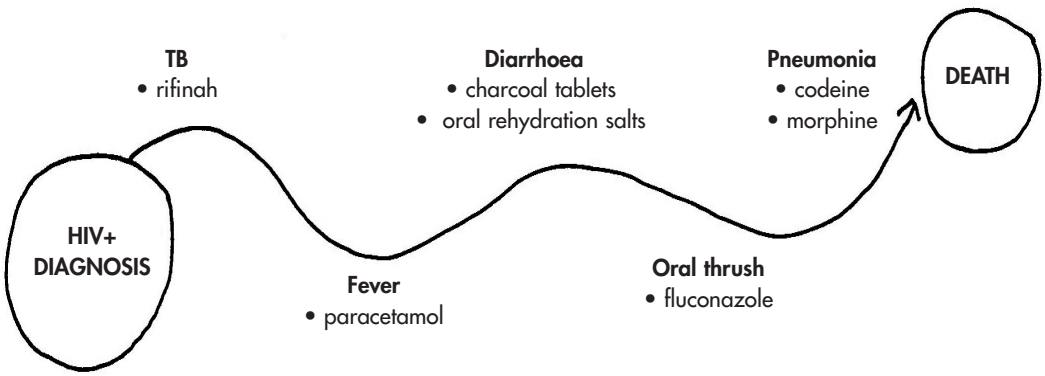
Instructions

1. Explain the aim of the activity.
2. On a large piece of paper, draw a long line to represent the lifeline of a typical person living with HIV/AIDS in your community. For example, it might start with when they are diagnosed as HIV-positive and end with their death.
3. Ask participants to suggest the name of a health problem experienced by a person living with HIV/AIDS. Examples might include fever or TB. Write each suggestion down on a small piece of paper.
4. Ask participants to place the pieces of paper on the lifeline, according to where the health problem might occur during the life of the person living with HIV/AIDS.
5. Ask participants for suggestions of treatments for each of the health problems. Examples might include paracetamol or TB drugs. Write them down next to the health problem on the lifeline.
6. Discuss what can be concluded about the treatment needs of people living with HIV/AIDS in your community.

Facilitators' notes

- Encourage participants to think of both traditional treatments (such as herbs) and 'western' treatments (such as pharmaceutical drugs).
- Encourage participants to assess the scale of each health problem, such as how severe it is and how many people living with HIV/AIDS experience it.

Example



Question A.2: Where do people living with HIV/AIDS get treatment in your community?

Questions for focus group discussions:

- Where is HIV/AIDS-related treatment available in your community?
- Where can people living with HIV/AIDS access HIV/AIDS-related treatment?
- What are the barriers to people accessing HIV/AIDS-related treatment?

Participatory group activity

Aim

To assess what treatment is available and accessible to people living with HIV/AIDS in your community.

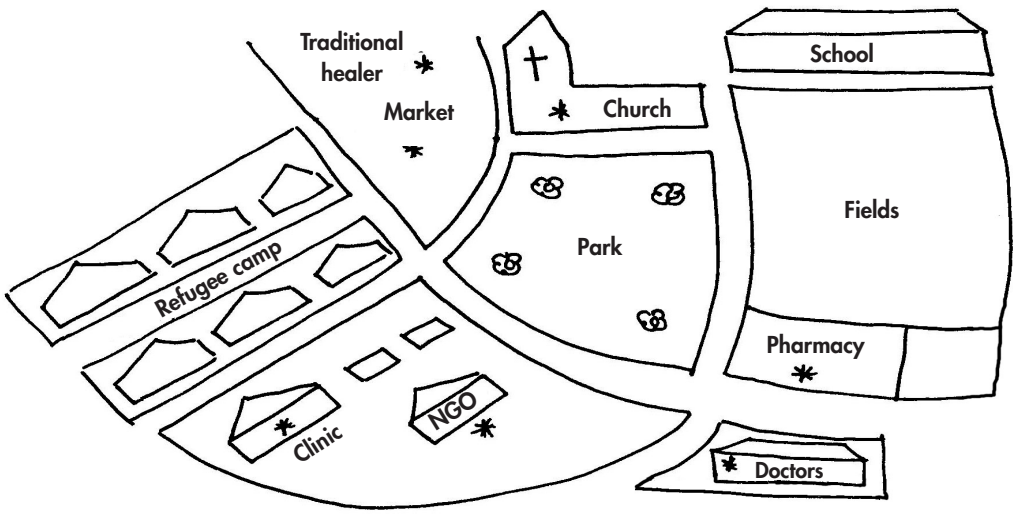
Instructions

1. Discuss with participants what is meant by 'available' and 'accessible' in relation to HIV/AIDS-related treatment (see Chapter 1.3.A and 1.3.B, on pages 24 and 26). Brainstorm about some local examples of what they mean in practice in your community.
2. Ask participants to draw a map of their community on a large piece of flipchart paper or on the ground. Ask them to include all the key features such as roads and clinics.
3. Ask participants to mark with stars the places where different types of HIV/AIDS-related treatment are available in their community, such as in the home or from a traditional healer.
4. Ask participants to assess how accessible each of the treatments is for people living with HIV/AIDS. If a treatment is not accessible, ask them to identify why.
5. Discuss what can be concluded about the availability and accessibility of HIV/AIDS-related treatment in the local community.

Facilitators' notes

- Ensure that participants mark both formal sources of treatment (such as hospitals) and informal sources (such as traditional healers).
- Help participants to think critically about whether all treatments that are available to people living with HIV/AIDS are also accessible to them.

Example



Question A.3: How do people living with HIV/AIDS seek and use treatment in your community?

Questions for focus group discussions:

- How easy is it for people living with HIV/AIDS to use different types of treatment?
- What prevents people living with HIV/AIDS from using treatment properly?
- How do social, financial and cultural factors affect how people living with HIV/AIDS use treatment?

Participatory group activity

Aim

To assess how people living with HIV/AIDS seek and use treatment in your community.

Instructions

1. Explain the aim of the activity.
2. Brainstorm about the different places where people living with HIV/AIDS seek treatment in your community and write them down on the lefthand side of a large piece of flipchart paper. Examples might include a pharmacy or hospital.
3. Along the top of the paper, write down the reasons why someone would choose to seek treatment from a particular place. Examples might include good location or low cost.
4. Draw lines to make a grid. Then take participants through the grid, assessing each place and ticking the boxes beside it if the reasons apply.
5. Ask participants to share typical stories of people living with HIV/AIDS using treatment effectively or not effectively. Ask them to identify factors that prevent people from using treatment effectively.
6. Facilitate a discussion of what can be concluded about how people living with HIV/AIDS seek and use treatment in your community.

Facilitators' notes

- Support participants to focus on the 'real life' reasons that affect people's decisions about using treatment, such as money and time.
- Support participants to really discuss (rather than just tick the box) why people would access treatment from a particular place.

Example

	Good location	Low cost	Friendly staff	Skilled staff	Recommended by others
Clinic	√		√	√	
NGO	√	√	√		√
Pharmacy	√			√	√
Etc.					

4.2.B Assessing needs and resources – the local environment

Before making a decision about what specific HIV/AIDS-related treatment work to do, an organization needs to understand what others are already doing in the area. This can help to avoid duplication of effort and to address people's treatment needs more effectively.

An assessment can provide an opportunity to analyse which other organizations are involved, what they are doing and how well they are doing it. This will help the organization to decide where it might make the biggest difference.

An assessment of the local environment might involve some or all of the following:

- other NGOs
- government
- hospitals
- doctors
- pharmacists
- donors
- groups of people living with HIV/AIDS.

It could focus on three key questions, each of which can form the basis of both focus group discussions and participatory group activities:

- **Question B.1:** Who is involved in providing treatment for people living with HIV/AIDS in your community?
- **Question B.2:** What HIV/AIDS-related treatment services are other organizations providing in your community?
- **Question B.3:** How effective is the HIV/AIDS-related treatment work being done by other organizations in your community?

Question B.1: Who is involved in providing treatment for people living with HIV/AIDS in your community?

Questions for focus group discussions:

- How many other organizations are involved in HIV/AIDS-related treatment in your community, and what type of organizations are they?
- What type of HIV/AIDS-related treatment work are they involved in?
- What is the quality of their HIV/AIDS-related treatment work – effectiveness, acceptability, efficiency, attitude to clients?

Participatory group activity

Aim

To identify which other organizations are involved in HIV/AIDS-related treatment work in your community.

Instructions

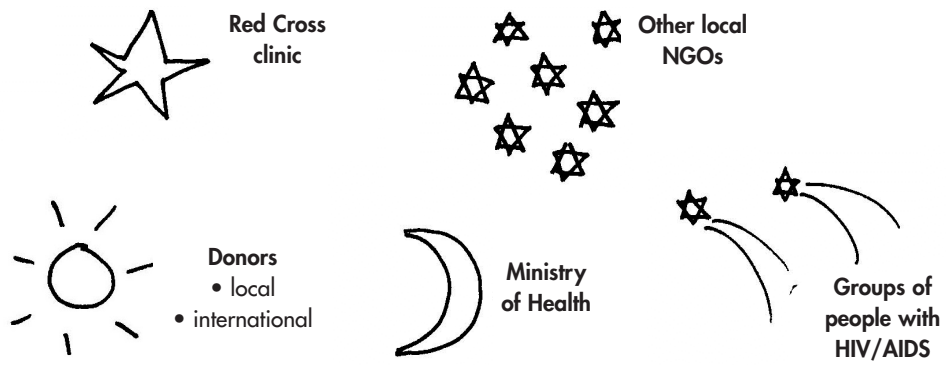
1. Ask participants to draw a map that shows the other organizations in HIV/AIDS-related treatment work in your community as different parts of a universe. Examples might include drawing another NGO as a star, or a hospital as a moon.

2. Ask participants to explain why different organizations have been drawn in different ways and what it shows about their work and their relationship to each other.
3. Discuss what can be concluded about who is involved in treatment work for people living with HIV/AIDS.

Facilitators' notes

- Encourage participants to use the parts of the universe to communicate their feelings about an organization. For example, if they feel positive about it, they might draw it as a sun.
- If participants are not comfortable with drawing a universe, ask them to draw the organizations as any other shapes that communicate how they feel about them.

Example



Question B.2: What HIV/AIDS-related treatment services are other organizations providing in your community?

Questions for focus group discussions:

- What HIV/AIDS-related treatment services are other organizations offering to people living with HIV/AIDS in your community?
- What scale of HIV/AIDS-related treatment services are other organizations providing?
- Where and to whom are other organizations providing HIV/AIDS-related treatment?

Participatory group activity

Aim

To assess what HIV/AIDS-related treatment services other organizations are providing in your community.

Instructions

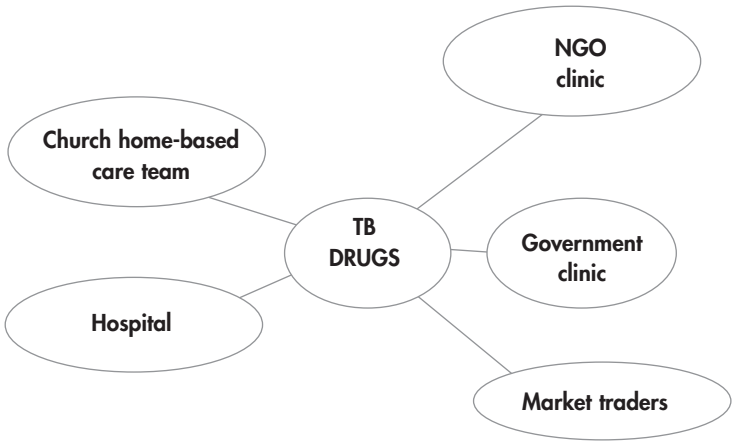
1. Explain the aim of the activity.
2. Ask participants to select an HIV/AIDS-related treatment that is available in your community. Ask them to brainstorm about the organizations that are providing it.
3. Ask participants to draw a diagram with the treatment in a circle at the centre and the organizations in circles around it. If the organization can provide a lot of the treatment, ask them to put it in a circle close to the treatment. If they can only provide a little, ask them to put it at a distance.

4. Repeat the activity for two to three other examples of HIV/AIDS-related treatment.
5. Discuss what can be concluded about the HIV/AIDS-related treatment services offered by other organizations in your community.

Facilitators' notes

- Encourage participants to select a variety of HIV/AIDS-related treatments – from simple drugs (such as paracetamol) to complex ones (such as antiretrovirals).
- Ensure that participants include both formal sources of the treatment (such as hospitals) and informal sources (such as markets).

Example



Question B.3: How effective is the HIV/AIDS-related treatment work done by other organizations in your community?

Questions for focus group discussions:

- What are the strengths of the HIV/AIDS-related treatment work done by other organizations?
- What are the weaknesses of their work?
- What are the significant gaps or duplications among other organizations involved in treatment?

Participatory group activity

Aim

To assess the effectiveness of the HIV/AIDS-related treatment work carried out by other organizations in your community.

Instructions

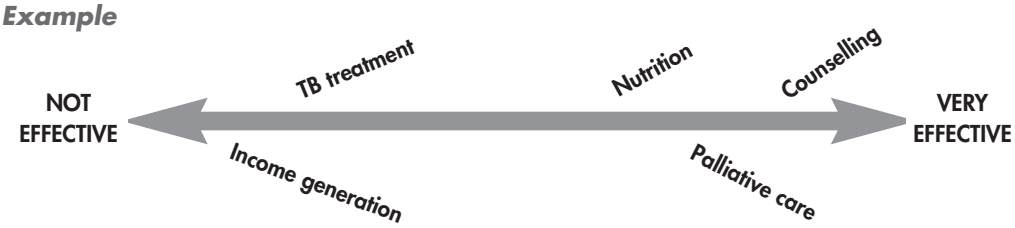
1. Explain the aim of the activity.
2. Ask participants to select an organization involved in HIV/AIDS-related treatment in your community. Write each type of treatment that it provides on a separate piece of paper.
3. Draw a ranking line with 'not effective' at one end and 'very effective' at the other.
4. Ask participants to place the pieces of paper along the ranking line, according to how effectively the organization provides the HIV/AIDS-related treatment.

5. Repeat the activity for another two or three organizations.
6. Discuss what can be concluded about how effective the HIV/AIDS-related treatment work is by other organizations in your community.

Facilitators' notes

- Encourage participants to look at a broad variety of organizations providing treatment, including government, nongovernmental and traditional.
- Support participants to offer honest and constructive criticism about the work of the organizations, rather than being too negative.

Example



4.2.C Assessing needs and resources – your NGO/CBO/PLWHA group

Before making a decision about what specific HIV/AIDS-related treatment work to undertake, an organization needs to understand its own capacity to do the work. Being too ambitious or wasting precious resources can lead to failure. Assessing an organization's capacity, therefore, can help to ensure that it is building on its strengths and improving on its weaknesses.

An organization needs adequate human resources with the right knowledge, skills and attitudes to carry out its chosen work. It also needs basic organizational systems and management to carry out a number of key tasks that support work on treatment, such as:

- identifying needs, setting objectives and planning the work;
- budgeting, accounting, documenting experiences and getting funds; and
- monitoring progress.

An assessment of your organization could involve some or all of the following:

- staff
- volunteers
- trustees
- donors
- management committee
- peer educators
- people living with HIV/AIDS.

It could focus on three key questions, each of which can form the basis of both focus group discussions and participatory group activities:

- **Question C.1:** How does HIV/AIDS-related treatment work fit in with your organization's mission?
- **Question C.2:** What are your organization's resources in relation to HIV/AIDS-related treatment work?
- **Question C.3:** How could your organization's current programmes support and sustain future work on HIV/AIDS-related treatment?

Question C.1: How does HIV/AIDS-related treatment work fit in with your organization's mission?

Questions for focus group discussions:

- Does work on HIV/AIDS-related treatment complement or conflict with your organization's current mission?
- Is there a demand from the community for you to add HIV/AIDS-related treatment to your organization's mission?
- Is there interest within your organization for HIV/AIDS-related treatment to be added to your organization's other work?

Participatory group activity

Aim

To assess the strengths and weaknesses of your organization to undertake treatment work.

Instructions

1. Explain the aim of the activity.
2. Ask participants to discuss the existing mission of the organization.
3. Draw two columns on a piece of flipchart paper. At the top of one, draw a smiling face and write 'Would support'. At the top of the other, draw a frowning face and write 'Would not support'.
4. Ask participants to list the ways in which treatment work would or would not support the organization's existing mission. Write the key points in the appropriate column on the flipcharts.
5. Discuss what can be concluded about how HIV/AIDS-related treatment work fits in with the organization's existing mission.

Facilitators' notes

- If participants do not know the organization's exact mission, ask them to brainstorm about its general aims and objectives.
- Encourage participants to think honestly and critically about how work on HIV/AIDS-related treatment might affect the organization both positively and negatively.

Example

Would support	Would not support
• Would strengthen our mission to provide comprehensive care • Would show that we are responsive to the needs of people with HIV/AIDS • Etc.	• Would make our NGO seem too medical • Would take us from our focus on psycho-social support • Etc.

Question C.2: What are your organization's resources in relation to HIV/AIDS-related treatment work?

Questions for focus group discussions:

- What management and administration systems does your organization have to support HIV/AIDS-related treatment work?
- What relevant staff, facilities and funding does your organization have?
- What linkages with other organizations involved in HIV/AIDS-related treatment does your organization have?

Participatory group activity

Aim

To assess the strengths and weaknesses of your organization's resources for carrying out work on HIV/AIDS-related treatment.

Instructions

1. Explain the aim of the activity.
2. Ask participants to brainstorm about what type of resources an organization needs for treatment work.
3. Divide a piece of flipchart paper into two columns, one headed 'Strengths' and the other headed 'Weaknesses'.
4. Ask participants to identify the strengths of the organization's resources in relation to work on HIV/AIDS-related treatment. Write the key points in the appropriate column.
5. Ask participants to identify the weaknesses of the organization's resources in relation to work on HIV/AIDS-related treatment. Write the key points in the appropriate column.
6. Facilitate a group discussion about what can be concluded about the strengths and weaknesses of the organization's resources to undertake treatment work.

Facilitators' notes

- Encourage participants to be very honest about whether the organization will be able to cope with the extra work and complexity of HIV/AIDS-related treatment.
- Encourage participants to think broadly about what type of resources are needed – including not just money but also time, space and skills.

Example

Strengths	Weaknesses
• Staff with enthusiasm and strong care skills • Counselling room that could be used for treatment • Good links with pharmacy • Etc.	• No specific skills for treatment work • No funds for treatment work • Staff already have huge workloads • Etc.

Question C.3: How could your organization's current programmes support and sustain future work on HIV/AIDS-related treatment?

Questions for focus group discussions:

- What programmes does your organization currently have, and what are their major strengths and weaknesses?
- How sustainable are your current programmes?
- How might your current programmes link with work on HIV/AIDS-related treatment?

Participatory group activity

Aim

To identify how an organization's current programmes might link with work on HIV/AIDS-related treatment.

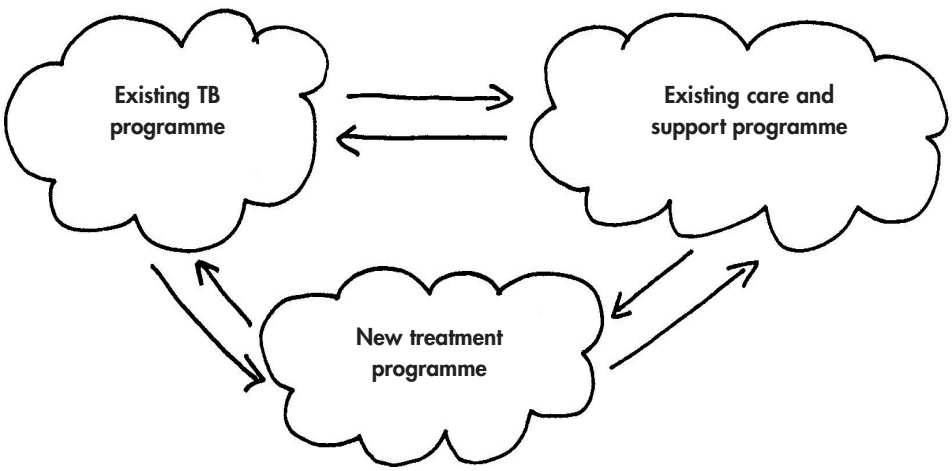
Instructions

1. Explain the aim of the activity.
2. Ask participants to analyse the organization's current programmes, and to identify their strengths and weaknesses.
3. Ask participants to identify how the existing programmes might support work on HIV/AIDS-related treatment.
4. Ask participants to draw a picture or diagram to show how the existing programmes might link work on HIV/AIDS-related treatment in practice.
5. Discuss what can be concluded about how your organization's current programmes might support future work on HIV/AIDS-related treatment.

Facilitators' notes

- Encourage participants to be honest about whether work on HIV/AIDS-related treatment will help or hinder the organization's existing programmes.
- Support participants to identify both programmatic links (such as sharing supplies of condoms) and organizational links (such as sharing administrative systems).

Example



4.3 Deciding what to do

4.3.A Analysing your findings

Having carried out an assessment of the needs and resources of people living with HIV/AIDS and the community, the local environment and your organization, it is important to analyse your findings.

This process involves three steps:

1. **sorting through the information:** to get it in order, and to identify common themes, areas of disagreement and gaps;
2. **identifying the key findings:** to draw relevant conclusions from the information; and
3. **checking the information:** to ensure that it correctly represents the views of the participants.

This process can be carried out in a participatory way. For example, sorting the information and identifying the key findings could involve using participatory activities with the staff and volunteers of your organization and representatives of the assessment participants. Checking the information could involve making a presentation of the key findings to a larger group of the assessment participants and asking for their feedback.

Participatory group activity

Aim

To analyse the findings of your assessment of needs and resources for carrying out work in HIV/AIDS-related treatment.

Instructions

1. Explain the aim of the activity.
2. Ask participants to gather together all the information from their assessment. Ask them to divide it into three piles according to the three parts of the assessment, namely people living with HIV/AIDS and the community; the local environment; and your organization.
3. For each pile, ask participants to analyse the information to see if there are:
   - common themes emerging from the information;
   - areas of disagreement within the information;
   - gaps in the information.
4. Based upon their analysis, ask the participants to identify three or four key findings for each part of the assessment.
5. Ask the participants to decide how they will check their analysis and key findings with the participants from the assessment.
6. Discuss what can be concluded about analysing the findings from the assessment of needs and resources for HIV/AIDS-related treatment.

Facilitators' notes

- Ensure that participants' analysis is based on the findings of the assessment rather than their personal opinions.
- Help participants to identify key findings that are as specific as possible and relevant to practical work on HIV/AIDS-related treatment rather than theoretical ideas.

Example

KEY FINDINGS		
People with HIV/AIDS and the community	**Local environment**	**Your NGO/CBO**
• People have a huge range of needs – from pain relief to antiretrovirals • Fear of stigma prevents people accessing treatment • People with HIV/AIDS feel treatment and support services lack coordination • Specific treatment for women with HIV/AIDS is lacking	• Very few organizations provide medical treatment beyond pain relief • TB programmes are very strong • Competition between NGOs is strong • The government is failing to coordinate efforts or give guidelines	• Has a strong established relationship with the community • Lacks sustainable funds for treatment work • Staff are overwhelmingly positive about treatment work • Lacks medical staff with specific HIV/AIDS-related knowledge

4.3.B Reaching a decision

Having analysed the results of your assessment, the next step is to decide what your organization will or will not do in relation to HIV/AIDS-related treatment. This process involves using the analysis of your results to set priorities for the future. This lays the foundations for developing polices and strategies to put the work into action.

It is important to decide who should be involved in making the decision when setting priorities. Decision-making about what to do will be more effective if you involve all those concerned, particularly those that will be directly affected by the work. They include:

- families
- community leaders
- staff, volunteers and trustees
- donors
- people living with HIV/AIDS
- other NGOs
- government.

The involvement of people living with HIV/AIDS in the decision-making process, as well as at all other stages, is especially important.

After the analysis of your assessment of needs and resources, the gaps in HIV/AIDS-related treatment will be clear. In fact, there might be a long list of things to do to improve the quality and coverage of treatment for people living with HIV/AIDS. Clearly, one group cannot meet all of those needs on its own.

When making your decision, it is important to set priorities that fit your organization's mission and are realistic and sustainable. The key priorities should be the ones that, based on your assessment, you believe will make the biggest difference.

Some important questions to think about:

- What have you learned about the priority needs of people living with HIV/AIDS?
- What are the main barriers to access to treatment?

- What is already happening to improve access to treatment?
- What still needs to be done to improve access to treatment?
- What are your organization's advantages and disadvantages in working on HIV/AIDS-related treatment?
- What work is realistic for your organization, considering its technical skills, other resources, and aims and objectives?
- Will what you are planning be sustainable – for example, in terms of the cost and the policy environment?

Further information on this subject can be found in an information sheet, 'Thinking creatively about what you can do – treatment in context', on page 112 at the end of this chapter.

Participatory group activity

Aim

To decide what your organization will and will not do in relation to HIV/AIDS-related treatment work.

Instructions

1. Explain the aim of the activity.
2. Ask participants to identify the four to six types of HIV/AIDS-related treatment needs that emerged as priorities from their assessments.
3. Write the treatment needs down the lefthand side of a piece of flipchart paper. Write criteria for prioritizing them across the top. Examples might include relevance, feasibility and sustainability. Draw in the lines to form a grid.
4. Ask participants to give each treatment a score, according to how much it meets the criterion. If it meets the criterion very well, give it three ticks. If it meets it quite well, give it two. If it meets it poorly, give it one.
5. Ask participants to identify the one or two treatments with the highest scores.
6. Ask participants to decide how their organization will provide that treatment to people living with HIV/AIDS in the community. Ask them to write a sentence summarizing what their organization will do.
7. Discuss what can be concluded about the organization's decision about what it will and will not do about HIV/AIDS-related treatment work.

Facilitators' notes

- Ensure that participants discuss each treatment and criterion in depth, as the prioritization process is vital and should not be rushed.
- Ensure that participants continually refer back to the results of their assessment, to ensure that their prioritization reflects the real needs and resources of the community.

Example

Type of treatment	Relevance to needs	Feasibility	Sustainability	Score
TB drugs	√√√	√√√	√√	8
Antiretroviral drugs	√√	√	√	4
Etc.				

4.3.C Communicating your decision

When you have agreed what your organization will do about HIV/AIDS-related treatment, you need to communicate it to all concerned.

It is important to let people know:

- what type of treatment your organization will be providing;
- when and how your organization will be providing it; and
- who can access it and on what basis (for example, at no cost or some cost).

In particular, your organization will need to communicate on an ongoing basis with:

- the people who were involved in the assessment;
- people who could access your services (people living with HIV/AIDS, families and caregivers); and
- other organizations with which you might collaborate (such as the government, drug suppliers and other NGOs, CBOs and PLWHA groups).

You should communicate with others even if you decide that your organization will not be doing work on HIV/AIDS-related treatment.

Participatory group activity

Aim

To decide to whom your organization will communicate its decision about HIV/AIDS-related treatment work.

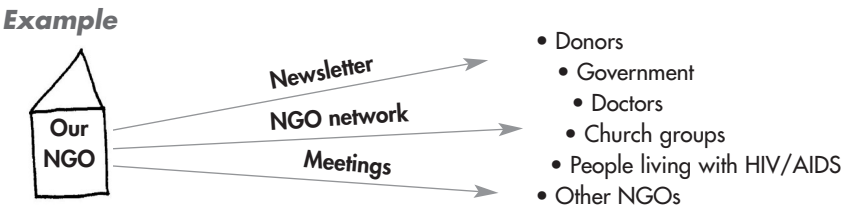
Instructions

1. Explain the aim of the activity.
2. Ask participants to brainstorm about whom they will inform of their decision regarding HIV/AIDS-related treatment work. Examples might include the government or other NGOs, CBOs and PLWHA groups.
3. Ask participants to identify how they will communicate with the audiences they have identified. Examples might include through a leaflet or through an NGO network meeting.
4. Ask participants to draw a picture to show how they will communicate their decision and to whom.
5. Discuss what can be concluded about how and with whom the organization should communicate its decision about work on HIV/AIDS-related treatment.

Facilitators' notes

- Encourage participants to think of the simplest, as well as cheapest, way to communicate their decision to others.
- Encourage participants to communicate their message to groups that they already have contact with and other potential partners for HIV/AIDS-related treatment work.

Example



Information Sheet 3

Thinking creatively about what your group can do – treatment in context

When you are considering the results of your assessments, you also need to look at the range of options for treatment work that your group might get involved in. It is also important to remember that treatment with drugs must be supported by, and integrated with, other forms of treatment and care, such as nutrition, counselling, traditional remedies, etc. (see Chapter 1.1.B on page 19).

The following table shows some of the options from which your group may want to choose. These are grouped according to where different types of treatment may take place.

Home	Community	Health-care facilities
• Universal precautions to prevent HIV transmission	• Social support and counselling	• Voluntary counselling and testing
• Safer sexual practices, including family planning	• Access to voluntary counselling and testing	• Access to safe blood, blood products
• Personal and environmental hygiene practices	• Community information and involvement	• Clinical management of pain, malaise and fever
• Emotional support for people living with HIV/AIDS, caregivers and families	• Support groups	• Clinical management of opportunistic infections
• Nutrition and safety of food and water supplies	• Accompanying people who need treatment	• Clinical management of sexually transmitted infections
• Using medicines and traditional remedies correctly and adhering to treatment regimes	• Nutritional counselling	• Preventive treatment and treatment for TB
• Support for DOT (directly observed treatment) regimes	• Support for DOT regimes	• Preventive treatment of PCP (*pneumocystis carinii* pneumonia)
• Sharing information about where to get more support	• Food programmes	• Nutritional assessment and counselling
	• Providing condoms, bleach, clean syringes	• Antiretroviral therapy for preventing mother-to-child transmission
	• Access to family planning services	• Antiretroviral therapy including HAART (highly active antiretroviral therapy)
	• Advocacy	• Clinical and laboratory monitoring of progression of HIV/AIDS
	• Assistance to orphaned and vulnerable children	• Access to breast-milk substitutes
	• Financial support	
	• Legal support	
	• Management of drug supplies	
	• Hospice	
	• Bereavement and funeral support	

4.4 Further sources of information

Facilitators' guide for needs assessments on access to HIV/AIDS-related treatment – a resource to support the development of a practical toolkit for NGOs, CBOs and PLWHA groups. International HIV/AIDS Alliance, 1998. Assessment tools, questionnaires for assessing treatment needs of people living with HIV/AIDS.

Positive, engaged, involved – PLHA participation in community-based organizations – research summary. Horizons–Population Council and International HIV/AIDS Alliance, 1999. A report summarizing the research results of different aspects of the involvement of people living with HIV/AIDS.

Needs assessment reports (Zambia, India, Côte d'Ivoire): development of a toolkit on access to HIV-related treatment. International HIV/AIDS Alliance, November, 1999–January 2000. Reports of needs assessments on issues of HIV/AIDS-related treatment access; results of these visits formed the basis for the development of the *Handbook on access to HIV/AIDS-related treatment*.

Key elements in HIV/AIDS care and support. Draft working document. WHO/UNAIDS, December 2000. A summary of care needs, principles and values of HIV/AIDS-related care, key interventions for care and support, structural elements for service delivery and prioritization of different elements of care.

Management support for primary health care – a practical guide to management for health centres and local projects. Paul Johnstone and John Ranken. FSG Communications Ltd, Cambridge, UK, 1994. Principles and practice of health-care management at local level, including understanding communities and individual needs, methods and examples of management.

The examples in this chapter are compiled from activities conducted during workshops on access to HIV/AIDS-related treatment in Cambodia, India and Zambia.

Chapter 5
Learning from and improving HIV/AIDS-related treatment work

Chapter 5 of this handbook helps NGOs/CBOs/PLWHA groups to develop a basic understanding of:

- the importance of keeping track of their work and managing change;
- monitoring what is happening and making use of the information gathered;
- evaluating how the work has affected the needs of people living with HIV/AIDS;
- tracking the organization's response to change within and outside the work;
- working out how to respond to changing situations;
- exchanging lessons with others involved in treatment work;
- deciding whether to increase or decrease their work, or keep it the same.

5.1 Monitoring and evaluating HIV/AIDS-related treatment work

5.1.A Keeping records of your work

A group involved in HIV/AIDS-related treatment needs records for managing and improving their work and responding to change. The aim of record-keeping is to provide useful information to track what has happened in your work.

Different types of records are needed to tell the complete story about your work and the people you are helping. These include:

- **quantitative** records, showing facts and figures about what work has been done; and
- **qualitative** records, showing information about human relationships, experiences and developments.

Both types of records can tell you about:

- **the people using your services**
  – quantitative records, such as statistics about the personal details of people (age, gender, etc.), their health problems, types and quantities of care received, treatments given, referral and follow-up appointments made and kept;
  – qualitative records, such as needs assessment interviews, meetings involving clients, case studies and experiences in using your services;
- **your organization**
  – quantitative records, such as statistics about the management of the work, including details and numbers of staff, patient attendance and records of drugs and other supplies;
  – qualitative records, such as notes about discussions, meetings, interviews, decisions taken and policies.

Case study – An NGO using qualitative and quantitative records to improve treatment

Dr Ahmed was puzzled. He was listening to someone at a meeting who was talking about pain and HIV/AIDS. The speaker said that people living with HIV/AIDS often have pain but it tends to be undiagnosed, untreated or ignored by health workers.

During the break, Dr Ahmed talked to others, including a doctor from a cancer hospital which had started to treat some HIV/AIDS patients as well. This doctor confirmed that the speaker might be right, at least in his limited experience; some of his HIV/AIDS patients had seemed just depressed or sad, but when he gave them analgesia they became brighter and more able to communicate.

Back at his clinic, Dr Ahmed wondered if he, too, had failed to understand about his HIV/AIDS patients' pain. He provided support to a number of community nurses, so he called a meeting with them. They decided to ask their HIV/AIDS patients more carefully about pain to get an idea of what was needed – a qualitative approach. They also kept some simple records, using a list of painkillers and recording the quantities of each drug they handed out and how many patients received them.

This simple mix of qualitative and quantitative research revealed that, although many people living with HIV/AIDS said they had pain, many thought they just had to tolerate it and did not ask for any pain relief. But it also revealed that some people had pain that was too severe for the mild painkillers that the nurses were able to provide. Even codeine, for moderate pain, was not offered because the regulations prohibited nurses from issuing it. Morphine was definitely not allowed except within specialist hospitals.

Dr Ahmed talked to other HIV/AIDS physicians and together they negotiated with the authorities and showed them the information that he and his nurses had gathered from patients. After more research, the regulations were changed to allow community nurses to provide codeine, with careful supervision by the doctor and recording of use in a special register.

The doctors and nurses also advocated that specially licensed community doctors be allowed to prescribe and provide morphine as tablets or syrup for patients with severe pain. Eventually, government officials and specialist doctors were convinced enough to allow a pilot analgesia project for a limited period.

Once again, gathering qualitative and quantitative information confirmed that there was a real need for morphine, that the right amounts of drugs were being used, and that none were being abused or diverted to illicit use by addicts. New laws were drawn up about the medical use of morphine and a training programme was developed to improve doctors' and nurses' understanding of pain control, based on WHO recommendations.

It can be difficult to keep good records as workers usually prefer to get on with their jobs and not spend time recording what they have done. They may not understand why the records are important. If records are kept but never used, people may stop bothering with them. There may also be a lack of relevant skills. It is important that:

- staff know why the records are important and how they will be used;
- the process of making records be as quick and simple as possible; and
- staff have the necessary skills for making the records you need.

Finally, a group needs to ensure that its records are accessible to anyone who needs to use them, while also ensuring confidentiality. It is important to think about the people who need to hear about your experiences and to find interesting ways to communicate with them, such as using photo diaries or wallcharts.

5.1.B Monitoring your work

It is important to monitor the quantity and quality of work as an HIV/AIDS-related treatment project progresses. Monitoring is an important management tool that can provide ideas and activities to:

- check on progress and report on it to staff, supporters and donors;
- help in day-to-day management and use of resources;
- share experiences and lessons learned with others;
- change what is not working and avoid duplicating what others are doing; and
- plan for the future.

Monitoring is an ongoing process, not a one-off event. It involves using some records regularly to review work. The records that are needed for monitoring must provide useful measures of progress and change. For example, quantitative information about people receiving treatment can help to show:

- the numbers of people seen and their health problems;
- their gender and age;
- the numbers and types of drugs dispensed; and
- the number of community health education and awareness talks given.

A group will also need to use qualitative methods of monitoring, which depend on observation, careful listening and questioning of the people involved in the work and people receiving treatment. Together, quantitative and qualitative monitoring will give a much broader and clearer picture of how work is progressing and whether the people living with HIV/AIDS are getting what they need.

Key questions

Key questions to ask when monitoring HIV/AIDS-related treatment work:

- What type of quantitative and qualitative information do you need to know about your treatment work?
- What records should be kept about the treatment work?
- Who should keep the records and how should they be kept?
- What should the records be used for and who should use them?

Case study – Monitoring a clinic service

In a busy clinic, records showed that prescriptions were being dispensed very quickly. Patients received their drugs within one minute of handing the doctor's prescription to the person dispensing the drugs. Quantitatively, this seemed to show that things were going well. The queues were short, dispensing was quite accurate and the number of patients was high. But, qualitatively, things were going badly. The patients did not remember being told anything about how to take their drugs, and the dispensers felt under pressure to keep the queues short or face criticism from their supervisor.

Understanding the whole story helped the manager of the clinic to work with the dispensers and their supervisor to improve the quality of their work. Together, they found new ways of managing queues while also taking time to check that patients understood their medication.

5.1.C Evaluating your work

While monitoring is ongoing, evaluation needs to take place only from time to time during HIV/AIDS-related treatment work. Evaluating work involves looking at the results of monitoring, asking probing questions about the information that has been gathered, and assessing how treatment work has gone. It can help to answer the following questions:

- What has been achieved?
- What difference has the work made to the treatment of people living with HIV/AIDS?
- How do the achievements match the organization's goals?
- What has been the cost – in human and financial terms – for the organization, people living with HIV/AIDS and the community?

Some of the key reasons to evaluate the work are:

- to improve the effectiveness and efficiency of the work;
- to help with future choices and decisions;
- to learn lessons that can be shared within the organization and with others; and
- to increase accountability to those who have an interest in the work.

The reasons for evaluating the work will depend on who has encouraged the evaluation. For example, a donor may have asked for it in order to decide whether to carry on funding, or people living with HIV/AIDS and the community may have asked for it to see if the project is meeting their needs. Each group will have different interests and requirements. It is important to be clear about the expectations of those requesting an evaluation before starting it.

The process of evaluation can involve many different people, including:

- staff and volunteers of the organization;
- people living with HIV/AIDS and other community members;
- other NGOs, CBOs and PLWHA groups; and
- donors and decision-makers.

Participatory methodologies, such as mapping and priority-ranking, are useful tools for evaluation because they help people to communicate more freely. Many of the tools included

in Chapter 4 on page 95 of this handbook can be adapted for evaluation, alongside other methods such as reviewing records and holding focus group discussions.

It is also important to relate the evaluation of the treatment work to the assessment of the needs and resources of the group (see Chapter 4.2.C on page 104).

Evaluating people's experiences, the organization's activities and project management

Ways to evaluate people's experiences include:

- analysing facts and figures from monitoring activities;
- asking questions, holding interviews and having group discussions;
- using written questionnaires;
- analysing reports, case studies and people's stories about themselves; and
- observing activities and meetings.

Ways to evaluate an organization's activities include:

- reviewing written information, such as reports, accounts and records;
- analysing the areas covered, numbers of people served and treatments prescribed;
- using verbal or written questions in questionnaires, interviews and surveys; and
- observing activities and procedures.

Ways to evaluate the management of a project include:

- reviewing records, reports, budgets, minutes of meetings and previous evaluations;
- directing verbal or written questions to individuals;
- interviewing individuals or teams;
- observing the work and practices; and
- holding discussions with staff and other interested parties.

An evaluation of an HIV/AIDS-related treatment project should cover areas such as:

- the people involved in the project;
- treatment activities;
- management activities; and
- links with others.

Many evaluations focus on particular aspects of a project, but the following questions are common to most.

- **Effectiveness**. To what extent is your work in HIV/AIDS-related treatment achieving its objectives?
- **Efficiency**. What has been the cost of achieving your objectives, in terms of the people involved and the funding?
- **Relevance**. Is the work appropriate to the needs of the people you are trying to serve? Are there other problems that should take priority?
- **Sustainability**. How long can the work continue and how can the necessary money, people and other resources be found?
- **Progress**. Is the work achieving its original objectives, or have those objectives changed?

- **Impact**. What are the effects of the work on people living with HIV/AIDS, the community, the HIV/AIDS epidemic and your organization? Has your work been helpful or made little difference? What effects has it had on economic, social and cultural factors? Has the impact remained local or spread wider? How does this affect your plans for the future?

5.2 Changing and improving HIV/AIDS-related treatment work

5.2.A Making the most of new resources and linkages

The overall aim of most organizations involved in HIV/AIDS-related treatment work is to help communities meet their treatment needs. However, these needs keep changing. It is important to be responsive and to assess needs on an ongoing basis. No group working in treatment can expect to respond to everything, so it is important to keep in touch with new, emerging needs. Even if a group cannot do much about them, it may be able to encourage others to help.

New resources may become available. It is important to look continually and actively for new people, materials and information that will make a difference. However, new resources also bring challenges. They will provide more effective ways of getting things done and keeping up to date, but they may also require new skills, people and materials to use them well.

New linkages will also come along. Others may be starting to do work that is closely connected with your own objectives. The key to finding out how their work will affect your own will be communication – getting to know them and their priorities and making solid connections with them to allow the sharing of information and/or resources.

New resources and linkages for HIV/AIDS-related treatment work:

- accessing new treatment guidelines to facilitate selection of the most appropriate drugs;
- meeting people who can help you by contributing their skills or training your team;
- finding new sources of drugs at reduced prices;
- getting more support from the political and business communities;
- having increased access to e-mail and the Internet, which widens the network of support and brings a lot more information;
- receiving extra funding, which allows the work to expand or keeps your projects going for longer.

5.2.B Coping with changes

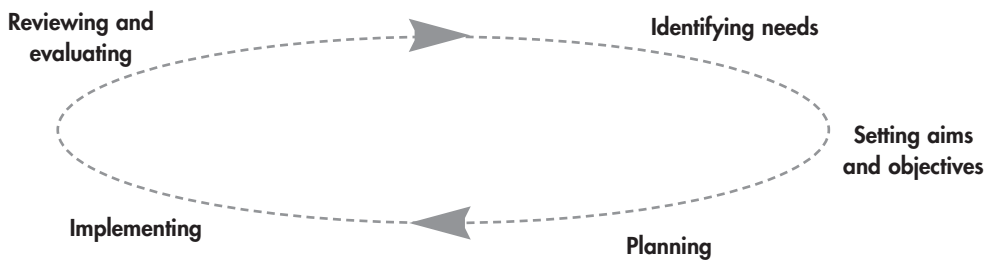
Change is a constant factor in the HIV/AIDS epidemic and people's lives. An organization must respond to changes in the community it serves. From time to time, it will also need to assess whether change is necessary within its own organization. Some unexpected changes may happen, but some can be predicted and plans can be made to deal with them.

As changes occur, new assessments of needs and resources should be made, to check that the treatment needs of the community are still being met. It will be helpful to return to the original assessments of needs and resources that were made before work began (see Chapter 3 on page 55) to evaluate the progress and assess whether the questions that were asked and the methods that were used are still appropriate or should be updated.

Changes that can affect HIV/AIDS-related treatment work:

- changes in the pattern of the HIV/AIDS epidemic – for example, the numbers and type of people affected;
- changes resulting from treatment work – for example, some successful programmes have seen a reduction in problems such as diarrhoea and oral thrush but also, because more people are now living longer with HIV/AIDS, have seen more cases of unusual opportunistic infections that require specialist treatment;
- changes in relationships within your group and with other individuals and organizations;
- changes in key material resources for treatment, such as new ways of using old drugs, the introduction of new drugs, and changes in drug prices;
- changes in other resources, such as funding, referral systems and human resources; and
- political and economic change, whether local, national or global.

Responding to change is not a fixed event; it can occur at any time during the cycle of work.



Changes should be seen as opportunities to improve treatment access for people living with HIV/AIDS. The effects of change on your organization must also be managed, as change that is too much, too fast or not enough can be confusing and stressful for staff and service users alike.

5.2.C Sharing your experiences with others

This handbook is based on the experiences of many local organizations working in challenging conditions with limited resources in a number of countries. One of its key aims is to share the lessons that these organizations have learned through their practical work on HIV/AIDS-related treatment.

Too often, efforts in treatment work are duplicated and mistakes are repeated just because one group's experiences are not passed on to others. Important questions to ask, therefore, are: What can your organization do to share the lessons from its work? What can you tell others about your successes, about things that did not work well, and changes you had to make? Sharing these experiences openly means that you and others can reflect and see how things might be done better in future.

Examples of how a treatment project might share its experiences with others include:

- linking up with other groups to share experiences at meetings or workshops;
- documenting experiences in reports and briefing papers and distributing them widely;
- meeting people living with HIV/AIDS and other community members to discuss the results of evaluations and to develop plans for the project;

- communicating key lessons and messages through the mass media, including radio and television;
- contributing articles to publications, whether your own organization's newsletter or a national journal on HIV/AIDS;
- contributing to national and international debates – for example, through the Internet; and
- sending representatives to national and international meetings and conferences to speak about your experiences.

The same methods can be used to help your organization to learn from other people's experiences. This might involve building links with a variety of different organizations involved in treatment work, including:

- other NGOs and CBOs
- government and policy-makers
- community health workers
- traditional healers
- media
- groups of people living with HIV/AIDS
- pharmacists and drug suppliers
- donors
- religious groups
- businesses.

Case study – Sharing experiences

An international NGO set up a meeting in an African country because it wanted to learn more about local NGO/CBO experiences of HIV/AIDS-related treatment. It also wanted to provide a chance for the local groups to learn from each other's experiences and build up their networks of support within the country.

The day before the meeting, participants received a short questionnaire asking:

- how they got started in HIV/AIDS treatment work;
- how they decided what treatment to offer;
- what challenges they faced and what helped or hindered them; and
- how they expected to develop their work in the future.

For the first half of the meeting, the whole group brainstormed about treatment and what it meant to them and their communities. A lot of different ideas came up – some were strictly clinical but others described the whole of family, social, spiritual and medical care as 'treatment'. During the coffee break, there was a lot of informal sharing of experiences and opinions sparked off by the brainstorming.

After the break, small groups discussed their answers to the questionnaire – they were pleased that they had some time to think about this before the meeting. Some had started offering treatment just because their patients needed it; others had seen the growing needs and had carefully worked out how to develop a comprehensive service. Everyone talked about the growth in need and their struggles to keep up with demand.

At the end, the whole group talked about how they had learned from each other and how they expected to develop their work. They needed support to help them in this – not just from overseas donors but from each other, the government, private sector businesses and from people living with HIV/AIDS themselves and their communities. This meant that they had to communicate with all these people about what they were doing and why it was important to support it. The international NGO staff gained a deeper understanding from the meeting, and used some of the ideas and priorities for their future planning.

Participatory group activity

Aim

To enable participants to share experiences of their work on access to treatment and to facilitate fresh thinking and planning for their work.

Instructions

1. Explain the aim of the activity and the importance of taking a fresh look at what they have done in order to plan better for the future.
2. Explain which topic is to be discussed in this meeting and why.
3. Divide the large group into smaller groups of not more than three to six people and ask them to brainstorm about their experiences around three or four aspects of the topic and record the main points on a flipchart.
4. Bring the small groups back together to report on their discussions.
5. Summarize what people have said and write the main points on a flipchart sheet that everyone can see.
6. Ask people from the same NGO/CBO to form a group to discuss what they have learned and how this might affect their plans for the future. If only one person from an NGO/CBO is present, s/he can work alone or may want to work with a group doing similar work.
7. In the large group, ask people to brainstorm about the following points:
   • What new things have they learned from the meeting about the main topic?
   • What are the main priorities for their own NGOs/CBOs in helping to make progress on this topic?
   • What needs to be done by others to enable their own work to succeed?

Facilitators' notes

- Make sure that the topic chosen for discussion is one that concerns all participants and that they can benefit from discussing it with others.
- Make the small group discussions easier by providing a few headings that people can use to focus their discussions. For example, if they are discussing involvement of the community in their work, they could look at different types of involvement – such as practical help, financial support, prevention work and so on.
- In the final discussion, encourage participants to be realistic and practical about what they want to do for the future and what help they want.

5.2.D Scaling up, scaling down or staying the same

The results of monitoring and evaluating your HIV/AIDS-related treatment work might tell you that your work is going well, you are reaching your goals and you do not need to alter anything. It is likely that the results of monitoring and evaluation will highlight areas that you need to change. These results can be reviewed and assessed on a regular basis as a part of the annual review and replanning process.

Key questions to ask in order to assess whether your work should change:

- Does the work still need doing?
- Have we been doing it in the best possible way? Should we do a different kind of work to achieve our goals?
- Should we be doing more work? What will happen to our group if we do more work?
- If all or some of our work has to increase, how should it increase? When should it increase? Where should it increase?
- Should we be doing less work? What will happen to our group if we do less work?

- If all or some of our work has to stop, how should it stop? When should it stop? Will it be continued by someone else?

If your work has been successful, you may want to reach out to more people. But work often starts to expand in response to demand and organizations do not plan what their response should be. This can lead to management problems and staff 'burnout'. There are a number of ways in which you can respond to this.

Scaling up means finding ways to do more work, either by doing it yourselves or encouraging others to do it. There are many possible ways to do this, including expanding your organizational size, building partnerships with others and integrating treatment into other areas of work. It will be important to consider whether you have adequate resources to scale up and can maintain the quality of your work.

Scaling down means finding ways to do less work, as a response to limited or reduced resources and/or needs. This may be a wise decision if your group is being stretched beyond its capacity or if other organizations are responding more effectively to the needs you aimed to address. It can help to ensure that the quality of your work is not compromised by trying to do too much.

Staying the same may be possible, although it should be remembered that change is part of life. Even to continue with the same type and amount of work, you will need to stay in touch with developments affecting people living with HIV/AIDS and your organization. Technical skills must be kept up to date, staff replaced as they move on, and team-building encouraged.

5.3 Further sources of information

An evaluation of the Ministry of Health/NGO home care programme for people with HIV/AIDS in Cambodia. International HIV/AIDS Alliance, June 2000. An evaluation report of an NGO- and government-run home-care programme in Cambodia.

Expanding community action on HIV/AIDS – NGO/CBO strategies for scaling-up. International HIV/AIDS Alliance, June 2001. A report sharing results of workshops for NGOs and people living with HIV/AIDS to exchange successes and lessons learned in scaling up successful community-based work.

Toolkits – a practical guide to assessment, monitoring, review and evaluation. Save the Children Development Manual 5. Save the Children Fund, 1995. A collection of principles, practice and tools for NGOs, including whom to involve, uses of information; applies to all kinds of development projects.

Comfort and hope: six case studies on mobilizing family and community care for and by people with HIV/AIDS. Best Practice Case Study. Geneva, UNAIDS, 1999 (UNAIDS/99.10). A collection of experience (case studies, good practice, lessons learned) from six care and support projects.

Organizations that contributed to the development of this handbook

Burkina Faso

- Centre Oasis – Association Afrique Solidarité, Ouagadougou

Cambodia

- Association of Farmers Development (AFD), Takeo Province
- Battambang Women's AIDS Project (BWAP), Battambang
- Cambodian Children Against Starvation and Violence Agency (CCASVA), Phnom Penh
- Cambodian HIV/AIDS Education and Care (CHEC), Phnom Penh
- CARE – Cambodia, Phnom Penh
- Centre National for Tuberculosis (CENAT)
- Hope – Cambodia, Phnom Penh
- Human Rights Protection & Rural Development Association (HURIPRUDA), Phnom Penh
- Indradevi Association (IDA), Phnom Penh
- Kasekor Thmey (KT), Kampong Cham Province
- Key of Social Health Educational Road (KOSHER), Phnom Penh
- Khmer Buddhist Association (KBA), Banteay Mean Chey Province
- Khmer HIV/AIDS NGO Alliance (KHANA), Phnom Penh
- Khmer Rural Development Association (KRDA), Battambang
- Médecins du Monde, Phnom Penh
- National Centre for HIV/AIDS, Dermatology and STD (NCHADS), Phnom Penh
- National Centre for TB and Leprosy Control, Phnom Penh
- Social, Environment, Agricultural Development Organisation (SEADO), Beanteay Meanchey
- Vithei Chiwit (PLWHA group), Phnom Penh
- World Vision – Cambodia, Phnom Penh

Côte d'Ivoire

- CeDReS, Abidjan
- Centre d'Assistance Socio-Médicale, Abidjan
- Centre Intégré de Recherches Biocliniques d'Abidjan, Abidjan
- Centre Plus Yopougon, Abidjan
- Projet COTRAME/IRD
- Projet RÉTRO-CI, Abidjan
- Joint United Nations Programme on HIV/AIDS (UNAIDS), Abidjan
- United Nations Development Programme (UNDP), Abidjan

India

- AIDS Awareness Group (AAG), New Delhi
- Chelsea, New Delhi
- Committed Communities Development Trust (CCDT), Project CHILD, Mumbai

- Delhi State AIDS Control Society, New Delhi
- India HIV/AIDS Alliance, New Delhi
- India Network of Positive People (MNP+), Chennai
- Lawyers Collective – HIV/AIDS Unit, Mumbai
- Maharashtra Network of Positive People (INP+), Mumbai
- Mamta Health Institute for Mother and Child, New Delhi
- Michael's Care Home, New Delhi
- Model HIV Counselling Centre, Safdarjung Hospital, New Delhi
- NAZ Foundation (India) Trust, New Delhi
- NGO HIV/AIDS Forum, New Delhi
- RMC Hospital, New Delhi
- Salaam Baalak Trust (SBT), New Delhi
- Salvation Army, Mumbai
- Shadows – Solomon Hospital, Chirala
- Society for Development Research and Training (SFDRT), Pondicherry
- Society for Service to Urban Poverty (SHARAN), New Delhi
- St Joseph's Hospital, Pondicherry
- United Nations Development Programme (UNDP), New Delhi
- World Bank, New Delhi
- World Health Organization (WHO), New Delhi
- YR Gaitonde (YRG) Care, Chennai

Philippines

- Action for Health Initiatives, Inc. (ACHIEVE), Metro Manila
- Hope Foundation, Manila
- Kabalikat Ng Pamilyang Pilipino, Quezon City
- Pamana Development Cooperative Federation Inc., Cavite
- Philippines HIV/AIDS NGO Support Programme (PHANSuP), Manila
- Philippines National AIDS Council, Manila
- Pinoy Plus Association, Manila
- Positive Action Foundation (PAFPI), Manila
- Remedios AIDS Foundation, Manila

Zambia

- Archdiocese of Lusaka Home-Based Care Programme, Lusaka
- Catholic Agency for Overseas Development (CAFOD), Lusaka
- Central Board of Health (CBoH), Lusaka
- Chikankata Health Services, Mazabuka
- Churches Health Association of Zambia (CHAZ), Lusaka
- Copperbelt Health Education Project (CHEP), Kitwe
- Development Aid from People to People (DAPP) – Hope Humana, Ndola
- Family Health Trust (FHT), Lusaka
- Joint United Nations Programme on HIV/AIDS (UNAIDS), Lusaka
- Kara Counselling and Training Trust (KCTT), Lusaka
- Kasaba Home-Based Care, Kasaba
- Mansa Community Home-Based Care, Sisters of Mercy, Mansa
- Mbala Catholic Diocese, Mbala
- Mongu Catholic Diocese, Mongu
- Ndola Catholic Diocese, Ndola
- Network of Zambian People with HIV (NZP+), Lusaka

- Our Lady's Hospital, Chilonga
- St Francis Community Home-Based Care, Livingstone
- St Francis Hospital, Katete
- St Theresa's Hospital, Ibenga
- Thandizani, Lundazi
- World Health Organization (WHO), Lusaka
- Zambia Catholic Secretariat (ZCS), Lusaka
- Zambia Integrated Health Programme (ZIHP), Lusaka

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together eight UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its eight cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners—governmental and nongovernmental, business, scientific and lay—to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials

Drawing on the broad experience of UNAIDS, WHO and the International HIV/AIDS Alliance, the *Handbook on access to HIV/AIDS-related treatment* provides nongovernmental organizations, community-based organizations and groups of people living with HIV/AIDS with a practical resource for responding to issues of access to treatment for HIV/AIDS in developing countries. The handbook will:

- **build practical skills** among NGOs, CBOs and PLWHA groups by using participatory activities and sharing experiences;
- **provide a training resource** for NGO support programmes, training organizations and individuals;
- **facilitate ongoing learning** about the HIV/AIDS-related treatment work of NGOs, CBOs and PLWHA groups.

The handbook is intended to assist groups in finding ways of understanding, planning and undertaking work on HIV/AIDS-related treatment. It is suitable for use with people of varying levels of experience and offers flexibility to facilitators who need to gear their work towards specific schedules and situations.

Joint United Nations Programme on HIV/AIDS

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