Training Manual

Community Mobilisation and Empowerment for Improved Access to Care, Support and Treatment

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SAT
Southern African AIDS Trust
Supporting Community Responses to
HIV and AIDS in Southern Africa

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Introduction to the training manual

This training manual aims to mobilise and empower communities to improve access to care, support and treatment for people living with HIV and AIDS. The action of improving access to care, support and treatment must come from the community, with FACILITATION and support from the CBOs and NGOs as appropriate. The aim of this training manual is not to create perfect model communities, but to mobilise communities to identify what they have that can be put to better use, and to make linkages and partnerships to expand the knowledge, skills and resources available to them. The focus on this toolkit is on holistic care, support and treatment rather than solely on treatment. This emphasis aims to encourage equal weight to be given to preparing for food security, psychosocial support, etc as well as expertise and access to treatments themselves.

Acknowledgements

The conceptual approach and structure of this toolkit was developed during a regional lessons sharing workshop on *Community Preparedness for Improved Access to Treatment* which was co-hosted by JSI UK and SAT in Zimbabwe in August 2004. It was further refined at the workshop on *Community Mobilisation and Empowerment for Improved Access to Care, Support and Treatment* which was co-hosted by JSI UK and SAT in Zimbabwe in September 2004. SAT and JSI UK would like to thank all the participants at this workshop for their time and expertise in sharing information and experiences on this theme.

CMEIACST Workshop Objectives

1. To strengthen the participants existing knowledge and conceptualization of Community Mobilisation and Empowerment for Improved Access to Care, Support and Treatment

2. To familiarise the participants with the CMEIACST toolkit and other resources for training at national level.

3. To gain input from the participants as to the appropriateness of the CMEIACST Toolkit and adaptation needs at national level.

4. To strengthen the skills and build the confidence of the participants to train NGOs and CBOs on CMEIACST at different levels (national, regional, provincial, local).

This toolkit has been compiled using information from the following sources:

o *Advocacy in Action: A toolkit to support NGOs and CBOs responding to HIV/AIDS.* International HIV/AIDS Alliance. *Access from* www.aidsalliance.org

o *Caring Together: A Home Care Handbook for People Living with HIV and AIDS their Families and other Carers.* Liverpool Associates in Tropical Health (LATH), 2003.

o *Delivering on universal treatment access through Health Systems in Southern Africa.* Regional Network for Equity in Health in Southern Africa (EQUINET), August 2004. Access from *admin@equinetafrica.org, www.equinetafrica.org.*

o *Eating healthy, staying positive: A manual book on nutrition for HIV positive People.* SAfAIDS, 2004. Access from info@safaids.org.zw

o *Greater Involvement of PLHA in NGO service Delivery: Findings from a Four-country Study. HORIZONS Research Summary, 2002. Access from www.popcouncil.org/horizons*

o *Handbook on access to HIV/AIDS–related treatment: A collection of information, tools and resources for NGOs, CBOs and PLWHA groups.* UNAIDS, WHO & International HIV/AIDS Alliance, 2003. Access from www.aidsalliance.org

o *Involving Men In Community Home Based Care for HIV and AIDS.* JSI UK & SAfAIDS, 2003. Access from info@safaids.org.zw or www.jsiuk.com

o *Positive Development: Setting up self-help groups and advocating for change.* Global Network of People living with HIV/AIDS (GNP+). Access from www.gnpplus.net

o *Raising funds and mobilizing resources for HIV/AIDS work: A toolkit to support NGOs/CBOs.* International HIV/AIDS Alliance. Access from www.aidsalliance.org

o *SAT Training and Practice Manual 1. How to plan and run a participatory workshop, by Southern African AIDS Trust (SAT).Access from www.satregional.org*

o *Stepping Stones. A training package on HIV/AIDS, communication and relationship skills.* A Welbourn, ActionAid. www.actionaid.org

o *Understanding and challenging HIV Stigma: Toolkit For Action.* CHANGE, ICRW, 2003. Access from www.changeproject.org

o *Young People We Care.* JSI UK, 2003. Access from www.jsiuk.com

o *Permaculture Nutrition Training Manual*, S Nordin, Malawi, 2003

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Community Mobilisation and Empowerment for Improved Access to Care, Support and Treatment (CMEIACST)
Regional TOT Skills Building Workshop   20-24 September 2004, Holiday Inn Hotel, Harare, Zimbabwe

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
08:00	Welcome, introductions, expectations, objectives, programme and ground rules What is Community Mobilisation and Empowerment, and why is it important?	Identifying the barriers to care, support and treatment and strategies to overcome the barriers Opportunistic Infections (OIs)	Improving linkages between those involved in providing care, support and treatment Leadership at the community level for improved access to care, support and treatment	Psychosocial support Ethics and equity for care, support and treatment	What are the strengths and weakness of your organisation to undertake HIV care, support and treatment work? What are your organisation's resources in relation to HIV care, support and treatment work? How could your organisation's current and potential programmes support and sustain future work on HIV care, support and treatment?
10:30	TEA				
11:00	How to mobilise and empower communities for improved access to care, support and treatment Understanding (comprehensive) care, support and treatment	Antiretrovirals (ARVs)	Stigma reduction Mobilising resources to support community empowerment for improved access to care, support and treatment	Introduction to needs assessments and analysis What are the care, support and treatment needs of people living with HIV and AIDS in your community? Where do people living with HIV and AIDS get care, support and treatment in your community?	Continued Action planning Cascade discussion Workshop evaluation/Workshop close
13:00	LUNCH				
14:00	Continued Linking care and prevention	Herbal remedies Nutrition Achieving food security:-nutrition gardens	Involvement of men and young people MIPA in service delivery for care, support and treatment	Continued How effective is the HIV care, support and treatment work in your community?	
16:00	CASCADE DISCUSSION & TEA				
		Field visit to high density nutrition garden			

1.1 What is Community Mobilisation and Empowerment, and why is it important?
Activity: 45 minutes

Aim:
To create a common understanding of *Community mobilisation and empowerment for improved access to care, support and treatment*

Instructions:
1. Explain the aim of the activity.
2. As a large group, ask the participants to share their understanding of what '*community mobilisation', 'community empowerment'*, and '*improved access to care, support and treatment'* mean. For example, what is the meaning of *'community*?'
3. As a large group ask the participants to explain why '*community mobilisation'* and *'community empowerment'* are important for improved access to care, support and treatment.
4. Clarify the discussion by sharing the formation in the attached Information Sheet as a presentation.
5. Ask for reaction from the participants and discuss. If time allows ask participants to share experiences and examples of how community mobilisation and empowerment has helped to improve programmes

Facilitators' notes
! There are many different ideas about what these terms mean. The most important task is to gain a common understanding which you are happy to use for the rest of the workshop. Definitions do not need to be exact or rigid, but should ensure that the focus for the workshop is on communities doing things for themselves, with the SUPPORT and FACILITATION of NGO/CBOS staff.

! In this toolkit, we focus on care, support and treatment to mean holistic care, support and treatment *see activity 1.3.* Treatment with ARVs is part of holistic care, however this toolkit aims to help communities to improve access to care, support and treatment as realistic in their situation which may or may not include ARV treatment, prophylaxis for OIs etc. *'Improving'* however, can mean maximizing what exists as well as efforts to improve access to medicines and professional and lay carers etc

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"Community mobilisation is helping communities be aware of an issue and take action."
"Community empowerment is giving skills so communities can take control of their destiny."
"Improved access to care, support and treatment recognises that there are resources already in existence in the community, but communities may need the capacity to recognise and build upon them."

Quotes from JSI UK/SAT CMEIACST Workshop participants, September 2004

Information Sheet: Community Mobilisation and Empowerment

What is community?
- o Often geographically defined - but not necessarily e.g. are men who have sex with men or sex workers are a community
- o Affected communities will have different priorities within and between them depending on age, gender, social or economic status
- o Includes individuals, households and groups but also…
- o Formal and informal, public and private services

What is community mobilisation and empowerment?
Community mobilisation and empowerment is a <u>process</u> through which <u>action</u> is stimulated <u>by a community itself, or by others</u>, that is planned, carried out, and evaluated by a community's <u>individuals, groups, and organisations</u> on a <u>participatory</u> and <u>sustained</u> basis to improve wellbeing.

Community mobilisation and empowerment is <u>not</u> ...
- o a campaign or a series of campaigns. It is a continual and cumulative communicational, educational and organisational process that produces a growing autonomy and conscience.
- o Social mobilisation
- o Community participation
- o Advocacy
- o Interpersonal communication

Although community mobilisation may utilise the above strategies, or may be a strategy utilised by them, these terms are not the same

Why community mobilisation and empowerment?
- o Communities are not only *on* the front line of AIDS – *they are the frontline* of response! Communities are therefore <u>the</u> key stakeholders
- o Communities bring additional resources that may not be available to the health system alone
- o To strengthen community members' skills and capacity to address the underlying causes of health problems and reduce barriers to access to care, support and treatment.
- o Communities can apply political pressure to improve services
- o To build social capital - social structures and norms need to be changed if true access to care, support and treatment is to be achieved by those who need them most. Community mobilisation and empowerment can help to facilitate these changes.
- o To increase community members' awareness of their right to decent care, support and treatment and to strengthen their ability to claim this right.

'We didn't mobilise and empower the community first so people ended up sharing drugs while at the same time drugs expired on the shelf.' - Botswana example

The critical steps in community mobilisation and empowerment
  - o Recognition of the need to mobilise
  - o Creating community ownership of the issue
  - o Identification of internal community resources, knowledge and skills to address the issue
  - o Identification of priority needs
  - o Community planning and action
  - o Increasing the capacity of the community

A community mobilisation and empowerment action cycle

Getting organised - creating recognition and ownership

Exploring CM&E focus and setting priorities

Evaluating together

Community action

Planning together
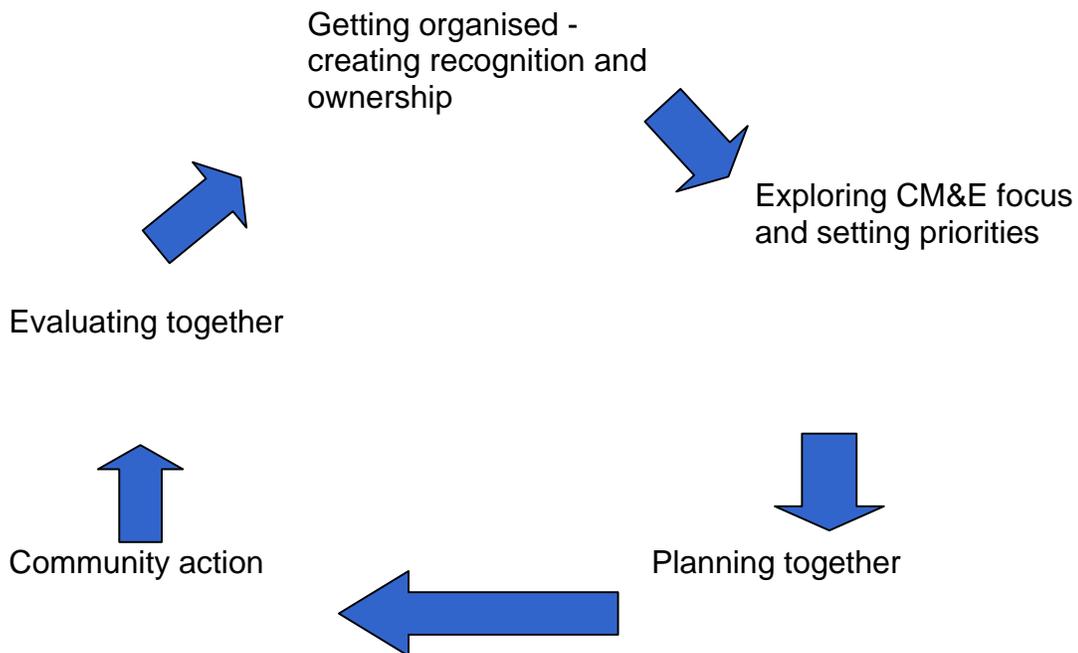
'In some places the government is giving the drugs at 'gunpoint', but because we started with community mobilisation, we found it easier to recruit patients for treatment and now we are being used as a model for the government.'
- Zambian example

1.2 How to mobilise and empower communities

Activity: 1 hour 15 minutes

Aim:
To identify different strategies to mobilise and empower communities

Instructions:
1. Explain the aim of the activity.
2. Divide the participants into groups. Ask the groups to identify the community mobilisation and empowerment strategies from their own experiences. Ask the participants to avoid jargon and explain the strategies in real terms/as real actions.
3. Ask the groups to share their work to make one list and encourage them to give each other feedback and ask questions.
4. Hand out the information sheet and identify any strategies, benefits, barriers that are missing from the group's list.
5. Facilitate a group discussion based upon questions such as:
    - ? What are the main benefits of community mobilisation work for community development?
    - ? What are the main challenges or barriers to community mobilisation work?
    - ? What successful strategies have been used to overcome the barriers?
6. To summarise, review the list and work with the participants to identify any strategies that have been missed.

Facilitators' notes

! Circulate around the groups to make sure that the participants are identifying practical mobilisation strategies

Information sheet: Comprehensive community mobilisation and empowerment

Community mobilisation and empowerment strategies
o Participatory baseline surveys
o Participatory planning
o Holding community meetings and giving feedback through regular reviews
o Forming community committees and/or organising community groups
o Networking with other stakeholders
o Raising community awareness (advocacy)
o Educating the community
o Gaining commitment from NGO forums
o Local resource mobilisation
o Identifying entry points (e.g. gate keepers, influential community leaders)
o Using MIPA (Meaningful Involvement of People With AIDS) to reduce stigma

Benefits
o Builds community capacity
o Motivates community participation and vice versa – community involvement is motivational
o Increases resource utilization
o Attracts support from other stakeholders
o Promotes sustainability (programmatic, financial, etc.)
o Allows for re-planning
o Enhances community ownership
o Easier to achieve goals and objectives because of common vision and unity

Challenges/barriers
o Inadequate supportive environment
o Poor access to services
o High level of stigma, denial and discrimination
o Impoverishment
o Inadequate information, skills and training
o Weak networks, poor coordination and lack of consistency (e.g. in messages)
o Cultural and traditional barriers
o Lack of understanding the community and environment
o Lack of appropriate representation by community groups
o Competition and duplication of efforts
o Poor governance

Strategies for sustaining relationships
o Information sharing/reports
o Establishment of strong networks
o Regular reviews and feedbacks
o Joint plans
o Make use of locally available resources
o Ensure close and participatory monitoring process
o Accountability and transparency of implementers to beneficiaries, government, etc.
o Involve the community from the beginning
o Be honest and realistic with the community about what may be achieved

1.3 Understanding (comprehensive) care, support and treatment

Activity: 45 minutes before lunch and 45 minutes afterwards

Aim:
To identify the components in comprehensive care, support and treatment for people living with HIV and AIDS.

Instructions:
1. Explain the aim of the activity.
2. Divide participants into groups. Ask each group to brainstorm – based upon their own experiences – the different components in comprehensive care, support and treatment for people living with HIV and AIDS. Ask them to write them on a piece of flipchart paper.
[LUNCH Break]
3. Bring everybody back together and ask the groups to share their results. Encourage the participants to ask each other questions and to make comments.
4. Read the story of Mr. Banda to the whole group. Ask them to identify parts of the continuum of care which were not available to Mr. Banda which would have improved his care, support and treatment.
5. Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
   ? Why is it important for care, support and treatment for people living with HIV and AIDS to be "comprehensive"?
   ? Are any of the elements of care, support and treatment more important than the others? Why?

Facilitators' notes:
! Encourage participants to think about the whole range of needs of people living with HIV and AIDS, rather than just their medical symptoms.
! Encourage participants to not focus on the differences between HIV and AIDS but address the needs as a whole.
! Ensure that participants include the "everyday" elements of care, support and treatment for people who are healthy and living with HIV, as well as for those who are ill. Examples include nutrition and a loving environment.
! Give out copies of Mr. Banda's story to the participants as a handout or show it as an overhead so that they can re-read the story to help them to participate during the session.
! The flipcharts from this activity will be used for activity 2.1 and 3.1. Keep them to hand.

Information sheet: Understanding (comprehensive) care, support and treatment

Care, support and treatment are based on an active concern for the well being of others and ourselves. People directly affected by HIV and AIDS need care. People living with HIV, 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 comprehensive HIV and AIDS care, support and treatment is to provide quality services to improve the quality of life of people with HIV, their families and communities. Comprehensive care, support and treatment is important because it helps efforts to prevent the further spread of HIV and AIDS.

Comprehensive care, an important part of care, support and treatment, is about responding to the needs of a person with HIV 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 includes the following important basics:

- diagnosis
- treatment
- referral & follow up
- nursing care
- counselling
- support to meet psychological,

"There is a thread running through all the elements – this makes it comprehensive."
"The impact of effectiveness is reduced if we do not address all elements."

- *Quotes from CMEIACST Workshop*

Each person with HIV has different needs, depending on the stage of illness and the circumstances. For example, a person with HIV who is not ill will have different needs and will require different care, support and treatment from those needed by a person with HIV who is very ill and confined to bed most of the time.

Comprehensive care for a person with HIV should happen within a **continuum of care**. This means responding to the full range of care, support and treatment 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 co-ordinated response from people with a variety of complementary skills – such as family members, counsellors, nurses, doctors, community health workers, people with HIV, pharmacists, and volunteers. It is vital that all of these people and places work together to ensure an efficient flow of information, resources and services between them – providing a continuum of quality care, support and treatment.

Comprehensive HIV/AIDS Care and Support

Supportive Policy & Social Environment

Clinical Care (medical & nursing)

VCT , PMTCT
preventive therapy (OIs, TB)
management of STIs and OIs
palliative care, nutritional support
antiretroviral therapy

Psychosocial Support

counseling
orphan care
community support services
spiritual support

Adults and Children Affected by HIV/AIDS

Socioeconomic Support

material support
economic security
food security

Human Rights & Legal Support

stigma & discrimination reduction
succession planning
PLHA participation

prevention

Case study:

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 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 to take 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 realised that Mr. Banda was afraid that his neighbours would see the Team visiting him, realise he had TB, and reject him. So, the Team helped Mr. Banda to talk to a trust-worthy 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.

Gets HIV diagnosis and TB treatment from doctor at hospital

Mr Banda

Referred to Home Based Care Team, but concerned about stigma

Talks through concerns with Medical Officer at NGO clinic

Gets TB treatment with support of relative at home
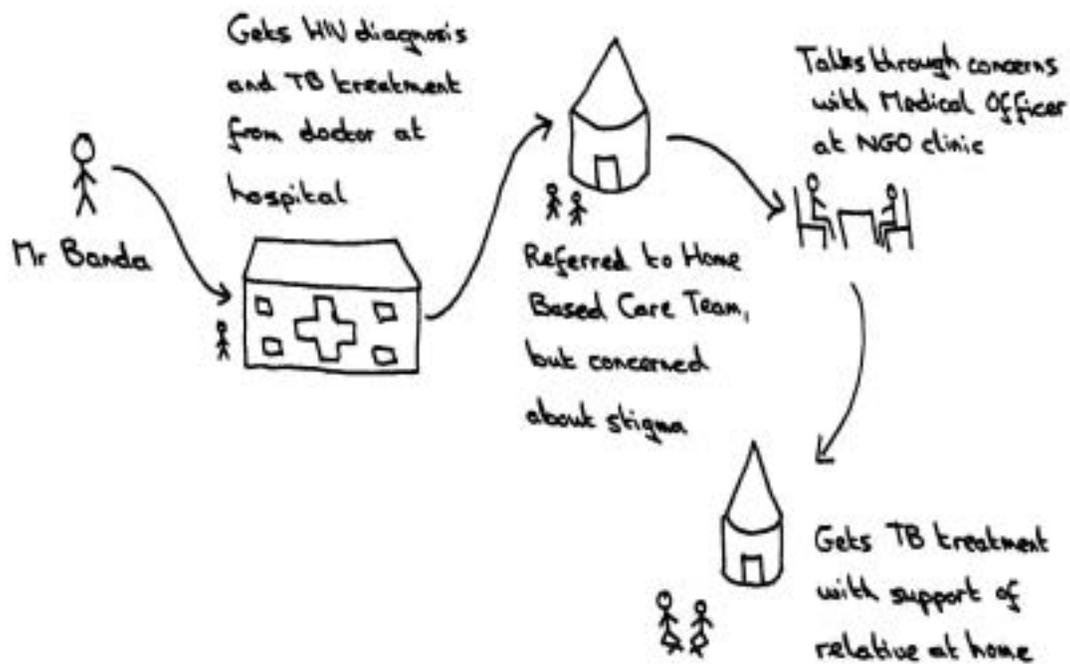
EXAMPLE 1:
At a skills building workshop, NGO/CBO participants shared their experiences about providing comprehensive care, support and treatment for people with HIV. They decided that they key elements included:

Personal and family hygiene	Counselling
Spiritual support	Nursing care
Environmental hygiene	Clothing
Education on diet	Blankets
Food	Relief of symptoms
Income generating activities	Treatment
Employment	Medicines
Sharing experiences	School needs
Transport	Singing

Afterwards, the facilitator led a group discussion about what had been learned from the activity. For example, participants agreed that effective care, support and treatment 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)

EXAMPLE 2:
Other elements identified at the JSI UK/SAT regional CMEIACST skills building workshop included:

Preparing meals, doing shopping, tending fields, etc. ("domiciliary care")	Establishing support systems for people affected and infected (carers, patients, etc.)
Giving the right information	Encouraging self-support
Advocating for supportive environments (laws, cultural practices, etc.)	

1.4. Linking care & support and prevention

Activity: 1 hour 15 minutes

Aim:
To identify the links between HIV care, support and treatment and HIV prevention.

Instructions:
1. Explain the aim of the activity.
2. Present participants with the following definition: *HIV prevention aims to prevent the transmission of HIV and re-infection.*

3. Divide the participants into 3 groups. Ask each group to discuss whether they agree or disagree with the following statements:

HIV care, support and treatment can help to reduce the need for HIV prevention. HIV prevention can help to reduce the need for HIV care, support and treatment.

4. Ask each group to also make a diagram or drawing showing the links between HIV care, support and treatment and HIV prevention.
5. In plenary 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:
    ? Does everybody have a similar view of the links between HIV care, support and treatment and HIV prevention? Why?
    ? What is the single most important link between HIV care, support and treatment and HIV prevention? Why?
7. Summarise day 1 by reviewing the topics covered in the day and summarising how they link, putting emphasis on the strategies that were identified for community mobilisation and empowerment, and the components of care, support and treatment which have been identified.

Facilitators' notes:
! Ensure participants are clear about what is meant by HIV prevention before they assess its link to HIV care, support and treatment. Ensure that their definition of care, support and treatment 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 care, support and treatment, rather than the theoretical ones.
! Ensure that participants keep focused on the links between HIV care, support and 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 care, support and treatment can help to reduce the need for HIV prevention.
HIV prevention can help to reduce the need for HIV care, support and 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 care,
support and treatment and HIV prevention in practice:

Epidemic begins

Treatment being available gives messages of hope
↓ More people get tested as there is hope
↓ People accessing treatment feel good about planning for the future
↓ People with HIV become more visible and speak out about positive living
↓ More acceptance of people with HIV
↓ People with HIV feel more empowered
↓ Empowerment and quality of life encourage people in prevention
↓ More people become involved in prevention

Epidemic slows

(Reference: Adapted from a workshop on held by India HIV/AIDS Alliance and the International
HIV/AIDS Alliance, India, February 2001).

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Information sheet: Linking care & support and prevention

Definitions: HIV prevention aims to prevent the transmission of HIV and re-infection. HIV care, support and treatment aims to improve the quality of life of people with HIV.

HIV prevention and HIV care, support and treatment help 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 with HIV and AIDS

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

✓ Good care and support activities include advice on condom use to prevent unwanted pregnancies, mother-to-child transmission, primary infection and re-infection.

✓ 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 and sexually transmitted infections

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

✓ Access to care, support and treatment has been shown to increase condom use and other preventive behaviour amongst people with HIV and 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 with HIV and AIDS makes the broader population more aware of HIV and AIDS and increases safer behaviour.

Case study:

In Cambodia, home care teams from local organisations support a large number of families affected by HIV and AIDS. Most of the people with HIV 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 and to be less afraid of the virus – there was less stigma around HIV and AIDS in the community making it easier to give education on HIV prevention.

DAY TWO

2.1 Identifying the barriers to care, support and treatment and strategies to overcome the barriers

Activity: 1 hour 15 minutes

Aim:
To identify barriers and strategies for improved access to care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Reflect back on the components of care, support and treatment from activity 1.3.
3. Working with the whole group, ask participants to identify the barriers to access to care, support and treatment for people living with HIV and AIDS in the community. Write each barrier on a crocodile head and place it in the river.
4. Ask the participants to share different strategies for overcoming the barrier and write each on a stepping stone and place them in the river. Encourage the participants to ask each other questions and to make comments.
5. Facilitate a brief group discussion about what has been learned from the activity, based on questions such as:
    ? What are the major barriers to access to care, support and treatment?
    ? Can you give any local examples of specific barriers or strategies which illustrate why we must not generalise too much?
6. Explain to the participants that the next two and a half days of the workshop will be skills-building focussing on some of the strategies used to overcome care, support and treatment barriers at the community level (indicate on the workshop schedule the strategies to be explored e.g. drug literacy, nutrition and food security, leadership, stigma reduction, resource mobilisation, involvement of men and young people, meaningful involvement of PLHA, psychosocial support, ethics and equity of care, support and treatment).

Facilitators' notes:
! For this activity use the metaphor of trying to cross a crocodile infested river – they need to avoid the crocodiles by creating stepping stones. Make a river on the floor of the workshop where everyone can see. You can use string for example to indicate the banks. Draw and cut out crocodile heads from A4 pieces of paper – make lots as each one will have one barrier written on it. Cut out round circles from A4 pieces of paper – each of these stepping stones will have a strategy written on. Preferably use different colour paper for the crocodile heads and stepping stones, or use different colour pen.

- ! Make sure that participants do not get carried away with the metaphor but instead concentrate on barriers and strategies. (Strategies are likely to be similar to those raised in Activity 1.2, 'How to Mobilise and Empower Communities.')
- ! The aim of the last question is to help the participants to consider the local level variations that may not fit with their generalisations. The aim is not to share many examples, but to make this point.
- ! Handout the information sheets if necessary or incorporate the information into the activity.

Information Sheet: Barriers to access to care, support and treatment

There are many different types of barriers to access to HIV care, support and treatment.

1. Organisational barriers

Access to HIV care, support and treatment becomes difficult if the necessary materials and skills are not available, and if services are not organised to support its proper use.

If health care and psychosocial support services are not fully available or accessible, access to HIV care, support and treatment will be very limited. This may happen because of:

✓ A lack of health services near to the people who need them.
✓ Inadequate organisation 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 unconfidential record-keeping or badly organised referral systems.
✓ Inadequate coordination and duplication of services – particularly amongst NGOs.

2. Physical barriers

In urban areas – where transport is more available and distances are smaller - 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 care, support and treatment is much more difficult.

Some of the common physical barriers include that:

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

> *"Lack of community involvement is the greatest barrier – if the community is involved, then most of the other barriers can be overcome."*
>
> *- Quote from CMEIACST Workshop*

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3. Social barriers

People might not access to HIV care, support and treatment because they have certain **beliefs** about the treatment. For example, they might think that drugs would not make a difference to them, or that unpleasant side effects out-weigh the benefits.

Attitudes to HIV and AIDS can also prevent people from accessing HIV care, support and treatment.

✓ **Secrecy** about a person's HIV status can result from people being afraid to talk about HIV and AIDS in their family or community.

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

✓ When people with HIV 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. Sometimes health workers refuse to provide treatment for people with HIV - because they fear that they might 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 care, support and treatment. But if people with HIV 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 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, have poor access to health care and HIV and AIDS adds to their difficulties. Overcoming stigma and discrimination is an important way of improving their access to HIV care, support and treatment.

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

✓ **Gender** can be a barrier if women are prevented from seeking health services, or if men – as breadwinners – are given priority.

False "cures":
Sometimes, people persuade those who have, or think they have HIV 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" - which can make the HIV virus 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 with HIV, their families and communities, often face difficult choices about the costs of treatment. For example, they might 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-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 with HIV 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 and AIDS a national emergency, and to use legal measures to import generics or introduce local generic manufacturing.
- ✓ Advocate with governments to provide drugs at no cost in government health schemes, to abolish taxes on essential drugs and to control mark-ups on drug prices and dispensing fees.

2.2 Opportunistic infections (OIs)

Activity: 1 hour 30 minutes

Aim:
To familiarise the participants with WHO clinical staging and opportunistic infections

Instructions:

1. Explain the aim of the activity
2. Give a brief in introduction to opportunistic infections using the *Information sheet: opportunistic infections* provided
3. Introduce the WHO clinical staging for HIV infection and disease, describing the key infections.
4. Go around the room and ask each participant to name an opportunistic infection and place it within the correct WHO clinical stage. Add additional OIs that may have been omitted.
5. Facilitate a discussion based on questions from the participants. Ask participants whether medicines are available in their communities to treat the various OIs.
6. Invite the participants to ask any questions they may have or they have heard others in the community asking.

Facilitators' notes:
! Discuss activity level of PLWHA at each stage level. E.g. very active, moderately active, tired and in bed during the day, in bed more than half the day.
! Remind participants that OIs can be treated but AIDS cannot be cured.
! Avoid giving too much medical detail. Participants (unless they are nurses and/or doctors) are not expected to become medical specialists.
! For "Guidelines for the prevention of opportunistic infections in persons infected with HIV," go to www.hivatis.org

Information sheet: Opportunistic infections

HIV attacks and multiplies in body defence cells called CD4 lymphocytes. This leads to progressive destruction of the body's defence system. It is possible to determine how well the immune system is doing by measuring the number of CD4 cells that are still there in the body.

As the body's defence/immune system becomes weaker and weaker, diseases that normally would not have successfully attacked the body take advantage. These diseases are therefore called opportunistic infections/diseases.

Clients need to seek prompt treatment for illnesses they may get. This is important because illnesses that are left untreated weakens the immune system further and unnecessarily as many treatments for minor illnesses are readily available.

Some opportunistic infections such as PCP, toxoplasmosis, some diarrhoeas and respiratory tract infections and TB can be prevented using certain drugs e.g. co-trimoxozole and isoniazid. This is called prophylaxis.

The condition of an HIV positive person can be staged according to the opportunistic diseases s/he may be having. This is the WHO clinical staging for HIV infection and disease shown below.

Understanding the WHO clinical stages for HIV infection and disease is useful in:
1. Deciding how far disease has progressed
2. Deciding when to start ARV treatment

WHO Clinical Stages for HIV infection and disease

Clinical Stage I:	- Asymptomatic - Persistent generalized lymphadenopathy *Performance Scale 1: Asymptomatic, normal activity*
Clinical Stage II:	- Weight loss less than 10% body weight - Minor mucocutaneous manifestations - Herpes Zoster within the last 5 years - Recurrent upper respiratory tract infections *Performance Scale 2: Symptomatic but normal activity*
Clinical Stage III:	- Weight loss more than 10% body weight - Unexplained chronic diarrhea for more than 1 month - Unexplained prolonged fever, intermittent, or constant, for more than 1 month. - Oral Candidiasis - Oral hairy leukoplakia - Pulmonary tuberculosis within the past year. - Severe bacterial infections such as pneumonia, pyomyositis. *Performance Scale 3: Bedridden for less than 50% of the day during the last month.*
Clinical Stage IV:	- HIV Wasting syndrome - Pneumocystis carinii pneumonia (PCP). - Toxoplasmosis of the brain - Cryptosporidiosis - Extra pulmonary cryptococcosis (includes cryptococcal meningitis) - Cytomegalovirus (CMV) - Herpes simplex virus (HSV) infection - Progressive multifocal leucoencephalopathy (PML) - Any disseminated endemic mycoses - Candidiasis - Atypical mycobacteriosis - Non-typhoid salmonella septicemia - Extra pulmonary tuberculosis - Lymphoma - Kaposi's sarcoma - HIV encephalopathy *Performance Scale 4: Bed-ridden for more than 50%of the day during the last month.*

2.3 Anti-retrovirals (ARVs)

Activity: 2 hours

Aim:
To gain a better understanding about the role and viability of ARVs at the community level.

1. Introduction to the goal of antiretroviral therapy (ART) and explain different types of ARVs and how they work.
   - Ask for a definition of ART and ARV
   - Ask for the benefits of ART (use information sheet to give additional benefits)
   - Using the benefits as a guide, ask how ARVs work (use information sheet to provide answers)
2. Explain when to start taking ARVs (including eligibility criteria)
3. Explain drug interactions and side effects
4. Explain benefits and limitations to ART
5. Introduce the main issues concerning ART adherence
   - Concept of adherence (Ask a participant to provide a definition)
   - Importance of adherence (Ask for personal experiences of not adhering/adhering to a prescribed medicine)
   - Measuring of adherence
   - Factors that enhance and hinder adherence (Ask participants what prevents people from adhering to ARVs)
7. Introduction to the use of ARVs in special circumstances
   - Women of childbearing potential (Include information on effect of some ARVs on effectiveness of oral contraceptives)
   - Pregnant women (PMTCT)
   - ART in Children
   - Post exposure prophylaxis (PEP)
8. Facilitate a discussion based on questions from the participants
9. Facilitate a discussion to identify what key messages our community needs about ARVs

Facilitators' notes:
- Avoid the tendency to give too much pharmaceutical detail. Participants should not be expected to become pharmaceutical experts. If there are health workers in the group (nurses, pharmacists, doctors), refer them for professional training with the appropriate institutions.
- Remind participants that information on ARVs is changing all the time. For updated guidelines on the use of ARVs for both adults and children, go to http://www.hivatis.org or e-mail atis@hivatis.org. For "Safe and effective use of ARV treatments in adults with particular reference to resource limited settings," go to http://www.who.int. A useful email discussion forum can be found through www.aidsmap.com
-

Information Sheet: Anti-retrovirals (ARVs)

HIV belongs to a group of viruses called retroviruses. The drugs that have an effect against HIV are therefore called **A**nti**R**etro**V**iral drugs **(ARVs)**. Treatment with antiretroviral drugs is called Anti Retroviral Treatment **(ART)**. ARVs are not a cure for HIV infection. They only suppress the multiplication of the virus.

GOALS OF ART
The major goals of ART can be summarized thus;

1. ARV's are used to cause a sustained suppression of HIV replication and hence viral load. This means that ARV's are working effectively, they should be able to reduce the quantity of viruses in the blood to undetectable levels.

2. ARV's help to restore and/ or preserve the immunity of the body. This means when ARV's are used the already fallen immunity could return to its normal or near normal state over a period of time.

3. When the immunity is restored, the body is then able to fight off most of the opportunistic infections, leading to an improved quality and quantity of life.

4. ARV's can be used to prevent HIV transmission in cases of accidental injuries like in the health setting (Post Exposure Prophylaxis) and to Prevent Parent to Child Transmission (PPTCT).

How ARVs work.
To understand how ARVs work, it is necessary to understand some of the stages that the virus goes through when multiplying itself in the human body. There are four major stages:

1. Entry into the CD4 cell. This stage is assisted by a part of the cell surface called the CD4 molecule.

2. Conversion of the viral genes from RNA type to DNA type so that it can enter the center of the CD4 cell where the process of manufacturing new cells begins. This stage requires an in the virus called **Reverse Transcriptase.**

3. The newly formed DNA of the virus becomes integrated into the DNA of the CD4 cell. This process is assisted by an enzyme in the virus called **integrase.** As a result of this, the CD4 cell begins to make viral part instead of normal cells.

4. The newly formed viral parts are assembled and mature into new viruses that can then attack other CD4 cells. The process of maturation requires another enzyme in the virus called **protease.**

ARVs work by blocking the stages above. They are divided into classes according to which stage they block. The types of ARVs that are available in the Southern African region are those that block the multiplication of the virus by inhibiting reverse transcriptase and those that inhibit protease. These are shown in the table on the next page.

Reverse Transcriptase Inhibitors		Protease Inhibitors
Nucleoside Reverse Transcriptase inhibitors (NRTIs)	Non nucleoside reverse Transcriptase Inhibitors (NNRTIs)	PIs
Zidovudine (AZT/ZDV) Didanosine (ddI) Stavudine (d4T) Lamuvudine (3TC) Zalcitabine (ddC) Abacavir (ABC) Emitricitabine (FTC) Tenofovir (TDF)	Nevirapine (NVP) Efavirenz (EFV)	Saquinavir (SQV) Ritonavir (RTV) Nelfinavir (NFV) Amprenavir (APV) Lopinavir (LPV) Indinavir (IDV) Atazanavir(ATV)

It is important to note that a single drug may have different names.

- **A chemical name** – This is the scientific name of the chemical substance that the drug contains. Researchers use this version of the name, but it is also sometimes abbreviated and used by health workers in place of the generic name or brand name. E.g. AZT
- **A generic name** – This is the name which is adapted from the chemical name and which is the shortest and easiest to pronounce. The World Health Organisation generally chooses it; it is also known as the international non-proprietary name (INN). E.g. Zidovudine
- **A brand name -** This is the name chosen by the manufacturer of the drug. This name is short and easy to remember in order to encourage people to ask for the product by name. The same manufacturer can own several brand names for the same drug. E.g. Ritrovir.
- The use of generic names of the drugs helps to reduce confusion surrounding drug names.

The drugs are used in combinations of at least three drugs. The combination will normally include 2 NRTIs and 1 NNRTI or 1 PI. The decision is based on the national guidelines and the clinicians' judgment. Use of less than three drugs for treatment promotes resistance to the drugs, which would be detrimental both to the individual and the community. Adherence to drugs should be observed to the maximum to avoid treatment failure due to resistance.

ART should be started neither too soon nor too late. Not too soon because of the potential side effects that could set in early in life, the high cost of treatment and the small benefit offered since the body would still be able to fight opportunistic infections. And not too late because then the immune system would have deteriorated so much and the benefit would be minimal.

ARV's should be used as a component of the comprehensive care package and NEVER as a substitute of that care. There will always be need for counselling, treatment of opportunistic infections, family planning, positive living skills, etc.

WHO AND WHEN TO START ARV's

There are both biomedical and social criteria upon which ARVs are started. Nations have developed guidelines for starting PLHAs on ARVs. The WHO recommends starting ARVs for adults based on the following criteria.
- Person confirmed HIV sero-positive
- Person in WHO clinical stage III or IV
- Person with CD4 cells less than 200 in any clinical stage
- Person with total lymphocyte count less than 1200 in areas where CD4s cannot be done

There are also other factors that could determine when a patient should start ARV's and these include;
- Patient's interest or readiness to take ARV's.
- Financial barriers
- Psychological barriers
- The patients' potential for adherence to ARV's.
- The existence of other illnesses like TB

SIDE EFFECTS OF ARVS

Like any other medicines, ARVs have side effects. Some of the side effects are severe, requiring immediate medical attention while others are mild and only require reassurance of the client or simple medicines like painkillers. Some side effects begin soon after commencing treatment while others come after several months or years. Patients should always report any complication they feel to the health worker. The health worker will then make an assessment and decide what action should be taken. Below is a list of possible side effects:

Minor side effects	Major side effects
Blue/black discoloration of nails	Little blood in the body
Nausea	Inflammation of the liver/yellow eyes
Headache	Tingling, pain, numbness of the feet or
Failure to sleep	hands
Anxiety	Changes in the distribution of body fat
Panic attacks.	Skin rash which is accompanied by
Abdominal cramps	fever or ulcers in the mouth
Diarrhoea	Severe abdominal pain
Dizziness	
Weakness	
Skin rash	
Loss of hair	
Nightmares	

ARVs can interact with other drugs leading to decreased concentrations in the blood for either drug or to an increase in the side effects. E.g. Efavirenz interacts with certain TB drugs.

Some ARVs need to be taken with food while others need to be taken on an empty stomach. E.g Nelfinavir is taken with meals while Didanosine is taken on an empty stomach. Efavirenz is not taken with fatty meals.

There is sometimes a transient worsening of patient symptoms 2-3 weeks after commencing ARVs. This is referred to as the immune reconstitution syndrome. It is a result of improvement in the immune system and the body beginning to defend itself against infections.

LIMITATIONS OF ARVs
- **ARV's are not a cure to HIV or AIDS**
- They are still very expensive
- ARV's have to be taken for life which isn't an easy task to face
- ARV's have adverse effects, toxicities and interactions with other drug
- ARV's require a very high level of adherence
- Drug resistance sets in very easily when ARVs are used wrongly

ADHERENCE
Adherence is the term used to describe the patient's behaviour of taking drugs correctly – in the right dose, with the right frequency and at the correct time. A critical aspect of adherence is the patient's involvement in deciding how and when to take the drugs. **Compliance** means the patient simply does what he or she has been told to do by the doctor/pharmacist. The patient is not involved in the decision making process.

- Adherence is one of the key determinants of treatment success
- Poor adherence leads to virologic failure, evolution of drug resistance and subsequent immunologic and clinical failure
- It is important to counsel patients carefully before initiating ART. This involves counselors, clinicians, nurses, pharmacist, family etc.
- ART should not be started on first clinic visit: treatment adherence counselling is necessary to prepare the patient in order to maximise adherence
- Once treatment has started, continued monitoring and support for adherence is necessary

Factors which affect adherence.

1. The **individual factors** for a person on treatment

- On an **emotional/psychological** level:
    o Depressive state, emotional breakdown
    o Guilt at having survived in the event of the death of a loved one (survivor's syndrome)
    o Level of self-esteem
    o Denial. If a person wants to "forget" that they are infected by the HIV virus, they tend to not want to take drugs as they remind them of HIV and AIDS.

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> **Fears associated with anti-HIV treatment**
>
> - Fear of not being able to control the side effects
> - Fear of physical discomfort, pain, tiredness
> - Fear of changes to physical image
> - Fear of social stigmatisation
> - Fear of unsuccessful treatment
> - Doubts about its long-term effectiveness.
> - Fear of the illness arising or returning
> - Fear of a fatal side effect occurring
> - Question of life expectancy

- On a **mental** level:
    - Inability to understand and remember prescriptions, dosage timetables, etc. (These abilities can be linked to the level of literacy and education)
    - Lack of belief in the effectiveness of the treatment (perceptions of medicine in general)

- On a **behavioural** level:
    - Possible difficulties in organising and managing personal time (for example, in relation to work schedules)
    - Reactions to side effects and other constraints of the treatment
    - The consumption of substances such as alcohol or drugs which can affect the administering of the treatment

- On a **physical** level:
    - For an HIV positive asymptomatic person, the treatment can be perceived as the start of the illness. The side effects of antiretroviral drugs are perceived as the first signs of AIDS.
    - For a symptomatic person, the disappearance of opportunistic infections and other pathologies can give the impression of being cured and no longer requiring the treatment.

2.   Social factors (environment)

- Situations in which the person taking the treatment must hide away to take their drugs (in the family, at the workplace, with friends, etc.)
- Stigmatisation, discrimination, rejection, social isolation
- The level of support from the family circle, in general and when taking the treatment
- Lack of financial resources and greater priorities for survival
- Caring for other ill people, children in particular
- The failure of the therapy for a person within the family circle can affect a person's belief in the effectiveness of their own anti-HIV treatment.

3. Factors linked to the treatment

- Large number of doses per day: The larger the number of doses, the more complicated the treatment is to take, in particular for PLHA taking other medication (preventive and/or interventive treatments for opportunistic infections and other pathologies). It is often thought that more than 2 doses of drugs per day leads to poor observance
- Side effects: The greater the number of side effects or adverse reactions, the more difficult it is to take the treatment
- Unsuccessful treatment: If a person thinks that the "illness is progressing" despite the treatment, they are less motivated to take the drugs.

4. Factors linked to healthcare professionals and structures

- A lack of knowledge and training on the part of healthcare professionals in relation to anti-HIV treatments and observance
- A lack of clear information on the following elements:
  o Dosage
  o Timetable for doses
  o Effects and effectiveness of the drugs
  o Possible side effects
  o Possible interactions with other drugs or substances such as alcohol and the risks incurred
  o Diet recommended with the treatment
  o Risks in the event of stopping treatment or incorrect administering of the drugs
- Failure to adapt the treatment to the personality and lifestyle of the person on treatment, for example to fit in with their schedule.
- Lack of availability and active listening for the person on treatment
- Refusal to take into account the side effects suffered by the person on treatment and the consequences of the treatment on the person's life (work, family life, emotions, sexuality, etc.).
- Perception of healthcare professionals regarding a person's ability to take their treatment correctly. If a doctor thinks that his or her patient is not able to follow the treatment, this can influence the patient.
- Distance between healthcare structures where the drugs are prescribed and dispensed and the person on treatment.
- Schedules unsuitable for consultations.

Adherence intervention strategies

- Educate and motivate: basic drug info, importance of adherence, timing of medications, drug interactions, etc
- Simplify regimen
- Tailor treatment to patient's life style
- Prepare for and manage side effects
- Employ an adherence team.
- Address patient related issues
- Recruit an adherence monitor
- Provide adherence promoting devices
- Use home based care staff to promote adherence
- Use adaptation of directly observed therapy for time to be determined.

ARVS IN SPECIAL CIRCUMSTANCES

Prevention Of Parent To Child Transmission.
The medicines most frequently used are nevirapine and zidovudine. Nevirapine is less costly and is taken as a single dose while zidovudine has to be taken for a longer period of time and is more expensive. Nevirapine is recommended by the WHO for PPTCT and is used by most African countries.

Post Exposure prophylaxis.
ARVs can be used to prevent transmission in cases of exposure like needle stick injuries and rape. Recommended procedures have to be followed and the drugs taken for one month.

Women of childbearing age
Certain ARVs have potentially harmful effects on the unborn baby and the mother during the first months of pregnancy. Health workers therefore need to know whether a woman of childbearing potential is pregnant or not. E.g. Efavirenz can cause abnormalities in the spinal cord of the baby.

2.4 Herbal remedies

Activity: 45 minutes

Aim:
To gain knowledge of the role of herbal remedies in care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Briefly discuss with the whole group what is meant by herbal remedies.
3. Ask the whole group to identify the main roles herbal remedies can play in care, support and treatment. Discuss whether herbal remedies are meant to be complementary or alternative to scientific medicine.
4. Divide the participants into groups. Ask them to list which herbal remedies (including both indigenous herbs as well as remedies brought into the community) they know that will contribute to each of the roles.
5. Bring the participants back together to share their work (try a floor gallery rather than presentations from each group). Ask for personal experiences of when herbal remedies worked, or did not work.
6. Handout and briefly review the Information Sheet with herbal remedies. Add remedies that have been listed by the participants that are not on the Information Sheet. Ask the participants to identify organisations that have more detailed information on herbs in their communities.

Facilitators' notes
- ! There are considered to be four main roles that herbal remedies can play in care, support and treatment: relieving symptoms, maintaining health/prevention of symptoms, body stimulants e.g. appetite, hope. If the participants have a different view, and if it is helpful to achieving the aim of this activity, use the roles they identify.
- ! A floor gallery simply means each groups lay their flipcharts on the floor and the participants view each others' work.
- ! Consider adding the local language names for the herbs to the information sheets.
- ! Do caution participants that some herbs can be toxic if used in the wrong manner or dosage.

Information sheet: Herbal remedies and their uses

The information in this information sheet has been taken from Chapter 6 of *Eating Healthy, staying positive: Manual book on nutrition for HIV positive people* published by SAfAIDS in 2004.

How can herbs and spices help you to stay healthy?

Herbs and spices can improve digestion, stimulate appetite and preserve foods. The following table gives the benefits of some herbs and spices that can be used by people with HIV and AIDS, and how to use them.

Herbs and their benefits in HIV infections

Herb	Benefit	Use
Aloe	Helps to relieve constipation	Use as extract; boil and drink the concentrated water. Use little only. Stop use when it causes cramps and diarrhoea. Apply slime of a freshly cut leave to a wound or cut to prevent infection.
Basil	Helps to relieve nausea and helps digestion. Is antiseptic for mouth sores.	Add to food to treat nausea and digestive problems. For mouth sores, prepare a tea and rinse/ gargle when cool.
Calendula	Flower heads have antiseptic and anti-inflammatory effect. Helps with infections of the digestive tract.	Use as a compress to treat infected wounds. To help digestion, take as a tea.
Cardamon	Helps with digestive problems, pain, diarrhoea, nausea, vomiting and lack of appetite	Add to food during cooking or prepare as a tea.
Cayenne	Stimulates appetite, helps fight infections, heals ulcers	Add a pinch to cooked or raw food. For an energising drink, add to fruit juice or water.
Camomille	Good for colds and for weakness after a cold or flu. Stimulate section of digestive juices.	Prepare tea from the leaves and flowers. Drink several cups per day.
Cinnamon	Stimulates appetite. Helps to increase appetite and reduce flatulence.	Add to food or prepare in tea. Especially ginger cinnamon tea is good for chesty colds and gives relief in TB
Cloves	Stimulate appetite, help weak digestion, diarrhoea, nausea and vomiting.	Use in soups, stews, warmed fruit juices and tea.
Coriander	Helps to increase appetite, reduces flatulence. Controls bacterial and fungi.	Add herb to soup and stew.

Eucalyptus	Has antibacterial function, especially in the lungs.	Prepare as a tea or add leaves to a hot vapour.
Fennel	Helps to increase appetite, reduces flatulence.	Add leaves to food. Use leaves to prepare tea. Use in limited amounts.
Garlic	Has an antibacterial, antiviral and antifungal property. Is active in the gut, lungs and vagina. Also good for thrush, throat infections, herpes and diarrhoea.	Add to food or prepare as a tea.
Ginger	Improves digestion, energises and stimulates appetite. Used for treating common colds, flue and nausea.	Use as a spice in meals or prepare a ginger tea.
Lemon	Antibacterial and helps digestion.	Add lemon juice to food and drinks.
Lemon grass	Has calming effect and soothes digestion.	Prepare as a tea.
Mint	Has anti-inflammatory effect and helps digestion.	Use as a tea or gargle for mouth sores. Chew leaves to aid digestion.
Neem	Brings down fever	Cut a fresh twig, remove leaves and boil for ten minutes. Drink as tea. The bark can also be chewed.
Parsley	Reduces colic, stimulates stomach secretions, produces a feeling of hunger.	Add raw to food.
Peppermint	Helps relieve nausea. Reduces colic. Helps to control diarrhoea and stop vomiting. Used for relieving tension and sleeplessness.	Prepare as a tea. Boil the leaves on a low fire for ten minutes, covered. Or add to food.
Thyme	Has antiseptic and anti-fungal function. Relaxes nervous coughing and increases secretions. Stimulates digestion. Good for intestinal flora.	Prepare as a tea. Use as gargle or mouthwash for mouth sores. Drink the tea.
Tumeric/ yellow root	Digestion aid, antiseptic and antioxidant.	Use powered in rice, cereals and stews.

A helpful resource of herbs in Zimbabwe is "Useful Indigenous and Traditional Herbs and Weeds," A Brazier, JSI UK (2004); http://www.jsiuk.com

2.5 Nutrition

Activity: 30 minutes

Aim:
To gain knowledge of the role of nutrition in care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Nutrition: Ask participants to give a definition for good nutrition, e.g. when foods and drinks provide people with the nutrients that they need for life and good health.
3. Nutrients: Ask participants to give different groupings for nutrients (proteins, carbohydrates, fats, vitamins, minerals, and water) and the role of each one. (See facilitators note below.)
4. Ask participants what the body does with nutrients: Builds and repairs damaged cells and tissues in the body; Provides energy for movement and work; Protects against disease and fights infection. Ask what other role nutrition can play? (See below.)
5. Food groups: Ask participants to define the 6 food groups: Vegetables, fruits, legumes & nuts, animal foods, fats, staples.
6. Current meal: Ask participants to write down or draw what most people in Zimbabwe/in their community eat and drink in a typical day, including amounts. Do they include the 6 food groups? Why do people eat these foods/drink these beverages?
7. A better meal: Ask participants to write down or draw what would be a better meal, using the different food groups. Discuss food availability, including whether these items can be grown locally, seasonally.
8. With participants, make a contract with yourself for Healthy Eating. Write down at least four ways in which you will improve your diet and that of your family.
9. Give out the information sheet on Healthy Eating.

Facilitators' notes
! Nutrients can be compared to a home and what is necessary for keeping it in order. You can draw simple pictures of bricks, mud, firewood, paraffin, a watchdog and water to depict the following groups of nutrients: Proteins are like bricks – they build the walls of all the structures of our body (hair, skin, muscles, etc.). Minerals are like the mud connecting bricks – they are required to connect bones, blood and other parts of our body. Carbohydrates are the fuel we need to give us energy for living, working, thinking, playing. Fats are also burned for energy but give more fuel than carbohydrates and are stored more easily – much like paraffin. Vitamins are like watchdogs – they protect our body from intruders that want to cause disease or sickness. Lastly, water has many cleansing functions in the body, similar to the way we use water for cleaning homes.
! The role of nutrition on care, support and treatment includes: giving energy for movement and work, develops and repairs damaged cells and tissues in the body, protects against disease and fights infection, aids absorption and tolerance of medicines, keeps body warm, maintains body weight, and is an expression of care and love.

Information sheet: Healthy eating

FOOD AND HIV

Food cannot cure AIDS or get rid of HIV, but it helps to keep the body strong to prevent and fight illness. For someone who has HIV to live well, he or she needs to have a balanced diet. This means eating enough of the food that has the important things (nutrients) needed by the body. Food can be sorted into 6 groups. These groups are just a guide to choosing a healthy diet, and remind us that variety is the key to good nutrition.

VEGETABLES	FRUITS
Provide vitamins, minerals, water & fibre – protects the body from illness Leafy greens, pumpkin, squash, carrots	*Contain carbohydrates, vitamins & water – gives energy and protect the body from illness* Banana, pawpaw, guava, mango, orange, marula, pineapple, msau
STAPLES	**ANIMAL FOODS**
Provide carbohydrates - gives power and energy to the body Grains: maize, millet, sweet potato, rice, yam, cassava, potato, sorghum, oats	*Proteins - builds and repairs the body* Meat, fish, eggs, milk/lacto, mopani, termites
FATS	**LEGUMES & NUTS**
Also gives power and energy to the body Oil, butter and margarine, fatty meat and fish, groundnut cake, sunflower seeds, avocados	*Proteins & carbohydrates – builds & repairs the body, & protects it from illness* Pulses (soya beans, sugar beans), groundnuts, nyimos, nyembas, tree nuts

A healthy meal is made up of at least one food from each of the 6 groups with plenty of clean water. Water helps break down the food and keep the body healthy. People living with HIV and AIDS should take at least 2 litres of clean water every day.

FOOD HYGIENE
- Cook all food well before eating.
- Wash all fruits and vegetables in clean water before eating.
- Boil water before drinking, if it is not clean.

Reference: Adapted from *Permaculture Nutrition Training Manual*, S Nordin, 2003
For more information on Nutrition and HIV and AIDS, go to http://www.who.int/nut/documents and http://www.pronutrition.org

2.6 Food security

Activity: 30 minutes

Aim:
To introduce nutrition gardens as one strategy to improve food security.

Instructions:
1. Explain the aim of this activity.
2. Introduce the resource specialist to share information about nutrition gardens or, if there is not a resource specialist available, hand out the information sheet and facilitate a discussion with the participants based on the information.

Facilitators' notes:
! Conduct a field visit if appropriate or possible (extra time has been given in the workshop timetable for this activity). Leave time afterwards for discussion of lessons learned.
! For a copy of a PowerPoint presentation on JSI UK's Low Input Gardening Approach, go to http://www.jsiuk.com
! At the CMEIACST field visit in Zimbabwe, the following lessons were identified by participants:
   - poor quality soil yielding high quality crops
   - don't need huge resources to start low input gardening
   - communities hold the key to solving their problems
   - the group involved the community, so the garden was for people HIV positive and HIV negative
   - the garden reduced stigma in the community by demonstrated that PLWHA are able to be productive members of society and it increased self-esteem and self-acceptance amongst the PLWHA
   - the group needed training in leadership and marketing

Information sheet: Nutrition gardens

Prepared by Anna Brazier, JSI UK Consultant

Involving the community beforehand

The following process can be used to establish a nutrition gardens project within a community.

✓ Step 1: Conduct a baseline survey to assess the needs of the community such as a questionnaire asking what land is available for cultivation, what crops are currently grown, whether the crops are consumed by the family or sold, how much water is available.

✓ Step 2: An introductory workshop raising awareness about the importance of good nutrition and the benefits of using a sustainable approach and the importance of planning and management skills. This workshop could be used to identify potential community outreach workers.

✓ Step 3: Follow the process explained below - assess resources, form goals, plan land-use areas, develop an action plan, implement the plan, manage resources according to LIG principles, keep records.

Strategies for community outreach

Here are some ideas for community outreach strategies which should be backed up with the trainer's own suggestions about outreach activities.

- Set up demonstration gardens at schools and community centres
- Set up nurseries to produce plants for the outreach programme
- Plan a schedule for demonstration days, exchange visits and training courses
- Develop awareness-raising and training materials – e.g. posters and leaflets
- Produce a newsletter
- Produce a programme for local radio or TV
- Link with others implementing nutrition gardens and hold exchange visits
- Hold nutrition garden open days at the demonstration gardens, give talks on gardening or nutrition and invite community members to exchange plants or seeds
- Hold competitions for the best garden and give prizes in the form of seeds, plants or tools

Monitoring progress (Indicators)

The success of nutrition gardens depends on generation and maintenance of community support as well as follow-ups, evaluation and monitoring. Records of inputs and outputs are important for the evaluation process. Ideally community groups should develop their own participatory monitoring tools.

Overall indicators that could be used to monitor the success of the nutrition gardens include:

- Improved nutrition/health, such as reduction in illness, weight gain of participants
- Economic indicators, taken from records of inputs and outputs
- Opportunity indicators, income generating activities, sharing ideas with others
- Psychosocial effects, increased enthusiasm and self-esteem
- Community effects, increase in group activities, reduction of stigma, increased community support

Ecological indicators such as:

- Productivity – amount of food crops being grown and harvested from the garden.
- Diversity – number of different crops and useful plants being grown in the garden.
- Sustainability – evidence of soil-improvement (compost, soil-improving plants etc), pest management, mulch, water management, seedling propagation and protection, fruit trees.
- Education demonstrations - such as water harvesting, water conservation (mulch, bottle-watering etc), efficient space utilization (use of container gardens, shapes of beds, paths, correct planting of herbs in and around beds), windbreaks, live fencing, repellant plants, food preservation and storage.

A simple monitoring matrix such as the example given below can be used by organisations to monitor overall indicators

Name of organisation	Who is involved?	Any events (sharing meetings or training)?	What are you proud of that has happened (crop, people, other)?	Has anything been particularly difficult (theft, drought?)
Demonstration gardens				
Home gardens (neighbours, volunteers etc.)				
Community/school gardens				
Lodgers using containers, bags or tyres				
Any other users?				

In order to help PLWHAs establish nutrition gardens we need to disseminate information on:
- The best crops to grow and eat and how to cook them for improved nutrition.
- Labour-saving cultivation and management techniques.
- Low-Input strategies to save money and sustain environmental resources.

Other issues include:
- Access to land
- Access to water
- Access to soil improving inputs
- Amount of labour involved in implementation
- Management and planning skills required
- Relations with other stakeholders involved in the garden
- Variety of crops grown
- Promotion of herbs, indigenous and traditional crops

The table below gives nutrition and gardening tips:

Nutrition tips	Urban sources and growing tips
Eat unrefined staple foods with every meal as a cheap source of energy and some protein.	• Buy or grow whole grains such as maize, sorghum, millet and wheat and take them to a grinding mill. This is cheaper and healthier than eating refined meal or flour. • Use the ground whole wheat flour to make your own bread, biscuits and cakes. • Cook sorghum or millet porridge occasionally as an alternative to maize. It is high in fibre, vitamins and minerals. • Grow cassava as a windbreak around the garden. Eat the tubers and leaves. • Grow sweet potatoes, madhumbes and brown rice in summer in water-logged areas. Plant Irish potatoes in winter.
Eat legumes every day for protein, vitamins, minerals and fibre.	• Grow climbing beans on fences and up walls. • Grow pulses such as cowpeas, groundnuts, roundnuts, sugar beans and soya beans in summer between rows of maize. • Grow pigeon peas as a windbreak around the garden. • Grow lentils, chickpeas and shelled peas in winter. • Grow green beans in beds all year round. • Eat peanut butter and roasted peanuts.
Eat animal and milk products regularly for protein, iron and B vitamins.	When you can afford it: • Buy sour milk (lacto). • Eat liver as a good source of protein, vitamins and minerals. • Fish, termites and mopane worms are good sources of protein and calcium. • Keep chickens for eggs and meat or rabbits for meat. These animals will also provide manure and pest control for the garden.

Eat yellow, orange, red or dark green vegetables and fruit every day for vitamins, minerals and fibre. **Cook vegetables for less than 8 minutes** ands avoid using bicarbonate of soda to preserve vitamins and minerals. **Eat plenty of fresh fruit for vitamin C every day.** You can also dry fruit or make it into juice or jam.	• Grow many different kinds of vegetables in your beds including carrots, green peppers, spinach and green peppers. • Grow traditional vegetables such as amaranth (bonongwe) and herbs to flavour cooking such as marjoram, basil, parsley, chives and thyme in beds. These are good sources of vitamin C and calcium. The strong smell of the herbs helps to repel pests. • Grow cucumbers, pumpkins, chowchows and squash on fences and up walls. • Grow pawpaw, tree tomato and citrus trees amongst vegetable beds and in sunny places. • Grow mangoes, Mexican apple and avocados on the south side of your garden if you have space. • Grow fast-growing indigenous fruit trees in maize areas and along boundaries such as Ziziphus spp. (Masau), Syzigium spp. (Mukute) and Azanza (Mutohe). • Grow mulberries, guava and banana trees on boundaries. • Grow granadillas on fences and grapes on trellises. • Grow strawberries in beds. • Grow gooseberries and raspberries around the edges of gardens.
Eat health sources of essential fats. These foods help weight gain and to stimulate the appetite.	• Grow pumpkins, sunflowers and sesame and collect and eat the seeds. They contain fat and protein. • Plant groundnuts and make and eat peanut butter for fat and protein. • Plant avocados if you have space. They are a good source of fat. • If you have space you can keep bees for a natural source of sugar.
Drink at least 8 glasses of clean water (boiled or filtered) each day. Avoid drinking tea or coffee with a meal as this can reduce absorption of iron from food. Instead drink herb teas, which help to stimulate the appetite.	• Make herb teas. Grow small herbs in beds such as marjoram, basil, and thyme in beds. Grow larger herbs such as lippia (zumbane), rosemary, mint and lemongrass. The strong smell of the herbs helps to repel pests. • Drink fruit juice. Plant fruit trees (orange, lemon, granadilla.)

Establishing nutrition gardens

There are five main types of gardens in urban areas:
• Household gardens – small beds or container gardens outside houses where vegetables and fruit trees are grown.
• Communal gardens – allotment style areas at community centers, clinics and other civic centers where vegetables and some annual crops are grown.
• School gardens – portions of school grounds that are allocated for cultivation by community members.

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- Roadside gardens – usually annual crops and sometimes vegetables planted on municipal land.
- Streambank or vlei gardens – crops or vegetables planted to take advantage near water sources. Wells are often dug in these areas.

Steps:

⇒ Assess available resources. Make a sketch map of the area available with all who use the garden or who make decisions about it. Mark: water sources, slope, other aspects, existing natural and human-made activities and structures (including buildings, roads, fences, paths).
   ✓ List problems such as poor soil, lack of water, lack of money to buy seed, theft.
   ✓ List potentials that can be identified such as water-harvesting from roofs, using kitchen waste for compost, using fences and walls as trellises for crops.

⇒ Form clear, simple, achievable goals about what the growers want to produce bearing in mind the information on nutrition above. If there are only one or two beds then sale of produce is unrealistic. List the annual and perennial crops that are to be grown and develop a planting calendar to ensure continuity of produce all year round, bearing in mind that different crops do better at different times of year. Talk about saving and storing seed and propagation of seedlings. Talk about the importance of keeping records of garden inputs and outputs, income and expenditure. Discuss the importance of using the garden to demonstrate low input gardening techniques to others.

⇒ Using the map begin to plan the land use areas. Site water consuming activities and crops closest to the water source and those that need less water further away. Discuss ways of conserving water such as using mulch, planting windbreaks, harvesting rainwater from roofs and roads, using waste-water and drip-irrigation or bottle watering.

⇒ Plan ways to save space such as reducing paths between beds, planting crops up walls and fences, planting in containers and planting tall, shady plants on the south side of the garden and shorter plants on the north-side.

⇒ Plan ways to improve and maintain soil fertility such as growing soil-improving plants, making compost, pit beds and liquid manure. Include discussions about keeping small livestock such as poultry and rabbits.

⇒ Discuss methods of natural pest and disease control including intercropping, use of repellent plants, attracting predators and home-made sprays and traps.

⇒ Make an annual action plan stating dates and resources needed for the planting, soil, water and pest and disease management activities listed above.

DAY THREE

3.1 Improving linkages between those involved in the provision of care, support and treatment.

Activity: 1 hour 45 minutes

Aim:
To identify who at the community level is involved in care, support and treatment and which relationships to strengthen for improved access to care, support and treatment

Instructions:
1. Explain the aim of the activity.
2. Ask for a volunteer to re-cap what was defined as 'comprehensive care, support and treatment.'
3. Draw a person in the middle of a piece of flipchart paper.
4. Working as a whole group, and using the outputs from activity1.3, ask the participants to identify who might be involved in providing care, support and treatment for the person with HIV and AIDS at the community level. Write their ideas around the person on the flipchart.
5. Divide the participants into groups. Ask them to indicate clearly, and with full explanation, the most important linkages to improve access to care, support and treatment between the different people or organisations they identified.
6. Ask the groups to explain **how** the community, with or without NGO support, can strengthen the linkages that are needed to improve access to care, support and treatment for the person living with HIV and AIDS. You could start with the question – 'What are the reasons why people often don't work together at the community level?'.
7. Bring the group back together. As appropriate, ask all groups to present, or one group to present and the other groups add.
8. Highlight anything you think they have missed and summarise the activity.

Facilitators' notes
! Make sure that you have the flipcharts available which were produced during activity 1.3
! Participants might think of linkages as only being 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 with HIV.
! Emphasise to participants that it is important to see people with HIV as active "providers" as well as "receivers" within the provision of care, support and treatment.
! Encourage participants to consider how "providers" of support might be able to help each other. For example, the family of a person with HIV could help health workers by sharing information about their needs and how they might be met.
! Sometimes the linkages are not about partnership building, but are about providing a missing link. For example, strengthening linkages between a local hospital and a testing facility may require transportation as well as effective referrals and counselling.
! Hand out information sheets or incorporate the information into the activity as appropriate.

Information sheet: Linkages for care, support and treatment work

Strengthening linkages between providers of care, support and treatment is an essential part of improving the quality of people's lives because:

✓ linkages bring together someone who needs care, support and treatment and someone who can respond to those needs in a supportive and effective way.
✓ linkages are based on identifying the needs of the person seeking care, support and treatment and helping them to live a better and longer life.
✓ linkages are two-way – with both people needing openness, co-operation and information for care, support and treatment to be effective.
✓ linkages are based on trust and need to grow over time.
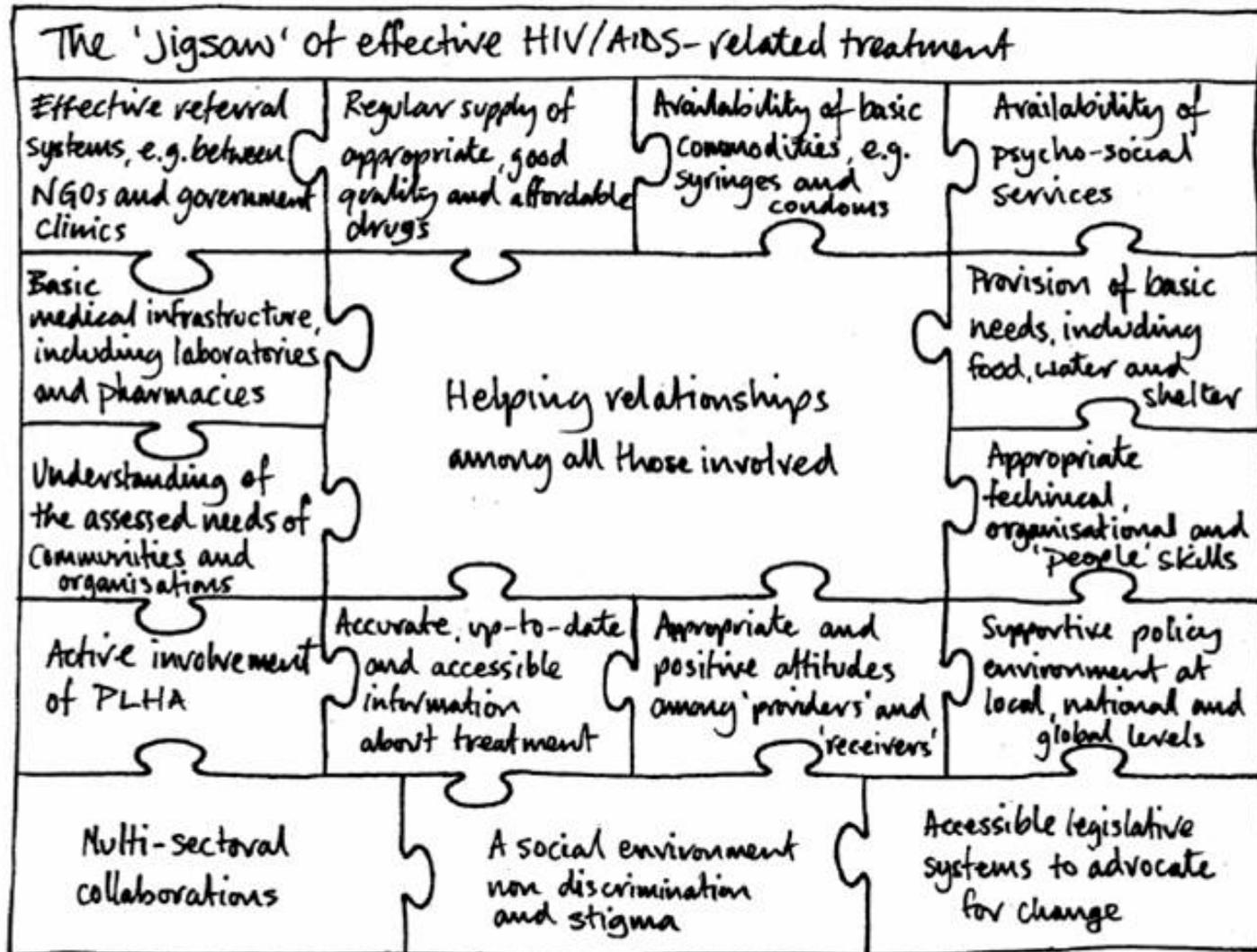
There are many kinds of linkages. These include between a doctor and a patient, and between a community volunteer and someone who is ill at home.

Strong linkages in care, support and treatment work are built and maintained in different ways:

✓ Making care, support and treatment available and accessible helps to build trust within the partners in the linkage. Strong linkages support good use of care, support and treatment - because even drugs need a supportive environment to work properly.
✓ People with HIV can both help themselves and support others affected by HIV and AIDS. Any relationship involving people with HIV needs to be based on a positive attitude and a belief that care, support and treatment is worthwhile.
✓ A health worker who prescribes HIV-related drugs has special technical knowledge and skills – which people needing treatment often do not have. The skilled helper and the person with HIV 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 with HIV needs to be respected as someone who can make choices about care, support and treatment. Care, support and treatment will be more effective if the helpers, with technical knowledge, encourage people with HIV to be actively involved in their own treatment.
✓ A person with HIV who helps her/his sero-negative partner to avoid infection and a sero-negative person who supports a person with HIV to maintain treatment use are also examples of helping relationships.

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Examples of the complementary roles of different types of organisations and groups:

✓ **Community leaders** can share effective strategies to overcome barriers to access to care, support and treatment at the community level.

✓ **Community and peer groups** can provide personal support for people with HIV, keep the larger community in touch with care, support and treatment needs, and help share accurate information and stigma reduction messages.

✓ **NGOs/CBOs** can provide people, training, information, ideas, material support and skills – such as in counselling - for care, support and treatment work.

✓ **VCT, HBC, PPTCT, TB & OI service providers** can be entry points and referrals for community care, support and treatment, and vice versa.

✓ **Government departments and extension workers** can provide policies, leadership, human resources and material support – such as skilled health workers, drugs and medical supplies – for care, support and treatment work.

✓ **Large and small businesses/private sector** can provide financial or "in kind" sponsorship for care, support and treatment work, and encourage public support.

✓ **Academic institutions e.g. schools, colleges** can be sites for sharing knowledge and guidance on care, support and treatment.

✓ **Specialist International NGOs and donors** can provide funds and other resources and partnerships for care, support and treatment work and facilitate learning from the experiences of other countries.

✓ **Religious organisations e.g. mosques, churches** can provide volunteers for care, support and treatment work, mobilise community support and help to reduce discrimination.

✓ **Media and organisers of public meetings** can provide accurate information about care, support and treatment issues and help to raise awareness and reduce stigma.

✓ **Traditional healers** live within the community and understand its norms. They are often the first service provider visited by people. With training, they can provide accurate information about care, support and treatment and refer clients to medical facilities.

✓ **Family members** can provide emotional and physical support, such as ensuring that the patient is fed, bathed, given attention and respect.

✓ **People living with HIV and AIDS** can provide care and support to people who are undergoing medical treatment through empathy and encouragement.

The 'Jigsaw' of effective HIV/AIDS-related treatment

Effective referral systems, e.g. between NGOs and government clinics	Regular supply of appropriate, good quality and affordable drugs	Availability of basic commodities, e.g. syringes and condoms	Availability of psycho-social services
Basic medical infrastructure, including laboratories and pharmacies	Helping relationships among all those involved		Provision of basic needs, including food, water and shelter
Understanding of the assessed needs of communities and organisations			Appropriate technical, organisational and 'people' skills
Active involvement of PLHA	Accurate, up-to-date and accessible information about treatment	Appropriate and positive attitudes among 'providers' and 'receivers'	Supportive policy environment at local, national and global levels
Multi-sectoral collaborations	A social environment non discrimination and stigma		Accessible legislative systems to advocate for change

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3.2 Leadership at the community level for improved access to care, support and treatment

Activity: 45 minutes

Aim:
To have a clear understanding of why leadership within the community is important for improving access to care, support and treatment, and what types of leadership can help.

Instructions:
1. Explain the aim of the activity.
2. Working with the whole group, ask the participants to brainstorm why leadership is important for improved access to care, support and treatment.
3. Ask the participants to describe different types of leadership that could exist at the community level which would help improve access to care, support and treatment. (E.g. religious, political, family, institutional (schools, clinics, police, etc.), informal leaders with influence & charisma - opinion leaders)
4. Ask the participants what are the barriers to gaining leadership for improved access to care, support and treatment. (E.g. lack of commitment, poor communication, lack of information and skills, role confusion, lack of transparency/accountability, culture)
5. Ask the participants to list strategies that can be used to involve leaders. (E.g. Involvement at planning stages to help give them ownership & ensure programme sustainability, build skills in providing accurate information, activate their potential to mobilise resources, build upon what they are already doing, exploit their ability to make influential decisions)

Facilitators' notes:
! For the initial brainstorm – make sure that the participants focus on leadership rather than on one individual as a leader. Encourage the participants to use their own experience and share practical examples.
! Encourage participants to balance thinking how to build on an existing leadership system, with being creative and looking beyond traditional roles and barriers in the community.

"Leaders can champion the cause of people living with HIV and AIDS."
"Leaders are change agents."
"Leaders can mobilise resource and; inspire communities."
"As role models, leaders can reduce stigma."

- Quotes from CMEIACST Workshop

3.3 Stigma reduction

Activity: 1 hour

Aim:
To identify effective strategies to reduce stigma in the community.

Instructions:
1. Explain the aim of the activity.
2. Divide the participants into two groups.
3. Ask one group to identify effective strategies for reducing self-stigma amongst people living with HIV and AIDS.
4. Ask the other group to identify effective strategies for reducing stigma within the community.
5. Bring the groups back together. Ask each group to present their work and encourage the other group to add their ideas and ask questions.
6. Facilitate a discussion based on the following kinds of questions:
    - ? Which strategies are the same for both groups?
    - ? Which strategies are different for the two groups and what does this mean for our community mobilisation and empowerment work?

Information sheet: Stigma reduction strategies

The way in which individuals discover and disclose their HIV status to others as well as the way they cope with their HIV status is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of responses to illness, social and economic contexts and norms

Stigma defined
Stigma is defined as an undesirable or discrediting attitude directed towards an individual with a certain attribute thereby reducing that individual's status in the eyes of society. Therefore stigmatization is societal labelling of an individual or group as deviant or different. Stigmatization arises from the perception that there has been a violation of shared attitudes, beliefs and values. This can lead to prejudicial thoughts, behaviours and/or actions on the part of governments, communities, employers, health care providers, friends and families. Stigma is a process and it can involve the following
- Pointing out or labelling differences
- Attributing different or negative behaviour as being the cause of his illness, or   sinful or promiscuous behaviour
- Separating us and them e g shunning, isolating and rejecting
- Losing status, discriminating and suffering isolation and loss of respect

Some words used to describe stigma
- To discriminate
- To shun, degrade, abandon
- To say something derogatory about someone
- To treat someone inhumanely

Types of AIDS-related stigma

Felt stigma
Refers to real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute or disease such as HIV or association with a particular group. For example an individual may deny her /his to HIV and refuse to use condoms or refuse to disclose their HIV status for fear of the possible negative reactions of family, friends and the community.

Enacted stigma
Refers to the real experience of discrimination. For example the disclosure of one's HIV status can result in loss of a job, health benefits or social ostracism based on real or perceived HIV status

Self – stigma
This refers to self blame, where people may feel they are being judged by others so they isolate themselves. PLHA practice self stigma and isolate themselves from their friends, families and communities. This can be viewed as a survival strategy such as when someone denies their risk of infection or fails to disclose their HIV status in order to avoid being ostracized.

Forms of stigma
- Name calling, Scape-goating, Finger Pointing
- Teasing, Ridicule, Labeling, Blaming, Shaming. Judging, Back Biting.
- Making Assumptions, Rumor, Gossiping
- Neglecting, Rejecting, Isolating, Separating
- Not sharing Utensils, Hiding, Staying at a Distance,
- Harassment, Physical violence, Abuse

Causes of stigma
To be able to effectively address stigma it is important to identify the causes and this will differ from society to society or community to community.
Key causes of Stigma
- Morality
- Poor Health care
- Poverty
- Gender
- Government policy
- Fatalism
- Media
- Ignorance

Stigma reduction interventions or Strategies
Can be either individual or community based interventions. In any community it is important to include strategies for supporting people living with HIV and AIDS. PLHAs play a crucial role in helping identify the different types of stigma and raising awareness about the damage and pain that stigma and discrimination bring

Community based interventions
- Awareness campaigns
- Information dissemination- factual and accurate information about HIV and AIDS through use of drama, poetry and role plays. Use of both the print and electronic media.
- Advocacy and involvement of the community, government, religious leaders and both the private and public sector
- Addressing some of the underlying structural factors driving the epidemic e g poverty through self help projects

Interventions aimed at PLHAs (passive interventions to more assertive)

• Withdrawing	• Fighting back
• Avoiding situations	• Going public
• Ignoring stigmatizers	• Talking to stigmatizers
• Joining support groups	• Self- assertiveness
• Counselling	• Build self esteem
• Sharing experiences with peers family, and friends	•

3.4 Mobilising resources to support community empowerment for improved access to care, support and treatment

Activity: 1 hour

Aim:
To be aware of hidden resources at the community level and different resource mobilisation approaches that a community can pursue.

Instructions:
1. Explain the aim of the activity.
2. Give an introduction to resource mobilisation at the community level using the Information Sheet: Mobilising resources to support community mobilisation and empowerment for improved access to care, support and treatment.
3. Ask the participants to work in groups of three's to discuss the following questions and prepare to share their ideas in plenary (no need for flipchart paper).
    ? What kind of resources do you think might be hidden or untapped in the community?
    ? What are the most successful community resource mobilisation ideas that you have heard of?
4. Ask the groups to share the answers to their questions. Address one question at a time. Allow as much discussion and experience sharing as time will allow.
5. Close by clarifying any misunderstandings and giving extra information, and then summarise what has been learned.

Information sheet: Mobilising resources to support community empowerment for improved access to care, support and treatment

Effective resource mobilisation relies on two basic things:

- ✓ availability of resources
- ✓ skills (and contacts)

Any community wishing to mobilise resources should start by identifying what resources they need and what resources are available locally. Much time and energy can be spent on resource mobilisation outside the community unnecessarily. If needs can be met locally this increases the likelihood that control of activities is kept at the local level and activities can be maintained over a sustained length of time.

It is crucial that needs are identified accurately with a list of essential and desirable resources clearly separated. Here is a list of the main groups of resources that are commonly identified:

- ✓ **Human resources** (E.g. Regular volunteers, nurses/ doctors/counsellors)
- ✓ **Material goods** (E.g. Office or service equipment, condoms, medicines, training materials, vehicles, IEC materials)
- ✓ **Free service and facilities** (E.g. office space, training facilities, transportation, publishing and printing)
- ✓ **Technical assistance** (E.g. Organisational and programmatic training, study visits, *How To* publications)
- ✓ **Money** (E.g. for human resources, material goods, services, and technical assistance)

Be ruthless, only list resources that you really need. Look at the list of essential and desirable resources and identify which can be readily mobilised locally. Remember, resources can be hidden in the community, but that does not mean they are not available. For example, people may have skills that are not known, make sure that adequate time is spent identifying the skills that people have. Here are a few ways to mobilise resources that are not readily (or obviously) available locally:

- ✓ Mobilise untapped resources (involvement of young people and men in home-based care work; identify skilled individuals that are not being utilised in the community e.g. retired nurse, administrator; ask local businesses/churches/ NGOs etc for goods that can be borrowed, or that they can access for you e.g. notebooks, IEC materials)
- ✓ Generate material goods locally (nutrition gardens; herbal remedies; share existing or under-utilised resources like school uniforms, and vehicles; sun-dried bricks/accommodation; make blankets from pieces of spare material)
- ✓ Establish income generating activities, particularly those that generate resources that can be used for your work if selling is unsuccessful (mushroom houses; chicken rearing; making herbal remedies etc).

✓ Asking for donations from community members and community members that live elsewhere (directly ask for material goods; money; expertise; time etc or hold a fundraising event)

If the resources needed are not readily available locally then a community must identify the most efficient way(s) of getting the resources that are needed. This largely depends on the skills (and contacts) that exist within the community. Here is a list of different approaches to resource mobilisation beyond the immediate community level:

✓ Contacting NGOs/churches initiatives/local government, submitting proposals
✓ Asking for donations (from companies etc)
✓ Running a small business (renting assets like a meeting area/facility, selling services, selling products)
✓ Running fundraising events (World AIDS Day activities/cultural events)
✓ Advocating for public resources to be made available

Here is a way to plan your resource mobilisation work. Follow the six steps before you start!

⇒ Step 1. Identify what you need (essential and desirable)

⇒ Step 2. Identify what you have and what is still needed

⇒ Step 3. Research the different ways that the resources could be mobilised (in the community and outside)

⇒ Step 4. Identify those that could provide the resources (in the community and outside)

⇒ Step 5. Identify who will be able to help you mobilise the resources (in the community and outside)

⇒ Step 6. Look at all the information you have gathered and identify the most efficient ways of mobilising the resources you need, make   a plan and share tasks

3.5 Involvement of men and young people in care, support and treatment

Men and young people are two important untapped resources at community level for care, support and treatment. Their involvement is not just crucial as extra resources, but also for reducing stigma and discrimination, and to support those that are already providing care, support and treatment.

Activity: 1 hour

Aim:
To know why and how to involve men and young people in care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Divide the participants into two groups.
3. Ask one group to discuss why and how to involve men in care, support and treatment.
4. Ask the other groups to discuss why and how to involve young people in care, support and treatment.
5. Bring the groups back together, ask both the groups to present their work.
6. Handout and discuss the Information Sheets on Young people supporting home based care, and the Information sheet on Involving Men.

Information sheet: Young people supporting home-base care

The Young People We Care Programme (YPWC), Zimbabwe, is an example of a programme actively engaging young people in care, support and treatment in the community. The YPWC was set up by John Snow International UK's, Zimbabwe HIV and AIDS Programme (JSI UK, ZHAP) and piloted by six organisations with existing young people programmes in Zimbabwe. Contact info@jsiuk.co.zw or www.jsiuk.com for further details.

The programme rationale and objectives
Responses in Zimbabwe have tended to address these 3 crises – infection amongst young people, family members living with AIDS, and the orphan crisis – as separate crises. Few programmes have bridged the gap between prevention, care, support and treatment, yet the same young people being encouraged to 'prevent AIDS' are living in households and communities where people are sick and dying from AIDS-related illnesses, and where children are bearing the brunt of the trauma. Young people themselves can see the need to assist with care, support and treatment as well as prevention in their communities.

The objectives of this Young People We Care programme are:
- To integrate HBC, OVC and young people programmes
- To change behaviour amongst young people
- To improve support for families affected by HIV and AIDS

The programme substance
The programme aims to help young people make a difference in their community by supporting them to implement the following kinds of activities:
- Knowing your facts about HIV and AIDS
- Being a young caregiver
- Ending the stigma
- Helping families (working alongside HBC and OVC organisations)
- Being a friend
- Making memory boxes
- Overcoming and avoiding abuse
- Making good choices about sex
- Helping children grieve
- Getting help from the community

"This programme is sweet. It truly bridged the gap between prevention and care. It prepared me to be a young caregiver and improve the way I view people living with HIV/AIDS and even those who are chronically ill. In my opinion this programme was made for people like me. I come from a single parent household, my father was bed bound. Since the course, it has been easier for me to cope. The programme has enlightened and strengthened me to carry on looking after him and other community members needing care, support and treatment." – YPWC Volunteer

Information sheet: Involving men

The following information is an extract from the *Involving Men in Community Home Based Care for HIV and AIDS* toolkit by JSI UK and SAfAIDS.

Why should men be involved in community home-based care?

The Involving Men in Community Home Based Care for HIV and AIDS toolkit has been put together because:

- Men need to be encouraged to become partners in the caring of family members with AIDS, including prevention, care, support and planning for the future.
- Women currently do most of the work around home-based care for people with AIDS because of their traditional role as carers in families. They deserve more solidarity and partnership from their men folk in providing what is essentially a family and community service for people affected by AIDS.
- If men get involved in home based care they may be in a better position to act as role models for younger men, show other men how to change their behaviour, protect themselves and their families against HIV and the consequences of AIDS. This shows how caring for people with AIDS can also help to prevent HIV from spreading.
- Some men are already involved in provision of home based care and would benefit from support from their peers.

What can men do?

- Men can work hand-in-hand with women to prevent HIV and to care and support People Living with HIV and AIDS (PLHAs).
- As leaders in the community, men can help reduce stigma and discrimination against PLHAs and their families.
- Men who are involved in home based care can be role models for other men, including helping them to be responsible in their relationships.
- Men who are HIV positive can provide good examples of living positively with HIV.
- Men can help families get the right social services
- Man can make a difference by talking about consequences of men's behaviour and stereotypes.

Gender roles in Community Home Based Care

In most of southern Africa, men are seen traditionally as leaders and providers in their communities. However, these ideas are slowly changing, with more women getting educated and taking senior positions as politicians, directors of companies, professors and so on.

Families

In families, men are still regarded as the decision makers. There are divisions in the duties men and women have in their homes. This idea persists eve though many households are headed by women, either because they have been widowed or because their husbands are working as migrant labourers and do not spend much time at home. Women will often have major decisions affecting their homes made by male relatives if their husbands are way from home. For these reasons, women usually do not have the power to ensure that they are protected. Women often become financially or materially vulnerable when their husbands are sick with AIDS, and are unsure whether they will have security if the husband dies.

Women and children

Customary practice can mean that the husband's relatives acquire all the family's property after the husband's death, making the family dependent on the good will of their in-laws for their materials well-being. There are Laws on Inheritance that families need to know. Regional organisations such as Women and Law in Southern Africa (WLSA) and Women In Law and Development in Africa (WILDAF) help women and their children to negotiate for their well being. If they choose, women can remain independent after their husband dies. Volunteers can discuss such issues with family members to reduce tension and conflict around property and care. <ale volunteers especially need to support the needs of women, talking to male members of the family and arguing on behalf of women and children, advocating for their needs and rights in general.

Because so many men have died of AIDS in our communities, there are more women living as widows with young children. The women may also be sick with HIV and need help from the community. There is a real need for planning for the future of their children with the extended family rather than waiting until after death when it may not be clear who should take responsibility for bring up these children. Planning for the future is an important area that male volunteers can get involved in.

Male volunteers

Male volunteers are in a good position to work with families, particularly when the father, the head of the household, is still alive and able to plan with his wife.

They can help them discuss how one would like their children to be looked after in the event of death. If he volunteer has come from a faith based organisation, the first time these issues are discussed with the family could be done with another senior person from the group present (such as a priest) so that it does not appear to be for his own personal gain.

For this reason, there may be more than one volunteer visiting a family living with AIDS, each with a different purpose. A female volunteer may attend to support the family in caring duties fir the person sick with AIDS, while a male volunteer may attend to discuss pastoral and planning functions with the head of the household (whether the father or the mother). They may negotiate meetings with the extended family to clarify issues, or to bring them into whatever decisions are taken.

Once male volunteers have become well known and respected for their contribution, they may also become accepted as persons who can teach about hygiene or protection from infection; duties usually assigned to women volunteers.

Roles for men in Community Home Based Care

As role models
When men get involved in CHBC, they are providing models of responsible behaviour that will help other men in the community to behave in similar ways. Young men and older men are more likely to listen to, accept, discuss and share issues with other men rather than with female volunteers.

As Advisors to families

Trained male volunteers will become sources of information and guidance to the families. Examples range from advising families on the risks of tuberculosis associated with HIV and how to check for symptoms; to where to go for voluntary counselling and testing (VCT); to the necessity of writing a will; or how to leave a memory book to help children come to terms with their parents having AIDS.

As advocates of CHBC to their communities

Men will succeed better in providing CHBC if they have the support and acceptance of the communities they live in. they are in a better position to mobilise community support for families living with AIDS and to identify resources for them.

3.6 Meaningful Involvement of People living with HIV and AIDS (MIPA) in service delivery for care, support and treatment

Activity: 1 hour

Aim:
To extract the learnings from the HORIZONS operations research study on GIPA for service delivery which are useful for improving access to care, support and treatment in the community.

Instructions:
1. Explain the aim of the activity**.**
2. Divide the participants into groups.
3. Ask the group to read aloud together the four-page HORIZONS operations research study summary.
4. Ask them to discuss which learnings from the study they feel can be applied to improve access to care, support and treatment at the community level.
5. Bring the groups back together. Ask each group to share their work, or ask one group to share and the others to add.
6. Ask the group to share their understanding of the phrase: *Patient expert.* Discuss the relevance of such a concept in your context.

Facilitators' notes:

! Ensure that the groups read through the study finding quickly but clearly.
! *Patient experts* is a relatively new term being used to describe the expertise that people living with HIV and AIDS gain by being on treatments themselves. Increasingly, people living with HIV and AIDS are being seen as 'experts' that can help other people living with HIV and AIDS to be able to use treatment effectively.

Information sheet: Extracts from a HORIZONS Report on the Greater Involvement of PLHA in NGO service Delivery: Findings from a Four-country Study

At the conclusion of the Paris AIDS Summit in 1994, 42 governments issued a declaration supporting greater involvement of people living with HIV/AIDS (PLHA) in policy formulation and service delivery. Despite growing recognition of its importance, there has been little research that examines PLHA involvement in the delivery of prevention, care, and support services in developing countries and its effects on PLHA, others affected by HIV/AIDS, and nongovernmental organisations (NGOs).

To address this gap, the Horizons Program and the International HIV/AIDS Alliance conducted a study of PLHA involvement in NGOs in Burkina Faso, Ecuador, Zambia, and Maharashtra State, India, between October 1998 and August 2001. The goal of the study was to identify the conditions that foster PLHA involvement and the strategies that organisations can use to achieve meaningful involvement of PLHA.

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

There are four distinct types of PLHA involvement.

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

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

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

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

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

Greater involvement is the most advanced stage of involvement, where PLHA take part in management, policymaking, and strategic planning as directors, trustees, or program managers, and may represent the organisation externally. This type of involvement implies a higher level of visibility that can expose PLHA to the risk of stigma and discrimination, although these PLHA are likely to be better able to cope because they generally have high levels of personal acceptance and support. PLHA involvement in management and decision-making occurs in the rights-based organisations, such as PLHA groups and networks. With one exception, PLHA who participate in management, policymaking, and strategic planning completed at least secondary education and are from middle-income socioeconomic groups. Most have been involved in the fight against the epidemic for many years and have had considerable training. Examples of this type of involvement include the following:

- At MNP+ in India and REVS+ in Burkina Faso, PLHA manage the organisation and specific programs, and at CHEP in Zambia, the coordinator and assistant of the PLHA program are both HIV-positive.

- At MNP+ and REVS+, PLHA were volunteer members of the board of trustees. At CHEP and Kara Counselling and Training Trust in Zambia, PLHA program coordinators are involved in organisational strategic planning.

PLHA who manage organisations and programs often have a significant representative role outside the NGO with which they are involved, expressing the perspectives of PLHA in different forums, and many participate in advocacy efforts in national and regional networks of PLHA.

DAY FOUR

4.1 Psychosocial support

Activity: 1 hour 30 minutes

Aim:
To identify the knowledge, skills and attitudes needed by an "ideal" psychosocial support provider.

Instructions:
1. Explain the aim of the activity.
2. Ask participants to provide definitions of knowledge, skills and attitudes using the Information sheet provided. Gives examples of what each one means in practice in relation to psychosocial support work.
3. On a large piece of flipchart paper, draw three inter-linking circles and label them "knowledge", "skills" and "attitudes." Draw an "ideal" psychosocial support provider in the centre where the circles overlap.
4. Ask participants to write the knowledge, skills and attitudes of an "ideal" psychosocial support 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. Divide the group into two groups. Give each group one of the following topics and a copy of the following relevant Information sheets*:*
   - Support groups
   - Support individuals
7. Ask the groups to read their Information sheet and answer the questions – recording their ideas as a five minutes presentation to share with the whole group. The presentation should include a brief introduction to the subject based on the Information sheet.
8. Ask the groups to share their work with the others.
9. Discuss any issues that emerge.

Facilitators' notes:

! Remind participants that no-one is perfect and that the "ideal" psychosocial support 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 care, support and treatment work to be effective. For example, a community health worker might have immense knowledge, but, without good communication skills and a positive attitude, their work will not be successful.
! If there is time, discuss what the challenges are for health workers to providing psychosocial support (e.g. too many clients, no training, burn-out)

Information sheet: Psychosocial support – knowledge, skills and attitudes

Knowledge, skills and attitudes are all important for establishing a helping relationship and providing psychosocial support to a person with HIV.

✓ **Knowledge** means an understanding of information and ideas. It is important for psychosocial support 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 care, support and treatment.

✓ **Skills** means knowing how to do something. They might relate to technical work (such as how to prescribe medicines) or "people" work (such as how to support a person with HIV to communicate their psychosocial support needs). Some of the most essential skills for providing psychosocial support include:
> - Listening   - Planning   - Taking action

✓ **Attitudes** means how individuals view issues and other people. Appropriate attitudes are vital for people involved in psychosocial support work. For example, if a person is open and genuine – rather than condemning or pitying people with HIV, 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 providing psychosocial support to be respectful and accepting of socially marginalised people like sex workers, prisoners, men who have sex with men or injecting drug users.

Some examples of the knowledge, skills and attitudes needed for psychosocial support work include:

Knowledge	Skills	Attitudes

✓ HIV transmission
✓ Nutrition
✓ Health education
✓ Positive living
✓ HIV-related treatment:
  • Symptoms and causes
  • Treatments for common problems
  • Drugs
  • New treatments
	✓ Communication:
	  • Asking questions
	  • Listening
	  • Checking people understanding
	✓ Planning / managing care, support and treatment with the person with HIV
	✓ Follow up and referral
	✓ Training
	✓ Counselling
	✓ Confidentiality
		✓ Compassion
		✓ Respect and non-judgment
		✓ Honesty
		✓ Common sense
		✓ Equality
		✓ Positive and encouraging
		✓ Acceptance

Information sheet: Support groups

The following information is an extract from Positive Development: Setting up self-help groups and advocating for change *written by the Global Network of People living with HIV/AIDS (GNP+).* www.gnpplus.net

Groups of people living with HIV are called many names – 'self-help', 'support' and 'PWA groups'. These names vary in different areas, so in this manual we use these different names – all of which mean groups run by, or for, people living with HIV. A group (self-help, support or PWA) can provide a chance for people to talk freely, in confidence, and be listened to and encouraged. A self-help group should encourage its members to reflect and learn from themselves and from each other. It may sometimes challenge members' attitudes, but in a safe and supportive environment.

To form a support group, or self-help group, it is important to be clear about why you want to get together. Some groups may be formed simply for members to have a place to talk to each other and share feelings and experiences. Other groups of people may join together to work towards a common goal or need, such as campaigning for improved medical care or providing information about HIV and safer sex. Groups may work with or without a particular leader or organiser, but it usually helps if everyone is clear about how the group should work. Working as a group can:

- help people feel that they are not isolated and alone with their problems
- provide a way to meet people and make friends
- help individuals to become more confident and powerful
- provide a basis to organise activities led by the members
- make links between people from different backgrounds and increase understanding and tolerance
- help to share resources, ideas and information, for instance about the latest available treatments or local support services
- make others in the community more aware of the situation facing people in the group by increasing the visibility of people living with HIV
- lead to change by creating a public or political voice.

Working together as a group can help people to become more aware of their own power. Even when people's ability to change their circumstances is limited by poverty or ill-health, there are ways to make the most of their personal skills and experience. A group has more influence than individuals working alone.

Group work questions:

1. What would you add, if anything, to the above description of support groups?
2. What do you think are the main challenges faced when establishing and maintaining support groups?
3. How can they be overcome?

Information sheet: Support individuals - Buddy systems

The following information is an extract from The Coping Centre for people living with HIV/AIDS (COCEPWA) website. COCEPWA are based in Botswana. www.cocepwa.co.bw

What is a Buddy?
A buddy is a member of COCEPWA who received special training. A buddy gets matched to a member of COCEPWA who needs support. Buddies give you help and support. The support can be about many things. You and your buddy may spend time talking together. Talking about you, your family, your health and the special problems that you have with HIV/AIDS. A buddy can help you in a crisis.

You can have a meal together at COCEPWA, drink tea, go for a walk. You and your buddy can plan your time together in whatever way works best for both of you. A buddy can go with you if you see a doctor, but also share your joy and have a good time together.

COCEPWA buddies come from all walks of life and religions. They are buddies because they want to help other members. Most buddies are PLWH/A themselves and know the problems that you face in Botswana as a person living with the virus. Buddies have received training about HIV and AIDS, and many of its problems. They know how to get more help. They know where to find special advice. Buddies know COCEPWA and the help it can provide for its members.

Buddies will respect all members of COCEPWA and have learned about confidentiality and privacy. You will respect their privacy too.

Buddy Basics
A buddy can help you with some basic tasks, but is mainly to talk to you, to listen to you and to advise you. A buddy offers you support. A buddy is taught at COCEPWA about Alcohol abuse, sex, HIV/AIDS, Medicines, Nutrition, Violence, and Suicide in order to have information that you may need. A buddy brings her/his own experience about living with the virus.

Most Buddies work with a COCEPWA member for six months or longer.

Group work questions:

1. Have you heard of other Buddy Systems outside Botswana? How do they differ?
2. What do you think are the main challenges faced when establishing and maintaining Buddy Systems?
3. How can they be overcome?

4.2 Ethics and equity for care, support and treatment

Activity: 1 hour

Aim:
To identify an ethical and equitable approach to HIV care, support and treatment work.

Instructions:

1. Explain the aim of the activity.
2. Divide the participants into 'buzz' groups (groups of 2-3 persons who stay where they are sitting). Discuss the meaning of the terms Ethics and Equity in their experience. Share in plenary and discuss why those terms are important in care, support and treatment.
3. Ask participants to draw from their own experiences to give examples of unethical or inequitable scenarios in care, support, and treatment.
4. Assign one of the following scenarios to the buzz groups:

   Scenario 1: A person with AIDS is refused treatment by a local clinic because "they deserve it", and "the money could be better spent on someone with malaria".

   Scenario 2: A health worker testing a sex worker for HIV without their consent, and then breaching confidentiality about the result.

4. Ask each group to discuss the scenario and identify the ethical and/or equity issues.
5. Bring the groups back together. Under each scenario, ask each group to read out their list of ethical and/or equity issues identified. Ask a volunteer or co-facilitator to list them on flipchart.
6. Facilitate a group discussion about ethical and/or equity issues on HIV care, support and treatment that were highlighted by the scenarios based on questions such as:
   - **?** Why might people act unethically? How can you support them to change their behaviour?
   - **?** Why might people treat people unequally? How can equity issues be addressed for care, support and treatment at community level?
   - **?** Is it ever appropriate to breach a person's confidentiality when providing HIV care, support and treatment? Why?

Facilitators' notes:
- **!** Encourage participants to draw the links between ethics and the other aspects of an "ideal" psychosocial support 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 for treatment work.
- **!** Be aware that the equity issues that you are looking for as part of discussion question 2, may come out during question 1.

Information sheet: Ethical and equity for care, support and treatment

A respect for ethics is an important part of effective HIV care, support and treatment. This means the principles or morals that shape people's personal and professional behaviour and their attitudes towards others.

An ethical approach to care, support and treatment is based on the principles of pro-actively doing no harm and minimising risk. Ethics are particularly important for work on HIV and AIDS – as it is a highly personal and sensitive subject. In addition, work on access to HIV care, support and treatment is, at times, complex and controversial – especially as it highlights issues of inequality.

Some examples of an ethical approach to HIV care, support and treatment work include:

- ✓ Empowering people with HIV 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 appropriate and equal participation by all those involved.
- ✓ Ensuring that benefits and difficulties are shared appropriately among those involved.
- ✓ Appropriate referral.

Wherever possible, an ethical approach to HIV care, support and 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.

Equitable provision of care, support and treatment helps to ensure equity of resources, services and commitment to care for all.

- ✓ 'Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair'
- ✓ 'Equity in health implies directing more resources for health to those with greater health needs'
- ✓ 'Equity in health means having the power to influence decisions over how resources for health are shared and allocated'

Equitable expansion of treatment programmes requires
- ✓ transparent, fair, participatory national decision making
- ✓ sustainable, fair financing integrated into national budgets
- ✓ strengthened district and participatory primary health care systems
- ✓ sustainable, equitable and effectively managed drug and personnel inputs

Reference: EQUINET presentation during a SAT/JSI Regional SHARE meeting on 'Community Preparedness for Improve Access to Treatment', August 2004.

4.3. Introduction to needs assessments and analysis

Activity: 30 minutes

Aim:
To ensure that participants understand the importance of carrying out an assessment and the process of assessment and analysis that will be followed.

Instructions:
1. Explain the aim of the activity.
2. Ask the group to identify the main reasons for carrying out a needs assessment.
3. Ask the group what are the practical issues that we need to think about when planning a needs assessment.
4. Give an introduction to needs assessments and analysis using the Information sheet provided.
5. Ask for any pressing questions

Facilitators' notes:
! There are many different reasons and ways to carry out an assessment. Make sure that the discussions are useful in affirming the need for assessments.
! This session comes near the end of a long week and many participants will already know about assessments. Try to present the information in an interesting way e.g. make posters or flipcharts with pieces of information and walk the participants around the room as you explain their content.

Information sheet: Introduction to needs assessments and analysis

The assessment process

Many NGOs/CBOs/PLHA groups become involved in HIV care, support and treatment work because they want to respond to the urgent needs of people with HIV. Groups working in HIV care, support and treatment should consider certain issues. These include:

✓ **Sustainability.** For example, does the organisation have 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 with HIV that the organisation can help compare with the total number who need care, support and treatment?

✓ **Equity.** For example, are people's health needs met in a fair and just way?

✓ **Quality.** For example, can the organisation provide care, support and 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 care, support and treatment services acceptable to people living with HIV and what are the community's attitude about the care, support and treatment?

What is an assessment?

To make good decisions about starting or increasing the scope of HIV care, support and treatment work, an organisation needs to begin with analysing the existing needs, resources and action in their community. This can be done through an assessment.

An assessment is a way to understand the context in which an organisation is working and to make strategic decisions about what to do. It can involve many different people and organisations, including community members, local leaders and the organisation itself. It enables people to share their "real life" experiences, opinions and concerns - usually through a mixture of focus group discussions and participatory activities.
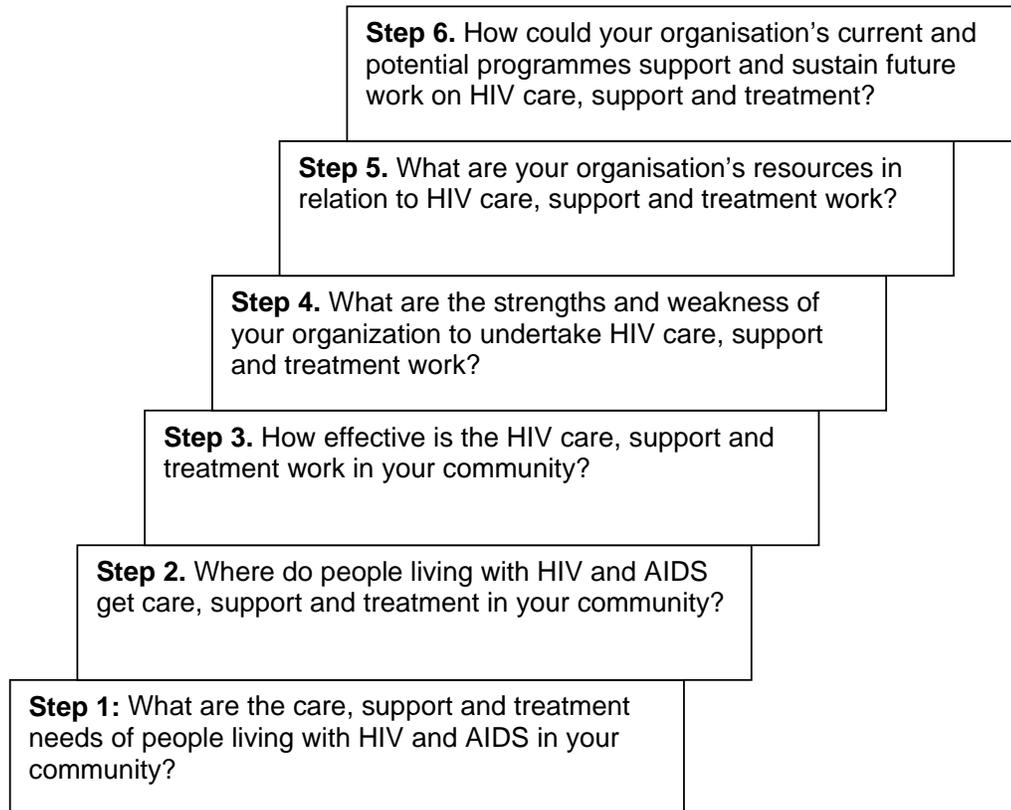
An assessment helps to ensure that action on HIV care, support and treatment is based upon the **real** needs of the community – rather than on what people think they are. An assessment can help an organisation to answer questions such as:
✓ What are the care, support and treatment priorities of people with HIV?
✓ What difficulties do people experience in using care, support and treatment services/advice?
✓ How could access to HIV care, support and treatment be improved?
✓ How could your organisation make the biggest difference possible?

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

The assessment process and analysis
The assessment is a participatory process involving 6 key steps:

Step 6. How could your organisation's current and potential programmes support and sustain future work on HIV care, support and treatment?

Step 5. What are your organisation's resources in relation to HIV care, support and treatment work?

Step 4. What are the strengths and weakness of your organization to undertake HIV care, support and treatment work?

Step 3. How effective is the HIV care, support and treatment work in your community?

Step 2. Where do people living with HIV and AIDS get care, support and treatment in your community?

Step 1: What are the care, support and treatment needs of people living with HIV and AIDS in your community?

Planning an assessment
To plan an assessment, an organisation needs to decide:

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, 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?

4.4 Step 1. What are the care, support and treatment needs of people living with HIV and AIDS in your community?

Activity: 1 hour

Aim:
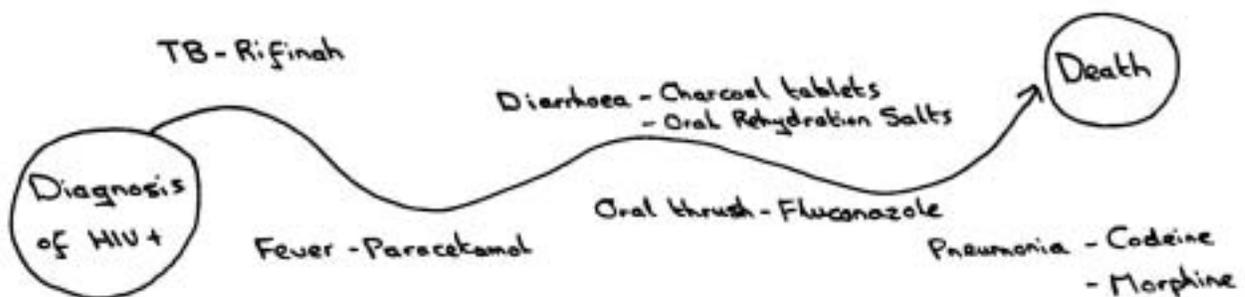To assess the care, support and treatment needs of people with HIV in your community.

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 with HIV 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 with HIV. E.g. fever, TB, etc.. Write each suggestion down on a small piece of paper. Encourage the consideration of social issues as well. E.g. depression, need for contraception or PMTCT.
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 with HIV.
5. Ask participants for suggestions of care, support and treatment for each of the health problems. E.g. paracetamol or TB drugs, psychosocial support from support groups etc. Write them down next to the health problem on the lifeline.
6. Discuss what can be concluded about the care, support and treatment needs of people with HIV 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 with HIV experience it.

Example:

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4.5 Step 2. Where do people living with HIV and AIDS get care, support and treatment in your community?

Activity: 30 minutes before lunch 1 hour after

Aim:
To assess what care, support and treatment is available and accessible to people living with HIV and AIDS in your community.

Instructions:
1. Discuss with participants what is meant by "available" and "accessible" in relation to care, support and treatment

> *Definitions of 'availability' and 'accessibility'*
> 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.
>
> For people to use treatment, it must not only be available – the treatment must also be accessible. This means that not only should the treatment be found in the appropriate place, it should also be easy for people to obtain and use the treatment properly.

   Brainstorm some local examples of what they mean in practice in your community.
2. In their small groups, 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 of the key features such as roads and clinics.
   - BREAK FOR LUNCH -
3. Ask participants to mark with a star the places **where** different types of HIV care, support and treatment are available in their community such as the home or traditional healer, and **what** kind of care, support and treatment is provided.
4. Ask participants to assess how accessible each kind of care, support and treatment is for people with HIV. If some aspects of care, support and treatment are not accessible, ask them to identify why, and how this can be improved.
5. Discuss what can be concluded about the availability and accessibility of HIV care, support and 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 with HIV, are also accessible to people with HIV.

Example:
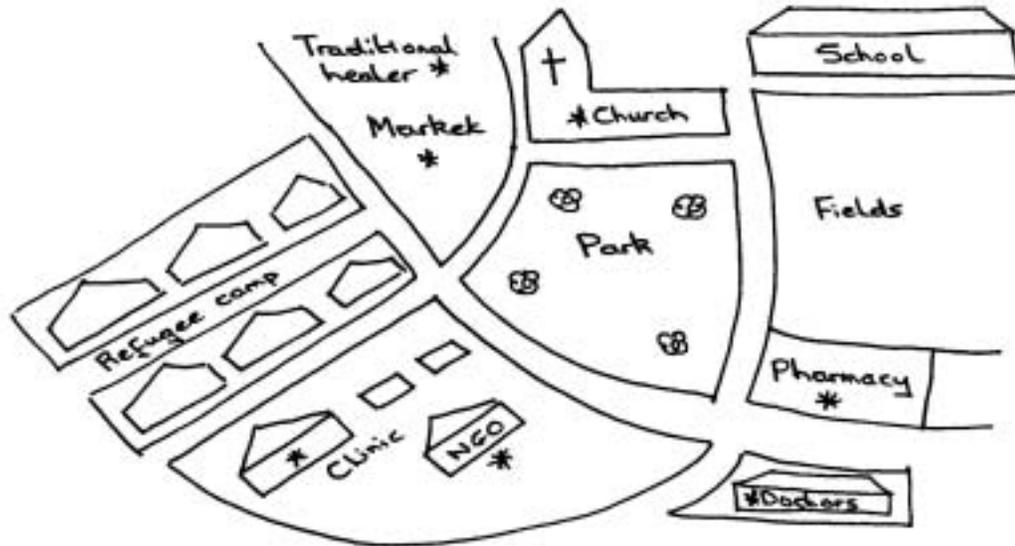
4.6 Step 3. How effective is the HIV care, support and treatment work in your community?

Activity: 1 hour

Aim:
To assess how effective the HIV care, support and treatment work is in your community.

Instructions:
1. Explain the aim of the activity.
2. In their small groups ask participants to make a measuring line with "not effective" at one end and "very effective" at the other.
3. Ask the participants to write the name of each care, support and treatment service provider in the community on separate pieces of paper.
4. Ask participants to place the pieces of paper along the measuring line – according to how effectively they provide the HIV care, support and treatments service. Ask them to discuss why the service is ineffective and how it can be improved.
5. Discuss what can be concluded about how effective the HIV care, support and treatment work is in your community, what needs to be improved and what gaps exist.

Facilitators' notes:
! Encourage participants to look at a broad variety of service providers for care, support and treatment, including government, non-governmental and "traditional."
! Support participants to offer honest and constructive criticism about the work of others, rather than being too negative.

Example:
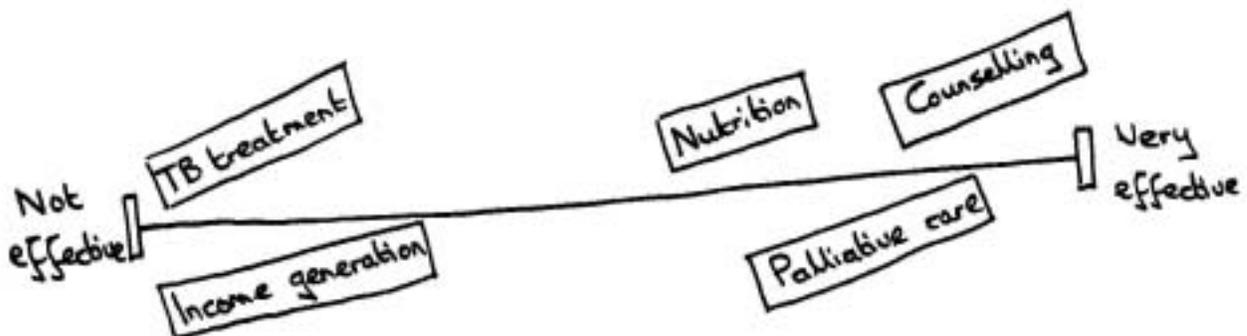
DAY FIVE

5.1 Step 4. What are the strengths and weaknesses of your organisation to undertake HIV care, support and treatment work?

Activity: 45 minutes

Aim:
To assess the strengths and weaknesses of your organisation to undertake care, support and treatment work.

Instructions:
1. Explain the aim of the activity.
2. Ask participants to discuss the existing mission of the organisation.
3. Draw two columns on a piece of flip chart 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 care, support and treatment work would or would not support the organisation's existing mission. Write the key points in the appropriate column on the flipcharts.
5. Discuss what can be concluded about how HIV care, support and treatment work fits with the organisation's existing mission.

Facilitators' notes:
!   If participants do not know the organisation's exact mission, ask them to brainstorm its general aims and objectives.
!   Encourage participants to think honestly and critically about how work on HIV care, support and treatment might affect the organisation's both positively and negatively.

Example:

5.2 Step 5. What are your organisation's resources in relation to HIV care, support and treatment work?

Activity: 45 minutes

Aim:
To assess the strengths and weaknesses of your organisation's resources for carrying out work on HIV care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Ask participants to brainstorm what type of resources an organisation needs for care, support and treatment work.
3. Divide a piece of flip chart paper into two columns, one headed "Strengths" and the other headed "Weaknesses"
4. Ask participants to identify the strengths of the organisation's resources in relation to work on HIV care, support and treatment. Write the key points in the appropriate column.
5. Ask participants to identify the weaknesses of the organisations' resources in relation to work on HIV care, support and 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 organisation's resources to undertake care, support and treatment work.

Facilitators' notes:
! Encourage participants to be very honest about whether the organisation will be able to cope with the extra work and complexity of HIV care, support and treatment.
! Encourage participants to think broadly about what type of resources are needed – including not just money, but also time, space and skills.

Example:

5.3 Step 6. How could your organisation's current and potential programmes support and sustain future work on HIV care, support and treatment?

Activity: 1 hour 30 minutes

Aim:
To identify how an organisation's current and potential programmes might link with their work on HIV care, support and treatment.

Instructions:
1. Explain the aim of the activity.
2. Give a presentation to the group based on the *Information sheet: Reaching a decision.*
3. In their small groups, ask participants to draw a picture or diagram to show how the organisation can integrate or add HIV care, support and treatment work to their existing and potential programmes.
4. With the whole group, discuss what challenges might exist when integrating or adding HIV care, support and treatment work to the organisation's programmes.

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 care, support and treatment work rather than theoretical ideas.
! Encourage participants to be honest about whether work on HIV care, support and treatment will help or hinder the organisation's existing programmes.
! Support participants to identify both programmatic links (such as sharing supplies of condoms) and organisational links (such as sharing administrative systems).

Example:
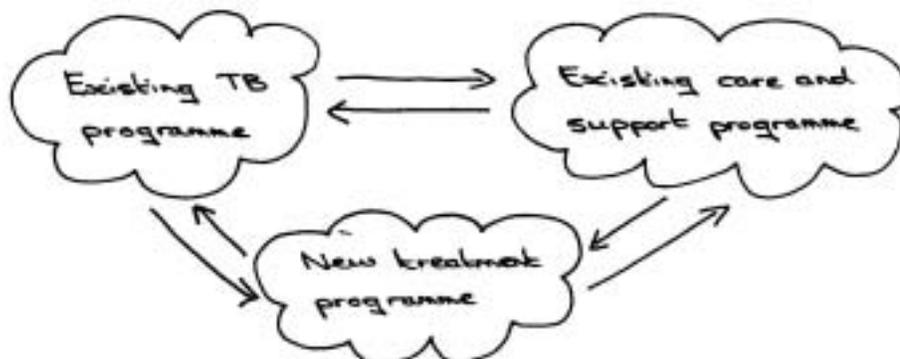
Information sheet: Reaching a decision

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

When setting priorities, it is important to decide:

✓ Who should be involved in making the decision?

Decision-making about what to do will be more effective if you involve all those that have been involved in the assessment, particularly those that will be directly affected by the work. They include:

- Families
- Community leaders
- Staff, volunteers and trustees
- Donors
- People with HIV
- Other NGOs
- Government

The involvement of people with HIV is especially vital to any work aiming to meet their needs. If people with HIV are involved throughout: from the assessment to the decision-making process through to the implementation of the work, their ideas and experiences can contribute greatly. Involving people with HIV in your care, support and treatment work can also help to improve access to treatment and reduce stigma and discrimination.

✓ How will the decision be made?

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

When making your decision, it is important to set priorities that fit your organisation'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 are:

✓ What have you learned about the priority needs of people living with HIV and AIDS?
✓ What are the main barriers to access to HIV care, support and treatment?
✓ What is already happening to improve access to HIV care, support and treatment?
✓ What still needs to be done to improve access to HIV care, support and treatment?
✓ What are your organisation's advantages and disadvantages in working on HIV care, support and treatment?
✓ What work is realistic for your organisation - 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?

[NB. Information on this subject can be found in an Information sheet: Thinking creatively about what you can do about treatment]

Information sheet: Thinking creatively about what your group can do about treatment

When you are considering the results of your assessments, you also need to look at the range of options for treatment work which 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 care, support and treatment – such as nutrition, counselling, traditional remedies etc.

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

Home	Community	Health Care Facilities
✓ Universal precautions to prevent HIV transmission ✓ Safer sex practices, including family planning ✓ Personal & environmental hygiene practices ✓ Emotional support for persons with HIV, carers and families ✓ Nutrition and safety of food and water supplies ✓ Using medicines & traditional remedies correctly and adhering to treatment regimes ✓ Support for DOT treatment regimes ✓ Sharing information about where to get more support	✓ Social support & counselling ✓ Access to voluntary counselling and testing ✓ Community information & involvement ✓ Support groups ✓ Accompanying people who need treatment ✓ Nutritional counselling ✓ Support for DOT treatment regimes ✓ Food programmes ✓ Providing condoms, bleach, clean syringes ✓ Access to family planning services ✓ Advocacy ✓ Assistance to orphaned and vulnerable children ✓ Financial support ✓ Legal support ✓ Management of drug supplies ✓ Hospice ✓ Bereavement & funeral support	✓ Voluntary counselling and testing ✓ Access to safe blood, blood products ✓ Clinical management of pain, malaise & fever ✓ Clinical management of opportunistic infections ✓ Clinical management of STIs ✓ Preventive treatment & treatment for TB ✓ Preventive treatment of Pneumocystis carinii Pneumonia (PCP) ✓ Nutritional assessment & counselling ✓ Antiretroviral therapy for preventing mother to child transmission ✓ Antiretroviral therapy including HAART ✓ Clinical & laboratory monitoring of progression of HIV ✓ Access to breast milk substitutes

5.4 Action planning

Activity: 30 minutes

Aim:
To develop an action plan for your organisation to operationalise your HIV care, support and treatment work.

Instructions:
1. Explain the aim of the activity.
2. Explain that the action plan that they will develop will include major activities to be undertaken by your organisation to operationalise the plans you made from Step 6. Show the participants the action planning table as an example for them to use.
3. Ask participants to list the major activities/steps that they need to take to put their plans in action.
4. Ask the participant to order the activities/steps by time and fill in the action planning table.

Facilitators' notes:
! Allow the participants to use their own style of action plans if they would prefer.
! Make sure that the participants identify the major activities/steps and don't go into too much detail.

Example:

Activity /step	Who will be involved	Who will be responsible	When will it take place	Where will it take place	How much will it cost

Sample Participant Feedback Form

Event:

Date:

Location:

We constantly monitor and evaluate our work to support the response to HIV and AIDS. We are always looking to increase the success of our work and to improve areas of weakness. Your feedback on this event is therefore very important to us. <u>Please tick the appropriate boxes</u> below and feel free to give us written feedback on any aspect of the event on the other side of the page.

Relevance: How relevant was this event to your organisation's needs?	Not relevant	Quite relevant	Very relevant
Learning: How much did you learn by participating in this event?	Didn't learn	Learned a little	Learned a lot
Application of learning: To what extent will you be able to apply what you have learned to improve your work?	Low	Medium	High
Facilitation: How well was the event facilitated?	Poor	Satisfactory	Good
Event planning & organisation: How well was the event planned and organised?	Poor	Satisfactory	Good

Comments