# NATIONAL AIDS PROGRAMME MANAGEMENT

# MODULE 6 IMPLEMENTATION OF HIV PREVENTION, CARE AND TREATMENT STRATEGIES

SUBMODULE 4 THE CONTINUUM OF CARE FOR PEOPLE LIVING WITH HIV/AIDS AND ACCESS TO ANTIRETROVIRAL THERAPY



**Regional Office for South-East Asia** 

## **National AIDS Programme Management**

**A Training Course** 

# Submodule 6.4: The continuum of care for people living with HIV/AIDS and access to antiretroviral therapy



2007

WHO Library Cataloguing-in-Publication data

World Health Organization, Regional Office for South-East Asia. National AIDS programme management: a set of training modules.

1. HIV infections – prevention and control – transmission. 2. Acquired Immunodeficiency Syndrome – prevention and control – transmission. 3. Training programmes. 4. Teaching material. 5. Health status – indicators. 6. Policy-making. 7. Outcome and process assessment (health care) – methods. 8. Substance abuse, intravenous. 9. Counselling. 10. Breastfeeding – adverse effects. 11. Manuals.

ISBN 978-92-9022-302-3

(NLM classification: 503.6)

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This publication is available on the Internet at http://www.searo.who.int/hiv-aids publications

Copies may be requested from: HIV Unit, Department of Communicable Diseases World Health Organization Regional Office for South-East Asia Indraprastha Estate, Mahatma Gandhi Marg, New Delhi 110 002, India Fax: +91 11 23370197; e-mail: hiv@searo.who.int

Editorial support, layout and typesetting: Byword Editorial Consultants Cover designs: Netra Shyam

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# The continuum of care for people living with HIV/AIDS and access to antiretroviral therapy

#### LEARNING OBJECTIVES

After completing this submodule, participants will be able:

- 1. To identify the elements of the continuum of care for PLHA.
- 2. To identify strategies for reducing HIV-related stigma and discrimination.
- 3. To describe the role of community support, peer support and counselling in HIV prevention, care and treatment.
- 4. To list the steps for strengthening clinical and community care for PLHA, including the scaling up of ART.
- 5. To assess the progress of national programmes towards meeting the needs of PLHA across the continuum of care.

### **INTRODUCTION**

At the United Nations General Assembly's high-level meeting on AIDS in June 2006, Member States agreed to work towards the broad goal of "universal access to comprehensive prevention programmes, treatment, care and support" by 2010. Working towards universal access is a very ambitious challenge for the international community, and will require the commitment and involvement of all stakeholders, including governments, donors, international agencies, researchers and affected communities. Among the most important priorities is strengthening of the health services so that they are able to provide a comprehensive range of HIV/AIDS services to all those who need them.

It has been recognized that the primary health-care strategy, based on practical, scientifically sound and socially accepted methods and technology, should be made universally accessible to individuals and families in the community. The concept of a continuum of care for people living with HIV/AIDS (PLHA) evolved on the basis of the

principles of primary health care. This concept puts the individual and family at the centre of the care and support system.

A continuum of care is needed for PLHA as their requirements for care vary and change over time. Following the diagnosis of HIV, PLHA require regular access to prevention, care, support and treatment services. They may need extensive psychological support, counselling for positive living, and information on HIV and sexually transmitted infection (STI) prevention.

To meet the overall goals of the programme – reducing HIV transmission and providing care, support and treatment to people affected by HIV and AIDS – a range of factors that contribute to the long-term health and well-being of the affected people should be considered.

The needs for care, support and treatment for PLHA are lifelong and these needs change over time. Effective clinical care is essential, but so are adequate nutrition, shelter, security and support.

This submodule describes strategies to strengthen the continuum of care and increasing access to antiretroviral therapy (ART) for those affected by HIV. It provides guidance for assessing current AIDS programmes so as to be able to identify their progress and the priorities for the strengthening of continuous care.

This submodule should be read particularly in conjunction with the modules on HIV counselling and testing, and management systems for the AIDS programme.

## **OBJECTIVE 1:** To identify the elements of the continuum of care

In the case of people affected by HIV and AIDS, effective prevention, care, support and treatment begins at the time of diagnosis and involves a wide range of community- and institution-based services and programmes.

A continuum of care can be established by understanding the elements that constitute the health and well-being of a person with HIV. People designing services and programmes need to take this into account, as providing access to only one aspect while neglecting the others will leave the person without support and jeopardize the goals of the programme.

# ELEMENTS OF THE CONTINUUM OF CARE FOR PLHA AND ANTIRETROVIRAL THERAPY

- An enabling environment in which stigma and discrimination against people affected by HIV and AIDS are minimized, they have access to the full range of services they need, and are able to participate in community life;
- Community support to assist PLHA to maximize their health and well-being, including spiritual care, nutrition, shelter, emotional support, access to employment and to poverty alleviation and livelihood programmes;
- Community support for families looking after people with HIV and AIDS at home, along with institutional back-up;
- Support to PLHA to prevent HIV transmission;
- Clinical monitoring, treatment and care that is of consistently high quality, locally accessible and affordable.

For example, giving a person a month's supply of ART and sending them back into an environment where they have no access to clean water, shelter and adequate nutrition is unlikely to result in an improvement in their health. Diagnosing people with HIV in voluntary counselling and testing (VCT) centres without referral to ongoing counselling, as well as community and peer support, is unlikely to result in a reduction in HIV transmission or help the affected people come to terms with the diagnosis.

The continuum of care involves a range of institutions.

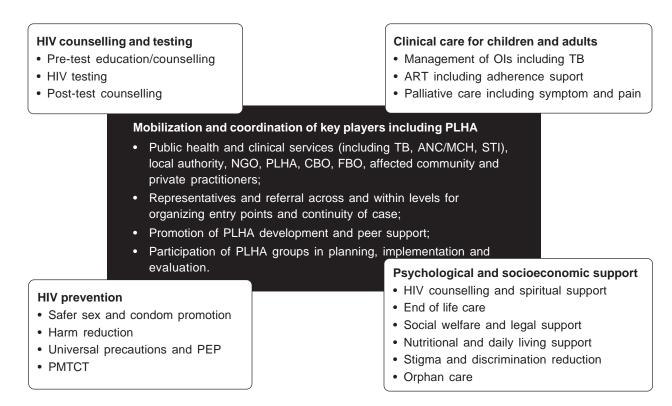
• Community and nongovernmental organizations have a key role to play in ensuring that individuals and families affected by HIV and AIDS can participate in community

life, have access to food and shelter, and have economic security.

- Existing health services and programmes are an essential part of the continuum of care.
- It is often inefficient and unsustainable to establish a set of HIV-specific services, when there is a range of mainstream support services and community resources that can be mobilized.
- In many places, the continuum of care can be broadened significantly by assisting the existing services and programmes to reach a point where they are comfortable with providing PLHA access to their services and programmes.

The key to an effective continuum of care is planning and coordination. Rather than providing a fragmented and unlinked set of services and programmes, the AIDS programme manager must ensure efficient coordination between prevention, care, support and treatment services so that PLHA can access the full range of services they need throughout their lives. Services need to be made available where they are required, and designed in a way that will maximize their use by the people who need them the most. Involving local PLHA in the design of the services that you want them to use is the surest way of ensuring this.

The diagram below provides a useful model for planning across the continuum of care.



Source: Adapted from HIV/AIDS care and treatment: a guide for implementation. Manila, WHO WPRO, 2004.

## EXERCISE A

#### (Country group work followed by country group discussion)

Describe in country groups, the current availability of clinical care services.

Draw a map of your country, setting out where services are currently available. Try to use the map to answer the questions below. The information from this exercise will assist you in carrying out the final exercise in this module.

1. Where do PLHA currently access HIV clinical services?

- 2. What HIV services are provided at different levels?
  - Tertiary hospital (national or provincial capital city)
  - District hospital and out-patients department
  - Primary care clinic
  - Aid post, or local or community health service

3. How does this map match with what you know about the geographical distribution of PLHA?

Inform your facilitator when you are ready for country group discussions.

# **OBJECTIVE 2:** To identify strategies for reducing HIV-related stigma and discrimination

The term "enabling environment" is used in AIDS programme planning to refer to a set of characteristics or factors that work together to assist the programme to meet its goals. In the early years of the response to HIV, fear about HIV transmission and moral judgements about the people who were affected by HIV led to an environment of stigma and discrimination. PLHA and families affected by HIV faced isolation and violence, and found it difficult to access the services and community support they needed. Many people isolated themselves and did not seek services or the community support they would normally have sought, as they feared rejection.

Strengthening the enabling environment means putting in place a set of policies and laws that will support the goals of the programme and reduce stigma and discrimination; training health and community workers to reduce their fear and increase their understanding of the needs of PLHA; establishing standards of care and support; revising laws, policies and procedures that work against the goals of the AIDS programme; and working with religious and community leaders to increase tolerance, reduce stigma and improve the level of care and support in communities.

The government, PLHA and institutions should protect PLHA from discrimination not only because of the need to ensure the human rights of every individual in general, but also to promote sound principles of public health. Discriminatory practices jeopardize public health in the following ways.

- Individuals who know or suspect that they have HIV may adopt evasive behaviours or be driven underground by discriminatory practices. Consequently, the very people who are at the greatest risk of acquiring and transmitting HIV are not accessible and reaching them with educational messages about the prevention of HIV becomes difficult.
- Valuable people, such as those with HIV who have access to or knowledge about important target groups, and who could be involved in peer education about HIV and AIDS, may decide against being involved in these activities because they fear the consequences of discrimination and stigma.
- Attempts to identify and even confine or isolate PLHA provide the general public with a false sense of security that all PLHA are known and confined or out of reach, and that precautions against the transmission of HIV are no longer necessary.

#### THE NATURE OF HIV-RELATED DISCRIMINATION

Discriminatory practices, or practices that lead to discrimination, may occur because there is a law or regulation mandating a discriminatory practice (for example, mandatory testing). They may also occur because there is no legal protection from discrimination for individuals in formal interactions, such as those between an individual and employer, landlord or health-care provider. Other discriminatory practices are related to the negative attitudes held by the general public or by certain important groups, such as peers, family members, community members or caretakers.

The following are some examples of practices that discriminate against PLHA, or which can lead to discrimination.

- (a) Imposing mandatory HIV testing: There is no public health rationale for mandatory HIV testing. It is not cost-effective and knowledge of the HIV status on its own does not change behaviour.
- (b) Denying appropriate health care to PLHA: PLHA should have the same access to care as is available to others with chronic or terminal illnesses, or to those who are HIV-negative with similar conditions, such as pneumonia or tuberculosis (TB).
- (c) Denying access to employment, educational facilities, shelter, health insurance, welfare benefits, or other social services: The risk of HIV transmission does not arise in any situation linked to these services.
- (d) Denying freedom to travel or migrate for employment or further educational opportunities, or to seek asylum or refugee status: A policy which debars PLHA from entering a country only increases the fear surrounding the disease, forces PLHA to go underground and shun prevention, care and treatment.
- (e) **Imposing a quarantine or detaining persons with HIV infection:** Confining or isolating PLHA provides a false sense of security to the general public because they believe that all PLHA have been identified.
- (f) Breaches of confidentiality that are either deliberate, such as informing an employer or others without the individual's consent, or are involuntary, especially in cases where medical records are not adequately protected or where reporting procedures are ineffective: Without the protection of confidentiality, persons at risk of HIV infection are likely to avoid contact with healthcare. Breaches in confidentiality about a person's HIV status may result in violence, rejection, loss of access to such services as employment, housing, insurance or social security benefits, and so on.
- (g) Forcing women with HIV infection to undergo abortion: As with mandatory testing, mandatory abortions may drive women with or at risk of, HIV underground, making it difficult to educate them on the prevention of HIV and on antenatal care.

# GATHERING THE INFORMATION NEEDED TO ADVOCATE FOR CHANGES IN DISCRIMINATORY PRACTICES

To gather the information necessary to advocate for changes in discriminatory practices, programme managers should work with PLHA groups, nongovernmental organizations (NGOs) and service providers to determine the extent of these practices. The following are required for this purpose.

- · Identifying the discriminatory practices, or recording those that others report
- · Identifying where the practice occurs and the people affected by it
- Determining who is responsible for designing and implementing the policy or who is behind the practice
- Determining the reasons that led to the establishment of the policy or practice.

#### **INITIATING A PROCESS TO LIMIT DISCRIMINATORY PRACTICES**

To promote the protection of individuals from discrimination, individuals, government organizations (GOs) and NGOs should consider the following actions.

- Change current laws or regulations whose purpose or intention is to allow for discrimination against PLHA.
- Advocate for laws or regulations that protect PLHA when no other legal protection exists. This relates to situations in which individuals face discrimination in formal interactions, such as those between an individual and a landlord, employer or healthcare provider.
- Provide information and education to help change the attitudes both of the general public and target audiences. Health-care or social workers should be educated on the impact of discrimination and on ways to improve reporting so that confidentiality is maintained.

To promote changes in laws, regulations and practices that improve support for and limit discrimination against PLHA, coordination among the health, legal, welfare and social sectors including NGOs is essential and could be facilitated by a multisectoral decision-making body that can mobilize political support and action for limiting discriminatory practices. Involving the community, especially PLHA, would help the National AIDS Programme (NAP) to collect information on the extent of discriminatory practices.

The NAP does not have the authority to change discriminatory practices or policies that may lead to them. However, the NAP management staff plays an important role in facilitating the efforts of those who can take corrective action to change discriminatory practices. The NAP manager should use the information gathered about discriminatory practices to initiate a process aimed at limiting such policies and practices. The NAP management should:

- (a) inform the national AIDS committee (NAC) and other appropriate institutions and organizations, such as the Ministries of Health, Justice and Foreign Affairs;
- (b) indicate the reason(s) why the discriminatory practice
  - impedes public health objectives in general
  - impedes the main objectives of the NAP;
- (c) propose alternative activities that promote individual rights and limit discrimination against PLHA, and which are specifically designed to remedy the harm caused by the discriminatory practice that has been identified; and
- (d) collaborate with and obtain assistance from national and international agencies.



#### (Individual work followed by country group discussion)

Review the list of discriminatory practices listed on page 12. These are practices that should be avoided. Then answer the following questions.

Identify a discriminatory practice that you know has occurred in your country in the recent past.

1. Specify where the practice is followed and whom it affects (that is, the target population). Indicate whether the practice is occurring incidentally, whether it is a regular practice, or the result of an institutionalized policy.

2. What do you think is the underlying reason for this practice?

3. Who has the capacity and power to change the practice? If you do not know, how can you find the answer to this question?

4. Describe the actions that you think need to be taken by the NAP management to bring about these changes.

Inform your facilitator when you are ready for country group discussions.

## **OBJECTIVE 3:** To describe the role of community support, peer support and counselling in HIV prevention, care and treatment

### COMMUNITY SUPPORT

The need for support, information and counselling starts from the time an individual is diagnosed with HIV. The main aim of programmes and services at this stage are:

- to help PLHA adjust to their diagnosis by providing ongoing support and counselling;
- to link them to support networks, NGOs, PLHA groups, community groups or other supportive structures;
- to assist them to devise and put in place long-term strategies to remain healthy and prevent HIV transmission;
- to help them identify ways in which they can maximize their health and well-being good nutrition, adequate shelter, economic security, maintaining hope and a sense of purpose, reducing stress;
- to introduce them to the range of clinical services including ART that they may need in the future;
- to work with community leaders and members to ensure that PLHA and their families are not cut off from community support.

The array of support services required at the community level depends on several factors. These are the number of PLHA thought to be present in the area concerned; the existence of support structures in the community that could be mobilized to provide HIV support; the capacity of local NGOs to contribute to support; and the setting, for example, the support that is needed or feasible in a poor urban area may differ significantly from that required in a rural area.

The AIDS programme has several roles to play in the setting up of support services:

- Helping networks of PLHA to provide information and support
- Working with national NGOs that have established contacts with the community, and assisting them to mobilize resources for care and support
- Ensuring that PLHA have non-discriminatory access to government programmes, such as those on poverty alleviation, food security, income support and vocational training
- Developing and monitoring laws and policies that reduce discrimination against and exploitation of PLHA

- Working with religious and community leaders to encourage them to provide PLHA with access to their support programmes and services at all levels
- Working with provincial and local governments to devise appropriate models and sustainable strategies for increasing local access to support
- Working with the Ministry of Health and private health service providers to assist them to develop strong links with community care and support services and programmes.

### LINKING HIV PREVENTION, CARE AND TREATMENT

This should be read together with the module on reducing HIV transmission (see Submodules 6.1 and 6.2), but it is important to think about the contribution that HIV care, support and treatment services can make to HIV prevention.

While programme planners often separate HIV prevention, care and treatment, people affected by HIV and AIDS do not usually make this distinction. The latter are encouraged to maximize their health and well-being, and minimize HIV transmission (positive prevention).

Health-care workers are also being encouraged to better recognize their role in assisting positive prevention.

Strategies that help encourage positive prevention are:

- employing PLHA as peer counsellors and outreach workers in health services;
- training clinical staff in HIV prevention counselling, including assisting PLHA to disclose to others who may be at risk, reinforcing safer behaviours and reducing vulnerability;
- providing PLHA networks with resources to inform and support newly diagnosed PLHA;
- producing and distributing written materials on maximizing health and well-being and minimizing HIV transmission, in the local language and at the appropriate literacy level;
- ensuring that condoms are available at the health services/facilities;
- developing strong referral links between HIV clinical services and illicit drug treatment, substitution and rehabilitation services.

## OBJECTIVE 4: To list the steps for strengthening clinical and community care for PLHA, including the scaling up of ART

## **GUIDING PRINCIPLES**

Several guiding principles should be kept in mind while planning clinical care and treatment services for PLHA. These are as follows.

- Involving PLHA in the design and evaluation of health services increases the latter's effectiveness and improves access.
- Health care starts from the time of diagnosis and while people may live for many years without symptoms, it is important for PLHA to have an ongoing relationship with a clinical service that can monitor their health.
- Decentralization of services is essential PLHA need to be able to access clinical services as close to home as possible, so that they can continue to work and participate in community life.
- Strong links between HIV services and other services, particularly TB services, lead to better health outcomes.
- Preventing or treating opportunistic infections (OIs) is a crucial part of HIV care, as many PLHA die from preventable or treatable OIs.
- The provision of ART is more effective if it is supported by a set of strategies for treatment preparedness and treatment adherence in the community.
- Interruptions in the supply of OI drugs and ART lead to unnecessary deaths.

### THE RANGE OF CLINICAL SERVICES REQUIRED

PLHA require a range of clinical services to help them maximize their health, though all these services need not be provided in one place. Further, an individual's need for these services changes over time. The range of services includes:

- monitoring the nutritional state, general health, progression of HIV infection, strength of the immune system;
- prevention, diagnosis and treatment of OIs, particularly TB;
- access to ART, monitoring the response to ART, changes in treatment regimens as required;
- treatment of HIV-related cancers, neurological disorders, mental illness and other illnesses associated with HIV infection;
- diagnosis and treatment of STIs;

- treatment to prevent mother-to-child transmission (PMTCT); and
- drug substitution, drug treatment and rehabilitation for injecting drug users (IDUs) with HIV.

# DECIDING WHICH SERVICES TO PROVIDE AT EACH LEVEL OF THE HEALTH SYSTEM

It is not feasible, or desirable, to provide specialized HIV treatment and care services at every local clinic. On the other hand, it is not possible for every PLHA in a given province or district to travel to the capital city for every aspect of their HIV-related health care. Hence, strategic decisions need to be made about where to locate health services and the NAP, along with the Health Ministry, has to play the primary role in coordinating this strategic planning.

The following steps are suggested for planning clinical care and treatment services.

- Establishing a multisectoral planning group, with representatives from relevant public and private sectors and NGOs:
- Examining the available strategic information to determine the distribution of needs, geographically and across population groups.
- Obtaining additional data on the services needed and those currently in use, if necessary.
- Examining available models of decentralized clinical care and treatment and adapting these to the context.
- Determining the set of services to be made available at each level of the system, and the site for the delivery of these (primary health clinic, maternal and child health clinic, STI clinic, etc.).
- Identifying the financial and other resources required.
- Determining the training needs of health-care workers.
- Establishing systems for the development of support services procurement and supply of drugs and diagnostics, stock monitoring, patient data systems, standards of treatment and care.

The model proposed by WHO sets out packages of care and treatment at three levels.

Advanced package of services and activities	
Provincial or tertiary-level hospitals	
Advanced diagnostic services	
Management of complicated cases	
Specialized services and support	
Essential package of services and activities	
Day-care centres and basic hospital services	
Comprehensive services, including ART and coordination	
Peer support for PLHA	
Supportive package of services and activities	
Health centre, community and family	
Basic care	
ART adherence support	
•••	

#### **GUIDELINES AND STANDARDS FOR CARE AND TREATMENT**

Global and regional guidelines are available to assist programmes to set standards of care. WHO has recently published revised versions of the guidelines for the management of HIV infection and ART in infants and children, and adults and adolescents.

The NAP has a key role in coordinating the adaptation of these guidelines at the national level. This is generally done by bringing together clinicians, PLHA, procurement and supply managers, and national and provincial health officials, who examine the global and regional guidelines and adapt them to local needs and available resources.

In addition to treatment guidelines, universal infection control guidelines need to be adapted, disseminated widely and enforced. These measures minimize unnecessary isolation of PLHA, occupational exposure to HIV and the transmission of HIV from patient to patient (*see also* Submodule 6.6).

Once the guidelines have been adapted, they need to be widely circulated and made a part of in-service and tertiary health sector training. Evolving and implementing plans for the development of a health workforce are essential elements of maintaining standards of care.

#### PARTICULAR ISSUES INVOLVED IN SCALING UP OF ART

A well-coordinated ART access programme is now a central feature of any programme providing care, support and treatment as the consistent availability of ART significantly improves life expectancy and the quality of life of PLHA, and reduces the burden of HIV

on individuals, families and communities. It can also have a secondary impact on the prevention of HIV by providing hope and a sense of future for PLHA and hence encouraging people to learn about their HIV status to maximize their health and the health of others.

Many countries have a specific plan for the scaling up of ART, or have included it in their care, support and treatment plans. Providing consistent access to ART requires careful planning and coordination. The WHO ARV Scale-up Toolkit (2003) sets out the main elements required for the successful scaling up of ART. These are as follows.

- Counselling and testing services
- Trained personnel with sufficient knowledge of HIV prevention and care and ART.
- Basic medical services that are capable of identifying and treating common HIVrelated illnesses and OIs, providing OI prophylaxis, initiating and monitoring ARV care, and referring individuals to higher levels of care or into community- and homebased care services.
- **Reliable laboratory services** including referral for CD4+ T-lymphocyte counts, viral load estimations, and drug resistance tests to monitor therapy.
- Reliable, affordable and continuous supplies of quality ART and OIs medicines and other essential commodities.
- Support to PLHA for treatment preparedness and adherence
- Effective patient monitoring systems to improve the quality of care and reporting on outcomes.

#### **TREATMENT ADHERENCE**

Assisting PLHA to adhere to ART is an essential factor in ensuring the success of HIV treatment programmes. PLHA leave prescribing clinics with a one-month supply of ART. It is important that they receive the support they need between clinic visits to adhere to their treatment regimen, as interruptions in taking their treatment, or taking ineffective doses of treatment will lead to drug resistance, illness and death.

There are several ways in which the national programme can support this.

- Support the involvement of PLHA groups in treatment preparedness assist individuals and communities to understand ART and the strategies required to maximize the benefits of treatment.
- Ensure that clinical staff is trained to provide PLHA with counselling and information on adherence.

- Train and support PLHA and members of affected communities to be adherence counsellors in clinics and the community.
- Produce and disseminate easy-to-understand written information on adherence.

#### LINKS WITH THE TB PROGRAMME

TB remains the most significant OI for PLHA in Asia.

The NAP has a key role in strengthening collaboration between the HIV and TB programmes. This collaboration must be bidirectional – ensuring that people diagnosed with TB are offered HIV testing and that PLHA receive effective TB prophylaxis, diagnosis and treatment.

South-East Asia Regional Office has developed a Regional Strategic Plan on HIV and TB that provides clear information, recommendations for programming and indicators for measuring progress.

#### Strategies for improved prevention and management of HIV/TB

#### 1. Prevent HIV transmission through:

- (a) targeted interventions
- (b) the 100% Condom Use Programme
- (c) harm reduction among injecting drug users
- (d) management of STIs
- (e) scaling up of HIV voluntary counselling and testing (VCT)
- 2. Prevent progression of latent TB infection to active TB among people living with HIV by using:
  - (a) INH prevention therapy (IPT) to decrease progression from latent TB
  - (b) TB preventive therapy to decrease the risk of recurrent episodes after completion of treatment

#### 3. Decrease morbidity and mortality for people with HIV-related TB by:

- (a) implementing a comprehensive directly observed therapy, short-course (DOTS) strategy
- (b) expanding ART access to strengthen the immune systems of PLHA with evidence-based ART regimens for people with HIV/TB
- (c) providing comprehensive care and support for PLHA
- (d) increasing access to co-trimoxazole prophylaxis

#### 4. Strengthen the health system's response to HIV/TB by:

- (a) enhancing collaboration between HIV and TB programmes
- (b) advocating for political commitment to tackle HIV/TB
- (c) mobilizing resources
- (d) improving surveillance
- (e) building partnerships with communities, PLHA and NGOs
- (f) strengthening the health system's capacity to provide prevention, care and treatment services
- (g) establishing referral systems
- (h) ensuring accountability, monitoring and evaluation
- (i) conducting operational research

Source: Adapted from the SEA Regional Strategic Plan on HIV/TB, 2003.

Cooperation between the HIV and TB programmes is essential. TB services need to be encouraged to incorporate an assessment of HIV risk and an offer of HIV counselling and testing into their care of people newly diagnosed with TB. HIV services need to encourage TB prophylaxis for people with HIV and to have strong links with TB services so that people with HIV-related TB are effectively treated.

#### PREVENTION OF MOTHER-TO-CHILD TRANSMISSION

#### Key lesson

Providing early access to ART for women with HIV who are either contemplating pregnancy or are pregnant eliminates the need for specific PMTCT treatment and has the additional benefit of maximizing the health and well-being of the mother.

Effective PMTCT touches upon all areas – prevention, counselling, testing, care, support and treatment (for more details, see Submodule 6.5).

#### HOME-BASED AND COMMUNITY CARE

In many countries, during the early stages of the epidemic, PLHA spent much of their time in AIDS wards, being cared for until their death, often isolated from the family and community. As the health services became overburdened by increasing demand, effective models of home-based and community care were developed. This was also a response to the desire of PLHA to be cared for as close to the home and family as possible.

Many innovative models of home and community care have emerged as a result. One example from a district in Thailand shows that the quality of life of PLHA can be enhanced with care and support from the hospital and from the community. Multisectoral collaboration, including government sectors, NGOs, non-profit private organizations, religious organizations, PLHA groups and other community organizations, is essential to provide home and community care.

The following factors need to be considered when planning for home and community care.

- What are the resources for care that already exist in the community? Who in the community currently cares for the sick?
- Are there tolerant and caring people in the community who can be mobilized to participate in home and community care retired nurses, religious groups, NGOs?

- What would they need (training, supplies, additional funding) to incorporate the care of PLHA into what they do?
- What would families need in order to feel confident to provide home-based care training, medical/nursing back-up?
- Can marginalized communities be trained and used as a resource to provide care for their own community members with HIV (sex workers, IDUs, men who have sex with men, ethnic minorities)?
- What links can be developed between local health services and families or communities giving home- or community-based care?

Securing the resources for home and community care often involves carrying out a cost analysis that compares the cost of institutional care with the cost of supporting NGOs, local health services and communities to provide home and community care.

## **OBJECTIVE 5:** To assess the progress of national programmes towards meeting the needs of PLHA across the continuum of care

Effective HIV care, support and treatment programmes bring together all the elements discussed so far to ensure that PLHA receive the care they need, at the place and time that they need, throughout their lives. Gaps in the continuum of care result in unnecessary isolation, suffering and death, and in increased HIV transmission.

EXERCISE C

#### (Country group work followed by intercountry group discusion)

In this exercise, you will assess the strengths and weaknesses of some key aspects of your current care, support and treatment programme and set priorities for the future.

Take your time to work progressively through the table on the following pages in country groups. If you do not have accurate information on the reach or utilization of services, say what you do know, or make some sort of educated guess. The main aim of the table is to generate a discussion on what exists at the moment and what needs to be strengthened first.

Inform your facilitator when you are ready for intecountry group discussions.

Consistency and quality issues: - existence of guidelines, trainino, monitoring of compliance with guidelines ART access, monitoring progress, adherence to treatment and drug resistance drug resistance Consistent supply of ART and Consistent supply of ART and	Programme elements	What is the current situation?	How can this area be strengthened?
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	Consistent supply of ART and drugs for Ols		

Programme elements	What is the current situation?	How can this area be strengthened?
HIV support		
<ul> <li>PLHA groups/networks</li> </ul>		
– counselling		
<ul> <li>social support/welfare</li> </ul>		
– spiritual care		
Prevention incorporated into care		
Ensuring a skilled, motivated and available workforce		
Home and community care		

#### **RESOURCES**

- 1. http://www.who.int/hiv/pub/guidelines/adult/en/index.html.
- 2. http://www.who.int/hiv/pub/guidelines/art/en/index.html.
- 3. http://www.who.int/hiv/pub/guidelines/pmtct/en/index.html.
- 4. Montaner JAS, *et al.* The case for expanding access to HAART to curb the HIV epidemic. *Lancet* 2006;**368**:531–6.
- 5. *HIV/AIDS care and treatment a guide for implementation*. Manila, WHO WPRO, 2004.
- 6. *Community-based HIV/AIDS care: a successful model from Thailand*. AIDS Watch, WHO/SEARO, 2000.

#### **Models**

- 7. A public health approach to scaling up antiretroviral (ARV) treatment a toolkit for programme managers. Geneva, WHO, 2003.
- Care, involvement and action mobilizing and supporting community responses to HIV/AIDS care and support in developing countries. Brighton, UK, International AIDS Alliance, 2003.
- 9. Ensuring equitable access to ART for women. WHO/UNAIDS Policy Statement, 2004.
- Community engagement for antiretroviral treatment participatory tools and activities for civil society organizations working with people with HIV – trainers' manual. Brighton, UK, International AIDS Alliance, 2006.

#### Guidelines

- 11. Guidelines on co-trimoxazole prophylaxis for HIV-related infections among children, adolescents and adults in resource-limited settings – recommendations for a public health approach. Geneva, WHO, 2006.
- Antiretroviral therapy for HIV infection in adults and adolescents in resource-limited settings: towards universal access – recommendations for a public health approach. Geneva, WHO, 2006 (http://www.who.int/hiv/pub/guidelines/adult/en/index.html).
- 13. Antiretroviral drugs for treating pregnant women and preventing HIV in infants a public health approach (http://www.who.int/hiv/pub/guidelines/pmtct/en/index.html).
- 14. Antiretroviral therapy of infants and children in resource-poor settings towards universal access recommendations for a public health approach. WHO, 2006.
- 15. SEA Regional Strategic Plan for HIV and TB.

- 16. *Management of HIV infection and antiretroviral therapy in infants and children A clinical manual.* New Delhi, WHO Regional Office for South-East Asia, 2006.
- 17. Antiretrovirals for HIV: A compilation of facts and product information. New Delhi, WHO Regional Office for South-East Asia, 2006.
- 18. Management of HIV Infection and antiretroviral therapy in adults and adolescents A clinical manual. New Delhi, WHO Regional Office for South-East Asia, 2007.



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