Access to Information on HIV/AIDS through Libraries Workshop Manual







HIV/ADS Information Training

International Federation of Library Associations (IFLA)

Freedom of Access to Information and Freedom of Expression (FAIFE) Committee

Why a training manual for librarians on HIV/AIDS Information?

There is clear evidence on how to prevent the transmission of HIV. Nevertheless, in 2007 2.5 million people became newly infected. 2.1 million died of AIDS. To protect themselves and others people need appropriate means of prevention and medication. They need access to information, services and treatment. Despite the combined efforts of the international community to make universal access become reality in the hardest hit countries, less than half of youth can correctly identify modes of HIV transmission. Only one in four HIV positive individuals has access to treatment. Comprehensive action is urgently needed. Information is a key resource in fighting the pandemic: people need to know how to protect themselves, people need to know where to get means of prevention, such as condoms and clean needles, and people need to know how they can find out about their HIV status and where they can get treatment if they are diagnosed with HIV. Providing and disseminating information is what librarians throughout the world are good at. Librarians can thus make a difference in fighting the pandemic by taking a lead role at the community level to spread life saving information. This manual gives an overview of basic facts about HIV/AIDS and helps to develop culturally sensitive ways of disseminating information corresponding to a variety of settings with differences in availability of time, staff,

information material, and technical and general infrastructure. It also takes into account the different levels of information literacy of those who librarians are trying to reach out to.

Who developed the manual?

The manual was developed at an IFLA/FAIFE workshop that took place in June 2007 in Dubai, United Arab Emirates. Participants of the workshop represented a wide range of cultural backgrounds. The working group consisted of librarians and experts in information science from India, Brazil, South Africa, Japan, USA, Uganda, UK, Mexico, United Arab Emirates and Germany.

How to use the manual?

The manual outlines a one day workshop for a group of 10 to 20 participants working in libraries or in other professions dealing with the provision of information. The workshop facilitator does not need to be an expert in HIV/ AIDS but should be familiar with the work of librarians. The kit includes short descriptions of each of the workshop sessions, PowerPoint slides that give an overview of the global dimension of the pandemic and general information about HIV and AIDS, slides that lead through the workshop, and a section that provides an overview of HIV/AIDS publications and further sources of information. At the beginning of each section there is a short note to the facilitator that informs about the purpose of the session and the preparation that is needed.

Preparation for the day

What is needed?

- A blackboard or a flip chart
- A laptop and a projector for a PowerPoint presentation (if available)
- If there is no laptop and projector available, it is recommended to print out some of the PowerPoint slides and some examples of HIV/ AIDS information material for the interactive session in the afternoon
 Video and audio material can be used if the necessary devices
- are available
- Paper for the participants to write on
- Print-outs of the HIV/AIDS quiz for each participant and of the ILO code of practice

What the facilitator needs to prepare:

The manual is self-explanatory. The facilitator should read through it carefully and have a look at the PowerPoint slides and the additional information in the annex. To adapt the manual to the local context, three workshop sessions need special preparation in advance.

 Ice breaker exercise: collection of (anonymous) personal information
 Local partners: the facilitator should collect information about local institutions and potential partners – preparation of a list for the participants
 Information literacy: choose some examples from the information material for the session on information literacy

A Day – Schedule (7.5 – 8 hours)

Morning (3 – 3.5 hours)

Introduction

Ice breaker exercise

Overview of HIV/AIDS

Coffee break

Prevention and treatment

Lunch (1.5 hours)

Afternoon (3 hours)

Interactive exercise / Barriers to information provision

Coffee break

Interactive exercise / Information literacy

Closing remarks

This seven and a half to eight hours schedule gives room to touch upon important aspects of HIV/AIDS information and leaves sufficient time for discussion of local settings andcultural barriers. However it follows a fairly strict time regime and if more time is available the schedule can be extended to a two to three days workshop.

Introduction (30 minutes)

Note to the facilitator: The introduction session serves to familiarize participants with the workshop setting and explain the purpose of the workshop. The participants learn what FAIFE is and how it works. The session also aims at personalizing the topic of HIV/AIDS through talking about the participants' personal experience and specific workplace situations.

1. House keeping

Information for participants about bathrooms, emergency procedures, etc – (depending on circumstances)

2. This is a FAIFE workshop. FAIFE is... (PowerPoint slide available)

IFLA/FAIFE was founded in Copenhagen in 1998. It is an initiative within IFLA (International Federation of Library Association and Institutions) to defend and promote the basic human rights defined in Article 19 of the United Nations Universal Declaration of Human Rights.The IFLA/FAIFE Committee and Office furthers free access to information and freedom of expression in all aspects, directly or indirectly, related to libraries andlibrarianship. IFLA/ FAIFE monitors the state of intellectual freedom within the library community world-wide, supports IFLA policy development and co-operation with other international human rights organisations, and responds to violations of free access to information and freedom of expression.Intellectual freedom is the right of every individual to both hold and express opinions and to seek and receive information. Intellectual freedom is the basis of democracy. Intellectual freedom is the core of the library concept.

IFLA/FAIFE is funded by the Swedish International Development Co-operation Agency (SIDA).

3. Purpose of the workshop

People have a right to know, especially when their own well-being and future depends on crucial information. In the case of HIV and AIDS, information becomes a live saving resource.

To prevent the transmission of HIV and help those who are already infected, a comprehensive approach and a supportive environment is key. That means people need:

- 1. Access to information about prevention and treatment
- 2. Access to sexual and reproductive health services,
- as sexual intercourse remains the main mode of transmission
- 3. Access to means of prevention such as condoms and clean needles
- 4. Access to treatment

Information, Education and Communication (IEC) are primary tools in fighting HIV and AIDS. Libraries can provide life saving information on the community level. It is thus a professional duty of librarians to offer appropriate information for those in need.

The morning part of the workshop aims at informing **librarians about the pandemic**, its global dimension and possibilities of prevention and treatment. HIV/AIDS information is a highly culturally sensitive issue. As sexual intercourse remains the most common mode of transmission, it is closely linked to sexual and reproductive health information and sex education. In many societies these topics go together with stigma and taboo. More than in most other fields of communication, effective dissemination depends on cultural settings, local resources, such as staffing and availability of media, and the information literacy of readers.

Circumstances vary from country to country and from library to library. The afternoon part of the workshop therefore aims at developing **locally adapt-able concepts of dissemination to deal with cultural (and other)** barriers and reach out to those who are most vulnerable, such as illiterate people and young women and girls.

4. Values and goals

While the dissemination of HIV/AIDS information depends on cultural and local settings, the right to receive such information is universal. It is included in article 19 of the United Nations Universal Declaration of Human Rights. Provision of HIV/AIDS information is thus not a question of charity, but a duty of humanity.

Article 19, United Nations Universal Declaration of Human Rights Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

At the United Nations' Millennium Summit in September 2000, 189 nations agreed upon the Millennium Development Declaration. The declaration presents eight Millennium Development Goals (MDGs) targeted for the year 2015 aiming at reducing extreme poverty and fostering human development:

Goal 1: Eradicate extreme poverty and hunger Goal 2: Achieve universal primary education Goal 3: Promote gender equality and empower women Goal 4: Reduce child mortality Goal 5: Improve maternal health Goal 6: Combat HIV/AIDS, malaria and other diseases Goal 7: Ensure environmental sustainability Goal 8: Develop a Global Partnership for Development

MDG 6 directly addresses the pandemic. Several other goals aim at improving living conditions that will also benefit the health situation. For example if a child attends primary school they have a much better chance to learn about HIV/AIDS and how to protect itself. If maternal health is improved motherto-child transmission during pregnancy is likely to be avoided. Each of these goals breaks down to specific targets that are supposed to be met by 2015.

The HIV/AIDS related target for MDG 6 is to halt and begin to reverse the spread of HIV/AIDS. Specific indicators were formulated to evaluate the international efforts in combating the pandemic.

These are the following:

HIV prevalence Among 15-24 year-old Pregnant Women (UNAIDS)
The condom use rate of the contraceptive prevalence rate and population aged 15-24 years with comprehensive correct knowledge of HIV/AIDS (UNAIDS, UNICEF, UN Population Division, WHO)
The ratio of school attendance of orphans to school attendance of non-orphans aged 10-14 years

5. Ethic Statements

Keeping in mind gender inequalities

Women and girls are among the most vulnerable to transmission through sexual intercourse. Added risk for young women is created through gender inequalities and practices like early marriage, sexual violence. Older men often search for younger 'HIV-free' partners. Young women married to older partners are many times not in a position to negotiate condom use if they fear that their partner is not being faithful or has been infected. Improving the situation of women and girls requires behavioural changes among women and men, and boys and girls. Empowerment of women needs to go hand in hand with programmes and campaigns that encourage men to assume their responsibility with regards to their partners and themselves.

The vulnerability of women and girls and discrimination against them has to be kept in mind when providing HIV/AIDS information through libraries. A careful analysis of the given situation should include questions such as the following: Is the library a safe place for girls to go to? Are girls able to visit the library? Is there a place where they can read or learn about HIV without having to be afraid of stigmatization?

Keeping in mind cultural differences and practices.

Information dissemination is not achieved by simply putting a book on the shelf. It requires a careful analysis of the cultural setting and practices. In societies where people are used to speaking openly about sex and already attend sex education in primary schools not much heroism is needed to spread the knowledge about effective means of prevention. In many countries most affected by the pandemic, however, talking about sexuality in public remains a taboo. In these societies librarians will have to carefully examine what is the best mixture of privacy on the one hand and accessibility of information on the other. Obviously there is not one single solution to this problem. To really make a difference in the fight against HIV and AIDS librarians in many societies will have to become advocates themselves. This manual also tries to point out ways of overcoming librarians' own discomfort in dealing with or discussing intimate and sexual matters with users. Especially in the developing world, innovative and creative ideas will be needed. Storytelling, drama, role play and music are in many societies much more effective ways of reaching people than the provision of written material. Finally, the concept of what a library is varies from country to country. The traditional image of an old building full of books where people go to read might not be suitable for many contexts. Also in the developing world there are many places where one will find librarians but no libraries. Whatever the given conditions are FAIFE calls for proactive librarianship that tries to reach out to as many people as possible. This is the only way how we can make a difference in the fight against HIV and AIDS.

Ice breaker exercise (30 minutes)

What is an ice breaker?

Ice breakers are activities undertaken at the beginning of an exercise to make people feel at ease.

Note to the facilitator: Chose an ice breaker exercise that corresponds to the given setting. What makes people feel at ease or raises their interest

in the workshop's topic very much depends on culture and country background, but also on the size of the group. In countries with high infection and prevalence rates, where HIV and AIDS are present in every day live, there might be a big need to talk about personal experiences. On the other hand, participants who have lost friends and family members to the pandemic will probably find it painful to talk about these losses. Also, in cultural settings where sexual matters are a taboo, a more energizing activity might be helpful to make people feel more comfortable.

1. HIV and the workplace – personalizing the pandemic

Note to the facilitator: The suggested ice breaker exercise aims at personalizing the topic and breaking it down from an abstract level to the individual life and work situation of the workshop participants. If you had a chance to collect anonymous information about the participants' knowledge and personal concerns in advance, use this information to give an introduction to the exercise.

The following question should be addressed in the icebreaker exercise:

- Do you know how many people in your workplace are infected with HIV?
- What are your organization's/company's policies regarding HIV/AIDS?
- What happens if you become HIV+ yourself?
- Do you know somebody who is HIV+?

2. Make it interactive (for other ice breaker options)

Depending on the size of the group and cultural practices this exercise can bem carried out in group work, with partners or as individuals. Suggested activities to choose from:

- Story telling
- Drama
- Video
- Role play

• Buzz groups (with four to five members): tell each other about people you know about HIV/AIDS and people you know who are HIV+ (dissemination, support, stigma, dignity embarrassment, treatment, etc.)

Overview of HIV/AIDS (30 minutes)

Note to the facilitator: Use the PowerPoint slides that come with the manual or download he newest version from the UNAIDS website (<u>www.unaids.</u> <u>org</u>). In case that there is no projector available pass them around as print outs or write some of the numbers on a blackboard.

Part 4: Participants should fill out the HIV/AIDS quiz before learning about modes of transmission, prevention and treatment.

1. Global dimensions of the pandemic

Every year UNAIDS publishes an "Epidemic update" with the latest global estimates of people living with HIV/AIDS, new infections in the last year, the number of deaths due to AIDS and the number of children living with HIV. The update also informs about regional distributions of the pandemic.

The 2007 slides can be found at: <u>http://data.unaids.org/pub/</u> EPISlides/2007/071118 epicore2007_slides_en.pdf

2. What is HIV/AIDS?

Most people have heard of HIV and know that it is a dangerous virus and that AIDS is a deadly disease. Many people however don't know much about what HIV does to the human body, how HIV relates to AIDS and how the virus is transmitted. This knowledge is crucial to understanding prevention efforts and avoiding stigmatization of people living with HIV/AIDS.

What does it mean? (Available as Power Point slide): HIV – Human immunodeficiency virus AIDS – Acquired immune deficiency syndrome

What does it do to the human body?

HIV attacks the immune system's protective CD4 cells. A person that is HIV+ is less able to fight off infection and can develop serious so called opportunistic infections (OIs).

Does somebody who is HIV+ have AIDS?

No, a person is diagnosed with AIDS when there are less than 200 CD4 cells and/or has one of 21 AIDS-defining OIs. People can be infected for years without AIDS breaking out.

If left untreated, HIV will almost always deplete the immune system. This leaves the body vulnerable to one or more life-threatening diseases that normally do not affect healthy people. This stage of HIV infection is called

AIDS, or acquired immunodeficiency syndrome. The more the immune system has been damaged, the greater the risk of death from opportunistic infections.

3. Symptoms of HIV and AIDS

Question to the participants: How can you tell if a person is HIV positive or has AIDS? The answer is that there is no easy way to tell. A person that is HIV positive can carry the virus for years without noticing any symptoms. The only way to tell whether a person has become infected is through a blood test. HIV attacks the human immune system and a person thus becomes more vulnerable to opportunistic infections and cancer that the immune system would normally prevent. Opportunistic infections are infections that can occur in almost all parts of the body system. Without treatment, HIV generally takes 8 to 10 years to progress to AIDS. The length of the period between infection and the development of systems depends on given circumstances. The weaker the immune system gets the more symptoms appear.

4. How is HIV transmitted?

Modes of transmission: Only precise and evidence based information can help to fight superstition and stigma and explain how effective prevention works. The fact that HIV is closely linked to sexuality makes open discussion about modes of transmission and means of prevention a difficult task in many cultures. If a person is HIV positive and not taking appropriate medication, the virus is highly concentrated in body fluids such as blood, seamen, the vaginal flora and breast milk. Transmission is possible, when one of these body fluids of an infected person enters the body of another person through open wounds or mucous membranes.

A quiz: There are many myths about the transmission of HIV. Even the participants of the workshop will probably not be able to correctly identify all modes of transmission. Use the quiz on HIV transmission knowledge that can be found in the annex of this manual to make the session interactive and to give participants the chance to test their knowledge about HIV. The quiz should be distributed and filled out before presenting the following information.

Note to the facilitator: The purpose of this exercise is not to make participants feel uncomfortable and have them present the results of the quiz to the whole group. Every participant should keep his/her paper and compare the answers with theinformation presented by the workshop facilitator.

1. Transmission through sexual intercourse

Unprotected sexual intercourse with one of the partners being HIV positive is the main mode of transmitting HIV. Oral sex is much less likely than vaginal or anal intercourse to result in the transmission of HIV. Girls andwomen are disproportionately vulnerable to HIV due to their physiological susceptibility which is at least 2 to 4 times greater than men's and gender inequality and discrimination.

Sexually transmitted infections(STIs)

Apart from HIV/AIDS there are severalother sexually transmissible infections for example the human papillomavirus (HPV) that can cause cervical cancer.

2. Blood and blood products

Apart from sexual intercourse HIV can be transmitted through exposure to HIV infected blood. Infection occurs when infected blood is introduced to a person's blood stream through open wounds or injection. Most at risk are injecting drug users who lack clean needles and therefore reuse needles of others. Also patients depending on blood transfusions in emergency settings or due to haemophilia run a risk of infection if blood products are not sufficiently screened and controlled.

3. Vertical transmission – mother-to-child-transmission

Another mode of transmission is the so called mother-to-child-transmission or vertical transmission. Without treatment and appropriate medical intervention HIV positive mothers are likely to pass on the virus to their children during **pregnancy**, **birth and through breastfeeding**. Withouttreatment, around 15-30% of babies born to HIV positive women will become infected with HIV during pregnancy and delivery. A further 5-20% will become infected through breastfeeding. With correct medication and medical support the risk of transmission can be greatly reduced.

Myths about the transmission of HIV (can be collected at the blackboard):

- HIV is transmitted through mosquito bites
- HIV is transmitted through drinking from
- the same cup or using the same toothbrush
- HIV is transmitted through shaking hands with an infected person
- HIV is transmitted through kissing

A very low concentration can be found in other body liquids, such as saliva, urine and tears. These liquids do not pose a risk of infection.

Question to the workshop participants: Can HIV be transmitted through oral sex?

Answer: Oral sex is a relatively low risk behaviour. Still there is the possible to contract HIV by having oral sex with an infected person, particularly where there is broken tissue or sores in the mouth of the person performing oral sex. HIV infectionthrough oral sex alone, however, seems to be very rare.

Coffee break (10 minutes)

Prevention and treatment (1.5 hours)

1. The role of libraries?

"Library and information services cannot sit on the fenc when their nations' young people are being decimated by the enemy from within who strikes silently and in darkness." [Kingo J. Mchambu 2002]

Information, education and communication (IEC) are a primary means of fighting HIV/AIDS. Libraries can provide access to important information and spread knowledge on prevention and treatment.

2. Reaching out to the most vulnerable

Vulnerable sections of the population, such as the poor, women and girls, orphans, youths (15-24 years), homosexuals, migrants, refugees, and commercial sex workers often lack access to libraries and important information. Active librarianship is thus necessary to reach out to populations in high risk situations.

Prevention

1. Why focus on prevention?

There is no vaccine for HIV/AIDS. As treatment still remains unaffordable or inaccessible for many people in the world, for now, prevention is the best approach to fight the pandemic.



2. Prevent sexual transmission: The ABC Approach

The ABC-Approach recommends three behavioural rules to prevent infection through sexual intercourse:

The ABC-Approach to prevent sexual transmission of HIV Abstain Be faithful Use a Condom

A. Abstinence

HIV is mainly transmitted through sexual intercourse. Technically, the most effective way to prevent infection is therefore to abstain from any sexual activity that includes contact with other persons' body fluids. Abstinence can mean to delay the onset of sexual activity or to refrain from having sex if already sexually active.

B. Be faithful

To refrain from sexual activity is not an option for many people. As the number of sexual partners increases the risk of infection, the second behavioural rule suggests to stick to one partner and be faithful if abstinence is not possible. If both partners have been tested negatively and are faithful to each other, infection through sexual intercourse is unlikely. Faithfulness, however, depends on the commitment of both partners and thus is not without risk. Many people have becoming infected through their partners cheating on them.

C. Use a condom

Finally, if one has more than one sexual partner, changes partners frequently or has doubt about the faithfulness of his/her partner the use of a male latex condom or the female condom provides the best protection from sexual transmission.

What is a female condom? Whereas the male condom is placed on the penis, the female condom is positioned inside the vagina. The condom can be inserted into the vagina several hours before sex, and both oil-based and water-based lubricants can be used. By removing the inner ring in the female condom, one may also use the product for anal intercourse.

Question to the workshop participants: Can you imagine a situation where ABC is not an effective approach to sexual transmission of HIV?

Limits of the ABC-Approach:

ABC is an effective means of prevention under certain conditions. There are circumstances, however, in which ABC does not work. The approach presupposes that one can choose his/her sexual partners; he/she can trust in the faithfulness of his/her partner; the necessary resources, such as condoms, are available; and the person is in the position to negotiate condom use. Young women married to older men are at risk if their partners have engaged with other sexual partners before or they have doubts about their partner's faithfulness. For these girls it might not be possible to negotiate condom use as their partners would probably see it as a proof of mistrust or blame them of not being faithful themselves. Also, women and girls in particular are many times exposed to sexual repression and violence and cannot make free and deliberate choices about sexual partners and condom use. The female condom is one possibility for women and girls in high risk situations to protect themselves.

3. Avoid exposure to HIV infected blood

A. Blood Supplies

Screening of blood products reduces the risk of transmission as units of blood that are found to be infected are removed from the blood supply. Unfortunately blood screening doesn't take place in all parts of the world.

B. Accidents

The strategy of universal precautions assumes that everybody's blood is potentially infectious with HIV. No blood exposure is regarded safe. First-aid kits usually include latex gloves that should be worn when touching another person's blood or open wounds.

C. Injections and syringes

A needle or syringe used for injection should never be shared with others. A fresh device should be used for each patient. In emergency settings with no access to sterile equipment, the risk of transmission can be reduced by boiling previously-used needles and syringes or washing them more than three times with full strength household bleach and rinsing them repeatedly with water. This measure cannot be regarded as safe and should only be used as a last resort.

Intravenous drug use with contaminated needles accounts for the secondmost important mode of transmission after sexual intercourse. Needle/ syringe-exchange programmes for intravenous drug users that offer sterile equipment reduce the risk of infection.

4. Prevent mother-to-child-transmission

To effectively prevent the transmission of HIV from a pregnant mother to her unborn baby a threefold strategy is recommended:

- Preventing HIV infection among prospective parents
- Avoiding unwanted pregnancies among HIV positive women

• Preventing the transmission of HIV from HIV positive mothers to their infants during pregnancy, labour, delivery and breastfeeding

Prevention of transmission during pregnancy, labour, delivery and breastfeeding is possible through treatment which will be explained later on.

5. Conditions conducive to risk behaviour

Consumption of alcohol and drugs

Consuming alcohol and drugs makes people less precautious and is often conducive to risky behaviour, such as unprotected sexual intercourse.

Humanitarian Settings

HIV spreads faster in situations of social disruption and instability. Violent conflicts, natural disasters or the displacement of people increase the risk of transmission. Emergency settings often lack even basic infrastructure, means of prevention or established channels of information dissemination. Situations of extreme stress are also conducive to risk behaviour.

Poverty

People living in extreme poverty usually lack access to information on means of prevention, such as condoms or sterile needles and services. They are often not in a position to make deliberate and informed choices to protect themselves.

6. Voluntary Counselling and Testing (VCT)

Why should I get tested?

In a world with HIV everybody should know his/her status to protect themselves and others. It is not possible to tell from any symptoms whether someone is HIV positive. An HIV antibody test is the only way to know for sure. Most people who have been tested have been worrying unnecessarily. Still, voluntary testing and counselling is recommendable to everybody as early discovery of an HIV infection offers the possibility of timely and adequate medical treatment and helps to protect others from transmission.

How does the test work?

Normally a small sample of blood is taking from the patient's arm, sent to a laboratory and tested. The standard HIV test looks for antibodies in a person's blood. A standard antibody test is at least 99.5 % accurate if antibodies can be found. Most people who have been infected develop detectable HIV antibodies within 6 to 12 weeks. Transmission to others is already possible within in the 6 to 12 weeks period even if antibodies are not yet detectable. A positive test result should be confirmed by a second test.

Where to get tested?

It is recommendable to get tested at a health clinic, at a doctor's surgery, or at a specialist HIV/AIDS voluntary counselling and testing (VCT) site. Medical staff or a professional counsellor will explain how the test works and what the results mean. If results are positive, they can support the patient in coping with the result and give information about treatment and living with HIV.

Voluntary testing vs. Mandatory testing

Mandatory testing means that testing is compulsory and people do not have a choice about whether to get tested or not. As mandatory testing conflicts with the right of self-determination, voluntary testing should be promoted. Voluntary testing means that the patient decides whether he/she wants to know his/ her status or not.

Confidential testing and Anonymous testing

Confidential testing means that the patient leaves his name, age and address when getting tested and that this information is only passed on to clinic staff involved in the testing process and in some cases to specific public health officials. If a patient prefers not to provide this information, he/ she can either leave false contact details – which might make it difficult to inform the person about test results – or ask for anonymous testing. If anonymous testing is requested, the patient will be identifiedonly through a code number.

Home sampling and testing

In some countries it is also possible to use an HIV sampling kit or an HIV testing kit at home. In the first case a sample of blood is sent to a laboratory and a special number can be called to find out about the result. In the second case the entire test is done at home. Both home sampling and home testing lack the presence of an expert to ensure that the test is done correctly. Another disadvantage is that the patient is alone when learning about the result and can't be supported by a professional counsellor. Sampling and testing at home are therefore only recommendable if there is reasonable doubt about confidentiality of medical sites and high probability of stigma and discrimination.

Treatment

People who have been infected with HIV are likely to become sick with AIDS within a short period of time. There is no cure or vaccine for HIV and AIDS, but antiretroviral drug (ARV) therapy can prolonger their lives for years and also fight symptoms and opportunistic infections (OIs). The international community has targeted universal access to HIV/AIDS treatment for 2010. Significant progress towards this goal has been made in recent years. Still, at the end of 2006 only one in four HIV positive people in low and middle income had access to ARVs. Scaling up the availability and accessibility of treatment in thedevelopment world remains one of the most urgent challenges in combating the pandemic.

1. Antiretroviral drugs (ARVs)

Antiretroviral therapy is the main way of treating HIV and AIDS and consists of a combination of drugs that people who have been diagnosed HIV positive have to take every day for the rest of their lives. HIV replicates itself in the cells of the human body and with these copies it infects other healthy cells and spreads out to the rest of the body. ARVs slow down this process of replication. Patients have to take a combination of drugs because the virus often mutates in the replication process and becomes resistant to one of the drugs.

2. Prevent and treat Opportunistic Infections (OIs)

In addition to treatment for HIV infection itself, therapies exist to prevent and/or treat many HIV-related opportunistic infections.

3. Prevent mother-to-child-transmission

• During pregnancy and delivery

In general the combination of antiretroviral drugs that an HIV positive woman is taking for her own health is also highly effective at preventing motherto-child transmission. The newborn babies will usually receive treatment for the first fewdays or weeks of life to lower the risk even further.

• Safer infant feeding

There is evidence that breastfeeding by an HIV positive mother diminishes the positive effects of treatment for the baby. HIV positive mothers are therefore advised not to breastfeed. However, the decision about whether to breastfeed or not depends on the availability of substitutes. In many countries, substitutes are not safe because there is no clean water available. Careful counselling is necessary to inform HIV positive mothers about risks and help them find the most suitable option.

4. Access to services and availability of drugs

The success of treatment depends on the availability of health services and the availability and affordability of drugs. Access to ARVs and treatment for OIs varies from country to country. The World Health Organization (WHO) defines three dimensions of access:

A. Availability:

- Reach-ability in the sense of physical access
- Affordability which describes economic access
- Acceptability, referring to socio-cultural access

B. Coverage:

- The proportion of a population needing an intervention who receives it
- Coverage depends on supply and demand

C. Impact

• Defined as reduced new infection rates or as improvements in survival

5. Institutions (hospitals, clinics, VCT centres)

To avoid resistance and effectively fight OIs and side effects, antiretroviral therapies require professional support and counselling through health care centres. Libraries can provide information about local facilities and access to therapy.

6. Conditions to support treatment

The success of treatment depends to a large extent on the degree to which the patient follows the medical prescriptions. Many HIV patients decrease the effect of the drugs by not taking them properly. It is thus recommendable to develop a personal "medication-adherence plan" to ensure that drugs are taken regularly and in the right combination.



7. Living positively

For people who are HIV positive it is important to maintain their physical and emotional health. For many it is helpful to get in touch with other people who are HIV positive to share experiences. Healthy nutrition and exercise is important for everybody but even more for those who are HIV positive. It is recommended to:

- Adopt a healthy diet
- Exercise regularly
- Avoid alcohol and tobacco, or certainly minimise their consumption
- Reduce stress
- Avoid all forms of infection (when possible) because they may compromise health and further weaken the immune system

• Don't use drugs other than those prescribed by a doctor• Visit a doctor regularly

Lunch (1.5 hours)

Barriers to Information Provision – Interactive exercise (1 hour)

Note to the facilitator: Blackboard or flip chart needed

The morning part of the workshop is dedicated to learning the basic facts about HIV and AIDS. The afternoon part focuses on effective librarianship and tries to identify the best way of information dissemination at the local setting. HIV/AIDS information is much more culturally sensitive than most other technical information and even more than most health information. In liberal societies it might be fine to show a prevention video with a kissing couple or gay men holding hands, in other places this might keep parents from showing the clip to their children. Because of its close thematic link to the sex education taboo, stigma and cultural or religious practices often hinder effective dissemination of information. In some countries effective dissemination is put in place by setting up an HIV/AIDS information corner in libraries. In other countries users would fear being associated with HIV/ AIDS and stigmatized when others see them looking at the material. But cultural barriers may not be the only obstacles to information dissemination.

The participants of the workshop themselves know best what are the crucial barriers when trying to reach out to the local users. The first session of the



afternoon part is therefore envisaged as an interactive exercise. Depending on the number of workshop participants, this exercise can be carried out in groups of about four people. Participants are asked to think of and write down barriers that they expect to face in disseminating information on HIV and AIDS.

After 30 minutes the result of the group work will be presented and collected on theblackboard/flip chart and clustered among the following categories:

- Cultural barriers
- Political barriers
- Economic barriers
- Resource barriers

Examples of barriers:

Cultural barriers (prepare specific examples from different cultures)

• **Taboo** – existing cultural taboos about sexuality and modes of HIV transmission create difficulties in openly discussing prevention and treatment

• **Stigma** – refers to the devaluation of people either living with HIV/AIDS or associated with HIV/AIDS. Stigma in many cases is followed by discrimination (UNAIDS)

• **Discrimination** – is the unfair or unjust treatment of individuals based on their real or perceived HIV status (UNAIDS)

• Attitudes towards homosexuality – in many societies homosexuals are stigmatized, discriminated and oppressed. Negative attitudes towards homosexuality detain many people from speaking openly about their sexual preferences

• **Status of women in society** – women and girls are among the most vulnerable to HIV/AIDS. Gender inequalities and discrimination are often obstacles to women's access to information, means of prevention, services and treatment

• **Religious views** – can constitute cultural barriers e.g. if they contribute to stigmatization, support traditional gender inequalities or condemn condom use



• Superstition and myths – can lead to risk behaviour and stigma

• **Cultural traditions** – any cultural tradition that contributes to risk behaviour, stigma and discrimination or gender inequalities constitutes a barrier to effective dissemination of HIV/AIDS information

Political barriers

• Lack of policies – the fight against HIV/AIDS requires an effective policy framework on a national and organizational level. Libraries for example should have clear policies for HIV/AIDS information dissemination and policies to protect HIV positive employees and users from discrimination.

• National policies – can be a barrier if they discriminate against people living with HIV, women or homosexuals

• **Oppression** – of people living with HIV/AIDS and HIV/AIDS advocates

• **Ideology** – political ideology is often the reason for a lack of policies, unjust policies, discrimination and persecution

• **Wording/rhetoric** – public speech by political leaders can discredit people living with HIV/AIDS or institutions advocating against the pandemic

• Lack of integration of HIV/AIDS policies within other policies – effective prevention and treatment is only possible if HIV/AIDS policies are linked to otherpolicy areas, such as sex education and public health services

• Lack of tolerance, diversity, openness – often one of the main obstacles to effective HIV/AIDS policy planning

• **Censorship** – official censorship and manipulation of information constitutes a barrier to effective dissemination of information

Economic Barriers

For users

• Access costs – for people living in remote areas it may not be affordable to come to the library because of:

• Travel expenses

• Loan costs – as they can not work in the time they come to the library/ training



 Opportunity costs – for example, taking care of children and other family members

• **Technology costs** – if HIV/AIDS information is provided through information and communication technology the availability of

• Electricity, bandwidth and suitable hardware and software is crucial

For the library

• Labour costs – loan that is paid to librarians

• **Cost of information materials** – a lot of material is available for free. Specific information and information in a local language might be a cost factor

• Maintenance – information has to be regularly renewed and updated

• **Training costs** – to inform employees about HIV/AIDS and keep them updated

• **Technology costs** – information and communication technologies can be a helpful tool in dissemination of information.

• Electricity, bandwidth and suitable hardware and software needs to be available at the library

• Skilled technicians are needed to maintain the system

• **Travel expenses** – if librarians try to reach out to people who can not come to the library themselves

Resource Barriers (quality, effectiveness of materials)

• **Language** – availability of material in local languages is crucial as the most vulnerable populations often do not speak other languages

 Format – the format should correspond to the information literacy of readers

• **Bias** – the resources should be evidence based



• **Publishing problems (local, regional, etc.)** – lack of resources and infrastructure or political censorship can lead to problems in publishing information

• **Hours of operation** – should address access problems of the most vulnerable. If the library only opens during the day, working people might have difficulties to come there. If it only opens in the evening, young women are unlikely to visit the library.

After listing potential barriers to effective information dissemination there should be some time left for open discussion about how to address these barriers and how to find solutions with given resources.

Coffee Break (10 minutes)

Information Literacy – Understanding/interpreting information (1 hour)

Apart from the barriers identified in the last session effective information dissemination to a large extent depends on the information literacy of those that should be reached. Information literacy again is highly culturally dependent. The message of an HIV/AIDS poster might be perfectly understandable in one context but cryptic in another. To do a successful job, librarians have to carefully analyze their users' skills to interpret andevaluate information.

Interactive Exercise:

Note to the facilitator: In the annex of this manual you will find a selection of HIV/AIDS information posters, pamphlets, videos etc. that can be downloaded from the Internet. A sample of this material should be presented to the workshop participants.

To actively engage with the material the participants should discuss the following questions:

- What is the main message of the material?
- How does the message relate to HIV/AIDS?
- Would the message be understood in

the local cultural context? If no, why not?

- What kind of reactions to the material can be expected?
- Would the message influence people's behaviour?
- Is the message of the material discriminating?
- Could this material be used in a library? If no, why not?
- How could the material be improved/adjusted to the local context?

Note to the facilitator: Collect the key points of the discussion and critique at the blackboard/flip chart and present a summary at the end of the session.



Policies and Partnerships (50 minutes)

Development of policies regarding HIV/AIDS

Note to the facilitator: If you decided to do the workshop in one day, there will not be much time for discussion left. If you have a broader time frame, use the code of practice of the International Labour Organization (ILO) (page 25) to discuss policies. If there is no time left, only hand out the ILO key principles and make some remarks about the necessity of policies.

To fight stigma and discrimination and ensure effective dissemination of information, each library should develop a policy framework regarding HIV/ AIDS. This policy should address the following aspects:

- Rights and workplace situation of employees living with HIV/AIDS
- Users that are HIV positive/have AIDS
- Way of presenting HIV/AIDS material
- corresponding to information literacy of users

• Way of addressing information barriers and reaching out to vulnerable populations

Partnerships

Note to the facilitator: Hand out the previously prepared sheet with information about local institutions and partners to the participants. Maybe the participants know institutions or potential partners you have not thought of. Add their ideas to the sheet and provide an updated version of the list to all participants after the workshop.

Why is it important to build partnerships with local leaders and institutions?

- Gain better understanding of local situation
- Possibilities of information dissemination through others
- Openly address stigma and discrimination
- Receiving financial and community support
- Avoid duplication

Local facilitators complete a form with a list of categories they fill in. List categories:

- Schools and education
- Media
- NGOs
- Community Leaders
- Faith-based organizations
- Community-based organizations
- Government organizations



- Advocacy groups
- International organizations
- Charities
- Grant-giving organizations

Concluding remarks

Annex

• Anonymous information about the participants that can be used for the ice breaker. The questions should be sent out to the participants in advance (when signing up for the workshop) and the others need to be collected before starting the workshop.

• Two more options for the ice breaker to choose from – if none of these fits the local context, other activities can be included to familiarize the participants with the topic of HIV/AIDS and make them feel comfortable.

• The HIV/AIDS quiz should be filled out by the participants before learning aboutmodes of transmission of HIV.

• Internet sources with HIV/AIDS information material that can be used for theinteractive session on information literacy

- ILO code
- Internet sources and further readings about HIV/AIDS



Questionnaire for participants (collected anonymously)

Only answer the questions you fill comfortable with.

Do you know somebody who is HIV+?

Yes / No

Do you know your HIV status?

Yes / No

Have you ever been tested for HIV antibodies?

Yes / No

Do you know how many people in your workplace are infected with HIV?

Yes / No

What are your organization's/company's policies regarding HIV/AIDS?

Yes / No

What happens if you become HIV+ yourself?

• I would loose my job.

Yes / No

• I wouldn't tell anybody.

Yes / No

• My friends and family would support me?

Yes / No



Ice breaker exercises

Note to the facilitator: It is important to choose an icebreaker exercise that fits the local context. You can also work with other activities such as drama, storytelling or group work or show a video if the group is very big.

1. Word tree

Generate a list of words related to HIV/AIDS for example gloves, body fluids and pregnancy, work place. Ask participants what comes to their minds when they think of them in the context of HIV and AIDS. Collect their contributions on the black board and try to group and interlink them. This ice breaker also offers the possibility to introduce important terms.

2. Create HIV prevention messages and posters

The workshop is about HIV/AIDS information dissemination through libraries. Ask participants to sit together in groups of four or six. Hand out big sheets of paper and text markers. Each group has 10 minutes time to think of an effective HIV prevention message and the design of a poster that should illustrate this message. Use the remaining 20 minutes to have the groups presenting their poster and discuss about in the big group.



Quiz on HIV transmission

Don't worry: the results of this quiz will not be presented to the whole group. It only gives you a chance to check your own knowledge before learning more about HIV.

Correct /Wrong

It is possible to contract HIV through...

Kissing

Drinking from the same cup

Sharing the toothbrush

Only anal sexual intercourse

Anal and vaginal sexual intercourse

Mosquito bites

Breast feeding

Exposure to infected blood

What protects you most against HIV infection?

Taking a shower after sexual intercourse

Contraceptive pills

Using a Condom

Taking the vaccine

A healthy diet

Which bodily fluids can infect you with HIV?

Saliva

Blood

Vaginal fluids

Breast milk

Semen

Tears

Urine



HIV/AIDS information material that can be used for the interactive exercise on information literacy

Note to the facilitator: Not every poster, pamphlet or video below might be suitable for your cultural context. Select the material corresponding to local circumstances. Watch the videos before showing them for the first time. If possible, collect some information material from local HIV/AIDS advocacy groups.

HIV/AIDS Posters

An online collection of HIV/AIDS poster of the U.S. National Library of Medicine http://www.nlm.nih.gov/exhibition/visualculture/safesex.html

625 HIV/AIDS posters from 44 different countries can be found in the History and Special Collections Division at UCLA Louise M. Darling Biomedical Library http://digital.library.ucla.edu/aidsposters/

HIV/AIDS Pamphlets

The Herskovits Library of African Studies at the Northwestern University Library provides an online collection of AIDS pamphlets from Africa <u>http://</u><u>www.library.northwestern.edu/africana/aidsexhibit/pamphlets.html</u>

HIV/AIDS Videos

Short clips targeting HIV negative gay men http://www.grandelusion.com/hiv/weissman.html

A big selection of AIDS videos in many different languages <u>http://www.aids-videos.org/</u>

MTV "Staying alive" campaign with HIV/AIDS clips from the last 25 years http://www.staying-alive.org/en/media/other_links/media_player



International Labour Organization (ILO)

10 key principles of the ILO Code of Practice on HIV/AIDS and the world ofwork:

- 1. HIV/AIDS is a workplace issue
- 2. No discrimination
- 3. Gender equality
- 4. Healthy work environment
- 5. Social dialogue
- 6. No screening for purposes of employment
- 7. Confidentiality
- 8. Continuing the employment relationship
- 9. Prevention
- 10. Care and support

The 10 key principles in detail can be found at: <u>http://www.ilo.org/public/</u> english/protection/trav/aids/code/tenkeyprins.pdf

More information about the ILO code of practice in many languages can be found at: <u>http://www.ilo.org/public/english/protection/trav/aids/publ/code-language.htm</u>



Further information about HIV/AIDS

General Information on HIV/AIDS

The international charity Avert provides comprehensive information on many aspects of HIV/AIDS on its website <u>http://www.avert.org/</u>

Global dimension of the pandemic UNAIDS publishes a yearly epistemic update on HIV/AIDS <u>http://www.unaids.org/en/KnowledgeCentre/HIVData/Epi-Update/EpiUpdArchive/2007/default.asp</u>

HIV/AIDS and the workplace

The United Nations "HIV and the workplace" programme provides detailed information on many aspects of HIV/AIDS. <u>http://unworkplace.unaids.org/</u>

The International Labour Organization has developed a code of practice regarding HIV/AIDS and the workplace.

http://www.ilo.org/public/english/protection/trav/aids/publ/code.htm

Stigma and discrimination

A brochure about dealing with HIV/AIDS related stigma and discrimination from the International Center for Research on Women (ICRW) (2006) <u>http://www.icrw.org/docs/2006_stigmasynthesis.pdf</u>

The role of libraries in the fight against HIV/AIDS.

An article by Ellen Forsyth focuses on the role of public libraries in reaching the Millennium Development Goals

Forsyth, Ellen, 2005: Public Libraries and the Millenium Development Goals, in: IFLA

Journal, 12, 31, 315-323.

The authors IFLA/FAIFE Theme report of 2006 call for proactive librarianship to fight HIV/AIDS, corruption and poverty. <u>http://ifla.org/faife/report/FAIFE-ThemeReport2006.pdf</u>



Others

Publications on many aspects of HIV/AIDS, such as the special vulnerability of young people, women and girls and migrant populations, as well as information on sexual and reproductive health, prevention and treatment can be found at the websites of the UNAIDS organizations:

www.unaids.org,

www.who.org,

www.unfpa.org,

www.unicef.org

