



# POSITIVE CONNECTIONS

Leading Information and Support Groups for Adolescents Living with HIV



Interagency  
Youth  
Working  
Group









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## SECTION

## 1

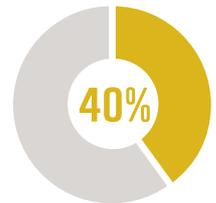
# Introduction and Overview

## YOUNG PEOPLE AND HIV

In 2012, young people ages 15 to 24 accounted for an estimated 40 percent of new nonpediatric HIV infections worldwide.<sup>1</sup> This group includes many adolescents, who are defined as young people ages 10 to 19.

Adolescence is often when young people begin having sex, which increases chances that adolescents living with HIV might pass the infection to partners who are HIV negative. Another concern is that girls living with HIV may become pregnant; if they do not know about or have access to services for preventing mother-to-child transmission, they can pass the infection to their babies.

With the success of pediatric antiretroviral therapy (ART), many more infants born with HIV (perinatally infected) are growing up into adolescents and young adults living with HIV. This population faces a unique set of psychological, emotional and sometimes



In 2012, young people ages 15 to 24 accounted for an estimated 40% of new nonpediatric HIV infections worldwide

“...it’s important to remember that adolescents living with HIV are first and foremost adolescents.”

physical needs that might differ from those of non-perinatally infected youth.

While care and treatment programs for people living with HIV (PLHIV) can be found in every country, there is a gap in provision of ongoing, supportive counseling for adolescents living with HIV (ALHIV). Adolescents who are newly diagnosed (or who have only recently learned of their status) need accurate information about their diagnosis and care and treatment options. They need information about preventing transmission to others and guidance about adhering to treatment. In addition to this important information, ALHIV need long-term counseling and support—not only to come to terms with their diagnosis, but also to discuss what it means to live with HIV, if and when to disclose their status to others, and how to envision their future.

Most of all, it’s important to remember that adolescents living with HIV are first and foremost *adolescents*. Like all young people, they are eager to learn how their bodies are changing; about their sexual identities; and about their reproductive health, including safer sex, prevention and treatment of sexually transmitted infections (STIs), pregnancy prevention and planning for safer pregnancy options.

## WHO IS THIS GUIDE FOR?

This guide provides a framework for adults who lead post-test information and support groups for adolescents who are living with HIV. The guide is designed for people who have been trained in or have experience in HIV counseling and testing, who work in a counseling capacity with ALHIV, who provide other psychosocial support services to ALHIV or who have been trained to work with adolescents in the context of reproductive and sexual health. These audiences include the following:

- Health care providers, such as nurses, doctors and community health workers
- Counseling professionals, including psychiatrists, psychologists, therapists and social workers
- Teachers
- PLHIV
- Parents and caregivers
- Faith-based leaders

Throughout, we refer to the adults leading the information and support groups as *facilitators*.

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## WHY IS THIS GUIDE NEEDED?

Any attempt to improve care and treatment for ALHIV and prevent new infections must begin by providing young people with factual information and support, beyond what they receive after their initial diagnosis.

Information and support are complementary, essential tools for helping ALHIV as they transition from counseling and testing to care and treatment and from childhood to young adulthood.

We designed this guide to help ALHIV do the following:

- 1 Understand their HIV diagnosis and participate in managing their care and treatment.
- 2 Learn that many young people live healthy and productive lives while living with HIV.
- 3 Identify strategies for positive living, including eating right, getting physical activity, avoiding drugs and limiting alcohol, and adhering to their treatment regimen.
- 4 Make informed decisions about their sexual and reproductive health—preventing transmission of HIV to others; avoiding reinfection; consistently

using family planning to prevent unintended pregnancy; and, if or when they wish to start a family, learning how to have healthy babies who are free of HIV.

- 5 Develop life skills such as understanding their emotions, communicating effectively, dealing with stigma and discrimination, making decisions about their future and improving their quality of life.

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## WHO SHOULD ATTEND THE INFORMATION AND SUPPORT GROUPS?

Adolescents who will benefit from these information and support groups include the following:

- Those who were infected perinatally or as children, who have known about their status for a while and who are making the transition from pediatric care and treatment to adolescent services
- Those who were infected perinatally or as children but who only learned about their status when they became adolescents

- Those who were infected as adolescents and who are making the transition from counseling and testing to care and treatment

Certain individuals might require additional counseling before attending the information and support groups. These include individuals who use drugs or abuse alcohol, young people who have been sexually assaulted or abused and individuals with severe depression or who are suicidal. Use your best judgment to determine if someone needs more immediate help or intensive counseling before they join (or in addition to joining) the group.

## What do young people think?

While this resource was being developed, FHI 360, GNP+ and Save the Children conducted informal interviews, surveys and discussion groups with ALHIV from Kenya, Botswana and Vietnam. They told us how they felt about learning of their diagnosis, dealing with disclosure, adhering to medications, dealing with stigma, and developing networks of supportive friends and family. Quotes from these young people appear throughout this guide.

## HOW TO USE THIS GUIDE

The guide is divided into six sections:

**SECTION 1. INTRODUCTION AND OVERVIEW** describes how this guide is to be used and how it is organized.

**SECTION 2. GETTING STARTED: INFORMATION FOR FACILITATORS** provides information about understanding the needs of ALHIV, a review of counseling and facilitation skills, and considerations when getting a group started.

**SECTION 3. LIVING WITH HIV: SESSIONS FOR INFORMATION AND SUPPORT GROUPS** outlines 14 sessions to be used in adult-led information and support groups for ALHIV. These sessions are designed to be used with groups, but the information and some of the activities might be used for one-on-one counseling as well. Facilitators might split the sessions into several parts depending on the amount of time they have to spend and the attention span of the participants.

**SECTION 4. IS YOUR PROGRAM WORKING** explains how you can track your program's progress and determine whether the program is providing support and accurate information to ALHIV.

**SECTION 5. APPENDICES** contains brief descriptions of additional activities and icebreakers, a list of websites and other resources, a chart about contraception for

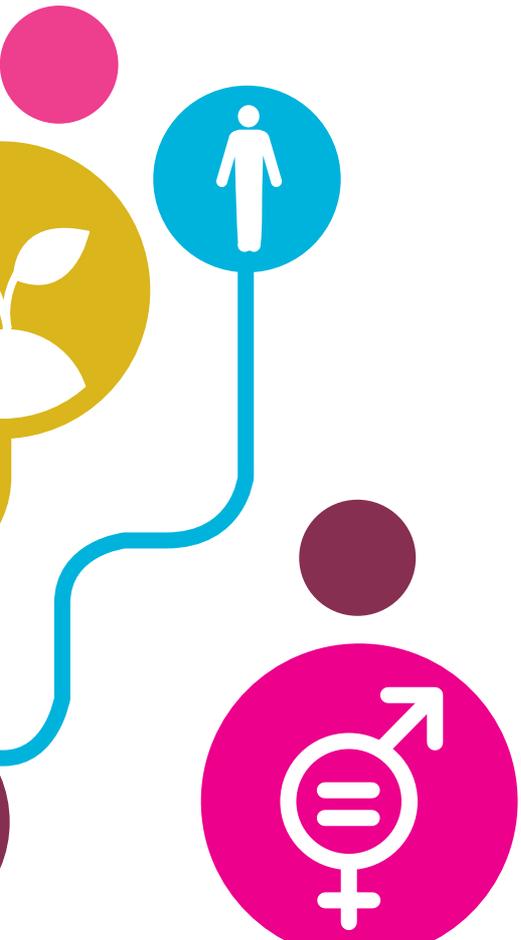
PLHIV, a chart that facilitators can complete to help them develop a referral network and a list that defines the acronyms used in this guide.

**SECTION 6. REFERENCES** includes a list of all the sources and resources noted in this guide.

Although we hope this document will be used globally, the HIV epidemic varies considerably among countries and regions. Regions with concentrated epidemics among people most at risk of HIV—injecting drug users, people who sell or trade sex, and men who

have sex with men—face different challenges than regions with epidemics among a general population. This guide primarily addresses general populations but could be adapted for use with most-at-risk populations (also called *key vulnerable populations*). We encourage you to make any adjustments needed to fit the context in which you are working. For example, you might include information about HIV prevalence in your own country or district. Or you could change the names used and situations described in the role plays to make them more realistic for your group.





SECTION

2

## Getting Started: *Information for Facilitators*

The needs of ALHIV are complex and in many ways very different from adults who are living with HIV. This guidebook focuses on discussions and activities for adolescents living with HIV. Before starting an information and support group, you might find it helpful to familiarize yourself with some background information about ALHIV and about facilitation guidelines.

This section includes the following topics:

- I. Understanding the Needs of ALHIV
- II. Providing Information and Support
- III. Starting an Information and Support Group
- IV. Group Counseling and Facilitation Skills

*“I think that we need more programs that support the unique experiences of young people living with HIV. ...I would have liked to have been supported a little more and tokenized a little less.”*

– Young adult living with HIV, responding to a survey of 98 ALHIV from 37 countries.

## I. UNDERSTANDING THE NEEDS OF ALHIV

### Defining Adolescence

This reference guide focuses on creating information and support groups for adolescents ages 10 to 19. Adolescence is characterized by a period of tremendous change and growth—physically, emotionally and socially. These changes become even more complicated for an adolescent diagnosed with HIV.

Adolescents are not a homogeneous group. Adolescents of the same age can differ in their physical, psychological or social development. There are many developmental differences between a young 10-year-old adolescent and a 19-year-old. These differences affect adolescents’ counseling needs and their capacity to care for themselves. Knowing the changes that occur during adolescence can help you understand adolescent behavior in the context of each individual’s phase of development.

Many considerations influence how adolescents respond to counseling and what kind of support they need. These considerations include each individual’s access to health care and information, confidentiality and consent issues, understanding of sex and sexual health, and sexual experience and values. Gathering information about the individuals in your group can help you to adapt the content and counseling to the needs of individuals

while ensuring that the group’s needs are met as well.

The remainder of Section 1 provides additional information about the stages of adolescent development; characteristics of adolescents and their implications for counseling; HIV transmission periods for adolescents (perinatal and adolescence); and considerations about gender and special populations. This information is adapted from WHO’s *IMAI One-Day Orientation on Adolescents Living with HIV*<sup>2</sup> and FHI 360’s *HIV Counseling and Testing for Youth*.<sup>3</sup>

### Characteristics of Adolescence and Their Implications for Counseling ALHIV

Adolescents living with HIV face a series of challenges quite different from those faced by adults living with HIV. Here are some important factors to consider when working with adolescents.

- **AGE:** Because younger adolescents are considered minors, parental or guardian consent might be needed to provide treatment and parents or guardians might wish to be involved. Laws regarding minors and confidentiality differ among countries. It is important to learn about these laws in your country. Also, do not make assumptions based on age about a young person’s knowledge or sexual experience. Ask the young people in

## STAGES OF ADOLESCENT DEVELOPMENT (WHO, 2010)<sup>2</sup>

CATEGORY OF CHANGE	EARLY 10–15 years	MIDDLE 14–17 years	LATE 16–19 years
<b>GROWTH OF BODY</b>	<ul style="list-style-type: none"> <li>• Secondary sexual characteristics appear</li> <li>• Rapid growth reaches a peak</li> </ul>	<ul style="list-style-type: none"> <li>• Secondary sexual characteristics advance</li> <li>• Growth slows down</li> <li>• Has reached approximately 95% of adult growth</li> </ul>	<ul style="list-style-type: none"> <li>• Physically mature</li> </ul>
<b>GROWTH OF BRAIN</b> (prefrontal cortex)		<ul style="list-style-type: none"> <li>• Brain growth occurs</li> <li>• Influence on social and problem solving skills</li> </ul>	
<b>COGNITION</b> (ability to get knowledge through different ways of thinking)	<ul style="list-style-type: none"> <li>• Uses concrete thinking (“here and now”)</li> <li>• Does not understand how a present action has results in the future</li> </ul>	<ul style="list-style-type: none"> <li>• Thinking can be more abstract (theoretical) but goes back to concrete thinking under stress</li> <li>• Better understands results of own actions</li> <li>• Very self-absorbed</li> </ul>	<ul style="list-style-type: none"> <li>• Most thinking is now abstract</li> <li>• Plans for the future</li> <li>• Understands how choices and decisions now have an affect on the future</li> </ul>
<b>PSYCHOLOGICAL AND SOCIAL</b>	<ul style="list-style-type: none"> <li>• Spends time thinking about rapid physical growth and body image (how others see them)</li> <li>• Frequent changes in mood</li> </ul>	<ul style="list-style-type: none"> <li>• Creates their body image</li> <li>• Thinks a lot about impractical or impossible dreams</li> <li>• Feels very powerful</li> <li>• Experiments with sex, drugs, and alcohol</li> </ul>	<ul style="list-style-type: none"> <li>• Plans and follows long-term goals</li> <li>• Usually comfortable with own body image</li> <li>• Understands right from wrong (morally and ethically)</li> </ul>
<b>FAMILY</b>	<ul style="list-style-type: none"> <li>• Struggles with rules about independence/dependence</li> <li>• Argues and is disobedient</li> </ul>	<ul style="list-style-type: none"> <li>• Argues with people in authority</li> </ul>	<ul style="list-style-type: none"> <li>• Moving from a child-parent/guardian relationship to a more equal adult-adult relationship</li> </ul>
<b>PEER GROUP</b>	<ul style="list-style-type: none"> <li>• Important for their development</li> <li>• Intense friendships with same sex</li> <li>• Contact with opposite sex in groups</li> </ul>	<ul style="list-style-type: none"> <li>• Strong peer friendships</li> <li>• Peer group most important and determines behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Decisions/values less influenced by peers in favor of individual friendships</li> <li>• Selection of partners based on individual choice rather than what others think</li> </ul>
<b>SEXUALITY</b>	<ul style="list-style-type: none"> <li>• Self-exploration and evaluation</li> <li>• Preoccupation with romantic fantasy</li> </ul>	<ul style="list-style-type: none"> <li>• Forms stable relationships</li> <li>• Tests how he/she can attract opposite sex</li> <li>• Sexual drives emerging</li> </ul>	<ul style="list-style-type: none"> <li>• Mutual and balanced sexual relations</li> <li>• Plans for the future</li> <li>• More able to manage close and long-term sexual relationships</li> </ul>

Adapted from the Orientation Programme on Adolescent Health for Health-care Providers, WHO, 2003 (Handout for Module B, the Meaning of Adolescence)

your group about their knowledge and experience to determine the content of your sessions.

- **STAGE OF DEVELOPMENT AND MATURITY:** Although development happens in stages, each young person experiences those stages in a unique way. For example, physical development and maturity might happen earlier than mental or emotional maturity. Adolescents who were perinatally infected might experience both physical and cognitive delays. Young people learn to think differently as they mature: Younger adolescents need simple, concrete explanations of key concepts, whereas older adolescents can often handle complex information and instructions. Physical and emotional maturity are especially important to consider when discussing drug regimens and adherence. As young people mature, they take on more responsibility and have a better understanding of the consequences of their actions.
- **GENDER:** Gender norms can affect how boys and girls view themselves and relate to others. They also affect how adolescents view their sexual roles, contraception use (including condom use) and decision making. Gender norms also affect societal acceptance of being sexually active: Boys' sexual activity is often viewed positively, whereas girls who are sexually active are often stigmatized. Gender norms can place girls at risk of sexual

violence, coercion or transactional sex and can influence boys to engage in risky behaviors such as drug and alcohol use, transactional sex and sex without a condom. (For more on this topic, see “Considerations about Gender” [page 13] and “Considerations about Special Populations” [page 14].)

- **MARITAL STATUS:** Married ALHIV might benefit from additional questions or discussion topics that take their married status into consideration. For example, some topics to discuss with married youth include pregnancy prevention as a couple or safer pregnancy options if they want a family, the benefits of couple's counseling, and safer sex practices for married couples. Also, many married girls have little power to negotiate safer sex, and their husbands might control their access to medical care. If married girls attend your group, they might need extra support.
- **HOME SITUATION:** The following are possible living situations for ALHIV: living alone, living as the head of household, living with parents or guardians, living with extended family, living on the street, living in an orphanage, attending boarding school or living in some other public or private institution. Their living situation affects their access to support and care, the quality and availability of support from adults and peers, and their access to information and services.

- **EDUCATION LEVEL:** ALHIV might be attending school, or their positive status might affect their ability to attend school. Neurodevelopment is delayed in many perinatally infected adolescents, and their educational outcomes may be poor. Literacy level affects how ALHIV understand information about their health and their care and treatment plan. Their level of education also affects their prospects for the future.
- **RELIGIOSITY OR SPIRITUALITY:** For some people, religion is a guiding force. ALHIV might benefit from a religious outlook and counseling from spiritual leaders. On the other hand, they might worry that they “have let God down,” feel extreme guilt and shame, be troubled about their afterlife or be stigmatized by the faith community. It is important to recognize the role of faith and religion for some participants and to help them explore how they can seek help from supportive faith groups and religious leaders.
- **LEVEL OF INFORMATION AND UNDERSTANDING OF RISK FACTORS:** Independent of their level of formal education, ALHIV may or may not have a good understanding about how HIV is transmitted and how they can spread the infection to others through unprotected sex, intravenous drug use or becoming pregnant while not on ART.
- **DISPOSABLE INCOME:** Their individual and family financial situation and the level of control of their

finances can affect whether ALHIV have money for health care, basic needs and transportation costs for accessing health services.

- **HIV TRANSMISSION PATTERN:** How an individual acquired HIV can affect how he or she is counseled and what information is needed. For example, those perinatally infected might be transitioning from pediatric care to adolescent care. They might have a different set of concerns and understanding about their care and treatment than someone who recently acquired the infection. (For more on this topic, see “HIV Transmission Periods for Adolescents: Perinatal or Adolescence,” page 12.) Also, the issues to be addressed by someone who was infected through injecting drug use are likely to differ in some respects from those of someone infected through sexual contact.
- **WHO ELSE KNOWS THEY ARE HIV POSITIVE:** This can affect how ALHIV approach disclosure, the level of control they have or feel they have about confidentiality, how they can cope with stigma and the level of support they may or may not already have in place.
- **HEALTH AND STAGE OF HIV DISEASE:** Considerations about their current state of health include whether they are asymptomatic or symptomatic, if they have experienced or are susceptible to opportunistic infections, if

*“When my mother died of AIDS four years ago, I felt something wrong inside me. I asked my relative to take me for a blood test. The doctor told me I was positive. I was so very sad and confused.”*

– 10-year-old Vietnamese girl

they need treatment, and what level of treatment and care they need. Mode of transmission is also likely to have an effect: Young people who acquire HIV during adolescence are less likely to be symptomatic, so they might need support more than they need medical treatment for AIDS or opportunistic infections.

- **PERSONAL AND FAMILY EXPERIENCE OF STIGMA AND DISCRIMINATION:** In addition to the usual stigma attached to living with HIV, adolescents who were infected perinatally might experience stigma for having a chronic illness, for possible stunted growth and cognitive delays and for poor school performance. Experience with stigma and discrimination might affect how a young person will approach sharing his or her status and seeking support from others. If young people have experienced stigma and discrimination, they might require help with developing trust in relationships and determining when and how to disclose their status to others. Additionally, the family as a whole might experience stigma and discrimination.

## HIV Transmission Periods for Adolescents: Perinatal or Adolescence

As you can see, ALHIV have a variety of individual experiences, challenges and needs. Now we will review how the needs of those infected perinatally differ from those of young people infected later in life.

## Adolescents who acquired HIV perinatally, during labor and delivery, or postpartum through breastfeeding

If they were made aware of their status at an early age, these adolescents might not remember a time when they were not living with HIV. They might have been attending pediatric services since infancy and be familiar with health services. On the other hand, some ALHIV might have been infected perinatally but only recently have learned about their positive serostatus. (*Serostatus* is a word used to describe whether particular antibodies are present in the body. *Seropositive* means someone does have the antibodies being tested for; *seronegative* means they do not. If someone is seropositive for HIV, it means their body has been producing antibodies for HIV and they are *HIV positive*.)

Several studies have shown that perinatally infected adolescents could experience developmental delays, which can affect their physical appearance and growth and their emotional and mental development. They could have poor language skills and suffer from problems with memory. They might also have missed school frequently because of their illness and hospital admissions. These issues could influence their ability to understand their illness and treatment as well as their ability to express themselves in a support group setting. If they have been on ART for a long time, these young people could be coping with long-term side effects of the medication, including nerve damage, diabetes and kidney or liver damage.

They might be less likely than those infected in adolescence to be “blamed” for their status. They might feel resentment toward their parents, and they are more likely to have experienced the loss of at least one parent or sibling to AIDS.

### **Adolescents who acquired HIV during adolescence**

These ALHIV might have only recently learned of their HIV diagnosis and generally have not had long contact with health services. Many adolescents only seek clinical services when they feel unwell or need contraception. Others only learn of their HIV status when they become pregnant. For example, approximately 16 percent of new HIV cases in Thailand are among pregnant adolescents. Many adolescents who acquired HIV during adolescence might not yet feel ill or need treatment. However, it is important that these ALHIV make contact with health providers so they can receive prevention, care, treatment and support services.

These ALHIV might be more likely than those who were perinatally infected to be blamed for acquiring HIV, which can affect their chances of facing stigma, discrimination and violence. ALHIV in most-at-risk groups—those who sell or trade sex, those who use injecting drugs, and men who have sex with men—face even more challenges. (For more on this topic, see “Considerations about Special Populations,” page 14.)

## **Considerations about Gender**

In most parts of the world, young women are more vulnerable than young men to HIV and AIDS because of biological, social, cultural and economic reasons. Most new infections of HIV occur among young women between the ages of 15 and 24.<sup>4</sup> Moreover, the consequences of living with HIV can differ significantly for young women and men, boys and girls.

Ideas about gender and the roles placed upon young women and men can influence their views on sexuality; their access to information and health services; and their ability to protect themselves from reinfection, STIs and unintended pregnancy. The following are some examples of how gender can play a role for young people living with HIV.

### **Girls and young women:**

- Are biologically more susceptible to STIs and HIV.
- Are at risk of morbidity and mortality as a result of early pregnancy.
- Might feel pressured or be forced to engage in intergenerational relationships.
- Are often pressured to prove that they are fertile.
- Experience higher rates of sexual violence, coercion and exploitation.
- Have less formal education than males.

- Are often unable to effectively negotiate condom use and are dependent upon their partner to agree to use them.
- Have less power and status and are therefore more vulnerable.

### Boys and young men:

- Experience peer pressure and social pressure to be sexually active.
- Tend to believe pregnancy (or even the presence of STIs) proves their masculinity.
- Are often taught to dominate and control, which can lead to violence and coercion.
- Do not feel comfortable using reproductive health services.
- Are not traditionally targeted for reproductive health services.
- Tend not to have the same level of responsibility if their partner does get pregnant, such as the burden of care.
- Experience stigma and abuse if they have sex with other men. Young men who have sex with men are rarely targeted with prevention messages and have few if any support resources in many countries.
- Have little or no support if they are victims of sexual violence.

## Considerations about Special Populations

Providing information and support to certain populations of ALHIV can be especially challenging because these young people might require special care or a different emphasis in counseling.

**Mobile populations** include adolescents whose work causes them to travel, members of the military, refugees, young people living on the streets and those displaced by civil conflict. These adolescents might lack a sufficient support network, access to ongoing health care and, in some cases, even basic nutrition and shelter. They might not be able to return for additional counseling and support, so consider this when inviting them to join the information and support group.

Many **orphans** are caring for siblings and chronically ill family members, living in financially stretched households or on their own. Some orphans engage in high-risk behaviors to support themselves and their families. Orphans are more likely than nonorphans to face poor nutrition, lack access to basic health care, not be enrolled in school, face psychological and emotional difficulties, and lack support to deal with a positive test result and commitment to a healthier lifestyle.

Be sensitive to the possibility that some participants might have been **victims of incest or rape**; if this is the case, recommend additional counseling. You should also refer them to legal and special support services.

Other groups of youth who might require particular attention include **those who inject drugs or sell or trade sex, and men who have sex with men (MSM)**. These are among society's most marginalized groups, and they often face explicit hostility and police harassment. Some people view programs aimed at helping these youth as tolerating or even aiding illegal behavior. You might need specialized training about the needs of these youth. Try to collaborate with groups that work with these populations and make referrals so ALHIV can get the specific support and treatment services they need.

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## II. PROVIDING INFORMATION AND SUPPORT

These are your goals as the facilitator of these group sessions:

- Provide factual, evidenced-based information.
- Offer emotional support to adolescents facing the challenges of living with HIV.
- Help your group support each other in ways that only peers can.

Participants in your support group will likely ask many of the following questions. These questions

and comments, adapted from WHO's *IMAI One-Day Orientation on Adolescents Living with HIV*,<sup>2</sup> represent common concerns according to people who work with ALHIV. (More information on all of these topics is provided within the support sessions outlined later in this document.)

### *“Will anyone want to have sex with me if they know I am living with HIV?”*

Adolescents need to know that it is possible, and it is their right, to enjoy a healthy sexual life, throughout their entire life, while living with HIV.

Sexual development begins before adolescence. For many people, sexual activity begins during adolescence. Growing up positive or receiving a positive HIV test does not stop adolescents' sexual development or diminish their interest in sex. Adolescents should be told that it is normal to have sexual desires. They need practical, evidence-based information and support to deal with their questions, concerns and fears about living with HIV and having or wanting to have sexual relations. This support is an important part of helping them maintain their self-esteem and their ability to care for themselves and current or future partners.

Fear that they will be rejected as a sexual partner (unless they remain silent about their serostatus) might discourage ALHIV from disclosing their status. Help them explore the risks and benefits of revealing

their HIV status to selected people. You might find it hard to raise and discuss these sensitive issues. You might need to examine your own views, fears and biases before raising these topics with ALHIV.

#### ***“How do I help to keep my partner safe?”***

Promoting consistent and correct use of male and female condoms and lubricants is an essential part of counseling. The prospect of using condoms all their lives can seem an impossible challenge to some adolescents, so it is important that they understand the implications of not using a condom, for themselves and their partners. Condoms are crucial to slowing the HIV epidemic and important as dual protection (preventing STIs, including HIV, and unplanned pregnancy).

Also, adhering to antiretroviral drugs (ARVs) is an important way to protect one’s partner. If someone is on ART, is adhering to treatment and has undetectable levels of the virus in their blood, the risks of transmission to a sexual partner are very low. Condoms, however, should also be used.

Couples’ HIV testing and counseling should be explored. This includes counseling about mutual disclosure, serodiscordancy (when one partner is HIV positive and the other is HIV negative), and HIV-positive seroconcordancy. You should

acknowledge that an individual’s situation might make couples’ counseling impossible. Support your participants’ decision.

#### ***“What kinds of contraception can I use?”***

Adolescents living with HIV can use almost any contraceptive method, with a few exceptions:

- ALHIV should not use spermicides or a diaphragm with spermicides—these have been shown to increase the risk of HIV transmission.
- A young woman with HIV can use an intrauterine device (IUD) if she has no symptoms of AIDS. She should also always use condoms for dual protection because IUDs provide no protection against HIV transmission.
- A young woman who has AIDS should not have an IUD inserted unless she is clinically well on ARV therapy. (But if a young woman who is already using an IUD develops AIDS, she may continue using the device safely.)
- Some ART drugs can reduce the effectiveness of oral contraceptive pills. If a young woman living with HIV is on ART, she should let her family planning provider know.

- New data have emerged regarding a **possible association** between the use of hormonal contraception, particularly progestin-only injectables, and HIV acquisition in women and transmission from HIV-positive women to male sex partners. Some studies have suggested there is a risk; others have not shown this association. Therefore, WHO concluded in February 2012 that women at risk of HIV or living with HIV may continue to use all existing hormonal contraceptives without restriction, but that a strong clarification about using progestin-only contraceptives should be added: ***Women using progestin-only injectable contraception should be strongly advised to always also use condoms, male or female, and take other preventive measures.***

Male and female condoms, when used correctly at every act of vaginal intercourse (always with water-based lubricants), can help prevent infection and unintended pregnancy. Condoms should always be used during anal sex and are recommended during oral sex to help prevent transmission of infection.

Also see Appendix 1. Contraceptive Methods for People Living with HIV (page 172).

#### ***“Will I be able to have children?”***

Yes, PLHIV can have and are having children. Like all people, ALHIV have the right to decide for themselves whether they want to have a child when they are ready. To do this, they need access to sexual and reproductive health information and services, including counseling on safer conception and pregnancy options. This will help them be aware of their reproductive choices, find out how they can significantly decrease the chances of giving birth to an HIV-positive child, learn about any possible health risks they need to be aware of and learn how to conceive safely if their partner is negative with much lower risk of infecting him or her. For this to be possible, sexual and reproductive health services and HIV care services need to be linked and ideally youth-friendly. You can provide appropriate referrals to your participants if available.

#### ***“Will I die soon?”***

Some adolescents might not understand the difference between HIV and AIDS. They might think that a positive test result means they will die soon. You should tell them that with earlier detection, effective drug regimens and a healthy lifestyle, it is possible to remain alive and healthy. They also need to know that if they do not get treatment or if they do not properly adhere to treatment, they are not likely to live as long as they would with treatment adherence.

*“I told my parents because they kept asking questions about my medication. Sometimes I was hiding it or throwing it away to avoid questions. I then disclosed to my mom in the presence of a counselor. I wasn’t sure I could do it alone.”*

– Young Kenyan woman

Emotional and spiritual support can help alleviate anxiety and depression, prevent suicidal ideas and help mitigate the strong emotions associated with living with a chronic and potentially fatal condition. Be prepared to provide referrals to mental health professionals and spiritual support, according to adolescents’ religious beliefs.

***“I am too young to have a chronic disease. My life isn’t worth living anymore.”***

Learning that you are HIV positive can be shocking at any age. For adolescents, it can be hard to imagine how they are going to live their whole lives with a chronic disease. Their dreams about relationships, family life and career are overshadowed by the news. You play an important role in providing hope and explaining that many adolescents and young people lead healthy and productive lives while living with HIV.

You should also encourage your participants to support each other as peers. Adolescents living with HIV often understand each other’s situation better than anyone else and are well placed to educate, counsel and advise one another. If possible, invite young people who are coping well with HIV to be guest speakers so that your group’s participants can understand that it is possible to live positively.

If you suspect that a young person in the group is clinically depressed or is considering suicide, refer him

or her to a mental health professional or local health clinic for assessment and treatment. Similarly, if you think that one of the participants has a problem with substance abuse, refer him or her to a suitable program for help.

***“I am afraid that people will reject me, shun me or be violent toward me.”***

Adolescents living with HIV often experience stigma, discrimination and isolation. Acts of discrimination can range from inappropriate and hurtful comments to physical violence. Young people might be wary of revealing their status to anyone (sexual partner, peers, family members or school officials) because disclosure might ruin their relationships, lead to abandonment or make them victims of abuse. Be prepared to provide appropriate referrals and intervention for young people who are being victimized.

Adolescents need support and advice on disclosure and on the implications of disclosure for their safety, security and future opportunities. HIV can have an enormous impact on access to education and employment. ALHIV should also be made aware of any of their country’s laws and policies related to the rights of PLHIV.

***“I can’t tell anyone that I am HIV positive.”***

Many people are fearful of telling family, friends, sexual partners and others that they are living with HIV. As

discussed above, disclosing one's status involves great risks. Doing so might not be in one's best interest. However, disclosure can also bring about benefits: getting support from understanding friends, family, teachers and spiritual leaders; receiving appropriate treatment and care from fully informed health care providers; and receiving encouragement from other young people living with HIV.

Adolescents should be taught to weigh the risks and the benefits of revealing their HIV status and supported in whatever decision they make about disclosure. It might also be helpful for you to assist group participants in identifying a "safe" person or persons to whom they can disclose their status and gain support.

***"I am afraid you will tell my parents; will you?"***

This raises issues of consent to treatment and confidentiality with minors. You should know what you are obliged to do by law, how existing laws and policies are translated into practice and, if necessary, how you can work with adolescents to help them determine whether disclosing to parents or guardians would be beneficial. If parents or guardians are likely to be sympathetic and supportive, they can play a key role in adolescents' long-term care.

***"I was born with HIV. Why did my parents wait so long to tell me?"***

Some adolescents with perinatally acquired HIV might feel resentful toward their parents and angry about not being told about their status earlier and involved in decisions about their own health. They should be allowed to voice their anger in a supportive environment.

In addition, adolescents with perinatally acquired HIV might have experienced the death of one or both parents or have other family members who are infected with HIV. They might have multiple caregivers, lack a stable home and suffer from depression. Be prepared to address issues of grief and provide appropriate referrals for young people experiencing depression.

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## III. STARTING AN INFORMATION AND SUPPORT GROUP

This topic offers guidance on how to plan and facilitate an information and support group. Your group might be a stand-alone support group, or it could be part of a broader program of youth activities.

### Eight Steps to Planning Information and Support Group Sessions

#### 1. Know your audience.

You should know the following basic information about the participants:

- How many youth will be attending?
- How old are the participants? If there is a wide age range, consider forming more than one group to accommodate the different needs of younger versus older adolescents.
- Why do they want to join an information and support group?
- Have they been recently diagnosed with HIV? Or have they known their status for a while?
- Are there any potential group dynamics that might affect the sessions?
- What is the gender makeup of the group? Are any of the participants married? How will exercises and discussions need to be modified for mixed or single gender groups? For young married girls?

- Where do they live? Do not assume participants live nearby. Young people often seek services outside of their immediate neighborhood to avoid being seen by family and friends.

#### 2. Consider co-facilitators to help lead the sessions.

In addition to a lead facilitator, the group would benefit from guest speakers who specialize in key topics such as nutrition, ART, psychology and others. Guest speakers should be knowledgeable about the content, experienced in working with youth and comfortable leading interactive exercises. Ideally, ALHIV—particularly those who have had some experience living with HIV—can also be tapped to help facilitate the sessions and lend support to their peers. This will boost the speakers' self-confidence while they provide hope to other ALHIV in the group. Also consider inviting a former participant in a group to co-facilitate.

#### 3. Determine what participants want to get out of the group and what information they need.

The sessions outlined in this guide provide a wealth of information that can help ALHIV. But the sessions are also meant to be tailored to meet the specific needs of the young people in a particular group. Once groups are formed, you can work with the young people to determine what knowledge and skills they hope to gain from attending the sessions.

#### **4. Find a location in which groups can meet.**

First, consider whether the location is convenient for participants. If possible, consult with the young people who attend or will attend your group. If possible, look into transportation options for group members. Next, determine what resources are available at the site. Try to visit the site before you begin the support group; this will alert you to any challenges posed by the facility. If it is not possible to visit the site beforehand, try to consult with someone who knows the facility well. When choosing a location, keep the following in mind:

- Ensure that the location will offer privacy (to respect members' confidentiality).
- If supplies are not available at the meeting place, bring chalk or markers for writing on chalkboard, white board or a flip chart (if available).
- Have enough chairs, mats or tables to facilitate discussion and interaction.
- Try to supply board games, balls and other activities as available so that young people can play and interact before or after the support session.

#### **5. Determine each session's duration.**

Balance the amount of time necessary for participants to assimilate new information, practice new skills and reflect on new attitudes with the amount of time the youth will have available.

Several of the 14 sessions in Section 3 cover a lot of information and could be split into smaller units if need be.

#### **6. Determine what materials you need.**

The activities listed in this guide include a materials list. If any materials listed are not available at your site, make adjustments as necessary.

#### **7. Establish a safe and comfortable learning environment.**

At the first session of your support group and whenever a new person joins, take the following steps:

- Review the purpose of the group and the sessions—to provide information and support to the ALHIV attending the sessions.
- Establish (or review) group agreements or ground rules. See “Establishing Group Agreements,” the next topic, for more details.
- Review the agenda, including stop and start times and times for breaks. Ask participants for input on these items to ensure that everyone agrees with the agenda.
- Discuss your role as facilitator and ask if participants have questions or comments.
- Let the participants know where they can take care of their basic needs (such as locations of restrooms and places to obtain food and drink).

- Consider beginning each session with an icebreaker, particularly if you have new participants joining. Feel free to use any you like, or select one from Appendix 2, “Additional Activities and Resources.”
- If possible, have refreshments on hand.

### Establishing Group Agreements

*(This information was adapted from materials by Teen Club, Botswana.<sup>5</sup>)*

One of the first things you and your group should do is to create and agree upon some ground rules to keep the meetings productive and respectful. Allow the participants to come up with their own list of agreements or rules while you record them on a chalkboard, white board or flip chart. The list should be posted for the duration of the group sessions. Make sure the rules include some form of the following:

- Respect for ourselves (modeling good behavior, dressing properly, good hygiene)
- Respect for each other (maintaining confidentiality and supporting each other, no stealing, no gossiping, no vulgar language, no taking advantage of younger members, listening to others when they are talking, being considerate of each other’s feelings, sharing equally with others—including food)
- Respect for our surroundings (cleaning facilities after use, not littering)
- Respect for the group (good participation and contribution during sessions, being punctual, listening to facilitators, no fighting or arguing or shouting with others)
- Respect for health and safety (taking medications, do not bring or use any drugs or alcohol, do not bring or use any weapons, no dangerous activities)

### 8. Identify ways to determine if the information and support group was effective.

An in-depth discussion of monitoring and evaluating is beyond the scope of this guide. However, refer to Section 4, “Is Your Program Working?” (page 151), for information about how to determine if your group is meeting its goals.

## IV. FACILITATION SKILLS

This topic provides an overview of the characteristics and roles of an effective group facilitator.

Effective facilitators need to be good communicators—especially when they are working with adolescents.

The following communication skills are essential for creating a safe counseling environment and ensuring that participants share information honestly and respectfully. This list was adapted from materials

designed for counseling ALHIV by the U.S. Centers for Disease Control and Prevention.<sup>6</sup>

### Nonverbal Communication

- Maintain eye contact.
- Demonstrate interest in what is being said; for example, nod your head or smile.
- Stand without barriers—such as a desk or podium—between yourself and the group, or consider sitting with the group.
- Demonstrate enthusiasm about the topic by moving around the room and gesturing.

### Verbal Communication

- Vary the pitch, tone and volume of your voice.
- Speak clearly.
- Encourage questions.
- Allow group members to answer each other's questions, but correct any misconceptions.
- Emphasize and summarize important points.
- Make smooth transitions from one topic to another.
- Give clear directions for activities.
- Use language that is easily understood and culturally acceptable to the group while being careful not to talk down to young people.
- Reinforce what is said by writing key points on a flip chart or chalkboard.

### Listening Skills

- Pay close attention. Practice “active listening,” which means paraphrasing participants' statements and repeating them back to indicate that you understand what the young people are saying.
- Try not to interrupt or finish people's sentences. It is OK to allow time for silence as participants gather their thoughts.

It is also important to pay attention to the nonverbal communication of your group. For example, a person's body language might indicate that they are uncomfortable discussing a certain topic or are bored or distracted during a session.

### How to Ask Questions

Ask questions to find out more about a young person's situation. It's very important to ask the right kinds of questions, in the right way, to get the information you need to help your participants. Be mindful that young people might need time to learn to trust you and others in the group before they are willing to share personal information.

### Closed- and open-ended questions

Closed-ended questions generally require only a one-word answer. They are often used to gather specific information quickly and efficiently.

**Examples:**

- ▶ Do you have children?
- ▶ Do you use a condom every time you have sex?

If you want to generate discussion, ask open-ended questions. For example, you might ask, “What do you know about protecting others from HIV?” (open-ended) rather than “Do you know how to protect others from HIV?” (closed-ended). Or, “What sorts of things are you doing to take care of your health?” (open-ended) rather than “Are you taking care of your health?” (closed-ended).

**Confirmation questions**

Confirmation questions can help you check what someone means, believes or understands.

**Examples:**

- ▶ You said that you could take the drugs at 7 in the morning and 7 in the evening. Is that right?
- ▶ You said that you felt sick each time you took your pills. Have I heard you correctly?

**Leading questions**

Asking leading questions is not an effective way to elicit information. They are asked in a way that leads the person being questioned to a particular answer. Leading questions often are based on the asker’s assumptions. They do not help participants open up about their true feelings or actions.

**Examples:**

- ▶ You take the drugs as I told you to, don’t you?
- ▶ You wouldn’t have unsafe sex, would you?

**Explanation questions**

These types of questions are sometimes useful, but often cause a person to feel interviewed, threatened or judged. They usually sound too direct to be helpful and end up making people close up, rather than open up.

**Examples:**

- ▶ Why did you forget to take your drugs? (It might be better to ask, “Can you think of methods to help you remember to take your drugs?”)
- ▶ Why haven’t you told your girlfriend about being HIV positive? (Try instead, “What do you think is preventing you from telling your girlfriend that you are living with HIV?”)
- ▶ Why did you miss your last appointment? (It might be better to ask, “What factors in your life make it difficult for you to keep your appointments?”)

**The Importance of Empathy**

Empathy means understanding the feelings another person is experiencing without becoming emotionally involved. Letting a person know that he or she has been heard demonstrates empathy. If you are sincerely empathetic, the young people in your group are more likely to talk openly.

For example: A girl says that she is afraid to tell her boyfriend that she has HIV. Someone showing empathy might say this: “Yes, this sounds very frightening. Many people find it hard to tell. Is there anything you think might help?”

### These are good techniques to show empathy:

- Acknowledge the situation and emotions the young person faces. For example, say: “This sounds like a very hard thing for you to do.” Or say, “Yes, many people have difficulty telling their boyfriends about their HIV.”
- Don’t scold young people when they don’t do everything that has been recommended for them.
- Don’t be judgmental.

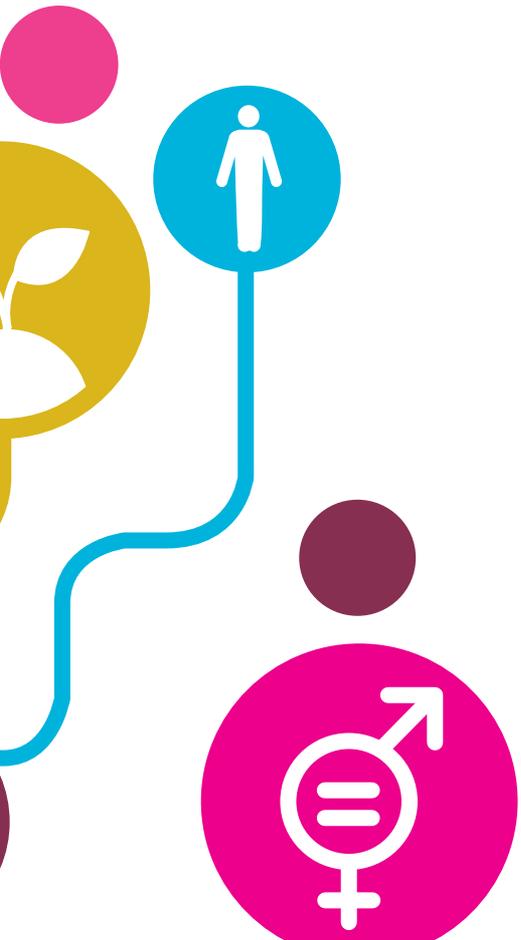
## General Tips for Facilitating an Information and Support Group for Young People

An information and support group should be emotionally safe and physically comfortable for all group members. The following tips will help you foster an optimal environment for ALHIV.

- Take interest in your group members and their ideas.
- Use positive encouragement to promote participation and learning among all group members.

- Be conscious of how you talk when leading a counseling session.
- Be aware of the power and gender dynamics that exist between you and the participants. If you are a woman, consider asking a man to assist with mixed-gender groups (or if you are a man, consider asking a woman). Invite a young person who has completed a similar group to act as a peer facilitator with you.
- Be aware of your body language.
- Listen as much as you talk.
- Do not do other tasks when listening to someone talk.
- Help group members explore their feelings.
- Validate group members and their contributions.
- Remember what it is like to be an adolescent, and recognize the strength and courage the group members show by participating in a support group.





## SECTION

## 3

# Living with HIV: *Sessions for Support Groups*

This section provides outlines of 14 sessions that you can use when leading information and support groups for ALHIV. We designed the sessions to build upon each other, so it would be helpful if the same group of participants completed the entire set of sessions together.

However, this may not always be possible, and new people might join the group at any time. Try to meet individually with new participants when they first join to explain how the group operates, to review the importance of confidentiality and to address any immediate concerns. At the beginning of any session with new participants in attendance, review the ground rules and make introductions.

*We encourage you to use these session outlines as a guide; there is no need to follow the sessions exactly as they are written. Your goals are to get participants talking to each other and to share important information with them, not to follow a strict schedule. Also, if time or attention spans are short, feel free to split the sessions into smaller units or break up the sessions with games or physical activities.*

Each session is composed of seven parts:

- ① **Background for the Facilitator** provides information about the relevance and importance of the discussion topic to ALHIV. Review this information before you begin each session. In fact, it would be helpful to read through the entire session before conducting your group meeting.
- ② **Today's Agenda** is a list of the ideas to be discussed and activities to be conducted. The agenda is flexible. You can run the session in whatever order best fits the needs of your group.
- ③ **At a Glance** summarizes the important learning points that you will be reinforcing with key messages, group discussion and activities in each session. Write these on a chalkboard or flip chart and refer to them frequently.
- ④ **Key Messages** provide more detailed information about each session's main topic. You can present the messages in your own words or, if necessary, read them aloud using the language provided. **But avoid long stretches of lecturing:** Check in with participants, answer questions, take breaks and mix in some activities.
- ⑤ **Discussion Questions** provide the opportunity for participants to explore their feelings and share their ideas and experiences in a safe environment. The discussion should be approached more as a group support activity than as a training activity. The questions can help you get discussions started, but you should allow group members some freedom to explore how they feel about the topic. Remember that confidentiality is important and should be agreed upon by group members at the beginning of each session. Also, while opinions are encouraged, they should not be mistaken for facts. It is important for you, as the facilitator, to stop the spread of misinformation and correct any myths or misconceptions.
- ⑥ **Activity Corner** provides recommended activities that will review information, build skills or reinforce key messages.
- ⑦ **Review and Wrap-up** provides some review questions that re-emphasize the key messages and help conclude the session. Also, participants' answers to the review questions will help you gauge how well your group understood the material. Use this information to plan future sessions. (Also see Section 4, "Is Your Program Working?")

In a few sessions, we recommend inviting a guest speaker to provide expertise on the topic. Before doing so, ask your participants if they are comfortable with an outsider attending the session. Choose suitable, trustworthy speakers who are bound by professional ethics to ensure the confidentiality of participants. Still, the final decision on guest speakers should be made by your group.

You may also want to consider inviting a young person living with HIV, perhaps a former group participant, to co-facilitate the sessions. Again, it would be important for the co-facilitator to agree to the terms of confidentiality.

At the first session, after introductions have been made and the participants have settled in, ask them to complete the form on page 168. (Make copies in advance.) Explain that this is not a test – you simply want to find out what they already know about living with HIV so that you can tailor the sessions accordingly. They do not even need to write their names on the form. You will also have them complete the form again at the end of the sessions and compare the before and after forms to see how much the participants learned.



### Background for the Facilitator

Review the following information on your own before leading this session.

HIV can be difficult to discuss with anyone, but talking with youth about HIV poses some additional challenges. As we discussed earlier, youth are not a homogenous group, so the messages you deliver should be tailored according to your participants' age, sex, emotional maturity and developmental stage, and their existing knowledge and experience. You will be explaining some very adult concepts and complex medical issues.

Before you begin your support group, it might be helpful to review some basic information about HIV. Human immunodeficiency virus (HIV) infects cells of the immune system and destroys or impairs their function. Infection results in the progressive deterioration of the immune system, breaking down the body's ability to fend off infections and diseases. Acquired immune deficiency syndrome (AIDS) refers to the most advanced stages of HIV infection, defined by the occurrence of any of more than 20 opportunistic infections or related cancers.

HIV can be transmitted through unprotected vaginal or anal intercourse or oral sex with an infected person; transfusions of contaminated blood; and the sharing of contaminated needles, syringes or other sharp instruments. It can also be transmitted between a mother and her baby during pregnancy, childbirth and breastfeeding.



#### NOTE TO FACILITATOR:

In the "Activity Corner" in this session (page 32), we recommend that you give each participant a notebook. If notebooks are unavailable, you could provide participants with loose-leaf paper.



### Today's Agenda

In this session, participants will do the following:

1. Discuss how the participants came to be in this information and support group and what they hope to gain from the group.

2. Learn the definitions of HIV and AIDS.
3. Learn how HIV infection occurs.
4. Find out how HIV affects the body and its immune system.
5. Learn about ARVs.

### At a Glance

#### Write these statements on the chalkboard or flip chart.

- HIV affects the immune system, which means your body has a hard time protecting you from illness and infections.
- There is currently no cure for HIV or AIDS.
- People living with HIV can lead healthy lives by taking medications known as *antiretrovirals* or *antiretroviral drugs* (ARVs).
- Taken exactly as prescribed by a doctor, antiretrovirals can make you feel better and can help reduce your risk of infecting others.



#### NOTE TO FACILITATOR:

Because this will likely be the first session with your group, be sure to establish ground rules and explain how the information and support group will be set up. (Refer to Section 2, “Getting Started,” for more information.) Allow time for introductions and for participants to get comfortable with one another and with you. If possible, have a health care worker on hand to answer any clinical questions related to their diagnosis. Also consider having a PLHIV attend the first few sessions to answer any questions about living with HIV.

- Even if you are taking antiretrovirals, you should still use condoms every time you have anal, oral or vaginal sex.
- People living with HIV have the same rights as everyone else: to have sex, to go to school, to get a job, to have a family.

Once you have finished with introductions, conduct an icebreaker like the one below, or use one of your own.

#### Icebreaker: “That’s Me!”

Before the session, prepare a list of 10 to 15 questions that will be relevant to the young people in your group. Here are some suggested questions: Who likes to dance? Who plays a musical instrument? Who likes vegetables? Who is feeling great today? Who wants to get started today?

Read the following instructions to the group, and then read the questions you prepared.

*“I’m going to read a series of statements. If the statement is true for you, put your arms in the air (or stand up) and say, “That’s me.”*

You can also participate!



## Group Discussion Questions

Use the questions below to lead a discussion about how participants came to join this group. The objective is to create a discussion through which participants can get to know each other and to create an open, safe environment where everyone feels comfortable.

Tell the group that you want to take some time to get to know one another. Gently encourage people to participate, but don't force anyone. To generate discussion, ask the group the following questions:

1. To start out, it would be helpful to share some information about ourselves. Only share as much as you are comfortable discussing. Please tell us your name and why you decided to join the group.
2. What information about living with HIV would be helpful to you?
3. What have you heard about HIV?
4. Without telling us their names, do you know anyone else who is living with HIV? What information have they shared with you? What was your reaction?
5. What are some immediate concerns or questions you have about living with HIV?
6. What are you feeling right now that you would like to share with the group?



### NOTE TO FACILITATOR:

Make sure to correct any misinformation that is shared, taking care not to embarrass the person who shared it.

7. This group is also called an *information and support group*. What is your experience with support groups? How can this group help provide you with support? How can you support others in this group?



## Activity Corner

Use the following activity to prepare your group for the rest of the sessions.

Give each participant a notebook, and tell them that the notebook is theirs to keep. Suggest that they could write notes about what they're learning during the sessions, record any questions they want to ask and document thoughts or feelings they experience. They could also write in the notebook between sessions and use it as a diary or to remind them of things they'd like to discuss in the next session. Explain that they should bring the notebooks with them to every session. You'll begin each session by asking if anyone has anything to share from his or her notebook. Assure the participants that sharing is voluntary; they will not have to share if they don't want to.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. This session contains a lot of information, so allow time for discussion and questions as you go, and take breaks as needed.

Tell the group that you are now going to review some important information about HIV and AIDS. Let them know that what follows is an overview and you'll go into more detail about many of these topics in later sessions. Encourage them to ask questions or share their own experiences.

- HIV stands for *human immunodeficiency virus*. It is the virus that causes AIDS, which stands for *acquired immune deficiency syndrome*. The immune system is considered “deficient” when it can no longer fulfill its role of fighting infection and disease.
- A person gets tested for HIV, not AIDS. Most HIV tests detect antibodies to HIV, which, if present, mean that the virus is also present. There are two main ways to test for HIV. One test, called a *rapid test*, gives results the same day. The other, called a *Western Blot*, must be sent away to a lab. Both ways are reliable. No HIV diagnosis is made with only one test; two positive tests are

needed to indicate that someone is infected with HIV.

- HIV can be transmitted in several ways.
  - HIV is most often transmitted from one person to another through certain body fluids. HIV is found in blood, semen, vaginal fluid and breast-milk. People usually get exposed to HIV by having sex without a condom with someone who is HIV positive.
  - Infants can get HIV from their mother before or during birth or through breastfeeding.
  - HIV can also be spread from one person to another by sharing needles used for injecting drugs.
  - HIV is not spread through casual contact such as hugging and kissing. Nor can you get HIV from eating and drinking with someone who is living with HIV.
- There are two major types of HIV (HIV-1 and HIV-2) and several other subtypes. HIV-2 is more common in parts of Africa. Both types can lead to AIDS.
- To survive and grow, HIV enters healthy cells in your body. HIV likes to enter CD4 cells, which are white blood cells that help your body’s immune system protect you against germs and viruses. Your body has billions of CD4 cells, but HIV takes



### NOTE TO FACILITATOR:

Many of the topics in this session are covered in more detail in later sessions.

control of them as it grows. A person is considered to have AIDS when his or her CD4 count drops below 200 or when he or she develops an HIV-related disease, called an *opportunistic infection*, such as pneumonia or certain kinds of cancers and yeast infections.

- At this time there is no cure for HIV infection or AIDS, but people living with HIV can lead healthy lives by taking medications known as *antiretroviral drugs* or *antiretrovirals* (ARVs).
- *Antiretroviral therapy* (ART) consists of using at least three different ARVs to keep HIV from replicating or making more of itself. This allows the CD4 cells to multiply and help keep the body healthy. These three drugs are often combined into a single tablet.
- The goal of taking ARVs is to have an undetectable level of the virus (*viral load*) in your blood. Having an undetectable viral load does not mean that HIV has disappeared entirely. An undetectable load means that viral levels are so low they can't be detected by a blood test. If a person has very little HIV in his or her blood, HIV won't be able to attack and weaken the immune system. If the immune system is strong, the person is less likely to get infections and illnesses. Also, an undetectable viral load reduces a person's risk of passing on (transmitting) HIV,

making it unlikely that someone living with HIV will infect others, although it is still possible to do so. This is why people should use condoms to prevent transmission, even if they are taking ARVs.

- Some people with HIV infection do not get better with ARVs. When a person does not get better, it usually means the virus has become *resistant* and the medications are no longer effective. Resistance to ARVs can develop in those who do not take ARV medications as directed or who skip doses.
- Most medications used to treat HIV have some side effects, but many effects are not too severe, especially with newer combinations of drugs. Sometimes side effects go away as your body gets used to the treatment, and others can be minimized by maintaining a healthy lifestyle and diet. Some common side effects include nausea or indigestion, diarrhea or loose stools, headache, fatigue and muscle aches. Fever is not a common side effect of ARVs and might indicate a serious condition. A person with HIV or AIDS who develops a fever should contact a health care provider. Abnormal discharge from the genitals is not a side effect of ARVs and might indicate the presence of a sexually transmitted infection (STI).
- People who are living with HIV (PLHIV) need to take precautions not to infect people who are HIV negative. They also must be aware that they could

reinfect someone who is already living with HIV. Even if both partners in a couple are HIV positive, each might have different forms of the virus, so having unprotected sex could lead to a second infection. One can acquire a new infection that is resistant to treatment drugs, meaning that the drugs will not work. Infection with a second strain is called *superinfection*. There are also other serious diseases that can be spread through blood and body fluids, such as hepatitis.

- The best way to prevent infecting a sex partner with HIV or any other STI is to use a condom every time you have vaginal, oral or anal sex. People who are living with HIV and who want to have children should talk to a health care provider about their safest options for becoming pregnant. If someone is on anti-retroviral therapy (ART) and they have an undetectable level of the virus in their blood, it is unlikely they will transmit HIV; so safe conception is possible.



**NOTE TO FACILITATOR:**

Ask the group what questions they still have about HIV before conducting review activities. Correct any misconceptions group members share. If there are questions you cannot answer during this session, write them on a flip chart and tell the group that you will find the answers before the next session.

Now, tell the group that they are going to do a brainstorming activity.



## Activity Corner

Use the following activities to help participants develop a better understanding of HIV and AIDS.

### I. LIVING WITH HIV BRAINSTORM

**TIME:** 30 minutes

**MATERIALS:** Flip chart paper or chalkboard; markers or chalk

**INSTRUCTIONS:**

Explain that the purpose of brainstorming is to generate a list of ideas together for solving a problem or answering a question. All responses are valid and should be recorded on the flip chart or chalkboard.

Ask the group two questions: “What does it mean to live with HIV?” “What do people living with HIV need to do?” Write the questions on a flip chart or chalkboard.

Write participants’ suggestions on flip chart paper. Record all comments. If someone mentions something that that isn’t true (for example, “don’t have sex”), write it on the flip chart paper and put a star next to it. Here are some possible answers:

Exercising and eating right  
Staying healthy

Not passing HIV to others  
Not having sex\*  
Not being able to have children\*  
Taking medications  
Keeping medical appointments  
Having the same rights as anyone else

After the group has created a list, go through each item and discuss. If the group mentions too many negative issues (such as no sex or bad health), emphasize that one of the support group's goals is to show them how ALHIV can live a positive, fulfilling life where they can engage in most of the same activities as people who are not living with HIV. Note that some of these activities (like having sex) require safeguards to protect their health and the health of others.

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## II. HIV REVIEW: CABBAGE TOSS

**TIME:** 10 minutes (about one minute per review question)

**MATERIALS:** HIV review questions, paper (Scrap paper can be used; any color is fine, but use green if possible. Have one piece of paper for each question.)

**PREPARATION:** Prepare the “cabbage” before the session using the suggested review questions below or some of your own. Write one question per page. Create a ball

with the sheets of paper by crumpling up one sheet. Then add another sheet of paper on top, and continue in this way until all of the sheets are added. The bundle of paper will resemble a cabbage with many leaves.

*Suggested Review Questions: (An answer key follows the instructions below.)*

1. True or False—HIV is not passed by:
  - a. Caring for a person with HIV
  - b. Living in the same house as a person who has HIV
  - c. Hugging/touching a person who has HIV
  - d. Using the same toilet as someone with HIV
2. Name two opportunistic infections.
3. List the ways HIV is transmitted from person to person. (Hint: HIV is present in four bodily fluids and is transmitted by three main activities.)
4. What kind of cells in the body does HIV attack?
5. Do antiretroviral medications cure AIDS?
6. Why is it important to always take your antiretroviral medications?
7. What are at least two ways to prevent transmitting HIV to another person?

8. In which of these body fluids is HIV NOT present?
  - a. Semen
  - b. Breastmilk
  - c. Blood
  - d. Sweat
  
9. True or False: HIV is not spread by kissing.
  
10. How long should ALHIV take their ARVs?
  
11. True or False: ALHIV can lead long, happy and healthy lives.

**Optional questions for groups with older ALHIV:**

12. Can ALHIV have children?
  
13. Is it okay for two people who are living with HIV to have sex without a condom?

**INSTRUCTIONS:**

Say the following to the group.

- We are going to play a game to review the information we discussed during this session.
- Please stand up and form a large circle.
- I have a “cabbage” here that has questions that will help us review what we learned.
- I’ll toss the cabbage to one of you. Whoever receives the cabbage will pull the first sheet off, read the question out loud and answer the question.

- That person will then toss the ball to another person who will take the next sheet of paper off, read the question aloud and answer the question. This will continue until all of the questions are asked.
- It is OK if you do not know or remember the answer. Let’s support one another and help anyone who doesn’t know the answer.
- Are there any questions about the directions?

Throw the ball to a participant.

If a participant answers incorrectly, ask if anyone else has a different answer. If no one answers correctly, state the correct answer before continuing the game.

**ANSWER KEY:**

1. True or False—HIV is not passed by:
  - Caring for a person with HIV (True)*
  - Living in the same house as a person who has HIV (True)*
  - Hugging/touching a person who has HIV (True)*
  - Using the same toilet as someone with HIV (True)*
  
2. Name two opportunistic infections. *Examples: certain yeast infections, several cancers, pneumonia.*
  
3. List the ways HIV is transmitted from person to person. *(Hint: HIV is present in four bodily fluids and is transmitted by three main activities.) HIV is transmitted from one person to another through blood*

or body fluids. HIV is found in blood, semen, vaginal fluid and breastmilk. People usually get exposed to HIV by having sex without a condom with someone who is HIV positive. Infants can get HIV from the mother before or during birth or through breast-feeding. HIV can also be spread from one person to another by sharing needles used for injecting drugs.

4. What kind of cells in the body does HIV attack? *CD4 cells. They are white blood cells that help your body protect you from germs and viruses.*
5. Do antiretroviral medications cure AIDS? *No*
6. Why is it important to always take your antiretroviral medications? *Skipping doses can lead the virus to become resistant and can also make it more difficult for ARVs to work when you do take them.*
7. What are at least two ways to prevent transmitting HIV to another person? *Examples: wearing condoms when you have sex, abstaining from sex.*
8. In which one of these body fluids is HIV NOT present?  
*d. Sweat*

9. True or False: HIV is not spread by kissing. *True*
10. How long should ALHIV take their ARVs? *As long as their health care provider recommends.*
11. True or False: ALHIV can lead long, happy and healthy lives. *True.*

*Make sure that if anyone says false, you ask probing questions such as:*

- a. What can you do to keep yourself healthy?
- b. What can you do if you don't feel happy?

**Optional questions for groups with older ALHIV:**

12. Can ALHIV have children? *Yes. Talk to a health provider to determine the safest way to pursue having children.*
13. Is it okay for two people who are living with HIV to have sex without a condom? *No, unless they are trying to conceive. Wearing a condom is the safest way to have sex. This prevents infection or co-infection for both partners.*

Now tell participants that they are going to do another activity called body mapping, which can help them be creative, explore their feelings and share their experiences.

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### III. BODY MAPPING

#### BACKGROUND:

*(The following activity was adapted from the “Body Maps” project of The Bambanani Women’s Group in Cape Town, South Africa.)* During this session, you will instruct participants to trace the shape of their bodies on large sheets of paper. In subsequent sessions, participants will add to their maps, incorporating concepts and experiences learned through counseling.

**TIME:** 1 hour to begin, then ongoing

**MATERIALS:** Large sheets of paper; writing and drawing tools (crayons, markers, pencils, chalk); other art supplies (such as colored paper, old newspapers or magazines, glue, paints)

#### INSTRUCTIONS:

Explain to participants that they are going to create body maps by tracing the shape of their bodies on large sheets of paper. They should ask someone to help trace their outline. (If any participants are uncomfortable having someone trace their body, it is OK for them to do a life-sized, freehand sketch of themselves.) Provide markers, crayons, pencils and other art supplies for them to begin adding information about themselves. They can use words, drawings or pictures cut out of magazines or newspapers to express this information.

Tell the group that they will continue to add information to their maps in later sessions. Offer the following suggestions of things to include in this first drawing:

- Birth date and place
- Handprints
- Footprints
- Favorite sayings
- Favorite activities

Walk around the room as participants work and see if anyone needs help or suggestions. After about 30 or 45 minutes, ask if anyone would be willing to show their body map to the group and talk about the significance of what they drew.



#### NOTE TO FACILITATOR:

See page 40 for an example of a body map. More samples from The Body Map Project can be found online at the following site:<sup>8</sup> <http://www.catie.ca/bodymaps/gallery.shtml#learn>



## SESSION

## 2

# Disclosure and Developing Trust in Relationships



### Background for the Facilitator

Review the following information before leading this session.

Disclosing one's HIV status can be beneficial but also risky. Family and friends can provide essential support if they are adequately informed. Health care providers who know their client is living with HIV can offer appropriate care and treatment. A romantic partner can provide emotional support and help practice safer sex. However, people who disclose their positive status also face the potential of stigma, violence and abandonment, often at the hands of the people closest to them.

Trust is an important part of disclosure. Adolescents who are living with HIV will question themselves: "Who can I trust? If I tell someone, will he or she reject me? Will they abuse or hurt me? Will they tell someone else that I am living with HIV or have AIDS?" Young people need support with determining who they can trust, deciding whom they want to share their status with and practicing how to disclose. You can help the participants in your group weigh the risks and benefits of

disclosing their status. Consider inviting guest speakers who are living with HIV and have already disclosed their status to share their experiences.



### Today's Agenda

In this session participants will do the following:

1. Learn the meaning of *disclosure*.
2. Discuss the meaning of trust and understand how to develop it.
3. Discuss the benefits and risks of disclosure.
4. Discuss how to handle people's reactions when one discloses his or her status.
5. Use role plays to practice disclosing to someone.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- Disclosure means sharing your HIV status with someone.
- Disclosure can be both risky and beneficial.



#### NOTE TO FACILITATOR:

Before you begin this session, make copies of the handout "Disclosing Your Status" on page 48.

- Some people might react very badly when they find out you are living with HIV; some people might be kind and helpful.
- You have the right to disclose your status, or not, to whomever you choose.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings.



### Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- *Disclosure* means sharing your HIV status with another person. Disclosing your HIV status is not easy and can be frightening.
- If you were infected perinatally, your parents or guardians might have disclosed your status to others before

you were old enough to know your status. They might have told a health care provider (to help keep you healthy) or a relative or close friend (for support).

- There are benefits to sharing your HIV status with people you trust. Supportive people who know your status can help you in many ways, such as providing emotional support, transporting you to doctors' appointments, reminding you to take your ARVs and helping you put into practice your plan for living positively. But disclosure can also be risky. Some people could take the news very badly. People who disclose their HIV-positive status often face stigma, violence and abandonment.
- It might be hard to know who will be supportive and who will react negatively. So, before disclosing, you'll need to consider carefully whom to disclose to and how and when to do this. You have the right to choose to whom, when and how you want to disclose your HIV status. You might decide to disclose your status to several people or not to tell many people at all. You also have the right to choose what information you share about your HIV status.
- You want your disclosure to be as positive an experience as possible, so give this process a lot of thought.



#### NOTE TO FACILITATOR:

Distribute copies of the following handout to participants and review with them.

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## HANDOUT: DISCLOSING YOUR STATUS

*(This handout is adapted from Healthy, Happy and Hot.)<sup>9</sup>*

- **Get a sense of people’s possible reactions.** Test how your friends, family or partner(s) might react to your HIV status by asking them questions such as “What do you think about HIV?” and “Have you met anyone with HIV?” or by talking about a news story related to HIV. This will help you get a sense of what people think about HIV and how they might react.
- **Practice.** Practice disclosing to people you trust who already know your status. This could include family members or friends and people in this group. Remember, though, that all people will not react in the same way.
- **Learn from others.** Speak to other young people living with HIV or members of your support group to learn from their experiences on different ways to disclose.
- **Consider timing.** Consider things like the best time to tell the person. When dating, some people tell their partner when they first meet while others wait until later. If you decide to wait, remember that you must do everything you can to keep your partner safe by abstaining from sex or using a condom every time. If you are in a long-term relationship, try to find a time when your partner is calm and has time for a long conversation.
- **Choose a safe place.** Think of disclosing in a location in which you feel comfortable and safe—whether it is a private place (like in your house or a friend’s house) or in a public place where other people are around. If you think the person you are disclosing to might get violent or angry, try to tell them in a safe environment and have a plan for your safety. For support, you might bring along a trusted friend or family member who already knows your status.
- **Be ready for a conversation about HIV after you disclose.** Your partner(s) might have questions about living with HIV, such as the risk of transmission and how to practice safer sex. They might also have questions about the source of your infection and about your relationship. Try to have some printed materials about HIV facts that you can give. A counselor can also help with this.
- **Remember that disclosure is a process.** More often than not, disclosing is a process rather than a one-time event. Expect several conversations. Your partner(s) might need time to deal with their emotions. They might have new questions about HIV.
- **Plan to be with people you trust after you disclose.** You can celebrate a positive outcome or get support for dealing with a negative outcome.



## Group Discussion Questions

Use the questions below to lead a discussion about disclosure. It is not necessary to use all the questions. The objective is to create a discussion where the group can share their fears and concerns about disclosure and explore ways they can develop trust in relationships and disclose their status with people they trust.

1. What does *trust* mean to you?
2. How do you know when you can trust someone?
3. How does someone know they can trust you?  
What can you do to build trust in a relationship?
4. What types of reactions do you think people will have when you share that you are living with HIV?
5. What are the benefits to sharing your status with other people?

### **Share the following points if they aren't mentioned by participants.**

- Those who love and care about you will be able to support you and make it easier for you to ask for help if you need it. Supportive loved ones will be able to encourage you through difficult times and congratulate you when you overcome difficult periods.
- Keeping something secret can be stressful. You might be able to relieve this stress if you share your HIV status with people you trust.

- As you disclose your status to people you trust and who love you, you can all work together to help you live a long, healthy and fulfilling life.
- When you disclose your status to a sex partner and follow up with safer sexual behavior, you are being fair and honest and helping to keep them safe.
- When you disclose your HIV-positive status within your community, you are helping to reduce the secrecy, stigma and discrimination surrounding HIV.
- When you share your HIV status openly, other PLHIV in your community are more likely to follow suit and share their HIV status too.<sup>10</sup>

### 6. What are the risks?

Possible responses:

- People might react negatively, reject me, call me names or become violent.
- I might lose the relationship with that person.
- The person might tell others.
- It would make going to school harder if everyone knows.
- It would make dating more difficult.

7. Who are some people to whom you could disclose, and what are the possible benefits and risks for each?

- **Family and friends—Benefits:** They could provide support and assistance. **Risks:** They might react negatively, reject me, call me names or become violent.
- **Service providers—Benefits:** They would provide access to prevention, treatment, support and care services, and timely information on HIV and prevention issues. **Risks:** They might judge me or tell my parents or guardians.
- **Teachers/principals—Benefits:** They might support me, help me keep up with my schoolwork, remind me to take my medications. **Risks:** They might judge me, tell others in my school, try to keep me from attending school.
- **Religious leaders—Benefits:** They might support me, provide spiritual guidance, help me cope with my emotions. **Risks:** They might react negatively, shun me or tell my parents or guardians.
- **PLHIV support groups—Benefits:** They could share their experiences, successes and challenges, and provide support. **Risks:** Very few risks, but it's possible they might not keep my status confidential.

- **My employer—Benefits:** I could be given access to workplace support and medical benefits that might be available. **Risks:** Telling my employer might put my job at risk.
- **Sex partners—Benefits:** I can discuss prevention strategies with my sex partner and go for testing and counseling together. My partner might provide support and love. **Risks:** My partner might react negatively, call me names, leave me or become violent.



### Activity Corner

Use the following activities to help develop a better understanding of factors associated with disclosing one's HIV status. Encourage participants to take notes.

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## I. DISCLOSURE REACTIONS— BEST RESPONSE GAME

**TIME:** 10 minutes or more, depending on how many reaction examples are used

**MATERIALS:** List of reactions (next page), chalkboard or flip chart and chalk or markers to keep score (optional)

### **INSTRUCTIONS:**

Tell the group that in this activity they are going to think of what to say to reactions people might have upon hearing about their HIV status. Remind participants that everyone's experience will be different, but that it is helpful to imagine how people might react and how to respond to those reactions.

Ask for volunteers to be "judges"; preferably pick one boy and one girl. You, the facilitator, will be the third judge.

Divide the rest of the group (not including the two judges) into two teams to play a game.

Explain that you, the facilitator, will share a reaction to disclosure, and everyone will imagine that this is the reaction they received after disclosing their status. Each group will then think of a way to respond to this reaction and, when prompted, share their response with the entire group. The judges will determine which group's response is the best, and the team that came up with it will get a point. When possible, the judges should tell the groups why one answer was chosen over the other.

Before you begin the game, share this example reaction and response with the groups:

You tell your best friend your status; he says,  
"Oh, my brother is HIV positive too. He got

infected when his girlfriend cheated on him. What happened to you?" This is one possible response:  
"Well, it's not really important how someone gets infected with HIV. But I'm glad you understand."

Now read a reaction from the list below. (Choose those that are most relevant to your group, or make up a few of your own.) After each reaction you read, give the groups time to discuss their responses before each group volunteers its favorite response.

When you finish going through the reactions and responses, total up the points to determine which team won.

### **LIST OF REACTIONS:**

1. You tell your teacher your HIV status; she says, "Thank you for sharing that with me. That must have been hard to do."
2. You tell your cousin your HIV status; he says, "Does that mean you're going to die?"
3. You tell your uncle your HIV status; he says, "I am also HIV positive."
4. You tell your friend from school your HIV status; she looks scared and walks away.
5. You tell your boss your HIV status; she says, "I hope you don't think you'll be getting any special treatment."
6. You tell a girl that you have a crush on your HIV status. She asks you, "Is it because you have been sleeping around?"

7. You tell your best friend your HIV status; he hugs you and begins to cry.
8. You tell your mom your HIV status; she says, “We should think about how to tell the rest of the family.”
9. You tell your priest your HIV status; he says, “I will keep you in my prayers.”
10. You tell your grandfather your HIV status; he says, “How did you get it?”
11. You tell your boyfriend or girlfriend about your HIV status; he or she gets very angry and threatens you.

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## II. DISCLOSURE ROLE PLAYS

**TIME:** 20 minutes or more depending on how many role plays

**MATERIALS:** Chalkboard and chalk or flip chart and markers

**INSTRUCTIONS:**

Ask each group member to make a list of two or three people to whom he or she might want to disclose his or her status. Ask participants to make notes about how each person on the list might react. Inform the group that they will use these lists as they practice disclosing their status to others using role plays.

Break into groups of three, and assign each person one of the following roles:

1. Discloser
2. Person disclosed to
3. Observer

Ask the discloser to select a person from his or her own list. The role play partner will pretend to be that person, so the discloser should tell the partner how they suspect the person might react.

Give the pair a few minutes to think about what they will say and to write some notes if that would be helpful.

Now, tell the groups that they will have five to seven minutes to do the role play, and then ask them to begin. Disclosers should tell their role play partners about their HIV status, and the partners will react to the news. Ask the observer to coach the discloser as needed and to pay attention to what went well during the role play and what might be improved. Remind participants to keep feedback positive and helpful.

After the first role play is done, the group members should switch roles and keep doing role plays until each person has had a chance to be the discloser.

After each small group has completed three role plays, ask participants to join the larger group. Ask for volunteers to share how they felt about the role plays.

Use the following questions to process the activity:

- How did it feel to share your status with someone?
- What went well?
- What was challenging?
- How can you use this experience when you prepare to disclose your status to someone you know?

End the activity by highlighting unique points and common themes.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.

### REVIEW QUESTIONS

- What do we mean when we talk about *disclosure*?
- What are some of the risks of disclosing your HIV status?
- What are some benefits of disclosing your status?
- How will you decide whom to tell about your status?



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets. Work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### WRAP-UP

Ask if the group has any last questions or concerns. Thank them for their attention and for sharing their feelings and ideas. Remind them that there are good reasons to disclose their status to people who are supportive and trustworthy (including their sex partners), but that some people will likely have very negative reactions. So they must choose wisely and seek support from the group if needed.



### Background for the Facilitator

Review the following information before leading this session.

*Adherence*—which means taking antiretroviral drugs (ARVs) properly and taking every dose—is crucial to avoiding drug resistance, remaining healthy, reducing the chances of infecting a partner and reducing the chances of delivering a baby who is HIV positive. Combination ART consists of using at least three ARV drugs to suppress HIV as much as possible and stop the progression of HIV infection. Antiretroviral therapy prevents HIV from multiplying in the body. If the virus stops reproducing, then the body’s immune cells are



#### NOTE TO FACILITATOR:

Invite a medical professional who can talk to the group about ARVs in this session. Also, be prepared to provide referrals to places where young people can receive ART. Remember, though, that young people often face barriers to following through on referrals, so help participants make a plan for getting to the referral site (see Activity III, “Creating an Adherence Action Plan,” on page 55).

able to live longer and provide the body with protection from infections. Huge reductions have occurred in death rates and suffering when a potent ARV regimen is used.



### Today’s Agenda

In this session, participants will do the following:

1. Learn how ART keeps PLHIV healthy and stops progression of HIV infection.
2. Discuss the prevention benefits of ART.
3. Discuss the benefits of adhering to ART.
4. Discuss the challenges of adhering to ART and develop some strategies for overcoming them.
5. Identify locations where they can get ARVs.
6. Create a plan to support participants in getting treatment and adhering to ART.



#### NOTE TO FACILITATOR:

If needed, remind participants what ART and ARVs are.

### At a Glance

Write these statements on the chalkboard or flip chart.

- Not everyone living with HIV takes antiretroviral drugs (ARVs). Doctors decide when someone should start taking them.
- ARVs help lower the amount of HIV in the blood.
- ARVs can help keep people who are living with HIV healthy.
- People with low levels of HIV in their blood are much less likely to pass HIV to others.
- For ARVs to work properly, you must take them exactly as recommended by your doctor.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings.



### Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- Not everyone living with HIV takes ARVs. Doctors determine when a PLHIV should begin ART.
- Adherence means taking medicine exactly as recommended by your doctor, all the time. Adherence is important for your health and the health of others.
- Adherence includes these steps:
  - Having a consistent supply of medicine.
  - Storing medications properly. Medicines usually come with recommendations about how they should be stored. The medication will be good only until the date on the package if it is stored as recommended. If you're not sure of a good place to store your medication, ask your health care provider or an adult you trust.
  - Taking prescribed medications every day.
  - Taking prescribed medications at the same time each day.
  - Following any food restrictions that might be associated with medications.
  - Keeping clinical appointments.



#### NOTE TO FACILITATOR:

Ensure that the participants in your group know how to tell time. Find out whether they have ready access to a watch or clock.

- Following up with health care providers as necessary.
- Adherence is challenging, and it is important to understand the challenges so you can make a plan to overcome them.
- ART helps lower a person’s *viral load*. The term viral load refers to how much of the virus is in your blood. There are tests that measure the amount of new HIV released into your blood.
- The best viral load test result is *undetectable*. This doesn’t mean there isn’t any virus in the blood; it just means that there is not enough for the test to find and count. If your viral load is undetectable, you are less likely to become ill or get opportunistic infections and you are less likely to pass HIV to others (although it is still possible to infect others).
- *Resistance* refers to how HIV sometimes does not respond to a particular drug. Resistance can happen when the virus changes its form. When the virus changes its form in a person’s blood, the prescribed ARVs do not work the same way or may not work at all. Taking medications regularly and as prescribed by a health care provider will keep viral load down and prevent drug resistance.

- For ART to be successful, people must adhere to it more than 95 percent of the time. Medications also must be taken at the same time every day (or within an hour of the same time).
- ART is not a cure. It must be taken for life and can be expensive.
- ART is also used in the prevention of mother-to-child transmission and has additional benefits for preventing transmission among couples where one person is HIV positive and one person is HIV negative.

*“I follow my [medicine schedule] strictly because I want to see my future. I want to see what will happen to me.”*

– 10-year-old Vietnamese girl



## Group Discussion Questions

Use the questions below to lead a discussion about adherence. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore their thoughts and questions about HIV and medical adherence.

1. What are some important things you need to remember when you are on ART?  
Possible responses:
  - Keep medical appointments.
  - Take medications on time.
  - Follow food and nutrition guidelines for ART.

2. What do ARVs do?

Possible responses:

- They keep the virus from multiplying.
- They help your immune system stay strong.
- They reduce your chances of acquiring AIDS.
- They can prevent transmission to babies and sex partners.

3. How do you get ARVs?

Talk about the locations in your community where people go to receive ARVs. Examples include clinics, hospitals and mobile clinics.

4. Why is adherence so important?

Possible responses:

- Medications keep you healthy.
- Missing doses of medications can cause the virus to build up drug resistance, which means the ARVs you're taking don't work.
- Adherence helps you live a long and healthy life.
- Adherence helps decrease the amount of HIV in the body.
- Adherence helps prevent transmission to babies and sex partners.

5. What are some challenges you might have in sticking to your plan?

Possible responses:

- Fear that people will find out you are living with HIV
- Side effects
- Inconvenience of taking multiple pills
- Forgetfulness and distractions caused by the complications of daily life
- Negative perception of medications as a constant reminder of HIV infection
- Lack of disclosure to people (family, friends, teachers) who might help with adherence if they knew you were living with HIV

6. What are some ways to manage those challenges? (More ideas will be generated in the "Activity Corner" that follows these questions.)

Possible responses:

- Develop excuses for reasons to get away for a few minutes to take medication.
- Try to take medications at the same time as something else you do every day (such as brush your teeth), if the timing is right.
- Set alarms at times medicine needs to be taken.
- Engage a trusted friend or adult to help remind you or distract attention away from you.

7. Does everybody with HIV infection have to take ARVs?

No, not everyone who is living with HIV has to take ARVs.

8. What happens if someone does not adhere to an HIV treatment plan?

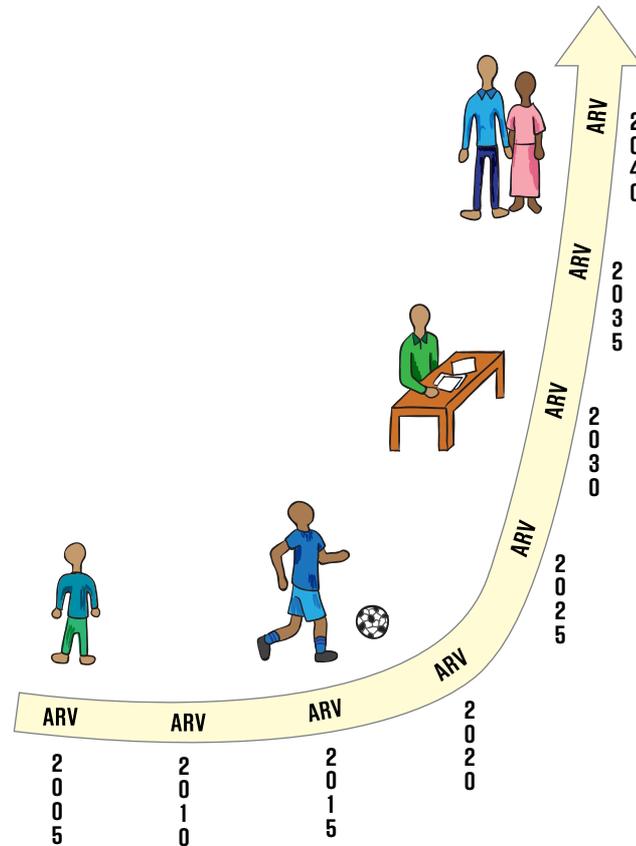
Possible responses:

- If ARVs are not taken at the right time every day, the right amount of medicine will not be in the blood.
- If there is not enough medicine in the blood, the virus will be able to infect the CD4 cells.
- Also, the virus may become resistant, meaning the drugs you've been taking don't work as well, or at all.



**NOTE TO FACILITATOR:**

It might be helpful to draw a visual on a chalkboard or flip chart paper that demonstrates how ARVs can help ALHIV live long, productive lives. See the sample image on the right, which was designed by Botswana's Teen Club (2009).<sup>5</sup> You can adapt the image to better represent the young people in your group, or ask participants to develop their own drawing.





## Activity Corner

Use the following activities to help develop a better understanding of adhering to an HIV medical plan.

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### I. BODY MAPS (CONT.)

**TIME:** 30 minutes

**MATERIALS:** Body maps; writing and drawing tools (crayons, markers, pencils, chalk); other art supplies (such as colored paper, old newspapers or magazines, glue, paints)

**INSTRUCTIONS:**

Ask participants to get their body maps. Tell them that during this session, they will be adding some things to their maps that relate to adhering to an HIV treatment plan.

Ask group members to add pieces to their maps that describe their feelings, questions or thoughts about ART and ARV adherence.

Ask if anyone would like to share what they added to the body map and explain how these new additions represent their thoughts or feelings. Let the group know that the next exercise will help them with practical tips for improving adherence.

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### II. OVERCOMING BARRIERS TO ADHERENCE

**TIME:** 45 minutes

**MATERIALS:** Flip chart paper and markers

**INSTRUCTIONS:**

Tell the group that they will brainstorm a list of the challenges related to adherence and come up with strategies to overcome these barriers. Remind participants that even if they are not on ART currently, this activity can be helpful in case they do begin taking ARVs in the future.

Ask the group for their ideas of what makes adherence challenging or difficult. Write their answers on the flip chart paper or board. Possible answers include these:

- Side effects
- Remembering to take drugs on time
- Cost
- Traveling away from home
- Work or school
- Pills that are hard to swallow
- Medications that taste bad
- Medicine that makes you feel sick
- Don't want others to know you are taking pills
- Running out of medicine

After the group has generated a good list, ask participants to form smaller groups of four or five people. Give each group a piece of flip chart paper. Assign each group two to three of the challenges generated by the larger group.

Instruct the small groups to discuss some strategies they could use to overcome their assigned challenges. Ask each group to write their ideas on the flip chart paper. After 15 minutes, invite the groups to share their strategies. After each small group has finished presenting their ideas, ask the rest of the large group if they have any strategies to add. Post the strategies for more discussion.

Process the activity with the following questions:

- Which strategies listed do you think you could follow?
- What makes these strategies realistic?
- Who can you call on to help you adhere to your treatment plan?

Summarize by highlighting common themes and unique points.

### III. CREATING AN ADHERENCE ACTION PLAN

**TIME:** 20 minutes

**MATERIALS:** Paper and writing utensils; flip chart and markers or chalkboard and chalk

**INSTRUCTIONS:**

Tell participants that they are going to make a plan with action steps to help them adhere to ART.

Ask the group what sorts of activities or tasks need to be accomplished if they are to adhere to their medications. Record answers on flip chart paper or chalkboard. Possible responses include:

- Getting transportation to medical appointments
- Getting the medicines
- Determining where to store the medicines
- Figuring out where and when to take the medicine
- Getting referrals to medical support and services

Once a list has been made, distribute paper and pens or pencils to each participant. Instruct participants to draw a line down the middle of their paper. On one side, they should write the tasks they identified. On the other side, they should list some concrete action steps they will take to carry out those tasks. (See the “Sample

*“I usually hang out with my boys on the street corner until 8:00, and sometimes I need to come up with excuses to take my meds at 6:00, [so I say] “I need to cook,” so I can get away.”*

*– Adolescent boy in Botswana*

ART Adherence Health Plan” below.) Once everyone is finished, ask if anyone would care to share their plan.

### SAMPLE ART ADHERENCE HEALTH PLAN

ISSUE	STRATEGIES/ACTIONS TO TAKE
Get transportation to medical appointments.	
Get medicine.	
Determine where to store the medicine.	
Figure out where and when to take the medicine.	
Get referrals to medical support and services, as needed.	

Finally, ask the group the following question: Once you have a health plan, it’s important to develop a routine to review it and adapt it if your needs or issues change. What are some ways to do this? Possible answers include these:

- Share the health plan with your provider, a friend or a family member.
- Have a monthly routine to check in with your plan to update your issues as your needs change.
- Check in with others in your information and support group about their progress on health plans.

## IV. ADHERENCE ROLE PLAY

Divide the participants into groups of three to four.

Give the groups 10 minutes to prepare a short role play in which they act out a challenge to adherence and a way to overcome the challenge. You can assign a particular challenge to each group, or have each group pick one from the list created in Activity II, “Overcoming Barriers to Adherence.”

Have each small group present their role play to the rest of the group.

Ask the large group to identify the challenge that was acted out. Ask if anyone has experienced a similar situation. If so, ask if they have any comments on how the challenge was dealt with in the role play. Did they handle the challenge in the same way or use a different strategy? Did it work? If not, what might they do differently in the future?



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### REVIEW QUESTIONS

- Does everyone who is living with HIV need ART? Why or why not?
- Why are ARVs so important for people taking them?

- What are some of the main things to remember about taking ARVs?

### WRAP-UP

Ask if the group has any last questions or concerns. Thank them for their attention and participation. Remind those who are taking ARVs how important it is to take them exactly as they have been instructed by a health care provider. If they find that they are having trouble, they should review their adherence plan and ask for support from someone trustworthy and responsible. Suggest that group members help each other as much as they can.



### Background for the Facilitator

Review the following information before leading this session.

Good nutrition and healthy habits are important for all adolescents. For ALHIV, nutrition interventions can help to manage symptoms, promote response to treatment and improve functioning and quality of life. One of the challenges in integrating nutrition and HIV care is time. In busy HIV clinics, it might be hard to find time to properly address nutrition. When pressed for time, health providers understandably tend to prioritize adherence and acute conditions. Therefore, counseling and support programs must address the importance of nutrition and healthy habits for ALHIV.

Another major consideration for adolescents, whether or not they are living with HIV, is drug use and alcohol abuse. Young people often experiment with drugs and alcohol, and ALHIV might be particularly susceptible to using drugs and alcohol to cope with depression about their diagnosis. Recreational drugs can interact with ARVs. These interactions can increase or decrease the levels of ARVs in the body. In the worst case, ARVs can

stop working because there won't be enough of them to fight HIV. Also, drug interactions can cause a serious, possibly fatal increase in the potency of recreational drugs. Additionally, drug and alcohol use can also lead to behaviors that put ALHIV and their partners at risk of unintended pregnancy, HIV or other STIs, or co-infection with another strain of HIV.<sup>11</sup>



### Today's Agenda

In this session participants will do the following:

1. Learn how nutrition affects HIV.
2. Learn how drugs and alcohol affect HIV.
3. Discuss how drug and alcohol use affect decision making.
4. Discuss how drugs and alcohol affect ARV regimens.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- Healthy food is essential for everyone.
- HIV makes it harder for the body to absorb

nutrients, so it is important that people living with HIV get proper nutrition to stay healthy.

- Eating healthy food can help with ARVs' side effects.
- Using drugs and abusing alcohol are unhealthy for everyone, but maybe more so for people living with HIV.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure the participants that they don't have to. Answer any questions that arise, and help process feelings.



### Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

The following information is adapted from *Nutrition and HIV/AIDS: A Training Manual for Nurses and Midwives*.<sup>12</sup>

- Adolescence brings about rapid growth, which usually increases your body's demands for energy and nutrients that you get from food. Getting proper nutrition will help ensure that you will have good physical growth, help prevent infections and help provide energy for you to do the activities you want and need to do.
- HIV can interfere with your body's ability to absorb important nutrients. So it is especially important to improve and maintain good nutrition and get regular physical activity to help prolong your health and delay the progression of HIV to AIDS. The impact of proper nutrition begins at the beginning of HIV infection—even before you might notice other symptoms. (Review the “Good Nutrition for ALHIV” chart on page 61.)
- People with HIV can get many infections (called *opportunistic infections* or OIs). Symptoms of opportunistic infections, such as diarrhea and vomiting, can prevent your body from absorbing vitamins, minerals and other nutrients you need to grow and remain healthy.



#### NOTE TO FACILITATOR:

Make enough copies of the “Good Nutrition for ALHIV” chart on pages 61-63.

- Many OIs are very serious, and they need to be treated. Some can be prevented. It is important to talk with your health care provider about preventing opportunistic infections. Good hygiene (keeping clean) is important for preventing OIs.
- HIV doesn't cause death directly. Instead, it weakens your body's ability to fight disease. Minor infections that are rarely seen in someone without HIV can be deadly to those with HIV. Getting proper nutrition can help reverse this cycle by keeping your immune system strong enough to prevent OIs and allowing you to absorb the nutrients you need to remain healthy and grow.
- ARVs work best when taken in conjunction with a healthy diet. Taking some medications on an empty stomach can make you feel nauseous.
- Drug use and alcohol abuse are concerns for all adolescents, but even more so for ALHIV. There hasn't been much research on drug and alcohol use and HIV progression. Research does show, however, that if you stay out late often, abuse alcohol, or use drugs, your physical health will be affected. It's great to have an active social life and be with friends, but getting enough sleep, eating regular meals and getting regular physical activity help all of us stay healthy. Drug use can affect sleep and appetite. Lack of sleep and poor diet can cause our

bodies and immune systems to weaken. This can make it easier for ALHIV to feel the side effects of ARVs or become more susceptible to OIs.

- When someone is taking ARVs to fight HIV, serious interactions between drugs and ARVs can occur. These interactions can lead to underdoses or overdoses of ARVs or recreational drugs. Some of these may be fatal.
- Drug and alcohol use can affect people's ability to make good choices. Being drunk or high means you could be more likely to take risks.



#### **NOTE TO FACILITATOR:**

The following handout is based on a poster developed by the U.S. Agency for International Development<sup>13,14</sup> and can be given to participants to reinforce healthy habits at home. The information is also provided as a reference for you when sharing key messages and leading discussions on nutrition. Please adapt the examples if some of the suggested food items are not common in your area.

## GOOD NUTRITION FOR ADOLESCENTS LIVING WITH HIV



### Importance of Good Nutrition

#### Need to eat well with HIV and AIDS

- HIV and AIDS increase the body's need for food
- People living with HIV and AIDS are more at risk for malnutrition
- When sick, more food is needed to recover
- Keeps you productive, able to work, grow food, and contribute to family income

#### Maintain body weight

- Eating well helps you maintain weight and increase strength
- Eating well helps you regain weight lost during illness

#### Fight infections

- Eating well helps fight illness
- Eating well helps you recover faster when sick
- Good health reduces the time and money spent on health care

#### Delay getting sick from AIDS

- Good nutrition helps make pills work better and easier to take
- Good nutrition delays the onset of AIDS



### Increasing Appetite

#### Eat when not hungry

- You are more vulnerable to infection if you're not eating
- You need to eat more food than normal when you're feeling sick
- Eat a variety of foods
- Eat throughout your illness
- Avoid alcohol since it reduces appetite

#### Drink porridge

- Drink porridge with soya flour or pounded groundnuts for increased strength
- Have a warm drink after waking up and before going to bed

#### Eat small quantities more often

- Eat small portions 5 to 6 times a day or every 2 hours
- Eat favorite and tasty foods
- Eat your favorite foods with spices (garlic, ginger, curry), onions, or tomatoes for flavor (unless you have oral thrush, diarrhea or another condition that spicy food can aggravate)

#### Make food easier to take

- Soft, mashed, and moist foods are easier to eat
- Grind meat and chicken or cut into smaller pieces for easier eating
- Drink with a straw if mouth is sensitive



### A Variety of Foods Is Needed

- Different foods protect the body in different ways
- Each meal should include all of the following three food types
- More food is needed when you are infected with HIV, even when you are not sick

#### Energy-Giving Foods

- Provide the body the strength to work
- Are insufficient on their own and must be combined with other foods
- Maize, rice, nshima, cassava, sorghum, potatoes, sweet potatoes, pumpkin, imyungu, fritters, bread, oil, margarine, butter

### Body-Building Foods

- Help make muscles and bones strong
- Help put lost weight back on
- Meat, fish, kapenta, chicken, eggs, soya, cow peas, intoyo, groundnuts, chikanda, samp, beans, caterpillars (finkubala), inswa, milk, sour milk (mabisi), maheu, munkoyo

### Protective Foods

- Help the body protect itself
- Add taste and flavor to meals
- Oranges, mango, pawpaw, pineapple, bananas, watermelon, lemons, masuku, tomato, avocado, eggplant, impwa, carrots, onions, peppers, mankolombwe, okra, sindambi, cat whiskers, ibondwe, green leafy vegetables like spinach, lumanda, cassava leaves, and pumpkin leaves



### Variety with Each Meal

- Different food combinations should be included in each meal
- It is important to eat at least three meals a day, plus snacks in between
- Drink clean fluids between meals

### Balanced breakfast

- EXAMPLE 1: Avocado, porridge and sour milk
- EXAMPLE 2: Banana, sweet potato and tea with milk

### Eat snacks

- Eat snacks in the morning and afternoon between meals
- If sick and not hungry, drinks and snacks are easier to take
- Eating small quantities often of a variety of foods is healthier than filling up with one big meal of nshima. EXAMPLE: Groundnuts, grilled cassava, and juice

### Balanced lunches and dinners

- EXAMPLE 1: Nshima, groundnut stew, banana, and orange juice
- EXAMPLE 2: Rice, beans, green beans, and water
- EXAMPLE 3: Nshima, kapenta, pumpkin leaves, and water



### Drink Plenty of Fluids

#### Drink clean water often

- Drink 8 cups (2 liters) of water a day
- Clean water by bringing it to a rolling boil
- Chlorine drops like Clorin can also be used to clean water but must be prepared according to instructions
- Keep well and water storage containers clean and covered

#### Take fluids when not hungry

- Drink between and after meals and snacks
- Not drinking can make sickness worse
- Drinking fluids does not provide as many nutrients as eating but is better than taking nothing
- Fresh fruit juice has vitamins
- Mix milk with light tea
- Sour milk (mabisi) fights germs that cause diseases

#### Take fluids with diarrhea

- Take oral rehydration solution (ORS) after each diarrheal episode
- Use only clean water when preparing ORS
- Drink clean water, chibwantu, rice water or soup broth
- Sip small amounts of clean water often or use a straw
- Take yogurt or sour milk
- Avoid sweetened juices, soft drinks, teas, and coffee
- Avoid hot drinks
- Avoid alcohol and acidic fruits
- Drink soups and porridge
- Add pounded groundnuts or soya flour to porridge for strength



## Home Cooking and Hygiene

- People with HIV and AIDS are more vulnerable to getting sick
- Keeping surroundings clean reduces the chances of getting sick

### Keep surroundings clean

- Keep toilets clean and covered
- Keep animals penned away from cooking area
- Clean up puddles of water
- Keep mats clean
- Sweep often and bury garbage

### Wash hands often

- Wash hands with water and soap or ash after using the toilet, cleaning a baby, and before and after preparing, cooking, or eating food
- Dirty hands are a major cause of infection

### Wash dishes with soap

- Wash dishes and pots thoroughly with soap
- Rinse and cover with a clean dish towel

### Rinse vegetables and fruits

- Dirt on produce skin carries germs that can cause sickness
- Rinse fruits and vegetables with clean water before eating or cooking

### Store dishes

- Wash food preparation area daily with soap
- Keep utensils clean and stored in a covered location away from insects and animals



## Take Most ARV Pills with Food

### Take pills with food (usually)

- Food can reduce nausea caused by some pills
- Pills are absorbed better with food
- Certain ARVs are taken without food
- Follow the advice of your health care provider

### Exercise, then eat and take pills

- Stretching or a short walk can increase appetite

### Take pills with liquids

- Drinking liquids prepares the stomach for pills and helps one swallow pills
- Clean water, fresh juice, milk with light tea, soup or rice water can be taken if food is unappetizing



## Group Discussion Questions

Use the questions below to lead a discussion about nutrition. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore their thoughts and questions about nutrition and positive living with HIV.

1. What does it mean to have a healthy diet with a variety of foods? Why is nutrition particularly important for young people living with HIV?  
Possible responses include these:
  - Improving and maintaining good nutrition may prolong health and delay the progression of HIV to AIDS.
  - HIV weakens the immune system. This may cause the body to become susceptible to OIs. These infections can make it difficult for the body to absorb important vitamins and nutrients.
  - Adolescents' bodies are still developing. All adolescents should try to eat a healthy diet so they can grow stronger and feel good.
  - HIV affects the body's nutritional status. Poor nutrition further weakens the immune system. Then your body can't fight off other infections, making you even sicker.
2. What might be some challenges to getting the variety of foods you need for staying healthy?
  3. What available foods are high in nutrition and affordable?
  3. What types of energy-building foods are available locally? (Use the handout, "Good Nutrition for ALHIV" as a reference.) What type of body-building foods are available locally? What types of protective foods are available locally?
  4. What do you usually eat at lunch? Does it meet the requirements for a balanced meal? What can you do to make it more balanced? What types of snacks can you eat that are good for you and taste good?
  5. What are some simple things you can do to make sure you get enough food even when you are not hungry? (Refer to the "Good Nutrition for ALHIV" handout for ideas, such as eating smaller meals more frequently, drinking porridge and making food softer and easier to eat.)
  6. Why is it particularly important to avoid drugs and excessive alcohol use now that you are living with HIV?  
Possible responses include these:
    - They can have negative interactions with ART.
    - They can negatively influence decision making.
    - They weaken the immune system.

7. Sleep is important for good health. What can you do to make sure you get enough sleep? What are some things that help when you have trouble sleeping?
  
8. Good hygiene is especially important when you are living with HIV because it helps to prevent OIs. What are some things you can do daily to keep clean and prevent germs and bacteria from getting into your body? What can you do in the morning? At meal times? Before bed? Where you eat? Where you sleep?
  
9. What are some ways you can take care of yourself to stay healthy? What are some things you can do every day to stay healthy?  
Possible responses include these:
  - Getting enough sleep and rest
  - Exercising or physical activity
  - Staying clean—washing hands before every meal, bathing regularly, washing clothing and sheets often
  - Talking about emotions through counseling or other support



## Activity Corner

Use the following activities to help young people develop a better understanding of how nutrition affects ALHIV.

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### I. BODY MAPS (CONT.)

**TIME:** 20 minutes

**MATERIALS:** Body maps; writing and drawing tools (crayons, markers, pencils, chalk); other art supplies (such as colored paper, old newspapers or magazines, glue, paints)

**INSTRUCTIONS:**

Ask participants to get their body maps. Tell them that during this session, they will be adding some things to their maps that relate to staying healthy by eating nutritious foods, by avoiding drugs and limiting alcohol, and by practicing good hygiene.

Ask group members to add pieces to their maps that describe their feelings, questions or thoughts about nutrition and staying healthy. These pieces could be images of healthy foods, or sports and other healthy activities. Participants could also choose to write a poem about staying healthy.

“Friends are going out to parties... but when you get there, they all buy alcohol. And even if you try to be responsible, you feel embarrassed. So you engage in risky behaviors to impress your friends.”

– Adolescent from Botswana

Ask if anyone would volunteer to show what they added to their body map. Give the group a little time to discuss their maps with one another.

---

## II. LINKAGES BETWEEN HIV AND NUTRITION

(This information is adapted from *Nutrition and HIV/AIDS: A Training Manual for Nurses and Midwives*.<sup>12</sup>)

**TIME:** 30 minutes

**PREPARATION:**

Write the following terms on notecards or paper before the information and support group session.

- Weakened immune system
- Increased nutrient needs
- Nutrients not absorbed properly
- No desire to eat, refusal to eat
- Nausea
- Frequent infections
- Frequent diarrhea

**MATERIALS:** Prepared notecards, flip chart paper, tape

**INSTRUCTIONS:**

Post two pieces of flip chart paper on a wall with these titles: “Effects of Poor Nutrition on HIV” and “Effects of HIV on Nutrition.”

Ask for a volunteer. Give him or her one of the notecards. Ask the participant to walk to the wall and tape the notecard under the appropriate heading. Continue with new volunteers until all the notecards have been posted.

After notecards are placed on a flip chart, ask participants to explain their choices, for example, why “No desire to eat” was placed under “Effects of HIV on Nutrition” rather than under “Effects of Poor Nutrition on HIV.”

Wrap up with a summary statement about why good nutrition is so important, especially for people who are living with HIV.

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### III. TALKING ABOUT DRUGS AND ALCOHOL

**TIME:** 60 minutes

**PREPARATION:** Write the following four questions on flip chart paper (one question per page). If flip chart paper is not available, draw lines down the middle of a chalkboard and write a question in each column.

1. What are some reasons young people use drugs?
2. What are some of the reasons young people drink alcohol?
3. What are the differences between responsible drinking and drinking to excess?
4. Why should people living with HIV avoid using drugs and abusing alcohol?

**MATERIALS:** Flip chart paper and markers or chalkboard and chalk

**INSTRUCTIONS:**

Begin by asking the group to call out all the different kinds of drugs and alcohol in their community. List answers on a flip chart.

Then post the four flip chart pages you created.

Ask the group to call out answers to each of the questions and list their answers on the flip chart pages. Go back to the brainstormed list of drugs and alcohol used in participants' communities. Ask participants which are most commonly used. Now ask them to form smaller groups, and assign each group one of the drugs participants said were used commonly in their communities.

Tell the small groups they have 10 minutes to prepare a short role play about situations they might face where people are abusing the assigned drug or alcohol. (They could use some of the answers to the four questions to inspire their role play.) In the role play, participants should demonstrate the ways they can stop using or stay away from drugs.

Share role plays. Close by summarizing the different ways identified to avoid drug use or alcohol abuse. Add the following strategies if not already identified:

- Refuse; don't be afraid to say "no."
- Make your voice strong and sure; sound serious!
- Do not send mixed signals.
- Walk away.
- Avoid the situation.
- Ignore the offer.
- Make friends with people who don't use drugs or abuse alcohol.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

- What about young people who aren't living with HIV? How is their health affected by drug use or alcohol abuse? (Make the point that young people who aren't living with HIV face nearly all of the same risks if they take drugs or abuse alcohol.)

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their attention and participation. Remind them how critical it is to try to eat healthy foods, but acknowledge that it's not always easy. Provide referrals, if possible, to organizations that can help those who suffer from hunger or malnutrition or have substance abuse issues.

### Review questions

- Why is it so important for someone living with HIV to get proper nutrition?
- Can you name five nutritious foods?
- How can drugs and alcohol affect you as an ALHIV?



### Background for the Facilitator

Review the following information before leading this session.

Young people might not understand all the emotional and physical changes that occur during adolescence and could be embarrassed to ask. They also might have questions about how their HIV status might affect these changes and vice versa. Providing adolescents with basic information about puberty can help them understand what they are experiencing and make it easier for them to ask questions and talk about what they are feeling.

Some studies suggest that perinatally infected young people might experience delays in puberty. There are many possible reasons for this, so those experiencing delays should be in the care of a health provider who can monitor and evaluate possible causes. It is also important that those experiencing delays are able to talk about it because these delays might add to their feelings of being different and unwell.

Ensure that your group understands that people change and develop at different rates, so it is best not to compare themselves with others. Young people can sometimes experience feelings of isolation and of being different from everyone else. Help them realize they are not alone—everyone goes through puberty, just not in the same way.

Not every topic in this session will be appropriate for every group. For example, if participants are older adolescents (16- to 19-year-olds), they might not be interested in discussing the changes that occur during puberty. Also, some topics might be easier to address in a group of only boys or only girls. If you decide to split the group up into same-sex smaller groups, you might also ask a guest facilitator who is the opposite sex of you to work with the appropriate group. Consider the needs of your participants and tailor the session accordingly.



#### NOTE TO FACILITATOR:

Make enough copies of the “Growing and Changing Fact Sheet for Girls” and the “Growing and Changing Fact Sheet for Boys” (pages 72–75) for all of the participants.



## Today's Agenda

In this session participants will do the following:

1. Learn the meaning of *puberty* and discuss the stages of development for girls and boys.
2. Learn how they can take care of themselves during this time of change.
3. Discuss questions they have about the changes they are or will be experiencing.
4. Discuss how HIV might affect these changes.
5. Examine myths and facts about sexual development.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- Puberty is a phase in which you go from being a child to being an adult.
- During puberty you will experience changes in your body and in your emotions.
- Change happens at different rates for different people.



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- Your body goes through many changes during adolescence—this time period is often referred to as *puberty*. Changes occur at different rates for everyone, and there is a wide range of what is considered “normal.” So try not to be concerned if you are changing at a different rate than your friends or peers are.



### NOTE TO FACILITATOR:

Distribute the “Growing and Changing Fact Sheet” handouts (pages 72-75). At this point, consider splitting the group up into same-sex groups. You and your co-facilitator should review the fact sheets with the participants. When you are done, bring them back together to go over the rest of the following key messages.

- You might experience changes not only in your body, but in your emotions as well. You might feel like your emotions change from minute to minute. You could feel sensitive or become easily upset. You might lose your temper more than usual or get angry with friends or family members more easily. All of these feelings are normal.
- It is also common to feel sad or depressed sometimes. It's important to talk to adults you trust about any feelings of anger, sadness or depression.
- During puberty, it is normal to become more aware of thinking about someone in a sexual way. Having sexual feelings is normal and nothing to feel guilty about. This happens in both boys and girls.
- Some of the stories you may have heard about sex might be myths. *Myths* are opinions or beliefs that might not be true. *Facts* are known truths. Today we're going to discuss some basic facts about puberty. Feel free to ask questions so that you can determine if something you have been told is a myth or a fact.
- Your health needs will change as you grow. Some of you might be switching from a pediatric (children's) health provider to one for young people or adults. Caregivers, family members and health care providers might begin to expect more from you;

they might expect you to take more responsibility for your own care and treatment. Sometimes you might feel ready for this new level of responsibility and decision making. But you also might feel like you want to go back in time, when you had fewer responsibilities. It's important to remember that most young people feel this way at one time or another.

- Good nutrition and hygiene—regular bathing and frequent hand-washing—are important for everyone. But they are even more so for those living with HIV, which can weaken your immune system and leave you vulnerable to infection. Good hygiene can help minimize germs and keep you healthy.

## HANDOUT: GROWING AND CHANGING FACT SHEET FOR GIRLS

(This information is adapted from *Family Life Education: Teaching Adults to Communicate with Youth*.<sup>15</sup>)

Girls develop from ages 9 to 24. Every individual will experience these changes at different times; this is normal. Most girls and young women will see the following physical changes.



Girls start puberty around age 9. Here are some of the changes that happen to girls during puberty (ages 9 to 12):

- They grow taller and gain weight (often before boys).
- Breasts begin to enlarge.
- Hips widen.
- Acne develops.
- Hair grows around genitals and under arms.
- Ovaries mature; menstruation (monthly bleeding) begins; able to become pregnant.



From ages 14 to 19 development continues:

- They grow taller and gain weight.
- Breasts may continue to grow, and nipples may become a darker color.
- Hips continue to widen.
- Hair continues to grow around their genitals and under their arms.



Between ages 20 to 24 development may continue:

- Breasts may continue to grow, and nipples may become a darker color.
- Hips continue to widen.
- Hair continues to grow around their genitals and under their arms.
- Development usually finishes by age 24.

The clitoris is the area of sexual arousal for a woman. About the size of a pea, it enlarges during stimulation.

The urinary tract opening is where urine leaves a woman's body.

The vaginal opening is where menstrual blood and tissue leave the body; the penis is inserted during sexual intercourse; and expansion occurs during delivery, to allow the birth of a child.

Ovaries contain thousands of immature egg cells. Monthly, the ovary releases a mature egg, which travels through the fallopian tube to the uterus.

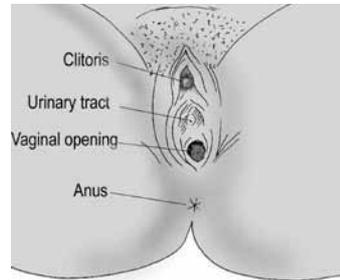
If an egg is fertilized by sperm, the fertilized egg generally attaches to the wall of the uterus where it can grow over nine months into a baby. If the egg is not fertilized, the egg, tissue and blood are shed during menstruation.

#### Menstruation:

- Is the first visible sign that a young girl can become pregnant and have children
- Is often irregular in the beginning but will become more regular with age
- Can start as early as age 9 or as late as age 16
- Has started when a little blood comes slowly out of the vagina
- Can last from three to seven days and happens about once a month for most girls
- Varies widely in flow and amount of blood.

The physical symptoms associated with menstruation include cramps, pain, bloating, weight gain, swollen or painful breasts, swollen hands or feet, headaches, dizziness or irritability. Girls may also

#### FEMALE EXTERNAL GENITALIA

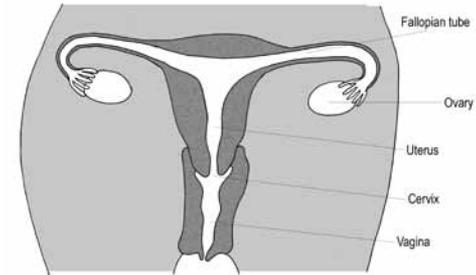


experience mood changes. Relief can be found with pain relievers, hot water compresses, herbal teas or other local remedies. If these do not help, visit a health care provider.

One of the cheapest things to use when you are menstruating is clean cloths. You can cut them to fit your underwear, sewing several layers of cloths on top of each other. Make sure that they are clean. Wash them thoroughly with cold water and bleach (about one part bleach to nine parts water), and hang them in a sunny place to dry. The sun is a very good disinfectant and kills germs. Toilet tissue is also inexpensive. You will need to make a thick long wad of toilet tissue. But toilet tissue is usually rough, and it can cause irritation and soreness to your skin.

Pads are also good. They are designed to fit neatly between your body and your underpants. Pads have a plastic lining to minimize leakage. If you use pads, you need to dispose of them correctly after use—wrap them in paper, and then dispose of them in a pit latrine or burn them. Do not flush them down the toilet, as they will block the pipes.

#### FEMALE INTERNAL GENITALIA



One nice thing about tampons is that you cannot feel them at all, but they do require extra care. If you choose to use them, always wash your hands before and after inserting a tampon. You also need to change tampons frequently (every four to six hours is recommended), as you can get an infection in your vagina if you leave a tampon in for an extended period time. Change your tampon before going to bed and when you wake up in the morning to avoid infections. Be sure to discuss any questions you have about your period and how to use tampons or pads with your health care provider.

Your menstrual period is part of you. If you prepare for it, you will find that it isn't hard to deal with. If you have heavy bleeding, with or without cramps, talk to your health care provider. There are medicines that can help. You can be active, do all the things you enjoy and still have fun during your periods—they shouldn't cause you to stop your daily routine. Remember, though, that the beginning of menstruation means that you are physically able to become pregnant.

## HANDOUT: GROWING AND CHANGING FACT SHEET FOR BOYS

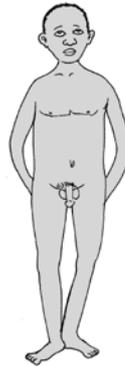
(This information is adapted from *Family Life Education: Teaching Adults to Communicate with Youth*.<sup>15</sup>)

Boys develop from ages 10 to 24. Every individual will experience these changes at different times; this is normal. Most boys and young men will see the following changes



Boys start puberty around age 10. Here are some of the changes that happen to boys during puberty (ages 10 to 13):

- Growth spurts occur.
- Muscles enlarge.
- Voice deepens.
- Acne develops.
- Sperm matures; wet dreams begin.



From ages 15 to 19 development continues:

- Genitals enlarge.
- Bones grow in the face, and the face looks less childlike.
- Skin and hair become more oily.
- Body sweats more.
- Chest and shoulders grow bigger.
- Hair grows on the face—first as mustache, then beard and sideburns.
- Hair grows around genitals, under arms and on chest.



From ages 20 to 24 development finishes:

- Body continues to grow.
- Genitals continue to enlarge.
- Hair continues to grow around genitals, under arms and on chest.

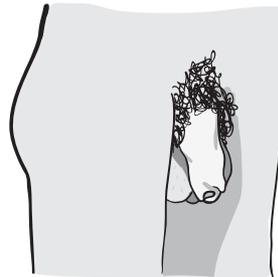
Males can be circumcised or uncircumcised. Circumcision can be done safely by professionals or trained traditional healers with clean medical instruments.

In circumcised males, the foreskin of the penis is removed, exposing the tip of the penis. In uncircumcised males, the foreskin covers the tip of the penis.

- Erections occur when the penis fills with blood and becomes hard and straight.
- Erections in young boys can happen for no reason at all or as boys develop sexual desire and think about sexual things.
- Erections begin in infancy; younger boys do not have control over when erections occur. As boys grow older, they learn to control erections better.
- It is very common for a boy to wake up with an erection. While he is asleep, a boy's penis can become erect five to seven times. This is healthy and normal.
- Having an erection is not a sign that a boy must ejaculate (release sperm) or have sex. If he waits, the erection will go down on its own without causing any harm.
- When a boy has an erection, he will find that he cannot urinate easily because a muscle blocks off the bladder. He will have to wait for the erection to go down before he can urinate easily.

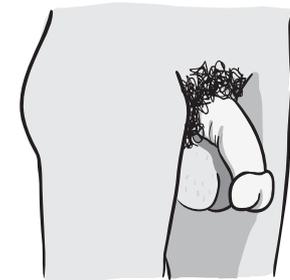
- A wet dream, or nocturnal emission, happens when a boy's penis becomes erect and he ejaculates while sleeping.

#### MALE EXTERNAL GENITALIA



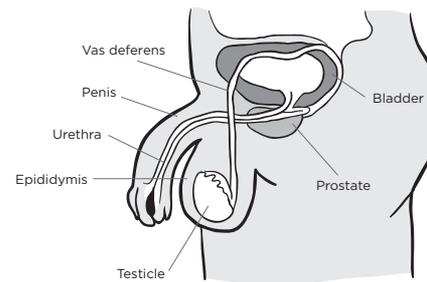
*Uncircumcised*

#### MALE EXTERNAL GENITALIA



*Circumcised*

#### MALE INTERNAL GENITALIA





## Group Discussion Questions

Use the questions below to lead a discussion about the changes that come with puberty. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore the changes that come with adolescence and ask their own questions about these changes.

1. What are some physical changes you have noticed about you or your friends? How do you feel about these changes?
2. What are some of the emotional changes?
3. Who can help you answer questions you might have about these changes?
4. What steps can you take to take care of yourself as you change and grow? How are your daily routines affected by these changes and by living with HIV?
5. What are some important daily health habits? What will you do first thing in the morning as you prepare for your day?
6. What are some special considerations for staying healthy and living with HIV?



### NOTE TO FACILITATOR:

If some of the group members will be taking ARVs, this would be a good time to discuss adherence and how they can integrate taking their medications with some of their daily routines, such as before brushing their teeth or having a meal.



## Activity Corner

Use the following activity to help develop a better understanding of the changes that occur during adolescence.

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## I. MYTHS AND FACTS

(*This information is adapted from Family Life Education: Teaching Adults to Communicate with Youth.*)<sup>15</sup>

**TIME:** 35 minutes

**MATERIALS:** Markers, tape

**PREPARATION:** Create a flip chart with the word *myth* written at the top on the left side and the word *fact* written on the top on the right side. Draw a line down the middle.

**INSTRUCTIONS:**

Ask participants to define *myth* and *fact*. Share the following if not said during the discussion:

- Myths are opinions, beliefs or traditional stories that are thought to be fact.
- Facts are known truths, events that have actually occurred, have been proven, or can be shown physically.

Ask the participants to write down a myth they have heard about sexual development or something that they are unsure about. The myth should be in the form of a statement and not a question. Collect their responses. Select some to write on the myths and facts flip chart, as in this example:

MYTH	FACT
Masturbation makes you infertile.	
A girl can't get pregnant if she's on her period.	
Wet dreams are a sign that something is wrong with the penis.	
When a boy has an erection he has to have sex.	
A girl can't get pregnant the first time she has sex.	
If someone is taking ARVs, it's impossible for him or her to spread HIV.	

Discuss the different myths. Explain the facts and summarize them on the flip chart. Below are some common myths that have been corrected.

- Masturbation does not cause any kind of sickness or infertility. Masturbation and masturbation with a partner are healthy and safe ways to fulfill sexual desire.
- A girl can get pregnant when she is having her period.
- Wet dreams are perfectly normal and do not indicate any kind of illness.
- When a boy has an erection, he does not need to have sex or ejaculate. If he waits, his erection will go down and he will be fine.
- It is possible for a girl to get pregnant the first time she has sex.
- Although taking ARVs is an essential part of your treatment and care and can reduce the risk of transmitting HIV, it does not completely prevent the spread of HIV. Abstinence or using a condom consistently and correctly helps prevent the spread of HIV.

Ask participants the following questions:

- What are the dangers of myths and misinformation about sexual development?
- What are the different sources for the myths? Which ones came from the community? Or from radio or television? Which are old myths? Which are more recent?
- What can you do to share the facts about these subjects with the community?

Remind participants that myths or misunderstandings are normal. Sometimes you won't know the answer, but participants should know they can find answers by asking professionals.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

## Review questions

- What sorts of changes happen to girls during puberty?
- What sorts of changes happen to boys during puberty?
- Why is good hygiene especially important for people who are living with HIV?

## Wrap-up

Ask if the group has any last questions or concerns. Thank them for their attention and participation. Assure them that lots of people are shy when it comes to talking about their bodies and that any of them can come to you in private to ask questions if they need more information or didn't understand something from the session.



### Background for the Facilitator

Review the following information before leading this session.

Part of adolescence is the exciting but sometimes awkward phase of starting to date and have relationships. It is natural for adolescents to begin to notice others in a sexual way. ALHIV are faced with an array of conflicting emotions—they may feel their sexuality, and therefore their relationships, are redefined because they are living with HIV. And while they need to consider how living with HIV plays a role in having relationships, they do need to hear that they can have relationships and have the right to do so.

It might be helpful to have a health care provider on hand to answer some of the group's questions about living with HIV and having sexual relationships—what the risks are and what precautions they should take to keep themselves and their partners safe. Participants also might have questions about sex that a health care provider can answer.

Consider inviting one or two guest speakers who are older adolescents or young adults living with HIV to discuss how they approach sex and relationships. Remember, too, to tailor this session as needed for your audience. Younger participants might not be sexually active or even all that interested in sex yet. As with all the sessions in this manual, you should find out what your participants most need and want to discuss, and adjust your plan accordingly.



### Today's Agenda

In this session, participants will do the following:

1. Discuss the meaning of sex.
2. Discuss sexual rights and responsibilities and how they relate to living with HIV.
3. Discuss how to make decisions about relationships and sex.
4. Learn how to talk about sex and set limits around sex with their partners.
5. Use case studies to explore decision making around sex.



#### NOTE TO FACILITATOR:

Make copies of these handouts: "How to Use a Male Condom" (page 88), "How to Use a Female Condom" (page 89), and "Condom Do's and Don'ts" (page 90).

## At a Glance

Write these statements on the chalkboard or flip chart.

- Sexuality is an important and pleasurable part of life, but it also carries risks: unintended pregnancy, STIs, transmitting HIV to an uninfected partner.
- Anyone, whether or not they are living with HIV, should wait to have a sexual relationship until they are ready for the responsibilities that come with it.
- You have the same sexual rights as everyone else: to have sex or not, to enjoy sex if you choose to have sex or to wait until you are older.
- You can have a sexual relationship when you are living with HIV, but you need to help protect your own health and the health of your partner.
- Consistent and correct use of condoms is the only form of contraception that also protects against HIV and other STIs.



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to.

Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

*(Some content for the key messages was adapted from the It's All One<sup>17</sup> curriculum.)*



### NOTE TO FACILITATOR:

Session 8, "Sexual Health and Positive Prevention," includes key messages and discussion questions about the following topics: positive prevention, STIs and their symptoms, and multiple concurrent partners. You might want to address these issues or questions now as they arise—group members can benefit from these discussions more than once.

- As you mature, you might start to have sexual feelings about people you know, whether they are of the same or opposite sex. This is common and normal. However, making decisions about when and with whom to have sex isn't always easy. Remember that in a healthy relationship, sex is never pressured, forced, traded or coerced.
- There are different stages to a relationship: attraction, dating and marriage or living together. At

some point the relationship may become sexual. It's important to understand what you want or value in a relationship before you have one.

- Having a sexual relationship means being ready for the responsibilities that come with it—practicing safer sex, being able to handle the possibility of pregnancy, having a healthy relationship between you and your partner that is emotionally safe as well as physically safe.
- Sex can refer to whether we are male or female. But it can also refer to certain sexual acts, such as vaginal sex, oral sex or anal sex between a man and woman; between two men; or between two women. Anal sex, whether practiced by same-sex or opposite-sex partners, is more risky than vaginal sex.
- People like to touch each other in ways that feel good. Sexual intercourse (sometimes referred to as *having sex*) can refer to several physical acts. During sex, a man's penis gets hard and he puts his penis into a woman's vagina, anus or mouth. If his penis is inside the woman's vagina, the man's sperm (which comes from the penis when he ejaculates) travels into the vagina and may result in pregnancy. Same-sex couples also enjoy sex in many similar ways.
- Some people choose to have sex and relationships with a same-sex partner. Same-sex couples

have the same feelings and relationship issues as mixed-sex couples. Same-sex partners have the same responsibility to protect themselves and their partners from HIV and STIs.

- People have sex for different reasons: to have a baby, to feel closer to their partner or just because it feels good. An important aspect of sexual experience is that it be wanted by both partners.
- Because of the various risks that go with having sex—sexually transmitted infections, unintended pregnancy and not being ready emotionally—it is recommended that you wait until you are ready for the responsibilities or possible consequences. If you are considering having sex with someone, take the time to get to know him or her. Will he or she be kind, respectful and faithful to you? Will he or she support your desire to protect yourself from pregnancy or a new sexually transmitted infection?
- Some sexual activities are also safer than others. Safer sex means sexual contact that does not involve any exchange of blood, semen or vaginal fluids.
  - It means being safer from STIs and safer from unwanted pregnancy.
  - It means covering up parts of the body that could be infectious.

- It also means that sexual contact happens in a caring and respectful way—no one feels pressured or forced into sexual contact.

Safer activities can include kissing, touching, cuddling, rubbing against each other, mutual masturbation, and using condoms correctly and consistently for sexual intercourse. We say *safer sex* rather than *safe sex* because sex can't be guaranteed 100 percent safe. One way to have safer sex is to be in a monogamous relationship (only one partner) where you and your partner don't have sex outside that relationship and where you are both free of any STIs. Another form of safer sex is to abstain totally (not have sex at all.)

- If you plan to have sex, condoms are the safest way to protect you and your partner from infection or reinfection. They are also the only form of contraception that protects against HIV and STIs. Condoms are available at clinics and pharmacies. Ask your health care provider where you can get condoms and if they are available for free.
- Many young people know that if they are considering having sex, it's really important to make sure it is safer sex. But it isn't always easy to talk with a partner about it, and it can be embarrassing. Some people may be less careful if they've been drinking, and others may forget in the heat of the moment. If



#### NOTE TO FACILITATOR:

If possible, have condoms available for those who want them. Use a penis model to show how to put a condom on. Distribute the handouts about condoms: "How to Use a Male Condom" (page 88), "How to Use a Female Condom" (page 89), and "Condom Do's and Don'ts" (page 90).

you are considering having sex, it is important to be able to talk about safer sex with your partner.

- Using alcohol or drugs might cause you to do things you would not normally do, such as have sex or unprotected sex. Being under the influence can also increase your risk of being a victim of sexual violence. Continued use of drugs and alcohol can lead to an increased number of sexual partners, other STIs, and physical and emotional problems.
- You can have a sexual relationship when you are living with HIV. Ideally, you will choose a sex partner to whom you feel safe disclosing your HIV status. It is important to remember with sex comes responsibility: You are responsible for your own health (protecting yourself from STIs and using contraception if you want to prevent pregnancy) and the health of your partner (using protection to prevent transmission of HIV).

Consider going to HIV testing and counseling with your partner. If one person is HIV positive and the

other is HIV negative (this is called a *serodiscordant relationship*), you should talk about ways to avoid transmitting HIV. Even if both partners are living with HIV (this is called an HIV-positive *seroconcordant relationship*), each partner could have a different strain of the virus and unprotected sex could lead to a second infection.

- You have the following sexual rights:
  - You have a right to wait until you are ready for sex.
  - You have the right to enjoy sex.
  - You always have the right to say “no.”
  - You have the right to be respected.
  - You have the right to say “yes” to some sexual activities and the right to say “no” to others. Everyone shares these rights.
- Sexual relationships can be enhanced when both partners share responsibility for giving and receiving pleasure. It’s important to consider the feelings of your partner.
- There are a lot of different expressions people use when talking about sex—some are just different terms used in your area or by your peers. Some are disrespectful and should not be used.



## Group Discussion Questions

Use the questions below to lead a discussion about sex and relationships. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore their thoughts and questions about sex, dating and how living with HIV affects their decisions.

### Dating and relationships

1. What are important qualities to look for in someone you want to date?
2. How does living with HIV affect the way you think about dating?
3. What are important elements or ingredients to a safe and healthy relationship?
4. At what point would you feel comfortable sharing your HIV status with someone you are dating? What should you consider when sharing this information?
5. Where are some safe places in your community where you can go to meet people and get to know them? How does living with HIV affect where you choose to go and whom you meet?

### What have you heard about sex?

6. What are some questions you have about sex? What concerns or questions do you have about living with HIV and having sex?

7. What role does your family play in what you have heard about sex? What role does radio or television play in what you have heard about sex?
8. What are other activities besides intercourse that you could do with your partner?
9. How will you know that you and your partner are ready for a sexual relationship?
10. How will you discuss your HIV status?
11. What are some ways to avoid unwanted sex? What can you do when someone makes unwanted sexual advances? How can you handle it?
12. Where can you go to get condoms? What can you say to your partner about using condoms with him or her? Do you know how to use condoms?



## Activity Corner

Use the following activities to help develop a better understanding of the factors associated with sex and HIV.

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# I. DATING AND RELATIONSHIPS CASE STUDIES

**TIME:** 30 minutes

**MATERIALS:** Copies of case studies

**INSTRUCTIONS:**

Inform the group that they will now talk about the role of sex in dating and relationships and discuss how living with HIV affects their decisions about sex and relationships.

Ask participants to form groups of four or five. Give each group a piece of flip chart paper. Assign each group one of these case studies:

- Gerard is 16, living with HIV and interested in asking out a girl he has seen at the weekly market. How should he approach this?

- Bintu is 15 and has been dating someone she met at her church. She recently found out she is HIV positive and was infected as a baby. Her boyfriend has been pressuring her for sex. How should she handle this situation?
- Yoshi, age 20, is living with HIV, has a steady girlfriend and plans to marry her when he is able to afford living on his own. He does not know his girlfriend's status. He thinks she knows that he is positive because she has seen him take his ARVs and he has said that he has a long-term illness. He wants to have sex, but he hasn't talked about it with his girlfriend. What should he do?
- Efia is 17 and has been dating Benjamin, also 17, for almost two years. She is also having sex with Richard, who is 28, and buys Efia food, clothing and minutes for her mobile phone. She recently found out that she is HIV positive and believes she was infected by Richard. Benjamin does not know about Efia's relationship with Richard. Efia is afraid to tell Benjamin about her HIV status. How could she handle this?

Tell the groups to read the case study and discuss the following questions for about five minutes:

1. What decision should the case study's main character make about sex in the relationship and why?
2. Who is involved in the decision, and what is their role?
3. What are the negative or positive consequences that might happen as a result of the decision?

Next, tell the groups that each group will draw four pictures that tell a story about the assigned case study. They should divide their group's flip chart paper into four boxes, one for each of the four pictures.

Tell the groups they have 10 minutes to draw their stories. After the groups finish their drawings, ask each group to share their work and answer the three questions about their case study.

Summarize by highlighting common themes and unique points. Remind participants that while questions such as these have no right or wrong answers, it does help to discuss concerns or questions with people they trust.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- Can you name some of the responsibilities that come with having sex?
- What are some of your sexual rights?
- Who can name three sexual activities that would qualify as “safer sex”?
- Is there a volunteer who can use the penis model to show us how to put on a condom?

### Wrap-up

Ask if the group has any last questions or concerns. Thank participants for their participation and attention. Remind them that people who are living with HIV have the right to date, be in relationships and have sex, but that their responsibilities include keeping their partners safe from HIV and other STIs, preventing unintended pregnancy and not reinfecting themselves with another strain of HIV. If they plan to have sex, the safest way is to use a condom correctly, every time.

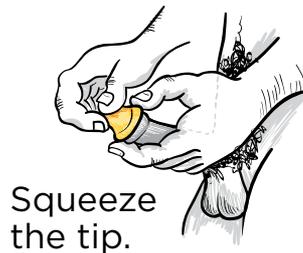
## HANDOUT: HOW TO USE A MALE CONDOM

1. Check the expiration date, if it has one. Be sure the package and condom appear to be in good condition. Open package at one corner, being careful not to tear into the condom. Sharp fingernails or rough handling can damage the latex.



Open Carefully...

2. Squeeze the tip of the condom. This is to eliminate air bubbles as you unroll it onto an erect penis. Leaving the tip empty helps reduce the chance of breakage and allows room for the ejaculation fluid (cum).



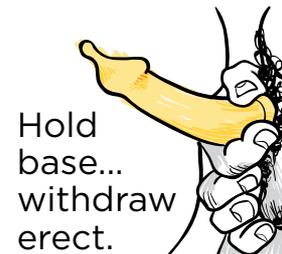
Squeeze the tip.

3. Unroll the condom fully, to base of penis, if possible. The proper fit is important, and a lot of different styles are available. And different sizes of condoms ARE available. You may apply a water-based lubricant if needed.



Unroll it fully.

4. After intercourse, withdraw while the penis is still erect, and hold onto the base of the condom to prevent contents from spilling.

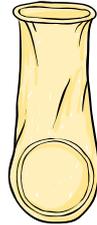


Hold base... withdraw erect.

## HANDOUT: HOW TO USE A FEMALE CONDOM

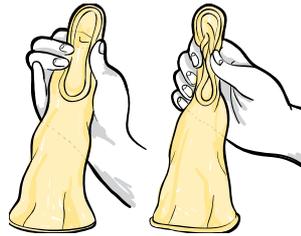
1. Use a new female condom for each act of sex.

- Check package for the date and damage.
- If possible, wash hands with mild soap and clean water.

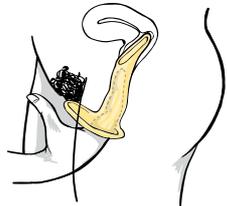


2. Insert condom before any physical contact.

- Can insert up to eight hours before sex.
- Hold ring at closed end and squeeze it.
- Insert ring into vagina as far as it will go.



- Insert a finger to push condom into place.



3. Ensure that penis enters inside of condom and stays inside it!

**Do This**

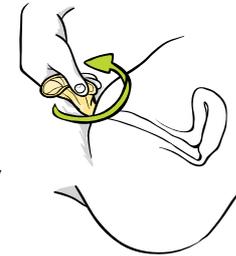


**Not This**

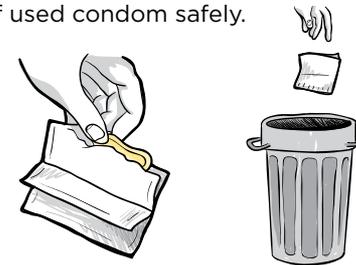


4. After the man withdraws his penis, hold outer ring, twist to seal in fluids, and gently pull condom out.

- The female condom does not need to be removed immediately after sex.
- Remove the condom before standing up, to avoid spilling semen.



5. Dispose of used condom safely.



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## HANDOUT: CONDOM DO'S AND DON'TS

### DO'S

- DO use only latex or polyurethane (plastic) condoms.
- DO keep condoms in a cool, dry place.
- DO put the condom on an erect (hard) penis before there is any contact with a partner's genitals.
- DO use plenty of water-based lubricant (like KY Jelly® or Astroglide®) after putting on latex condoms. This reduces friction and helps prevent the condom from tearing while having sex.
- DO squeeze the air out of the tip of the condom when rolling it over the erect penis. This allows room for the semen (cum).
- DO hold the condom in place at the base of the penis before withdrawing (pulling out) after sex.
- DO wrap the used condom in tissue or a piece of paper, and then throw it away.

### DON'TS

- DON'T use out of date condoms. Check the expiration date carefully. Old condoms can be dry, brittle or weakened and can break more easily.
- DON'T unroll the condom before putting it on the erect penis.
- DON'T leave condoms in hot places—like your wallet or in your car.
- DON'T use oil-based products, such as baby or cooking oils, hand lotion or petroleum jelly (like Vaseline®), as lubricants with latex condoms. The oil quickly weakens latex and can cause condoms to break.
- DON'T use your fingernails or teeth when opening a condom wrapper. It's very easy to tear the condom inside. If you do tear a condom while opening the wrapper, throw that condom away and get a new one.
- DON'T reuse a condom. Always use a new condom for each act or kind of sex you have.



### Background for the Facilitator

Review the following information before leading this session.

According to several studies, unintended pregnancies occur at a very high rate for ALHIV. Young mothers, especially those under age 17, are more likely than women in their 20s to suffer pregnancy-related complications. The risk of dying during childbirth is two to four times higher for women under 20, depending upon their health and access to health care services. For these and other reasons, it is recommended that young women wait to begin a family. A description of contraceptive methods for PLHIV is located in Appendix 1.

ALHIV also might feel pressure from their families and communities to have or not to have children. During this session, it is important that participants be given the opportunity to discuss their feelings about these pressures and how they can respond to them. They need to be able to explore in a safe, nonjudgmental environment what having a family would mean for them while remaining clear on the medical and social realities given their condition.



### Today's Agenda

In this session, participants will do the following:

1. Discuss how to make the decision about starting a family—what needs to be in place for the baby to be raised in a loving, safe and healthy environment?
2. Learn about the risks associated with pregnancy in women under 20.
3. Learn how to prevent pregnancy, and find out what methods are best for people who are living with HIV.
4. Discuss how living with HIV plays a role in the decisions one makes about getting pregnant and having a baby.
5. Discuss how to care for a baby and how living with HIV affects that.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- When a woman is too young, pregnancy can be dangerous for both mother and baby.
- Many girls leave school if they become pregnant, which limits their future opportunities.

- You can prevent pregnancy with contraception. Most methods can be used by women who are living with HIV, but condoms are always recommended to prevent spreading HIV.
- People who are living with HIV have the right to have children when they are ready. It is very important to talk a doctor about the safest way to conceive.
- Taking ARVs exactly as prescribed can lower a woman's chances of passing HIV to her unborn child.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



### Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

*(Some of this content is adapted from Teen Talk.<sup>10</sup>)*

- At some point in your life, you might decide that you want to start a family. This is common and normal. However, if a woman is too young, pregnancy—wanted or unwanted—can be dangerous for both mother and infant. Complications of childbirth and unsafe abortion are among the main causes of death for women under 20.
- A few facts to remember: A girl can become pregnant the first time she has sex; a girl can become pregnant even if her partner does not completely ejaculate (come) inside her vagina; and she can become pregnant even if she has never had a menstrual period.
- A woman can become pregnant when, as a result of sexual intercourse, a sperm from the man fertilizes an egg from her ovary. The fertilized egg attaches to the uterus and the growth of a baby begins. After approximately nine months of growth and development, the baby is born.

- Delaying childbearing can help you and the health of your future children. You can prevent pregnancy by using contraception. Your health care provider can tell you about the different methods, and you can decide which method best fits your lifestyle. (A description of contraceptive methods for people living with HIV is located in Appendix 1, “Contraceptive Methods for People Living with HIV,” page 172. Try to have a health care provider on hand to answer questions, or refer participants to a facility that provides contraception.)
- Most family planning methods can be used by women who are living with HIV, but condoms are recommended for both young men and women living with HIV. People who are living with HIV should use condoms correctly every time they have sex to prevent unintended pregnancies and STIs and to prevent the spread of HIV or reinfection.
- For both men and women living with HIV, it is important to discuss your HIV status and your partner’s HIV status with your health care provider when you decide to start a family. Together you can decide the safest way for all concerned to start a family.
- A pregnant woman living with HIV can pass HIV on to her child during pregnancy, labor and delivery, and breastfeeding. Without ARVs, the risk of an HIV-positive mother passing HIV to her unborn child is between one to three babies of every 10 born. By taking ARVs, a woman can dramatically reduce the risk of transmitting HIV to her baby. If you are or become pregnant, you should talk to a health care provider as soon as possible to find out what ARVs you should be taking and when.
- Some women may be taking ARVs for their own health and then become pregnant. If this happens to you, you should talk with your doctor to discuss the risks and benefits of the drugs to the baby and whether the medicines need to be changed.
- Women who are living with HIV should breastfeed exclusively for the first six months, which means the baby gets all of his or her nourishment from breastmilk. After that, the baby can be breastfed and given other sorts of food. Mothers should continue taking ARVs while breastfeeding.
- Living with HIV can affect your plans to start a family. It is important for women to consult with their health care providers before they try to get pregnant. For women, the amount of virus in your body can affect your efforts to get pregnant as well as the well-being of you and your unborn child.

Once again, maintaining an undetectable viral load is the main goal of strict adherence to ART. Having a low viral load means one is less likely to transmit HIV to their unborn child.

- Taking care of yourself and your health is important to the health of your future family.



### Group Discussion Questions

Use the questions below to lead a discussion about pregnancy planning and prevention. It is not necessary to use all the questions. The objective is to create a discussion where participants can safely explore the questions of how living with HIV affects the decision to have a family, how they feel about using contraception and what methods will work best for them.

### Pregnancy Prevention

1. Think of a young person you know who has a baby. What challenges are they facing?
2. What have you heard about family planning or contraception?
3. Where can you go to get contraception?
4. Where can you go to get condoms? What can you say to your partner about using condoms with him or her?

5. What is your responsibility in preventing pregnancy? What is your partner's responsibility? What will you say to your partner about preventing pregnancy?
6. How does living with HIV affect your decisions about pregnancy prevention and family planning?

### Starting a Family

1. How will you know you are ready to start a family? What are some of the reasons you do or do not want to start a family?
2. What are important skills and qualities that a parent should have?
3. What needs to be in place before you decide to start a family? What type of housing will you need? What type of income will you need? How will you know when you are ready?
4. How long do you think you should wait to start a family?
5. How does living with HIV affect your decision to have a baby?
6. Is it OK to decide not to start a family? Why or why not?



## Activity Corner

Use the following activities to help develop a better understanding of family planning.

# I. GUEST SPEAKERS ON FAMILY PLANNING METHODS AND ON LIVING WITH HIV AND HAVING A FAMILY

**TIME:** Approximately 45 minutes

**MATERIALS:** Guest speaker from a local clinic to discuss family planning methods that are available locally; guest speakers who are living with HIV and have had a child

### INSTRUCTIONS:

Ask the guest speaker from the clinic to share information about different contraceptive methods and how living with HIV might affect choices. Encourage questions from the group.

Ask guest speakers to share their experiences about living with HIV and having a family. Ask the participants to write questions on paper or ask the guest speakers directly. Include the following questions, if appropriate:

- What are the challenges of living with HIV and taking care of a baby? What do you enjoy most about having children?

- What challenges did you have while you were pregnant and when you delivered the baby?
- What fears did you have about having a baby that you have overcome?
- What role does your husband or wife, boyfriend or girlfriend take in helping with the baby?
- What role does your family take in helping with the baby?
- What are your plans if you should start to experience health problems related to living with HIV?
- What and when do you plan to tell your child about living with HIV?
- What advice would you give to someone who is living with HIV and wants to start a family?
- How much does living with HIV play a part in the way you raise your child?
- How does your treatment plan or drug regimen affect your ability to care for your baby?

Summarize by highlighting common themes and unique points. Close by thanking the guest speakers.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- What are some good reasons to wait until you are older to have children?
- Who can name some effective ways to prevent pregnancy?
- If and when you decide to have children, what is the first thing you should do?

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their participation and attention. Let them know about local health facilities or pharmacies where they can get contraception. Remind them that above all else, they should always use condoms. If and when they decide to have children, they should talk to a health care provider about the implications of their positive status for pregnancy.



### Background for the Facilitator

Review the following information before leading this session.

Sexual and reproductive health rights are recognized around the world as human rights. Along with these rights comes great responsibility, particularly for those living with HIV. Incorporating prevention methods into one's life can be difficult, whether you are living with HIV or not. ALHIV may experience unique challenges when trying to practice positive prevention. These may include stigma and discrimination, lack of accurate information and lack of access to care and prevention services. While knowing their status and gathering information is a start, it helps if the group members can explore their personal roles in preventing the spread of HIV and STIs.

The goal of this session is to help the group members recognize the unique risks associated with STIs for people living with HIV and to help them identify practical steps for practicing positive prevention as part of their daily lives.

It might be helpful to have a health care provider on hand to answer some of their questions about HIV and STIs and the unique risks given their status.



#### NOTE TO FACILITATOR:

Make copies of the "Positive Prevention" handout (page 102).

**Positive prevention** is defined as a set of strategies that help PLHIV live longer and healthier lives. By practicing positive prevention, PLHIV can:

- Reduce the risk of HIV transmission to their partners.
- Protect their sexual and reproductive health—and avoid being infected with other STIs.
- Delay the progression of HIV by getting proper nutrition and sufficient rest and exercise and adhering to ART.



## Today's Agenda

In this session, participants will do the following:

1. Learn the meaning of sexual health.
2. Learn the meaning of positive prevention.
3. Discuss strategies for positive prevention.
4. Participate in a condom negotiation role play.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- *Positive prevention* occurs when people who are living with HIV protect their own health, delay the progression of HIV and reduce the risk of transmitting HIV to others.
- One important step in positive prevention is to seek care, support and treatment services.
- Having sex without a condom puts people at risk for unintended pregnancy, HIV and STIs.
- The best way to protect yourself and others against the spread of HIV and STIs is to choose abstinence. The next best option, if you choose to have sex, is to use condoms correctly every time you have anal, oral or vaginal sex.
- People living with HIV can get STIs more easily and might have more serious symptoms. They can also become infected with another strain of HIV.



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

*(Some content for the key messages and the handout was adapted from "Happy, Healthy, and Hot,"<sup>9</sup> the It's All One!<sup>17</sup> curriculum and Teen Talk.<sup>10</sup>)*

- *Sexual health* refers not only to keeping yourself and your partner physically healthy, but also keeping yourself safe, helping your partner feel safe and experiencing sexual pleasure.

- Positive prevention is a way for you to stay healthy and to prevent passing HIV to others.
- Sexually transmitted infections (STIs) are transmitted through unprotected sex.
- If someone who is living with HIV becomes infected with another STI, he or she is more likely to transmit HIV to his or her sex partner than is a PLHIV who does not have another STI.
- People who are infected with STIs are more likely than someone without an STI to acquire HIV if they are exposed to it.
- People living with HIV might get some STIs more easily and can have more serious symptoms. Some STIs have no symptoms or take a long time to develop. Untreated STIs can lead to health problems such as infertility, cervical cancer and anal cancer.
- STIs can be passed to babies during pregnancy and delivery.
- For girls, HIV can make it easier for you to get vaginal infections—yeast, bacterial vaginosis and pelvic inflammatory disease—and abnormal growths of cells on your cervix that can turn into cancer if left untreated. Get regular medical

checkups and contact a health care provider if you notice any sores, bumps or vaginal discharge.

- For boys, HIV can reduce your resistance to infections that cause open sores or warts on your penis and even discharge. If untreated, these infections can get worse or can be passed onto others and can increase your vulnerability to picking up other infections. Get regular medical checkups and contact a health care provider if you get sores on or around your penis or experience any discharge.
- Multiple and concurrent partners (MCPs) means having more than one sexual partner at a time or many partners over the course of a lifetime. In many countries, it is common for men or women to have two or more sexual partnerships that can overlap for weeks, months or years. MCPs greatly increase the risk of HIV transmission because if one person in the network has unprotected sex and gets infected with an STI (including HIV), he or she places other members of the sexual network at risk of infection.
- Having a sexual partner who is much older (and who has potentially had more sex partners than a younger person) can also be risky.
- The best way to protect yourself and others against the spread of HIV and STIs is to choose not to

have sex. The next best option after abstinence is to have a relationship with just one person who is not having sex with anyone else and whose HIV status you know. If you choose to have sex, the best way to protect yourself is to use condoms consistently and correctly. Condoms provide dual protection, which means protection from HIV and other STIs as well as from unintended pregnancy. (If participants don't already have them, distribute copies of the handouts on condoms: "How to Use a Male Condom," page 88; "How to Use a Female Condom," page 89; and "Condom Do's and Don'ts," page 90.)

- Even if both you and your partner are living with HIV, you still need to use a condom and practice safer sex. Keep in mind, there are different strains (types) of HIV. More studies are showing that reinfection with a different HIV strain can and does happen. The main concern is that one partner might infect another with a strain of HIV that is resistant to ARVs. Make sure to use a condom every time you have sex. In addition to preventing reinfection, they also help protect you from unintended pregnancy and from STIs, which could put additional strain on your immune system.
- You have the right to have a safe and healthy sex life, and so do your partners. It's important to make decisions about sex that will keep you and your partner safe and healthy.



## Group Discussion Questions

Use the questions below to lead a discussion about sexual health and positive prevention. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore ways they can protect themselves and their partners from STIs and reinfection.

1. What do you know about STIs? How does living with HIV affect the consequences of getting an STI for you and for your partner?



### NOTE TO FACILITATOR:

If no one mentions it, remind participants of what happens if someone living with HIV gets an STI:

- They might have more serious symptoms than someone who is not living with HIV.
- The STI might compromise their immune system.
- They are more likely to pass HIV to their partner than if they didn't have an STI.

2. Do you know someone who has been or have you been in a sexual relationship with more than one person at a time? How can this situation put the individual and his or her partners at risk?
3. What can you say to your partner about MCPs? What can you do to protect yourself?

4. What is the role of disclosure in staying sexually healthy?
5. What is the role of taking ARVs in positive prevention?
6. What does *safer sex* mean to you? What are some safer sex activities you and your partner can engage in?
7. What questions do you have about STIs? What is your personal role in preventing the spread of HIV and other STIs?



### Activity Corner

Use the following activities to help develop a better understanding of preventing HIV transmission.

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## I. LEARNING ABOUT POSITIVE PREVENTION

**TIME:** 45 minutes

**MATERIALS:** Handout on “Positive Prevention,” flip chart paper, markers

### INSTRUCTIONS:

Divide the group into small groups of about four people. Distribute flip chart paper and copies of the handout on positive prevention. Ask the groups to spend about 10 minutes reviewing the handout together. When they are done, ask them to take about 20 minutes to discuss the following questions and write their answers on the flip chart paper:

- What does *positive prevention* mean to you?
- What are you doing in your life to practice positive prevention?
- How does striving for positive prevention affect your daily life and routines?
- How does positive prevention affect your relationships with others, including friends and family? What about sexual relationships?

When the groups have finished, ask if any group would be willing to share their flip chart with the others. See if others have anything to add.

Point out common themes and important messages.

## HANDOUT: POSITIVE PREVENTION

Positive prevention is a way for you to stay healthy and prevent passing HIV to others. Effective positive prevention includes these steps:

**KNOWING YOUR STATUS:** Positive prevention begins when you receive a positive HIV test result. Having already gone for an HIV test and received the results, you have begun the “prevention” process already, as it shows that you are taking responsibility for your own life and the lives of your loved ones. If someone else, like a parent or guardian, told you that you are HIV positive, they are helping you take the first step in positive prevention.

**DEALING WITH SELF-STIGMA:** When you first find out you are HIV positive, you might experience feelings of shame, guilt or reduced desire to have sex. These feelings are perfectly normal, but they are also a sign that you are stigmatizing yourself. Joining this group is one way of working through

those feelings; it often helps to talk to other young people who are living with HIV and find that you are not alone.

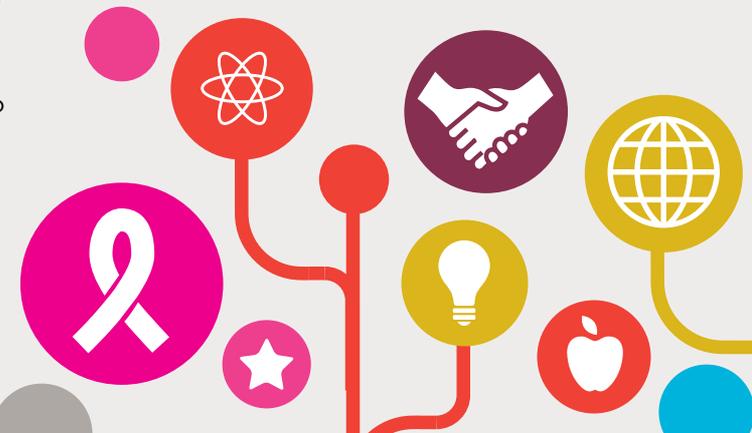
**DISCLOSING YOUR HIV STATUS:** Once you know your HIV status, it is important to think about disclosure. Will you disclose your status, and who will you tell? As we’ve discussed, disclosure has risks, but there are benefits, too. Think about people who could support you in both practical and emotional ways.

**SEEKING SERVICES FOR PREVENTION, CARE, SUPPORT AND TREATMENT:** With positive prevention, you will feel better in time. You might be ready to be in a relationship or have sex. Being on ART will reduce your viral load and make HIV transmission to a partner much less likely, but is not 100 percent effective. So you should continue to use condoms.

**LIVING A HEALTHY LIFESTYLE:** This is important to positive living. As you get access to counseling and other services, you can reinforce or begin to adopt a lifestyle that will keep your body and spirit healthy.

**PLANNING FOR THE FUTURE:** As you accept your status and begin to use relevant services, you can plan your future in terms of these factors:

- When to start treatment and how to stay on treatment
- How to build and maintain a support network for yourself
- Making and meeting your goals, whether they are professional, educational or social



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## II. TALKING ABOUT SAFER SEX

(Content for this activity was adapted from “Safer Sex.”<sup>18</sup>)

**TIME:** 1 hour

**MATERIALS:** Three flipchart pages (labeled “Safe,” “Safe with precautions” and “Unsafe”), blank flipchart pages, markers and tape; or chalkboard and chalk

### **INSTRUCTIONS:**

Post the three flip chart pages (or write the categories on the chalkboard). Ask participants to think about different types of sexual activities and which category —“Safe,” “Safe with precautions” and “Unsafe”—the activities belong to. Ask participants to come up and write the different activities on the different flip chart pages (or under the chalkboard labels). (Note: You can also ask them to share their responses from their seats, and you can write the responses on the appropriate flip chart page or chalkboard.)

Include the following responses if not mentioned:

### **Safe sexual activities (because there is no exchange of body fluids)**

- Massage, hugging, touching
- Masturbation

- Social kissing (kissing with closed mouth)
- Rubbing against each other
- Fantasy (just thinking about sex)
- Kissing the body (clean skin, not sexual areas or open sores)
- Saying *no* to anything you don’t feel comfortable about

It is often assumed that these kinds of activities are only a lead-in to sexual intercourse. Many people find that these safer forms of sexual activity are more than enough to express their emotions and their love for each other.

### **Sexual activities that can be safe with precautions**

- French kissing (kissing with an open mouth)  
(This can be safe as long as there are no sores or bleeding gums and as long as the kiss isn’t so hard it draws blood.)
- Sex with a condom used correctly

### **Unsafe sexual activities**

- Anything that allows blood contact
- Sex without a condom
- Using condoms that have been used before, or continuing to use one after it has broken
- Getting body fluids—semen, menstrual blood or urine—inside the body of the other person, such as in the vagina or anus or on open cuts

**Share the following with the participants:**

*Starting a conversation with a partner (or potential partner) about safer sex can be hard. It can be even harder to talk about HIV status with a potential partner. Ideally, though, both partners should know their own and each other's status before they have sex. This way you can make appropriate decisions about what sorts of protection you will need and what kinds of sexual activities are safe and unsafe.*

*It is often difficult to be assertive when negotiating safer sex. You could worry about your partner's reaction. You might worry about not knowing how to use a condom.*

*Also, gender roles—or the traditional ways people think men and women should act—affect people's desire and ability to use condoms. For example, we often expect women to be sexually innocent, so girls feel that if they suggest using condoms they'll be seen as promiscuous. Some young men think taking risks is a sign of masculinity. And because of traditional gender roles, men often have more power in a relationship, which makes it hard for women to insist on using condoms. But as we've discussed, condoms are absolutely necessary to limit the chance of passing HIV and other STIs to an uninfected partner or for potentially passing a second strain of HIV to an infected partner.*

Ask if anyone has ever started a conversation with a partner about condoms. See if anyone is willing to share what they said. If no one offers, make some suggestions:

- Be very straight forward and say something like, "I use condoms. Do you?"
- Work up to the conversation by saying something like, "What do you think about condom use?" or "I saw a display at a health center on safer sex today. What do you think about safer sex?"

Ask participants some excuses they may have heard when they discuss practicing safer sex and using a condom with their partners. List their answers on a flip chart. Ask participants to identify possible responses to the different excuses.

Share the following possible excuses and responses if not listed:

<b>“I hardly ever have sex.”</b>	It only takes one contact with a person with an STI to be at risk of catching it—a person can have an STI for a long time without realizing it and still pass it on because it won’t go away on its own.
<b>“I don’t pay for sex.” Or “I’m not gay.” Or “I’m not an injecting drug user.”</b>	Some people still have the mistaken idea that only sex workers, gay men and injecting drug users get HIV and AIDS—anyone can get HIV and AIDS. Condoms reduce the risk of getting HIV and AIDS and many other STIs.
<b>“It destroys the romance and spontaneity.”</b>	Ways to get around this are to keep condoms close at hand, like in a handbag, strategic places around the house or a bedside table. This way you don’t have to stop and search for a condom. (Don’t keep a condom in a warm place such as a wallet or car for too long or it will get damaged.) You can make putting on a condom fun by using different types of condoms and lubricant.
<b>“Hey, I’m not dirty. I’m clean.”</b>	Getting an STI doesn’t mean a person is dirty; it simply means the person has come into contact with someone else who had an STI. They may have no symptoms or visible signs of the infection.
<b>“Don’t you trust me?”</b>	Certainly you may trust your partner, but can you trust his or her previous partner(s) and their previous partners? Also, taking care of each other’s health does not mean you don’t trust each other. Taking an STI test together can be a very positive experience.
<b>“I thought we loved each other.”</b>	If a person pressures you this way and is willing to take these risks with your health, perhaps it’s time to rethink what you really want from a partner.
<b>“But I’m (or you are) already using contraception.”</b>	Condoms are not only for protection from pregnancy but also provide some protection from STIs.
<b>“It’s not as good with a condom.”</b>	So maybe sex with a condom on doesn’t feel exactly like sex without one—but people very soon get used to it and enjoy sex just as much. And because you’re both safer physically, you feel better and more relaxed emotionally.

Share these additional persuasion lines to have safer sex, and ask the group if they have heard or used any others:

- Let’s stay safe together.
- I know you don’t think it’ll feel as good, but let’s give it a go and see.
- Come on; it can be fun.
- I’ll put it on for you.
- I’ll last longer.
- I don’t want you to get an infection or pregnant.
- I feel embarrassed talking about it too... but it’ll be worth it.
- It’s really important to me.
- Are you ready to be a daddy/mummy?
- I won’t have sex without it.

Share the following guidelines for discussing safer sex with partners:

- Decide when and where you want to talk. Pick a neutral place.
- Decide what you want to say.
- Don't drink or use drugs before you talk.
- Plan to talk sometime other than when you are about to have sex.

Explain to participants that if their potential partner doesn't use condoms, they have a few options. They could:

- Ask why and be persuasive about the benefits.
- Practice other methods of safer sex that don't involve the exchange of any body fluids.
- Decide to walk away and not take that risk.

Remind the group that they deserve protection from unwanted pregnancy or an infection.

### Condom Negotiation Role Play

Inform participants that it's good to be prepared to talk about condoms and safer sex before they get into a situation where they need to have that discussion. Let them know that in the next exercise, they are going to get a chance to practice.

Ask participants to form groups of three. Inform them that there are three roles:

- **Partner 1:** This person wants to introduce safer sex. The person in this role will ask his or her partner what he or she knows or feels about safer sex. Then this person will deliver his or her message about wanting to practice safer sex, wait for a response, deliver the message again, and be clear and assertive about safer sex choices.
- **Partner 2:** This person is resistant to using condoms or practicing safer sex (use one or more of the excuses listed on the flip chart).
- **Observer:** This person observes the conversation and provides feedback: what worked, what didn't, suggestions for improvement. Please remember to keep your tone and suggestions positive.

Ask the participants to decide who will play which role first.

Ask those playing the role of Partner 1 to take a few minutes to prepare what they want to say. Inform the participants that they have approximately three to five minutes for their role plays.

Ask the groups to begin. Visit the groups and quietly observe their role plays. Provide additional guidance as needed.

Inform the groups when their time is up. Ask participants to discuss the role plays in their groups. Ask the person playing the role of Partner 1 to assess his or her own performance before getting feedback from the observer. Ask them to keep in mind these questions: What went well? What was challenging or difficult? What would they do differently next time?

**NOTE:** If there is enough time, allow participants within the groups to switch roles and complete another role play.

Ask the small groups to join the larger group. Ask participants what they learned from this activity and how they can use it in their real-life experiences. Highlight common themes and unique points.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- Who can remind us what *positive prevention* means?
- What are some of the dangers to having unprotected sex (sex without a condom)?
- What are the risks to having more than one sexual partner at a time? What are the risks of having many sexual partners over your lifetime?

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their participation and attention. Acknowledge that you went through a lot of information in this session and that it could be hard to remember everything. Let participants know that they can always ask you for a refresher, for clarification or for a referral to a health care provider. Assure them that just because they are living with HIV does not mean that they can never have sex again, but that they will have to be responsible about staying safe themselves and not passing HIV or other STIs on to their partner.



### Background for the Facilitator

Review the following information before leading this session.

Violence and HIV infection are linked in several ways:

- Violence can lead to HIV, as when a young person is infected with HIV through an act of sexual violence.
- Violence in a person's past can cause emotional trauma that may lead young people to engage in high-risk behaviors. This trauma may also lower a young person's self-esteem and perceived self-efficacy and make him or her less likely to seek HIV treatment if it is needed.
- Adolescents living with HIV may be targeted with violence because of their status.

This session will focus on the increased threat of violence that ALHIV may experience as a result of their HIV status. Violent acts can be perpetrated by oneself (such as suicide), other individuals (such as rape) or at the systems level (such as war). In this session, we describe violence between individuals.

Remind the group that violence between individuals is a sensitive and complicated subject and that what people say during this or any session should not be shared outside of the group. Participants are here to help and not judge one another.

Because this topic is so complex, co-facilitate this session with a local support person if possible, such as a counselor or person who works with victims of sexual abuse. Find a co-facilitator who can be available to the participants after the session is over as well.

Your role as an influential and trusted adult is to help young people do the following:

- Identify violence and recognize their right to live without it



#### NOTE TO FACILITATOR:

Create a list of support personnel, such as doctors, law enforcement, mental health workers and those who provide crisis support. Be sure to complete the referral list (see Appendix 3) and make it easily accessible for this session.

- Understand that they are not at fault and should not blame themselves
- Find professional help if needed



## Today's Agenda

In this session, participants will do the following:

1. Learn the definition of violence and describe the relationship between HIV and violence.
2. Identify and explain the different forms of violence, focusing on those that someone with HIV may be particularly vulnerable to.
3. Identify and discuss how to access community resources for victims of violence.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- People might be violent toward you because of your positive HIV status.
- Violence comes in many forms.
- Violence can be committed by someone you know and trust or by a stranger. In either case, it is wrong.
- Violence toward you is not your fault. You have the right to feel safe.



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- Violence is an action or behavior that is intended to result in harm. Violence also includes the threat of such an action or behavior.
- Violence comes in many forms; you have the right to feel safe and live free of all forms of violence.
- Violence is NEVER the victim's fault.
- A person living with HIV might become the target of violence because of his or her status.

- Someone to whom you disclose your status might become violent toward you. As we discussed in the session on disclosure, you have to think carefully about the people you can trust. When you decide to disclose to someone who you fear could become violent, consider bringing along a trusted friend or adult who already knows your status.
- Violence or a fear of violence can make people afraid to get care and treatment.
- A perpetrator of violence can be an adult, an older teenager or someone your own age. The perpetrator is usually someone the victim knows, for example a parent, a step-parent, an uncle or aunt, a neighbor, a teacher or someone else in the community. A perpetrator might also be a stranger. Both boys and girls can be victims of violence at any age.
- Help and resources are available to victims of violence.



**NOTE TO FACILITATOR:**

If at any time during the session any group member shares that he or she has been a victim of any type of abuse, be sure to follow up with additional counseling or a referral.



**Activity Corner**

Use the following activities to help develop a better understanding of violence and what it includes.

**I. MYTH OR FACT**

Tell the group that you will begin by finding out what they already know about violence. Read each statement and have the group yell out whether it is a myth or a fact. If the statement is a myth, explain why.

1. All people have the right to live free of violence.  
**FACT**
2. Sharing someone else's HIV status without his or her permission is a form of violence.  
**FACT**
3. A man has the right to hit his wife if she tells him that she is HIV positive.  
**MYTH.** It is never acceptable to perpetrate violence against someone else.
4. Sexual violence, such as rape, can be perpetrated by a stranger or a known sexual partner.  
**FACT**

5. Some women ask for or provoke men to rape, batter or abuse them through their behavior or dress.

**MYTH.** Nobody asks for or deserves to be violated. Violence is always the fault of the perpetrator, not the victim.

6. Anyone, man or woman, young or old, can perpetrate or be the victim of any type of violence.

**FACT**

7. People with HIV are targeted with violence because they deserve it.

**MYTH.** People with HIV are targeted with violence for many reasons, including stigma and discrimination, but they DO NOT deserve violence. No one deserves to have violence perpetrated against them.

8. It is OK for a man to force his wife to have sex. That isn't rape.

**MYTH.** Rape is sexual intercourse against someone's will. If a woman does not wish to have sex with her husband, it is her right to say no.

9. Emotional violence, such as teasing or neglecting someone, is not really harmful to the victim.

**MYTH.** Many people say that emotional abuse is as harmful as any other type of abuse.

10. People living with HIV might suffer violence because of their status.

**FACT**

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## II. DESCRIBING VIOLENCE

Tell the group that this activity will focus on three types of violence between individuals: emotional, sexual and physical.

Divide the participants into three smaller groups. Assign each group a type of violence (physical, sexual or emotional). Ask each group to write down examples on a flip chart page of the type of violence assigned to their group. Remind them to list examples that might be especially likely for young people living with HIV.

After 15 minutes, ask the small groups to share their answers one group at a time. Post the flip chart pages on the wall, and leave them up throughout the session.

### Emotional violence:

Humiliating the victim, such as disclosing his or her status; controlling what the victim can and cannot do; deliberately doing something to make the victim feel ashamed, such as name calling ("AIDS carrier" and the like); isolating the victim from friends and family; denying the victim access to money or other basic



#### NOTE TO FACILITATOR:

If the following examples of violence are not mentioned under each of the categories in this activity, be sure to bring them up after that group's presentation.

resources; forcing the victim to leave his or her home; withholding medical attention.

### **Sexual violence:**

Forcing someone to engage in any sexual act (such as intercourse, touching, kissing) against his or her will; engaging in a sex act with someone who is unable to decline (because of illness, disability or the influence of alcohol or other drugs, or due to intimidation or pressure); conducting any unwanted sexual contact or sexual harassment (such as lewd comments or gestures).

### **Physical violence:**

Scratching; pushing; shoving; throwing; grabbing; biting; choking; shaking; slapping; punching; burning; using a weapon; and using restraints or one's body, size or strength against another person.



## **Group Discussion Questions**

Use the questions below to lead a discussion about violence that targets people living with HIV and the resources available to young people who are dealing with violence. It is not necessary to use all the questions. The objective is to create a discussion where the group can share their thoughts and concerns about staying safe and what to do if they have experienced violence in the past or experience it in the future.

At the start of this discussion, pass out the sheet of local referrals or write each resource on the board and ask participants to copy the resources.

1. Were you surprised by any of the examples of violence that the small groups shared? Did you recognize each one as an example of violence before today?
2. Which types or examples of violence that we have discussed are most likely to affect adolescents living with HIV? Why?
3. Why do you think young people living with HIV are targeted with violence?
4. Many people, regardless of their HIV status, blame themselves if they experience violence. For example, people who experience sexual violence often wonder if they put themselves at risk through where they went or what they were doing. As we have said, it is never the victim's fault. What could you say to a friend that would help him or her understand that the violence he or she experienced was not his or her fault?
5. It can be helpful to victims to tell someone they trust about the violence they have experienced. If someone has been victimized, who can they tell? What makes a person safe to talk to?
6. What services might someone need if they have been victimized?

7. What happens if a young person acquired HIV through sexual abuse or forced sex? What specific struggles might he or she have?
8. Although it is never your fault if you are the victim of violence, is there anything that you could do to limit your potential for exposure to violence?
9. What is the role of others in helping to create a safer community?



**NOTE TO FACILITATOR:**

If no one brings up peer pressure, mention that peer pressure can be used positively to discourage bullying or sexual violence. Also, what might the participants do, without putting themselves in danger, if they saw or heard that violence was being perpetrated against someone else in this group?



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.

### Review questions

- Does a victim of violence ever deserve the violence? Why or why not?
- What are some examples of emotional violence?
- What are some examples of sexual violence?

- What can you say to show support to a friend who is in a relationship that is violent?

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for sharing their stories and discussing this difficult topic. Remind them that, as always, what they hear in this session must remain confidential. Offer to make referrals for anyone who has been a victim of violence and anyone who fears that someone might become violent toward them. Let them know they are not alone.



**NOTE TO FACILITATOR:**

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets. Work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.



### Background for the Facilitator

Review the following information before leading this session.

Everyone needs good communication and problem-solving skills to meet the demands of everyday life. These demands are different for ALHIV, who must be able to speak about living with HIV with their health care providers, caretakers, friends, family, sex partners and people in their community. Some examples of effective communication skills include *speaking to be understood*, *listening to understand* and *being assertive*. Problem-solving is about dealing with problems in a logical, effective way. All of these skills play a role in developing and maintaining healthy family, community and romantic relationships.



### Today's Agenda

In this session, participants will do the following:

1. Discuss how communication affects their relationships with family, caregivers, health care providers and others in their communities.
2. Learn how to be good communicators and why this is especially important for ALHIV.

3. Learn how to be assertive in their daily lives—especially when dealing with their care and treatment and in asserting their rights.
4. Learn how to manage conflict and handle disagreements.
5. Discuss how to solve problems effectively.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- Being assertive means standing up for yourself.
- You need good communication skills for talking to health care providers, to your friends and family, and to any sex partners.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have

to share. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- **Speaking to be understood** means to say things in a way that encourages people to listen and really hear you.
- **Listening to understand** means to listen in a way that is receptive, not judging and not reacting to what is being said. It often means trying to see something from another person's point of view.
- **Assertiveness** means to stand up for yourself with confidence and be clear with yourself and others about what you want. Assertiveness does not mean being a bully, using threats or yelling.
- **Problem-solving** includes these steps:
  1. Identify the problem.
  2. Identify possible solutions.
  3. Evaluate the possible solutions and choose one.
  4. Identify any possible roadblocks or challenges to the solution.
  5. Identify ways to handle the roadblocks or challenges.



## Group Discussion Questions

Use the questions below to lead a discussion about communication. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore how they can become effective communicators in their daily relationships.

1. What do we mean by *good communication*?
2. Think of a person you know who is a good communicator. What makes that person a good communicator?
3. Do you know anyone who you think is a bad communicator? What makes that person a bad communicator?
4. Can you think of a time when you felt that you “spoke to be understood”? What did you say or do that helped make you a good communicator?
5. What are some important things to remember when listening to someone? Think of a time when you were a good listener. What were the results of being a good listener?
6. Think of someone you know who is a good listener. What do they say or do that makes you feel like they are listening?
7. What does being assertive mean to you? Think about a time when you were being assertive. What were you doing or saying? What were the results of being assertive?
8. Think of a time when you had to solve a problem. What was the problem? What were the steps you

took or the process you went through to solve the problem? What worked? What would you do differently?

9. What is a recent situation where you had to discuss something about your care and treatment with your caregiver or health care provider? What communication skills did you use well? What would you have done differently?
10. What are your challenges or roadblocks to being a good communicator? What can you do to overcome those?
11. Think of a time you had a conflict or problem related to your HIV status. How did you handle it?
12. Why do you think assertiveness and communication are especially important for people who are living with HIV?



### Activity Corner

Use the following activities to help develop a better understanding of effective communication.

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## I. DEVELOPING ASSERTION MESSAGES

**TIME:** 45 minutes

**MATERIALS:** Chalkboard or flip chart and markers

### INSTRUCTIONS:

On a chalkboard or flip chart, write the following four words, which will become helpful reminders when participants work on their assertion messages:

Behavior  
Feelings  
Effect  
Action

Then say the following:

*Has anyone ever done something that upset you, but you didn't know how to tell them? Were you worried that you wouldn't know what to say or that you would sound awkward? It helps to prepare what you want to say and how you want to say it. In this exercise, we're going to practice ways to assert ourselves by following these steps:*

1. Identify the **behavior** you would like someone to change. State the facts about what is happening without sounding judgmental.  
**Example:** You leave out my medications for everyone to see every day.
2. Tell how you **feel** about the behavior. Share what you are feeling in response to the person's action without assigning blame.  
**Example:** When you do this, I feel angry and betrayed.

3. Explain how the behavior **affects** you. Tell them what their action makes you think or believe about the situation.

**Example:** I think it is a reminder to everyone that I am different and that they think of me as sick.

4. Tell them what **action** you would prefer.

**Example:** I am asking that you not leave my medication out for others to see. Instead, maybe you could leave it in a drawer for me.

Next, share another example of a four-part message:

**BEHAVIOR:** When you answer the doctor's questions instead of letting me answer them...

**FEELINGS:** I feel frustrated and powerless.

**EFFECTS:** When I am not able to answer the doctor's questions, I feel like I don't have a voice about the decisions being made about my life.

**PREFERRED ACTION:** I am asking that you let me interact with the doctor. I understand that you also have questions, but I want to be part of the discussion.

Tell participants to form groups of three. Each person should think of a problem they would like to address (it should be an issue they don't mind discussing with the group) and then develop

a four-part assertion message in response to that issue. When everyone in the group has come up with their message, participants should practice using their assertion messages with one another. Encourage participants to role play possible negative responses and to practice focusing on the message.

After 20 minutes, ask the participants to come back and form the large group. Ask for volunteers to role play their messages in front of the group. Ask the group to give feedback about the role play, and give your feedback as well.

Next, ask everyone the following questions to process the activity:

- How did it feel to use the four-part message?
- How did you handle a negative response?
- What are some ideas for things to say when someone doesn't listen?
- How can you use the four-part message at home? At the clinic? At school?

Wrap up the activity by highlighting common themes and unique points.

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## II. USING THE PROBLEM-SOLVING MODEL

**TIME:** 20 minutes

**MATERIALS:** Chalkboard or flip chart and markers

**INSTRUCTIONS:**

Remind the group of the five problem-solving steps: (Write the steps on a flip chart or chalkboard before the session.)

1. Identify the problem.
2. Identify possible solutions.
3. Evaluate the possible solutions and choose one.
4. Identify any possible roadblocks or challenges to the solution.
5. Identify ways to handle the roadblocks or challenges.

Next review the following example (or make up one of your own):

**Step 1. Identify the problem.**

**Example:** I cannot remember to take my ARVs on time.

**Step 2. Identify possible solutions:**

- a. I could ask my mother to remind me.
- b. I could ask a friend to remind me.

- c. I could take my medicine when I do certain everyday activities, like brush my teeth, eat my meals or go to bed.

**Step 3. Evaluate the possible solutions and choose one.**

My mother and friend aren't always around when I need to take the medications, so relying on them might not be the best solution. I think I should try to take my medicine close to the time that I do certain activities every day.

**Step 4. Identify possible roadblocks or challenges to the solution.**

My weekend activities are different from my weekday activities.

**Step 5. Identify ways to handle the roadblocks or challenges.**

I think I should make a list of which medications I need to take and at what times of the day I generally should take them. Then, I should figure out which activities best match with those times. For example, on school days, maybe I could take my medicine right before I leave for school. On the weekends, when I don't go to school, I usually do morning chores on Saturday and go to church on Sunday; I could assign those times as my times to take my medicines on weekends.

Once everyone understands the five-step process, ask participants to think of a problem they would like to solve and then work through the problem using each

of the five steps. They could make a chart like the one below and draw pictures for each of the steps, or just write them down.

**1. Identify the problem.**

**2. Identify possible solutions.**

**3. Evaluate the possible solutions and choose one.**

**4. Identify any possible roadblocks or challenges to the solution.**

**5. Identify ways to handle the roadblocks or challenges.**

Ask participants to work on their problem-solving model individually. After 15 minutes, ask if any participants want to share their examples with the group.

Use the following questions to process the activity: How well did the model work in helping you think about your problem? What was helpful? What was challenging? How can you use this model in other situations? What did you learn by sharing your models? How do you know if you have a “good” solution?



### Final Review and Wrap-up

Use the following questions to re-emphasize this session’s key messages, and then wrap up for the day.

#### Review questions

- What do we mean when we say that someone is “assertive”?
- What makes someone a good communicator?
- Why is assertiveness and communication especially important to adolescents who are living with HIV?



#### NOTE TO FACILITATOR:

Participants’ responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

#### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their attention and participation. Remind them that it takes practice to be assertive and be a good problem solver. Suggest that they practice assertion messages and problem solving with each other between sessions, if possible, to become even more skilled.



### Background for the Facilitator

Review the following information before leading this session.

For ALHIV, the psychosocial effects of living with HIV are compounded by the changes experienced during adolescence. Coming to terms with their status and dealing with stigma and discrimination are just some of the issues that ALHIV confront on a daily basis. Anxiety, depression, anger, guilt, and loss of self-esteem and confidence are a few of the emotions that they may experience. They are anxious about their future—what will happen to them? Will they die? Who will care for them? How will they be treated?

The experience of adolescents who were infected perinatally might differ in some regards from young people who were infected later in life. If they've known of their status since they were children, perinatally infected youth might be more accustomed to living with HIV. They could face less stigma than youth who were infected behaviorally and who might then be blamed for being HIV-positive and suffer more guilt. On the other hand, perinatally infected

young people might be coping with more anger or resentment toward their parents or grief over the loss of a parent to AIDS. They might also be dealing with a more advanced stage of illness. Orphans and vulnerable children, particularly those who have been institutionalized, might experience serious identity issues and may lack a sense of belonging, culture, status, self-respect and confidence because they did not have their parents or family to help instill these feelings in them.

The effects of these different emotions can create a stress level that can become physically damaging and affect their self-care and treatment efforts.

In this session, group members are encouraged to explore the full range of emotions they might experience on any given day—from happiness to anger to peacefulness. They will discuss grief and loss and share stories and strategies that have helped them through some difficult times.



## Today's Agenda

In this session, participants will do the following:

1. Identify different feelings and emotions and how people experience them.
2. Discuss grief and loss and how to recognize the stages people might go through during these feelings.
3. Discuss strategies for dealing with grief, anger and fear and for beginning to feel better over time.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- Living with HIV can affect your feelings in many ways. It is normal to feel sad, angry and worried.
- In time, with support, you should begin to feel better.
- You are not alone. You can talk to me (the facilitator); to people in this group; and to trusted friends, family or other adults.



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- It's normal to have many different feelings.
- No matter how you came to be infected with HIV, you do not deserve to be ill or to be treated poorly.
- During puberty you might notice that your feelings change quickly or that you are experiencing several different feelings at once. Feelings can help guide you in life, but they can also make you feel like you are not in control.
- Understanding your emotions can help you be true to yourself and sort out the difficult situations you face every day.
- Living with HIV can affect the different feelings and moods you are experiencing. You might feel angry about your status or guilty, sad or depressed. You also might have developed new friendships and relationships that you feel are supportive.

- Grief is a common, normal emotion. Grief is the emotional suffering you feel when you lose someone or something important in your life, such as the loss of safety or security, loss of an important relationship or the loss of your health. Some of you might have felt this sense of loss when you learned your status.
- Grieving is a personal and very individual experience. There are no wrong or right ways to grieve.
- The grieving process takes time. Healing happens gradually; it can't be forced or hurried. Some people start to feel better in weeks or months. For others, the grieving process is measured in years. Many people experience the following stages when grieving:

**Denial:** "This can't be happening to me."

**Anger:** "Why is this happening? Who is to blame?"

**Bargaining:** "Make this not happen, and in return I will \_\_\_\_."

**Depression:** "I'm too sad to do anything."

**Acceptance:** "I'm at peace with what happened."

If you are experiencing any of these emotions, it might help to know that your reaction is natural and that you'll heal in time.

- Often we are tempted to label emotions as good or bad. But they are just emotions, and it is fine to

feel them. Getting stuck in feelings of anger and sadness, however, can cloud your judgment and make it hard for you take positive action.

- Being able to identify and understand the feelings you experience can help you to manage them, so you don't feel like they are managing you.



## Group Discussion Questions

Use the questions below to lead a discussion about emotions. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore the different emotions they experience, how they experience them and healthy ways to manage them.

1. What are some of the emotions that you have been experiencing over the past week? What emotions tend to show up frequently?
2. Think of a time where you were happy. Who were you with? What were you doing? What are some activities that make you happy?



### NOTE TO FACILITATOR:

Provide the following information as an additional suggestion for managing fear: When you are feeling scared or overwhelmed, the best thing you can do is calm yourself so that you can think clearly. Deep, regular breathing allows your body to relax. Counting slowly while taking deep breaths can help to calm you when you are feeling scared, anxious or overwhelmed.



**NOTE TO FACILITATOR:**

Ask group members to share with the group a particular place or memory that helps them feel calm.

3. Think of a time when you were scared. What were you doing? What were you scared of? What helped make you feel better? Who can you talk to about feeling scared? What are some actions that you can take to help overcome your fear?
4. Think of a person who faced one of their fears. What did he or she do that was brave? What did he or she do to overcome fear?
5. What are some ways that you calm yourself? What are some techniques that you have heard of?

Another way to be calm is to think of a calming memory or place. Close your eyes and get a clear picture of the place—a place where you felt comfortable and safe.

6. Think of a time when you were angry. Who were you with? What were you doing? Were other feelings mixed with the anger? What did you say or do as a result of your anger? How did the situation turn out? Would you do anything differently next time?



**NOTE TO FACILITATOR:**

Suggest the following to help manage anger: Use your breathing to calm yourself down. Try not to respond right away. Instead, walk away if you can and give yourself time to calm down. Find someone you trust to talk to about the situation.

If your anger involves another person, write them a note or let them know how you feel. Use the four-part assertion message to explain what they did to upset you and how it felt.

7. Think of a time when you were sad. What made you start feeling that way? Were other feelings mixed with the sadness? Was there something you or someone did that helped? One of the best things to do is to talk to someone about it. Who are some people you can talk to about how you are feeling?
8. It is not easy to discuss a time when you experienced a great loss, but it might help us learn from each other. Think of a loss you have experienced. What were you feeling? How did you experience grief? How did your body feel while you were grieving? Who did you talk to about it? What helped you?



**NOTE TO FACILITATOR:**

Suggest the following to help deal with grief: Some things that help with grieving are talking to others and revisiting nice memories. If you have lost someone you loved or cared about, it might help to keep a special reminder about that person; draw comfort from your faith; or do something in that person's honor, such as volunteering at a hospital or in the community. It's important to give yourself time and to talk with others about your loss— this will help to lighten the load.

Emotions related to grief will be intense at first but in time should become less strong. If you do not gradually begin to feel better and if you spend all of your time thinking about whatever has made you grieve, this could be a sign that you are depressed and it could be time to talk to a trusted adult.

9. What are some steps you can take toward feeling better?



## Activity Corner

Use the following activities to help develop a better understanding of dealing with emotions.

# I. UNDERSTANDING WHAT CAUSES EMOTIONS

**TIME:** 30 minutes

**MATERIALS:** Chalkboard and chalk or flip chart and markers; paper

**INSTRUCTIONS:**

Ask the group what kinds of things trigger emotions. Make sure the following are mentioned:

- Events in the present (an interaction with someone, losing something, physical illness, financial worries)
- A memory
- A thought
- Another feeling (if we feel ashamed and then feel angry about feeling ashamed, for example)

Tell participants that when dealing with emotions, it is important to be able to recognize what prompts them. Sometimes it isn't the event itself that causes the emotions, but rather how we interpret the event.



**NOTE TO FACILITATOR:**

Be sure to emphasize that some serious events do cause emotions and that no matter the cause, it's OK to feel however one feels about them.

Create the following chart on the chalkboard or flip chart and review the examples.

EVENT	INTERPRETATION	EMOTION	OTHER POSSIBLE INTERPRETATION
I see my boyfriend with my best friend.	My boyfriend is cheating on me with my best friend.	Anger, sadness, betrayal	They are just talking. It's good for my friends to get along with my boyfriend.
I get bad marks in class.	The teacher must not like me.	Sadness, anger	It's true, I didn't do as well as I could have. But I think the teacher does like me and just wants me to do my best. I should ask him or her for help.
I hear a storm coming.	I have heard of people being hurt or killed in a storm. Maybe that will happen to me.	Fear	I've been in lots of storms that weren't dangerous, although I can still take shelter to be safe.
(Fill in with examples after participants have created their own tables.)			

Point out that the emotion comes after the interpretation is made, after you have the thought about the reason something is happening.

Ask participants what can be done in different situations to handle the emotion (if it is troubling). One thing that leads from the event to the emotion is positive or negative self-talk (the interpretation). Ask the participants to come up with another interpretation for each of the examples. (See the chart above for some examples.)

Ask each participant to make a table with examples from his or her life. Let participants know that they will

not have to share the examples unless they want to. When they are finished filling out their tables, add to the flip chart or chalkboard table with examples from participants who feel comfortable sharing. Brainstorm as a group about other interpretations that could lead to positive instead of negative emotions.

Also mention that sometimes it is appropriate or OK to feel sad, angry or afraid. Ask for examples of what can help when participants feel this way (you can remind them of some of the ideas mentioned in the group discussion).



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- Are there any feelings that are not normal to have about living with HIV? Why or why not?
- Who can name some steps people can take to feel better?
- What is something you can do when you are feeling sad to help you feel better?

### Wrap-up

Ask if the group has any last questions or concerns.

Thank them for their attention and participation.

Remind them that it is normal to have all kinds of feelings about living with HIV or about life in general.

Suggest that during the coming weeks, they think of things that might help them feel better, like turning to each other for support, talking to other supportive friends or adults, talking to a spiritual leader in their community, or trying to engage in hobbies or activities that they enjoy. Again, remind them that they are not alone and that they can talk to you if they feel they need help.



### Background for the Facilitator

Review the following information before leading this session.

The stigma and discrimination surrounding HIV and AIDS can be as destructive as the disease. The denial of basic rights—such as access to care and treatment, opportunities for employment and housing—not only results in more suffering and loss of dignity, but can further contribute to the spread of the infection. For example, people may be less likely to seek counseling, testing, treatment and support because it could mean facing discrimination, lack of confidentiality, job loss or other negative consequences.

That is why information and support are important tools for ALHIV. Young people need to know their rights in terms of employment, welfare, education and family life, and they need clear information about care and treatment. For this reason, it may be a good idea to invite someone familiar with your country's laws who can explain in simple terms how young people living with HIV are protected or affected by the current laws.

Some groups of young people who are living with HIV are even more vulnerable to stigma and discrimination than others. Young people who acquired HIV through sex or injecting drug use are more likely to be blamed for their status than someone who was born HIV positive. Young men who have sex with men might be coping with homophobia, ranging from mild to extreme, particularly in countries that criminalize homosexuality. Likewise, young people who sell sex or use injecting drugs face not only stigma and discrimination but also legal repercussions, all of which make them less likely to seek information, counseling, care or treatment.

In this session, group members will look at how stigma and discrimination originates, how to stop negative self-talk and self-stigma, and how to use their communication skills when dealing with stigma and discrimination in their communities. It is important that participants examine how they may be discriminating against others.



## Today's Agenda

In this session, participants will do the following:

1. Discuss their rights regarding care and treatment, school, work and life.
2. Learn the meaning of *stigma*, *self-stigma* and *discrimination*.
3. Discuss the signs of negative self-talk and how to address them.
4. Discuss how to use their skills—communication, problem solving, managing their emotions and knowing their rights—when dealing with stigma and discrimination.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- *Stigma* means viewing someone negatively because of something that is different about them.
- *Discrimination* means excluding people from opportunities that are available to other people.
- You might face stigma and discrimination as a result of living with HIV.
- People living with HIV have the right to:
  - Get health care
  - Attend school
  - Get a job
  - Find housing
  - Live free from violence



## Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- *Stigma*, according to the dictionary, means “a distinguishing mark of shame or social disgrace.” It also means not valuing a person and viewing them negatively because of something that is different about them; for example, they are living with HIV, they have a disability or they are very poor.
- *Self-stigma* is when you judge yourself negatively. Self-stigma might cause you to believe that you are not good enough or that it is your fault that you are

living with HIV. Believing these things prevents you from respecting your own rights. It's important for your health and well-being to change the negative self-talk into positive self-talk.

- *Discrimination* means excluding or restricting members of one group from opportunities that are available to other groups. When someone is not allowed to go to school because of their HIV status, this is discrimination.
- It's important to know your rights and how they are protected in your country. Different countries have different laws, but most countries support the following rights:
  - To health care, which includes access to care and treatment in relation to HIV
  - To attend school and get an education
  - To have a job
  - To find housing or a place to live
  - To privacy
  - To liberty and security, including freedom from violence
  - To decide whom you want to marry, if you want to have children or use family planning, where you want to live
- The effects of stigma and discrimination can be wide-ranging. Here are examples:
  - Being shunned by family members

- Not being allowed to go to school
  - Finding it hard to make friends
  - Having nobody to talk to about your problems
  - Being treated differently at work, or finding it hard to get a job
- One way to address stigma is to begin with your feelings about yourself. Pay attention to your feelings and the way you think about yourself. Try to think positively about yourself. You will also need to use your communication skills when others treat you poorly or disregard your rights because of your status. Because more people are speaking publicly about living with HIV, awareness and understanding are increasing.



### Group Discussion Questions

Use the questions below to lead a discussion about stigma and discrimination. It is not necessary to use all the questions. The objective is to create a discussion where the group can explore how they want to respond to stigma and discrimination, particularly self-stigma.

1. When is a time that you may have judged someone or treated someone poorly because they were different?
2. When is a time you felt discriminated against? What happened? How did it feel to be discriminated against? How did you handle the situation?

- What would you do the same? What would you do differently?
3. What are some positive ways to handle discrimination? What communication skills can you use when dealing with discrimination? What emotions do you need to manage? What can you say?
  4. Self-stigma begins and ends with you. What types of negative things do you say to yourself? How do those things make you feel? What can you do to stop the negative self-talk? What is the positive self-talk you can replace it with?
  5. What questions do you have about your rights and how they are protected? Where can you go for more information about your rights?
  6. What steps should you take if you feel your rights are being violated? What can you say to the person stepping on your rights? Where can you go to get support?
  7. Fear is a common reason for discrimination. What can you do or say to address people's fears about HIV?
  8. What information do you think is important for people to have about living with HIV?
  9. If you are comfortable disclosing your status and talking to others, is there anything you can do to educate people you know about living with HIV?



## Activity Corner

Use the following activity to help develop a better understanding of stigma associated with HIV.

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## I. SELF-TALK AND STIGMA

*(This activity is adapted from Together Learning Choices.)*<sup>19</sup>

**TIME:** 30 minutes

**MATERIALS:** Flip chart or chalkboard with scenario chart on page 132.

**INSTRUCTIONS:**

Share the following situations, and ask the participants how they can coach themselves through the situation with communication skills such as assertion messages, listening to understand, speaking to be understood and positive self-talk. Go through one example together. Then ask for volunteers to share their thoughts on the other scenarios.

## SCENARIO CHART

SCENARIO	POSITIVE SELF-TALK	ASSERTION MESSAGE OR OTHER SKILL
1. You are meeting your boyfriend/girlfriend tonight, and your guess is that he/she wants to break up because you are HIV positive and he/she is not.		
2. Your mother learns that you are living with HIV and starts yelling at you and telling you to leave.		
3. Your friend tells you that he doesn't want to be seen with you now that you are living with HIV.		
4. You are going for a job interview, and you have heard that the employer might ask if you are living with HIV.		
5. Your boss fires you because he thinks he'll lose customers if people find out your status.		
6. You caught someone writing "AIDS" on your door.		
7. Some of the children at school call you names and won't let you sit next to them.		
8. The nurse asks you to use a separate entrance at the clinic.		

Summarize some of the best suggestions.



## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- What are some of your rights, not only as a person living with HIV but as a person? Do you feel your rights are different from those of an adult? Why or why not?
- What does *self-stigma* mean, and what can you do about it?
- Who can you turn to if you feel you are being discriminated against?

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their attention and participation. Acknowledge that people who are living with HIV often face a lot of stigma and discrimination and that it can be hard to deal with. Sometimes even people living with HIV stigmatize others or themselves. Remind participants of their strategies for dealing with stigma, and refer them to any legal organizations or other programs that might be able to help them if they experience discrimination.



### Background for the Facilitator

Review the following information before leading this session.

As ALHIV continue to mature, they will be expected to play a larger role not only in managing their own care and treatment, but in contributing to their households and the community at large. Critical thinking is an important skill for young people to learn as they take more responsibility in making decisions about their care and treatment and their futures. There is a lot of information and misinformation in the world today, particularly about HIV and AIDS. Critical thinking includes identifying trustworthy sources of information, learning to ask follow-up questions and evaluating information to make sound decisions.

Values help guide young people in setting goals and making decisions about their future. Values can also give adolescents a sense of connection and a sense of self-worth—a particular challenge for young people living with HIV.

A general lack of means or finances can play a large role in increasing the vulnerability of ALHIV to STIs,

pregnancy and transactional sex. However, with the security of a steady income, a good education, or a job or career, an ALHIV is more likely to:

- Have greater self-esteem and confidence
- Make plans for their future
- Wait to have sex until they are ready
- Stand up for themselves
- Delay having children until they are older

An essential component of care and treatment is psychosocial well-being. Planning for the future and having a sense of hope helps cultivate mental and spiritual health and gives ALHIV a sense of purpose and belonging.



### Today's Agenda

In this session, participants will do the following:

1. Discuss their personal set of values.
2. Discuss how to make decisions using critical thinking and their personal values.
3. Discuss how living with HIV has affected the values they have and the decisions they make.



#### NOTE TO FACILITATOR:

If possible, make copies of these handouts for your group: "Values Bubbles" (page 139) and "Livelihoods Images" (page 141).

4. Discuss career or work goals and steps to take to achieve these goals.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- People living with HIV can live long and healthy lives, so it is important to plan for your future.
- Deciding what you value will help you plan what you want in your future.
- Having a goal for the future can help you decide what to do with your life now.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



### Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- The word *values* refers to what is important to us. Some examples of values might be getting a good education, spending time with family, staying healthy or having a family of one's own someday. When we act according to our values, we feel better than if we aren't being true to our values and ourselves.
- *Critical thinking* refers to our ability to find and use information that we trust to make good decisions. Finding information that is accurate and trustworthy is not always easy; we know that stories we hear or read can be misleading. This is why it is important to consider the source of the information: Is it a friend who tells many stories—some true, some not? Is it a health care provider you trust? Is it a respected newspaper, or is it a gossip magazine?
- Some decisions we make might involve our emotions and the emotions of others, but critical thinking still plays a role. For instance, if your partner says he or she loves you and wants to

*“Before I went to school, my family saw me as a burden. I’ve become important now that I finished and have a job.”*

– Young Kenyan woman living with HIV

have sex with you, you might feel he or she is being truthful. But you also know that you don't feel ready for a sexual relationship. By using your personal values and information about staying healthy, you can reason with your partner about why waiting for a sexual relationship is important to you and makes sense for your relationship at this time.

- Having a goal for the future can help you to determine what you can plan for today. For example, thinking about how you want to make a living in the future can help you decide the best course of action for what you are doing right now—going to school, saving money and staying healthy by living in a positive way.
- Values and critical thinking are important tools to use as we look to the future and work toward our goals.



## Group Discussion Questions

Use the questions below to lead a discussion about personal values. It is not necessary to use all the questions. The objective is to create a discussion where the group can share and explore their values and discuss how to use them to make decisions.

1. What would you consider some examples of values?
2. How do you know when someone is living according to their values?
3. How do you react to someone who doesn't share your values?
4. If you had to name the three most important values, what would they be? What are some values that you experience as part of your day-to-day living?
5. How does living with HIV affect your values?
6. Have you had an experience when you felt that one of your values wasn't being respected? What can you do when you feel your values aren't being respected?
7. Think of a decision you need to make in the near future. How can you use your values to make the decision?
8. What are some tough decisions you have had to make recently that are related to living with HIV? What worked well? What didn't?
9. What sources of information do you trust? Where can you go for information? Who do you trust to help you in making decisions?

10. What are some ideas you have about your future? What are your goals? What type of work do you want to do? What relationships do you see yourself having?
11. How do your values play a role in deciding your goals? How does critical thinking play a role in making decisions about your future?



## Activity Corner

Use the following activities to help develop a better understanding of how to plan for the future.

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## I. VALUES BUBBLES

**TIME:** 30 minutes

**MATERIALS:** “Values Bubbles” handout (page 139) or paper and pencils

**INSTRUCTIONS:**

Review the definition of *values*. Ask participants to brainstorm about their values. List their responses on the chalkboard or flip chart.

Give each participant a “Values Bubbles” handout.



**NOTE TO FACILITATOR:**

If you are unable to reproduce handouts, draw the bubbles on the board. Give out paper and pencils, and ask the participants to reproduce the bubbles on their paper.

Inform participants that they are going to write or draw a picture of the value that they feel is most important to them in the biggest bubble.

Inform participants that in the remaining bubbles, they should write or draw other values. Allow enough time for the participants to write or draw their values on their handout.

Ask participants to get up and find other participants who share their big bubble value and to form a group with them. If they don’t find anyone with the same value, they should join a group that they feel comfortable joining.

Ask participants to discuss with their group what is important about this value for them and their reasons for choosing it over the other values. Allow a few minutes for discussion.

Ask participants to identify and share with each other the value they find most important for making decisions about their future. Ask participants to discuss with their group what is important about this value for them

and their reasons for choosing it over the other values. Allow a few minutes for discussion.

Ask participants to return to the larger group; then ask the following questions:

- What did you learn by doing this activity?
- What was challenging about discussing your values?
- What were some of the things you discussed with the others in your group? What did you learn about others?
- How can you use what you learned in your daily life?

Wrap up the activity by highlighting common themes and unique points.

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## II. JOURNEY TO THE FUTURE

*(This activity is adapted from Family Life Education: Teaching Adults to Communicate with Youth.)<sup>15</sup>*

**TIME:** 50 minutes

**MATERIALS:** Flip chart paper, markers, tape, “Livelihoods Images” handout (page 141)

**INSTRUCTIONS:**

Ask participants to form groups of four. Give each group a piece of flip chart paper or have them use the chalkboard.

Inform the groups that they will now think about one thing a young person might imagine doing as an adult—for example, finishing school, having a certain job or raising a family. Then they will think about the steps that person could take to make that future happen.

Instruct them to divide their flip chart into six boxes and to number the boxes one through six. Tell them first to draw the young person’s future activity in box six; they can either use an image provided (see the “Livelihoods Images” handout) or create their own image. After that, in boxes one through five, they will draw a series of pictures that illustrate steps that lead

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## HANDOUT: VALUES BUBBLES

Most Important  
Value to Me

to the potential future illustrated in box six. (If any participants prefer to write instead of draw the steps, that's fine, too.) Provide the following example:

1	2
3	4
5	6



Tell the groups that as they work on the stories, they should think about the following questions: (Write the questions on flip chart paper or the chalkboard.)

- What resources will the person in your example need to reach his or her goal?
- What kinds of activities should he or she avoid to reach the goal?
- What is the role of self-confidence? How can someone develop self-confidence?
- What role will parents or caregivers play?
- Who else might be helpful?
- Are there resources in the community that could be useful?

After 20 minutes, invite the small groups to share their stories. Wrap up the activity by highlighting common themes and unique points.

## HANDOUT: LIVELIHOODS IMAGES





## Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- What does the word *values* refer to?
- Why are values important?
- What are some trustworthy sources of information?
- What are one or two steps you can take now to help plan for your future?

### Wrap-up

Ask if the group has any last questions or concerns.

Thank them for their attention and participation.

Encourage the group to think about their values and how their values affect their current and future decisions. Remind them that people with HIV can live happy and productive lives, so it pays to think about long-term goals and what kind of adults they hope to become.



### Background for the Facilitator

Review the following information before leading this session.

Adolescents living with HIV will need support from a variety of individuals and groups in their community. No one agency or organization can offer everything in terms of clinical, social and emotional support. As time goes on, their health status might change; therefore, their care and treatment needs could change. You can help them identify resources in their community and help link them to those resources.

A well-established referral network is vital to meeting the needs of ALHIV and maintaining contact with those who require ongoing support. It is important to ensure confidentiality when referring the young people from your group. It may also be helpful to visit the organizations or groups that you have identified and introduce yourself. By visiting the organization in person, you can also determine how youth-friendly it is: Does it keep flexible hours? Is the staff nonjudgmental and welcoming? Do they serve young women as well as

young men? Are the fees affordable? Are they conveniently located and accessible?

You can create a referral network for your clinic or program by taking these steps:

- Create a referral chart, book or set of referral cards. You can use the “Referral Chart” (Appendix 3, page 179) as a template.

*“The key issue for me is there was exceptionally minimal support offered when I found out I was positive. ...I was in a precarious emotional situation but was simply given a few pamphlets by the STI clinic. Immediate follow-up, counseling and so forth should be available when youths test positive. It should not be an onus upon the youth to engage with resources for HIV; that kind of mindset does not exist right after you test positive.”*

– Survey respondent (young adult living with HIV)

- List the names of other reputable organizations in your community that work with young people.
- For each organization, list an address, telephone number and name of a person for young clients to contact. Try to ensure that this contact person has experience working with youth.
- Make this list available to all staff in your clinic or program.
- Regularly update your referral book to ensure that contact information, location or hours of any organization in your network have not changed.

Remember your limits and set boundaries regarding your role in group members' care and treatment. Explain those limits to the group so that they do not feel rejected if and when you refer them to other counseling and support services.



### Today's Agenda

In this session, participants will do the following:

1. Discuss how they will get support from family or friends or both.
2. Discuss how they will get support from health care providers.
3. Discuss how they will get support in the community.
4. Identify their next steps for getting support, care and treatment.

5. Discuss challenges to getting the support they need and strategies to overcome them.
6. Listen to a panel of specialists and draw a community map of support and services.

### At a Glance

**Write these statements on the chalkboard or flip chart.**

- You deserve support! Think about the people in your life who will be helpful.
- You can ask me, your health care provider and other trusted adults for suggestions on support services.
- Support each other, and ask for advice from other people you know who are living with HIV.



### Activity Corner

Remind participants that they can use their notebooks between group meetings to record their feelings, any questions they have and any successes or challenges they experienced since the last session.

They could also take notes during the session, if they like. Ask if anyone would like to share anything they wrote, but assure participants that they don't have to. Answer any questions that arise, and help process feelings that people share.



## Key Messages

Share the following key messages with the group. Describe the concepts in your own words or read them aloud using the text provided. Allow time for discussion and questions as you go, and take breaks as needed.

- As you get older, your care and treatment needs may change.
- It is important to identify what you need in terms of support so that you know who to contact and how to let people know what you need.
- Your health care provider might be able to refer you to some organizations, but other people might be able to help you as well—people from this group, other people living with HIV, or groups or organizations in the community.
- This is a time when your communication skills will be very useful! You will need to be able to explain to others how they can best help you.



## Group Discussion Questions

Use the questions below to lead a discussion about finding support. Read them aloud using the text provided or describe the concepts in your own words. Before the session, prepare any visuals that will help you illustrate the information. Encourage participants to take notes.

1. What types of services and support will you need to live a healthy and positive life?
2. Where can you find these services? Who will help you get there? How will you pay for the different things you need—medicine, shelter, food, transportation?
3. In what ways can your family and friends support you?
4. Who are your health care providers now? Will they change? What do you need to discuss with them about your care and treatment? If appropriate, how will they support you in pregnancy prevention and safer sex?
5. What is your community's role? In what ways might religious groups, churches or mosques be able to help you?
6. What might your teachers and others at your school do to make sure you are getting the support you need?
7. (If age appropriate) How can you receive an income, either by finding work or starting a business in your community? What sorts of programs or training are available for learning a trade in your community or district?
8. How can you link to other people in this group for information and support?
9. What are your next steps to continue your care and treatment? Who do you need to talk to? What do you need to do?

*“[Before joining a club for young people living with HIV], I didn’t think there were people in the same situation as I am. I was always depressed ... kicking myself, thinking “why me, why me.” I was just waiting for the day I would die.”*

– Adolescent from Botswana

10. What questions do you have about your care and treatment plan? What information do you feel you still need? Where can you go to get additional information and support?



### Activity Corner

Use the following activities to help develop a better understanding of how to plan for the future.

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## I. YOUR COMMUNITY OF SUPPORT: PANEL OF SPECIALISTS

**TIME:** 45 minutes

**MATERIALS:** Invite a panel of guest speakers from your community. Include speakers from the local clinic, organizations that provide support to youth, religious groups or community-based groups that work with PLHIV, other nongovernmental organizations (NGOs) that work in the region, organizations that offer psychosocial support and local school or trade training programs. Include community leaders and guest speakers who are living with HIV.

### INSTRUCTIONS:

Introduce the panelists to the group. Explain that the panel was invited to (1) answer participants’ questions about living with HIV and (2) share how each panelist can be a resource and part of each participant’s community of support.

Introduce each panelist and ask them to tell the group about themselves and their work and how they can work with young people living with HIV.

Ask participants to write down any questions they have for the panelists on a piece of paper. Assure participants that their questions will remain anonymous. Inform the group that they can also ask the panelists questions directly. Include the following questions if appropriate:

- What are ways you currently support ALHIV at your clinic or organization?
- What are ways you can help reduce stigma and discrimination for ALHIV in the community? In school? At the clinic? In your organization?
- In your opinion, what are ways ALHIV can contribute to your organization, clinic, school or the community?
- How can ALHIV use you and your organization or group as resources for support?

Summarize by highlighting common themes and unique points. Close by thanking the panelists. If possible, invite the panelists to remain for the community “Map of Support” activity.

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## II. MAP OF SUPPORT

**TIME:** 40 minutes

**MATERIALS:** Paper and pencils

**INSTRUCTIONS:**

Explain to participants that in the last activity, they learned about adults in the community who are available to help them. In this next exercise, participants will identify where support and services for ALHIV can be found in their communities.

Divide the group into smaller groups of three or four people each. Inform them that each group will draw a community resource map. Give each group a piece of flip chart paper and markers. Ask each group to draw a map of their community, labeling key places that might provide support and services, such as these:

- Clinics and hospitals for care and treatment, STI screening, antenatal care and family planning

- Churches or mosques for counseling or other charitable support
- Pharmacies
- Traditional healers
- Schools
- Madrasahs
- Organizations that work for and with youth—such as NGOs and youth groups
- Alcohol and drug counseling centers
- Services that handle rape and sexual abuse
- Vocational training or educational institutions
- Microfinance lenders, or livelihood or entrepreneurship centers
- Other

After 20 minutes, ask the groups to share their maps. Discuss the following questions with the entire group:

- Which services are designed for young men?
- Which services are designed for young women?
- Which services are youth-friendly?
- Which services will not be judgmental of ALHIV?
- Which types of services are most trusted to give quality care?
- Which services are most accessible to young people because of location, cost or hours of operation?

Advocate for places that are designed specifically for adolescents or that are youth-friendly. Encourage participants to visit places to find out more about the services these resources provide. Tell them that they will feel more comfortable when they go for services if they understand ahead of time what these facilities and organizations offer.

Here are examples of things to find out:

- Hours of operation
- Cost
- Services available
- Person they can contact
- Description of what will happen during services



### Final Review and Wrap-up

Use the following questions to re-emphasize this session's key messages, and then wrap up for the day.



#### NOTE TO FACILITATOR:

Participants' responses will also help you learn whether any of the group members are confused about certain topics. If so, you could make a note to address those topics again the next time the group meets, work one-on-one with someone who is having trouble with the information or invite an expert to give more information at a later meeting.

### Review questions

- Why is a support network so important?
- Who can be part of your support network?
- What are some ways that supportive people might be able to help you?

### Wrap-up

Ask if the group has any last questions or concerns. Thank them for their bravery in talking about their status and their feelings.

Encourage the group to develop their own personal support maps to remind them who they can turn to for help with various needs. Remind participants that they can act as each other's support network. Help them set up a system for supporting each other once the group has ended: they might exchange phone numbers or arrange a regular time to meet informally as friends. Also remind them that they can contact you for help even after they are no longer attending the group.

**NOTE TO FACILITATOR:**

If your support group is ongoing—that is not limited to the 14 sessions outlined here—let participants know that they can continue to come to future meetings. The material will likely be repeated, but the more experienced group members can help and support new members.

After all participants have had a chance to speak, share your insights about what the group has accomplished and thank the participants again for all of their hard work and commitment.

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## CLOSING

If your support group will end with this session, consider doing this brief closing activity as a way to wrap up the entire 14 sessions.

**TIME:** 20 minutes

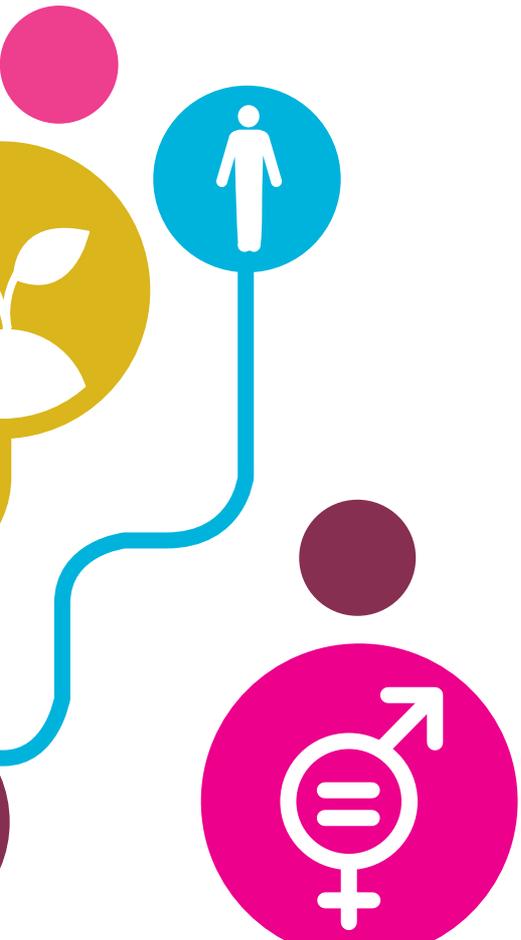
**MATERIALS:** None

**INSTRUCTIONS:**

Ask participants to stand and form a circle.

Inform participants that as a way to close, each of them will take a turn sharing what they have learned or achieved and acknowledge what they have accomplished as a group. Start with the first person to your left and give each person a chance to speak, one by one. Tell participants that they are not required to speak if they do not wish to.





SECTION

4

## Is Your Program Working?

We all hope that our programs are making a difference in the lives of ALHIV. Sometimes we might get a *sense* that the program is working. For example, we might hear positive comments or see that participants enjoyed an activity. But this sort of feedback does not tell us if participants actually gained skills or learned specific information.

This section explains how you can track your program's progress and determine whether the program is meeting its goal of providing support and accurate information to ALHIV.

### **How will keeping track of my program's progress and determining its impact help my program?**

Tracking some simple information about your information and support group—such as what topics were covered, how many people attended your sessions and how much participants learned—can help you to understand which aspects of your program work well, which need improvement and how well your program is meeting its goals. To do this, you must routinely collect information; doing so will help you identify problems and fix them quickly. Also, donors are usually interested in this kind of information, and keeping good records might increase your chances of securing future funding. It is much easier to find funding for a program that has been shown to be successful.

### How do I track my program's progress and determine its impact?

We have provided two simple forms to help you collect the information you need to track your program's progress and determine its impact.

**FORM 1. TRACKING PROGRAM PROGRESS** (pages 153 through 167). The group's facilitator or an experienced observer should complete this form after each session. With this form, you will document the following information:

**Participants**—Record the number of participants who attended the session, their age and sex, and how they were referred to the group. Please note that you should not record participants' names or other identifying information because confidentiality is crucial.

**What participants learned**—At the end of each support group session, you'll find review questions to help you get a sense of how well participants understood the material. On the "Tracking Progress Form," write some brief notes about participants' responses to the questions. This information can help you determine whether the session needs to be improved and if you should explain any of the material again in later sessions to increase participants' understanding.

**Facilitator comments**—Record any general comments you have about what worked and what might help you improve the session in the future.

See page 153 for an example of a completed form. In this example, the information collected would help the facilitator see that at the session's end, participants still didn't understand what ARV therapy is and that he or she should explain that information again in the next session. Also, the facilitator noted that boys do most of the talking, so he or she could try to encourage girls to actively participate.

A blank "Tracking Program Progress" form begins on page 154.

**FORM 2. MEASURING PROGRAM IMPACT.** This form helps you determine what your participants learned by attending the information and support group sessions. Ask participants to complete a copy of this form at the beginning of the first session and at the end of the last session. If any participants join the group after Session 1, please have them complete the form before their first session and make a note of when they joined the group.

**Please make sure that participants understand that this form is not a test.** You are asking for their opinions to help you tailor the sessions and make sure you are covering the information they want and need to know. Tell participants that they do not need to write their names on the form because you are simply going to compare the sheets filled out before and after the support group to see what the group has learned or how their opinions or behaviors have changed.

When you compare results at the beginning and end of your program, you can see what numbers participants chose for each statement before and after attending. For example, see statement one:

*I understand how to prevent the transmission of HIV.*  
False 1 2 3 4 5 True

If the average participant answer was “3” before the program and “5” after the program, you know that you have improved your participants’ knowledge of the transmission of HIV.

Other statements can help demonstrate how participants’ skills have changed over time. For example, see statement five:

*I am able to consistently take my HIV medications and go to the doctor regularly.*  
False 1 2 3 4 5 True:  
*I am not on medication.*

Page 168 is a blank “Measuring Program Impact” form for participants to fill out before their first session. Page 169 is a blank “Measuring Program Impact” form for participants to complete at the end of the last session.

### EXAMPLE: PART OF A COMPLETED “TRACKING PROGRAM PROGRESS” FORM

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
1 Date: <b>January 4, 2012</b>	Male <b>10</b>  Female <b>8</b>  Total <b>18</b>  Age range of participants <b>17 to 23</b>  Number of new participants <b>18</b>	From counselor at secondary school, from teen clinic at hospital, from Catholic church	Who can tell us the difference between HIV and AIDS? <b>Most of group could tell difference. Some confusion on whether you get AIDS when first infected.</b>  Can anyone explain how HIV is transmitted? <b>Most of group could name blood and sex. Only a few knew breastmilk.</b>  How can you prevent passing HIV to a sex partner? <b>Everyone said condoms. Some incorrectly thought withdrawal.</b>  What is antiretroviral therapy? <b>Only one could describe ARV therapy accurately.</b>	<b>Group was very talkative overall. They are interested in the topic and seem excited to know other positive adolescents. Most of them had learned basic HIV facts before. The young men talked more than the young women.</b>  <b>Note to self: try to draw girls into the conversation more and give them a chance to ask and answer questions.</b>

## BLANK FORM 1: TRACKING PROGRAM PROGRESS

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
1 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Who can tell us the difference between HIV and AIDS?</p> <p>Can anyone explain how HIV is transmitted?</p> <p>How can you prevent passing HIV to a sex partner?</p> <p>What is antiretroviral therapy?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
2 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What do we mean when we talk about disclosure?</p> <p>What are some of the risks of disclosing your HIV status?</p> <p>What are some benefits of disclosing your status?</p> <p>How will you decide whom to tell about your status?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
3 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Does everyone who is living with HIV need ART? Why or why not?</p> <p>Why are antiretroviral medications so important for people taking them?</p> <p>What are some of the main things to remember about taking ARVs?</p>	



**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
5 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What sorts of changes happen to girls during puberty?</p> <p>What sorts of changes happen to boys during puberty?</p> <p>Why is good hygiene especially important for people who are living with HIV?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
6 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Can you name some of the responsibilities that come with having sex?</p> <p>What are some of your sexual rights?</p> <p>Who can name three sexual activities that would qualify as safer sex?</p> <p>Is there a volunteer who can use the penis model to show us how to put on a condom?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
7 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What are some good reasons to wait until you are older to have children?</p> <p>Who can name some effective ways to prevent pregnancy?</p> <p>If and when you decide to have children, what is the first thing you should do?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
8 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Who can remind us what positive prevention means?</p> <p>What are some of the dangers of having unprotected sex (sex without a condom)?</p> <p>What are the risks to having more than one sexual partner at a time?</p> <p>What are the risks of having many sexual partners over the course of your lifetime?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
9 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Does a victim of violence ever deserve the violence? Why or why not?</p> <p>What are some examples of emotional violence?</p> <p>What are some examples of sexual violence?</p> <p>What can you say to show support to a friend who is in a relationship that is violent?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
10 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What do we mean when we say that someone is assertive?</p> <p>What makes someone a good communicator?</p> <p>Why is assertiveness and communication especially important to ALHIV?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
11 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Are there any feelings that are not normal to have about living with HIV? Why or why not?</p> <p>Who can name some steps people can take to feel better?</p> <p>What is something you can do when you are feeling sad to help you feel better?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
12 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What are some of your rights, not only as a person living with HIV, but as a person? Do you feel your rights are different from those of an adult? Why or why not?</p> <p>What does self-stigma mean, and what can you do about it?</p> <p>Who can you turn to if you feel you are being discriminated against?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
13 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>What does the word values refer to?</p> <p>Why are values important?</p> <p>What are some trustworthy sources of information?</p> <p>What are one or two steps you can take now to help plan for your future?</p>	

**BLANK FORM 1: TRACKING PROGRAM PROGRESS** *CONTINUED*

FORM 1. TRACKING PROGRAM PROGRESS (to be completed after each session)				
Session	Participant description	Ways that participants were referred	Facilitator comments on review questions (found at the end of each session)	Overall facilitator comments
14 Date	<p>Male</p> <p>Female</p> <p>Total</p> <p>Age range of participants</p> <p>Number of new participants</p>		<p>Why is a support network so important?</p> <p>Who can be part of your support network?</p> <p>What are some ways that supportive people might be able to help you?</p>	

## FORM 2: MEASURING PROGRAM IMPACT—BEFORE BEGINNING SESSIONS

**Please circle the number that best describes how true each statement is for you.**

**Definitely false is number 1; definitely true is number 5.**

1. I understand how to prevent the transmission of HIV.  
False 1 2 3 4 5 True
2. I know where to go to get treatment for HIV.  
False 1 2 3 4 5 True
3. I know the right way for someone with HIV to eat and exercise to stay healthy.  
False 1 2 3 4 5 True
4. When I want to share my HIV status with someone else, I am able to do this.  
False 1 2 3 4 5 True
5. I think it is very important to take my HIV medications exactly as my doctor tells me to.  
False 1 2 3 4 5 True
6. I am able to consistently take my HIV medications and go to the doctor regularly.  
False 1 2 3 4 5 True  
I am not on medication.
7. I know what kind of contraception I can use to prevent an unwanted pregnancy.  
False 1 2 3 4 5 True
8. Young people living with HIV have the same rights as all other young people.  
False 1 2 3 4 5 True
9. I have friends and family who know my status and support me.  
False 1 2 3 4 5 True
10. I know where to find services for adolescents living with HIV.  
False 1 2 3 4 5 True
11. I am good at telling others what I need or want.  
False 1 2 3 4 5 True
12. When I feel sad or angry, I have things that I can do to feel better.  
False 1 2 3 4 5 True
13. When I experience stigma against persons living with HIV, I have someone to talk to.  
False 1 2 3 4 5 True
14. I have goals that I want to accomplish as an adult.  
False 1 2 3 4 5 True

## FORM 2: MEASURING PROGRAM IMPACT—AFTER SESSIONS ARE COMPLETED

Approximately how many sessions of this support group did you attend? (Please circle one.)

1-5                      6-10                      11-14

**Please circle the number that best describes how true each statement is for you.**

**Definitely false is number 1; definitely true is number 5.**

1. I understand how to prevent the transmission of HIV.

False 1 2 3 4 5 True

2. I know where to go to get treatment for HIV.

False 1 2 3 4 5 True

3. I know the right way for someone with HIV to eat and exercise to stay healthy.

False 1 2 3 4 5 True

4. When I want to share my HIV status with someone else, I am able to do this.

False 1 2 3 4 5 True

5. I think it is very important to take my HIV medications exactly as my doctor tells me to.

False 1 2 3 4 5 True

6. I am able to consistently take my HIV medications and go to the doctor regularly.

False 1 2 3 4 5 True

I am not on medication.

7. I know what kind of contraception I can use to prevent an unwanted pregnancy.

False 1 2 3 4 5 True

8. Young people living with HIV have the same rights as all other young people.

False 1 2 3 4 5 True

9. I have friends and family who know my status and support me.

False 1 2 3 4 5 True

10. I know where to find services for adolescents living with HIV.

False 1 2 3 4 5 True

11. I am good at telling others what I need or want.

False 1 2 3 4 5 True

12. When I feel sad or angry, I have things that I can do to feel better.

False 1 2 3 4 5 True

13. When I experience stigma against persons living with HIV, I have someone to talk to.

False 1 2 3 4 5 True

14. I have goals that I want to accomplish as an adult.

False 1 2 3 4 5 True



SECTION

5

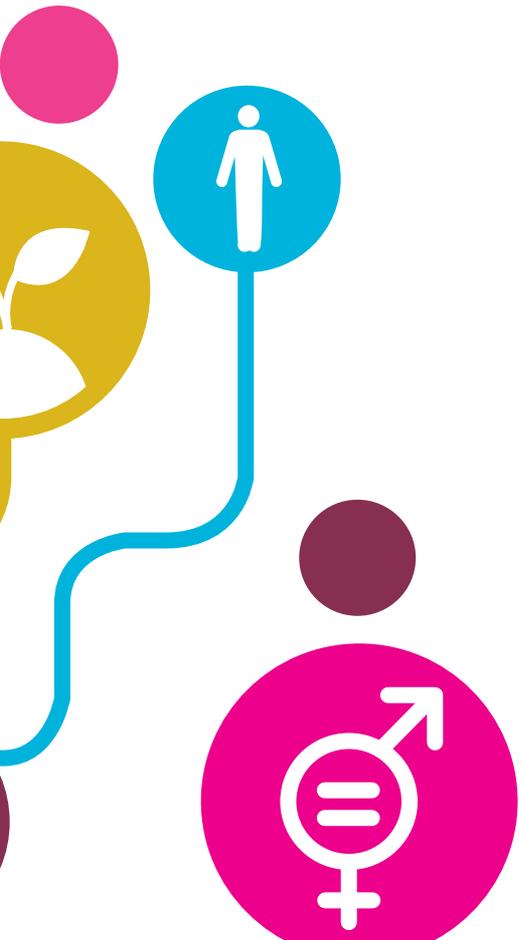
# Appendices

[Appendix 1. Contraceptive Methods for People Living with HIV](#)

[Appendix 2. Additional Activities and Resources](#)

[Appendix 3. Referral Chart](#)

[Appendix 4. Acronym List](#)



## APPENDIX 1.

### Contraceptive Methods for People Living With HIV

This table can help people living with HIV choose a contraceptive method. All methods are safe for people who are infected with HIV, have AIDS or are taking ARV medications, except as specifically noted.

METHOD	CONSIDERATIONS FOR PEOPLE LIVING WITH HIV
Male and female condoms	<ul style="list-style-type: none"> <li>• The only method that helps protect against both pregnancy and STIs, including HIV.</li> <li>• Must be used correctly every time to be fully effective.</li> <li>• Maintaining consistent and correct use can be difficult.</li> </ul>
Combined oral contraceptives (COCs) and combined injectable contraceptives	<ul style="list-style-type: none"> <li>• Women whose ARV regimen contains ritonavir generally should not use COCs or combined injectable contraceptives because ritonavir may decrease their effectiveness.</li> <li>• It is generally recommended that women using any other ARV regimen can use COCs and combined injectable contraceptives safely. Because some other ARVs (NNRTIs) may still affect effectiveness to some degree (less than ritonavir), it is important to compensate for this by not missing oral contraceptive pills or by getting injections on time. Adding condoms ensures additional protection.</li> </ul>
Progestin-only pills (POPs)	<ul style="list-style-type: none"> <li>• Women whose ARV regimen contains ritonavir generally should not use POPs because ritonavir decreases their effectiveness.</li> <li>• It is generally recommended that women using any other ARV regimen can use POPs safely. Because some other ARVs (NNRTIs) may still affect effectiveness to some degree (less than ritonavir), it is important to compensate for this by not missing POPs and by taking them at approximately the same time each day. Adding condoms ensures additional protection.</li> </ul>
Progestin-only injectable contraception	<ul style="list-style-type: none"> <li>• New data have emerged regarding a possible association between the use of hormonal contraception, particularly progestin-only injectables, and HIV acquisition in women and transmission from HIV-positive women to male sex partners. Some studies have suggested there is a risk; others have not shown this association. Therefore, WHO concluded in February 2012 that women at risk of HIV or living with HIV may continue to use all existing hormonal contraceptives without restriction, but that a strong clarification about the use of progestin-only contraceptives be added: <b>Women using progestin-only injectable contraception should be strongly advised to always also use condoms, male or female, and take other preventive measures.</b></li> </ul>
Implants	<ul style="list-style-type: none"> <li>• It is generally recommended that women using ARVs can use all implants safely. Because some ARVs (NNRTIs and ritonavir) may affect effectiveness of implants to some degree, also using condoms is recommended for enhanced pregnancy protection.</li> </ul>
Emergency contraceptive pills (ECPs)	<ul style="list-style-type: none"> <li>• Researchers believe that ARVs do not reduce the effectiveness of ECPs.</li> <li>• There is no evidence for increasing ECP dosage for women on ARVs.</li> </ul>

METHOD	CONSIDERATIONS FOR PEOPLE LIVING WITH HIV
Copper-bearing intrauterine device (IUD) and levonorgestrel intrauterine device	<ul style="list-style-type: none"> <li>• Women at risk of HIV infection or infected with HIV can generally have an IUD inserted.</li> <li>• Women who have AIDS, are taking ARVs and are clinically well can generally have an IUD inserted.</li> <li>• Women should not have an IUD inserted if they have AIDS and are not taking ARVs, or are taking ARVs but are not clinically well.</li> <li>• If women acquire HIV or develop AIDS while they have an IUD in place, it generally does not need to be removed.</li> <li>• Women with gonorrhea or chlamydia should not have an IUD inserted until they are infection free.</li> <li>• IUD users with AIDS should be monitored for pelvic inflammatory disease.</li> </ul>
Female sterilization and male vasectomy	<ul style="list-style-type: none"> <li>• All young people who consider sterilization or vasectomy, regardless of their HIV status, should make sure that they are ready to permanently terminate their fertility.</li> <li>• Delay sterilization and vasectomy if currently ill with AIDS-related illness.</li> <li>• Special arrangements are needed to perform female sterilization on a woman with AIDS and a vasectomy on a man with AIDS. The procedure should be undertaken only in settings with experienced staff and sufficient equipment and support.</li> <li>• Female sterilization and vasectomy do not prevent transmission of HIV.</li> </ul>
Lactational amenorrhea method (LAM)	<ul style="list-style-type: none"> <li>• Women who are infected with HIV or who have AIDS and choose to breastfeed their infant can use LAM.</li> <li>• Exclusive breastfeeding (without introducing other foods, liquids or water) for the first six months of baby's life is safer than mixed feeding and minimizes the risk of HIV transmission through breastmilk. This pattern of breastfeeding is also required for LAM to be effective.</li> <li>• If a woman's monthly bleeding returns before six months, she will need another contraceptive method while continuing to breastfeed exclusively.</li> <li>• Women with HIV and their health care providers need to consider the infant feeding options available and to weigh their various risks and consequences.</li> </ul>
Fertility awareness methods	<ul style="list-style-type: none"> <li>• Calendar-based fertility awareness methods rely on regular menstrual cycles. For women with advanced HIV (low CD4+ cell count), irregular cycles may be common and make these methods difficult to use.</li> <li>• For most people, fertility awareness methods are less effective than are other modern methods of contraception.</li> </ul>
Spermicides	<ul style="list-style-type: none"> <li>• Women at high risk of HIV infection and who have very frequent intercourse should not use spermicides.</li> <li>• Spermicides are not generally recommended for women with HIV or those who developed AIDS.</li> </ul>
Diaphragm	<ul style="list-style-type: none"> <li>• Diaphragms may help keep infectious organisms from reaching the cervix, but diaphragms do not protect against HIV infection.</li> <li>• Because diaphragms are used with spermicides, they should not be used by women at risk of HIV.</li> <li>• Diaphragms are not generally recommended for women who have HIV or have developed AIDS.</li> </ul>

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## APPENDIX 2.

### Additional Activities and Resources

#### ACTIVITIES

##### Name Game

**TIME:** 10 minutes

**MATERIALS:** None

**INSTRUCTIONS:**

Instruct participants to sit in a circle. Ask for a volunteer to start by saying an adjective that describes him or her and that starts with the same letter as his or her name, for example, “Cool Chris” or “Awesome Amy.” The second person should repeat the first person’s adjective and name before going on with his own adjective and name.

Continue until the last person repeats everyone’s adjectives and names and ends the activity with her own adjective and name.

##### Go-Rounds

**TIME:** 15 minutes

**MATERIALS:** Go-round topics

**INSTRUCTIONS:**

Say the following: In a moment, I’ll read a statement. We’ll then go around the room, and each person will say something about the statement.

Select one to five topics from the “Suggested Go-Round Topics.” Read the first statement aloud to the group, and allow each participant to say something about it. Continue with the other statements as time allows.

Suggested Go-Round Topics:

- One thing you’d like to change about the world
- Something pleasant that happened to you in the last week
- A color that describes how you feel right now
- A characteristic that you look for in a friend
- A value you’d like to teach the world
- A book or movie you’d like to recommend
- One thing you’d like the group to know about you
- If you were a type of weather, what would it be?
- Something not everyone knows about you
- Something that makes you feel happy
- Something you’re good at that ends in ...ing (such as swimming, talking, running)

## Remember Game

**TIME:** 10 minutes

**MATERIALS:** None

### **INSTRUCTIONS:**

Ask participants to form pairs. Instruct participants to face each other in their pairs.

Ask them to closely observe each other from head to toe for 30 seconds. Then have participants turn their backs to each other and change one thing about the way they look (such as taking off their glasses or unbuttoning one button on their shirt)

Instruct participants to face each other again, and ask them to see what is different about their partners.

## People-to-People

**TIME:** 20 minutes

**MATERIALS:** None

### **INSTRUCTIONS:**

Ask participants to pick one partner each and form a large circle. There should be an even number of people in the circle, and one person should stand in the middle and be the caller (the facilitator may need to participate to make the circle even).

The facilitator then names a pair of body parts like “elbow to knee,” and each of the pairs attach one person’s elbow to the other person’s knee. Keeping these parts attached, this will continue for three or four more times until pairs are tangled up. Then the facilitator calls “people to people” and the process starts over, with participants finding a new partner. The person who doesn’t find a partner becomes the new caller.

## RESOURCES

### HIV- and AIDS-Related Information

Avert.org: An online resource with easy to understand information on HIV transmission, prevention, treatment, care, epidemiology, pathology, politics and more.<sup>20</sup>

<http://www.avert.org>

The Body: An online HIV and AIDS resource with a four-part mission: (1) Use the Web to lower barriers between patients and clinicians; (2) demystify HIV and AIDS and their treatment; (3) improve patients' quality of life; and (4) foster community through human connection.<sup>11</sup>

[www.thebody.com](http://www.thebody.com)

Global Network of People Living with HIV and AIDS (GNP+): An organization with several regional networks working to improve the quality of life for all people living with HIV and AIDS.<sup>21</sup>

<http://www.gnpplus.net>

IPPF HIV and AIDS related films: In 2008 IPPF, GNP+ and UNFPA supported Hope's Voice International to develop a multimedia stigma reduction campaign in Mexico, South Africa and Swaziland. Using video interviews, the project documented the experiences of young people living with HIV in each of these countries. Topics include disclosure, family planning, prevention, positive living, stigma and others.<sup>22</sup>

<http://ippf.org/our-work/what-we-do>

Facilitator's guide, *IMAI One-Day Orientation on Adolescents Living with HIV*: This guide to a one-day course for health workers was developed as additional training for the WHO Integrated Management of Adolescent and Adult Illness (IMAI) package.<sup>2</sup>

[http://whqlibdoc.who.int/publications/2010/9789241598989\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241598989_eng.pdf)

FHI 360's HIV Counseling and Testing for Youth: This HIV counseling and testing manual is designed for service providers and counselors working with youth.<sup>3</sup>

<http://www.fhi360.org/resource/hiv-counseling-and-testing-youth-manual-providers-and-manual-trainers>

## Needs of ALHIV

Body and Soul Charity: A UK-based organization supporting people living with HIV. Its Teen Spirit section (for people ages 13 and up living with HIV) provides comprehensive information and resources geared specifically toward ALHIV.<sup>23</sup>

<http://www.bodyandsoulcharity.org>

Does HIV Look Like Me? A campaign conceived of by ALHIV from Hopes Voice International. This effort uses mass media to target stigma, discrimination and ignorance about the HIV and AIDS pandemic. Thus far 200 “ambassadors,” young people living with HIV, have participated in the campaign, using film, photography and speaking opportunities in schools, churches and community groups to raise awareness about HIV and people living with HIV.<sup>24</sup>

[www.doeshivlooklikeme.org](http://www.doeshivlooklikeme.org)

Global Youth Coalition on HIV/AIDS (GYCA): A youth-led global network of 5,000 young people working to end the spread of HIV and AIDS in more than 150 countries worldwide. GYCA prioritizes (1) networking and sharing of best practices, (2) capacity building and technical assistance, (3) political advocacy and (4) preparation for international conferences. Find other young people in your country and mentors, donors, funders, scholarships, trainings and event opportunities related to HIV, AIDS and sexual reproductive health.<sup>25</sup>

[www.youthaidscoalition.org](http://www.youthaidscoalition.org)

Hopes Voice International: An ALHIV-led organization committed to promoting the education and prevention of HIV and AIDS to young adults. This organization aims to empower youth who are living with HIV to be leaders in educating their communities and be catalysts for change around the globe.<sup>26</sup>

<http://www.hopesvoice.org>

Kids ART Education Series (KAES): This package shares knowledge, facts and a series of creative and fun activities centered around children and ART. Children can share it with their peers, family, friends and other members of their community. Children are a critical group of PLHIV and are often overlooked when efforts are made to promote community ART literacy.<sup>27</sup>

<http://www.saf aids.net/?q=node/520>

My Sex Life: Info for Poz Youth: A youth-friendly, informative guide on safer sex and sexuality for ALHIV by the AIDS Committee of Toronto and Positive Youth Outreach, Canada.<sup>28</sup>

<http://www.actoronto.ca/home.nsf/pages/mysexlife>

Regional Psychosocial Support Initiative (REPSSI): This initiative offers technical assistance and resources for psychosocial support for children affected by HIV and AIDS in the East and Southern Africa region. Some of the resources that can be used as additional activities are *Making a Hero Book*, the *Tree of Life Talking Book* and *Living with X: A Body Mapping Journey in the Time*

of HIV and AIDS. An additional resource is *Mobilizing Children and Youth into Their Own Child and Youth-led Organizations*.<sup>29</sup>

<http://www.repsi.org/>

### **Information on Drug and Alcohol Use**

Recreational Drug Use and HIV: This article is part of *The Body*, an online HIV and AIDS resource.<sup>10</sup>

<http://www.thebody.com/content/art38737.html>

Youth RISE: An international youth network for reducing drug-related harm.<sup>30</sup>

<http://youthrise.org/>

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## APPENDIX 3.

### Referral Chart

Organizations or clinics that provide HIV-related services

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide contraceptive services

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide STI screening or treatment

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide care for victims of sexual violence

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide psychological or mental health counseling

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations that work with adolescents (such as YWCA, YMCA, scouts, youth groups)

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations that can provide information and training related to job skills, livelihoods or education

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations that can work with victims of bullying or school violence

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide services for prevention of mother-to-child transmission of HIV

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Pharmacies or other locations that can provide information on ARVs (including information on storage, adherence and side effects)

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations or clinics that provide nutrition counseling and help

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

Organizations that have information related to the rights of PLHIV

Name of organization	Address	Telephone	Contact name	Email address
1.				
2.				
3.				
4.				

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## APPENDIX 4.

### Acronym List

AIDS	Acquired immunodeficiency virus	NGO	Nongovernmental organization
ALHIV	Adolescents living with HIV	PLHIV	People living with HIV
ART	Antiretroviral therapy	POPs	Progestin-only pills
ARV	Antiretroviral drug	REPSSI	Regional Psychosocial Support Initiative
ECP	Emergency contraceptive pill	STI	Sexually transmitted infection
FANTA-II	Food and Nutrition Technical Assistance II	UNAIDS	Joint United Nations Programme on HIV/AIDS
GNP+	Global Network of People Living with HIV	UNICEF	United Nations Children's Fund
GYCA	Global Youth Coalition on HIV/AIDS	USAID	U.S. Agency for International Development
HIV	Human immunodeficiency virus	WHO	World Health Organization
IMAI	Integrated management of adult illness		
IPPF	International Planned Parenthood Federation		
IUD	Intrauterine device		
KAES	Kids ART Education Series		
LAM	Lactational amenorrhea method		
MCPs	Multiple and concurrent partners		
MSM	Men who have sex with men		

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