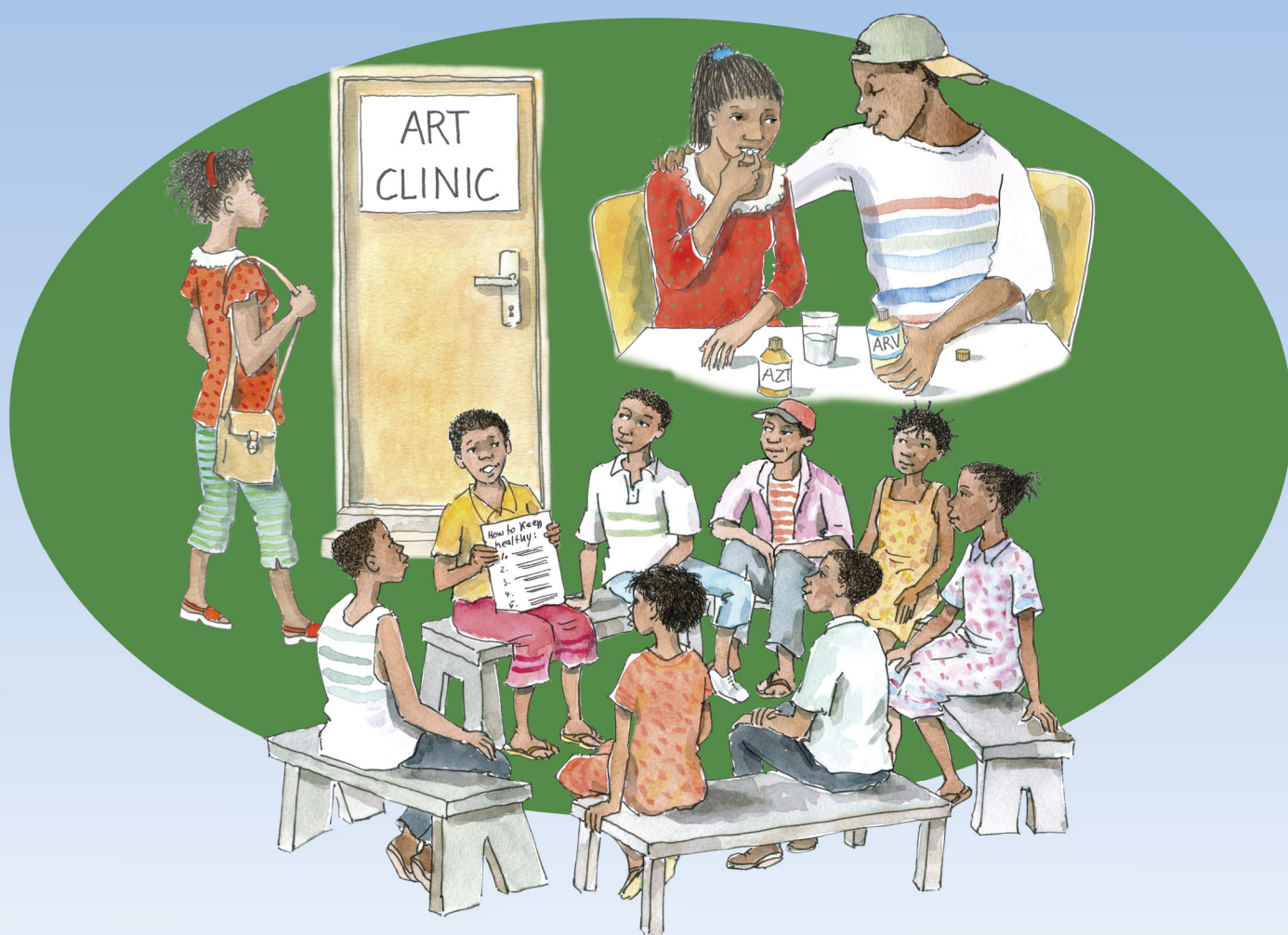




# Adolescent HIV Care and Treatment

A Training Curriculum for  
Multidisciplinary Health Care Teams

## PARTICIPANT MANUAL



March 2011



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## Abbreviations and Acronyms

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3TC	Lamivudine
ABC	Abacavir
ADHD	Attention deficit hyperactivity disorder
ALHIV	Adolescent(s) living with HIV
ALT	Alaninaminotransferase, a liver enzyme
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
AST	Aspartate transaminase or aspartate aminotransferase, a liver enzyme
AZT	Zidovudine
BMI	Body mass index
BSE	Breast self examination
CAB	Client/consumer/community advisory board
CD4	T-lymphocyte CD4 cell count
CHIPS	Collaborative HIV Paediatric Study
CMV	Cytomegalovirus
COCs	Combined oral contraceptive pills
CrCl	Creatinine clearance
CTX	Cotrimoxazole
d4T	Stavudine
ECPs	Emergency contraceptive pills
EFV	Efavirenz
FAO	Food and Agriculture Organization
FBC	Full blood count
FTC	Emtricitabine
GNP+	Global Network of People Living with HIV and AIDS
GYCA	Global Youth Coalition on HIV/AIDS
HBsAg	Surface antigen of the Hepatitis-B-Virus (HBV)
HIV	Human immunodeficiency virus
HIV VL	HIV viral load
ICW	International Community of Women Living with HIV
IMAI	Integrated Management of Adolescent and Adult Illness
INH	Isoniazid
IPT	Isoniazid preventive therapy
IRIS	Immune reconstitution inflammatory syndrome
IUD	Intra-uterine device
LAM	Lactational amenorrhea method
LFT	Liver function test
LPV/r	Ritonavir boosted lopinavir
MoH	Ministry of Health
MTCT	Mother-to-child transmission (of HIV)
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OIs	Opportunistic infections

ORS	Oral rehydration solution
PCOE	University Teaching Hospital's Department of Paediatrics HIV Centre of Excellence in Zambia
PI	Protease inhibitor
PITC	Provider-initiated HIV testing and counselling
PMTCT	Prevention of mother-to-child transmission (of HIV)
POPs	Progestin-only oral contraceptive pills
QA	Quality assurance
QI	Quality improvement
RFT	Renal function test
sdNVP	Single-dose nevirapine
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TB	Tuberculosis
TDF	Tenofovir
TSE	Testicular self-examination
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

## Foreword

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Despite a 25% reduction in HIV incidence in Zambia between 2001 and 2009, HIV prevalence for the population as a whole was still estimated to be 13.5% in 2009<sup>1</sup>. In 2009 alone, 59,000 adults were infected with HIV as well as 17,000 children. UNAIDS estimates that a total of 120,000 children between the ages of 0–14 years are now living with HIV in Zambia. Of the children with perinatally acquired HIV (that is, HIV infection acquired through mother-to-child transmission of HIV [MTCT]), without treatment about half will die before their 2<sup>nd</sup> birthday. According to UNICEF's *Children and AIDS: Fifth Stocktaking Report, 2010*, of the 120,000 children living with HIV, about 59,000 are in need of ART. Of those 59,000, 36% are receiving it. Given this increased access to paediatric HIV care and treatment, more and more perinatally infected children are living longer and reaching adolescence and adulthood.

In addition to adolescents with perinatally acquired HIV, many adolescents have acquired HIV during their youth. Prevalence figures for Zambia's youth are sobering: 8.9% of young women (15–24 years of age) and 4.2% of young men are infected with HIV — many, if not most, acquired HIV behaviourally, primarily through sexual transmission.

Given the prevalence of HIV in Zambia's adolescent population (those between the ages of 10–19 years), the Ministry of Health (MoH) is committed to developing HIV services that specifically serve the needs of this population. Whether behaviourally or perinatally infected with HIV, adolescents living with HIV (ALHIV) face unique health, adherence, and psychosocial issues and challenges. Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients in care. Zambia already has successful models of adolescent HIV care and treatment services (such as the Adolescent HIV Clinic at University Teaching Hospital PCOE in Lusaka), that can be scaled up nationally. But scaling up depends on making a commitment to adolescent HIV services and continuously improving the knowledge and skills of healthcare workers so that they can best address the specific needs of adolescent clients. This “Adolescent HIV Care and Treatment Training Curriculum for Multidisciplinary Healthcare Teams” represents a key step in the MoH's commitment to ensure the rollout of HIV-related services that truly serve the needs of ALHIV. Young people are our future!

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<sup>1</sup> UNAIDS. (2010). Report on the Global AIDS Epidemic. *Global Report*. [http://www.unaids.org/globalreport/Global\\_report.htm](http://www.unaids.org/globalreport/Global_report.htm)



## Module 1

### Introduction and Course Overview

**Session 1.1: Welcome and Introductory Activity**

**Session 1.2: Training Objectives, Agenda, and Ground Rules**

**Session 1.3: Training Pre-Test**

**Session 1.4: Values Clarification**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Know more about the trainers and other training participants and have discussed expectations for the training.
- Be able to explain the importance of a training specific to adolescent care and treatment.
- Understand the training objectives and agenda.
- Have set training “ground rules”.
- Have completed the training pre-test.
- Have explored their own values and attitudes around adolescents and adolescent HIV care and treatment.



## Session 1.1      Welcome and Introductory Activity

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### Session Objective

**After completing this session, participants will:**

- Know more about the trainers and other training participants and have discussed expectations for the training.

### Exercise 1: Getting to Know Each Other: Large group discussion and individual reflection

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To provide an opportunity to get to know one another a bit better</li> <li>• To create a comfortable learning environment</li> <li>• To introduce and understand the role of the adolescent co-trainer (optional)</li> <li>• To discuss participants' concerns about adolescent HIV care and treatment, expectations for the training, and personal and professional strengths</li> </ul>
<b>Instruction</b>	<p><b>Introductions</b></p> <ol style="list-style-type: none"> <li>1. Participants will be asked to state their name and position, and to share one memorable experience from their own adolescence (good or bad).</li> </ol> <p><b>Individual Reflection</b></p> <ol style="list-style-type: none"> <li>2. Participants should take a few minutes to think about the following questions, and then to write their responses on card or paper.             <ul style="list-style-type: none"> <li>• <b>Concerns:</b> What concerns or worries do you have about providing care to adolescents living with HIV?</li> <li>• <b>Expectations:</b> What do you hope to learn from this training course?</li> <li>• <b>Strengths:</b> What is one personal strength you think helps, or will help you, work effectively with adolescent clients?</li> </ul> </li> <li>3. Participants will be invited to discuss their concerns, expectations and strengths with the group.</li> </ol>

## Session 1.2      Training Objectives, Agenda, and Ground Rules

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### Session Objectives

**After completing this session, participants will:**

- Be able to explain the importance of a training specific to adolescent care and treatment.
- Understand the training objectives and agenda.
- Have set training “ground rules”.

### Key Facts about Adolescents and HIV

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#### Globally:

- In 2007, 40% of new HIV infections in people age 15 and over were among youth 15–24 years of age.
- 5.4 million youth are living with HIV — 61% of whom are in sub-Saharan Africa.
- Due to increased accessibility of ARVs, more children perinatally infected with HIV are living longer and reaching adolescence and adulthood.

#### In Zambia<sup>1, 2</sup>:

- 120,000 children between the ages of 0–14 years are living with HIV<sup>3</sup>.
- Among young women, HIV prevalence is more than twice that of men of the same age:
  - The HIV prevalence for 15–24 year old males is 4.2%.
  - The HIV prevalence for 15–24 year old females is 8.9%.
- 37% of young men and 34% of young women have comprehensive knowledge of HIV and can correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission<sup>4</sup>.
- 48% of young men and 38% of young women reported using a condom the last time they engaged in higher-risk sex.

## **Why a Training on Adolescent HIV Care and Treatment?**

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- Young people are at the centre of the HIV epidemic, as they are particularly vulnerable to HIV infection for social, political, cultural, biological, and economic reasons.<sup>5</sup>
- 74,200 women with HIV give birth each year in Zambia:
  - In 2009, 69% of HIV-infected pregnant women received ARVs to reduce the risk of mother-to-child transmission
- With increased access to paediatric HIV care and treatment, perinatally-infected children are living longer and reaching adolescence and adulthood.
- More young people are being tested for HIV because of increased awareness, reduced stigma, greater access and acceptance of testing, etc. Adolescents who are pregnant are being tested for HIV through PMTCT programmes.
- Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.
- Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients.
- We have successful models of adolescent HIV care and treatment services in Zambia (such as at the University Teaching Hospital in Lusaka), and regionally, that can be scaled-up nationally.
- Healthcare workers need the knowledge and skills to meet the specific needs of adolescent clients.
- Young people are our future!

## **Adolescent HIV Care and Treatment Training Objectives**

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By the end of this training, participants will be able to:

1. Understand how adolescence differs from childhood and adulthood, and how to ensure HIV-related services are tailored to the special needs of adolescents (youth-friendly).
2. Define the package of HIV-related care and treatment for adolescents.
3. Discuss how to establish trust and rapport with adolescent clients using effective counselling skills.
4. Conduct a psychosocial assessment and provide psychosocial support services to adolescent clients.
5. Screen for major symptoms related to persistent mental illness in adolescents.
6. Provide developmentally appropriate disclosure counselling and support to adolescents and, where appropriate, their caregivers or partners.
7. Identify common barriers to adherence and provide age-appropriate support to prepare adolescent clients and caregivers for adherence and to support adherence to care and medicines over time.

8. Support adolescents to live positively and attain key life skills.
9. Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients as a component of sexual health services.
10. List the contraceptive choices available to ALHIV.
11. Provide an overview of PMTCT services for adolescents living with HIV.
12. Actively link adolescents with facility and community-based support services.
13. Prepare and support adolescents through the transition to adult care.
14. Discuss how information from monitoring and evaluation can be used to support programme improvement.
15. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
16. Develop a site-specific action plan for implementing adolescent HIV care and treatment services.

## Training Syllabus and Agenda

The training includes 15 modules, each with its own learning objectives. Each module is divided into a number of sessions.

- Module 1: Introduction and Course Overview
- Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services
- Module 3: Clinical Care for Adolescents Living with HIV
- Module 4: Communicating with and Counselling Adolescents
- Module 5: Providing Psychosocial Support Services for Adolescents
- Module 6: Adolescents, HIV, and Mental Health
- Module 7: Providing Disclosure Counselling and Support
- Module 8: Supporting Adolescents' Retention in, and Adherence to, HIV Care and Treatment
- Module 9: Positive Living for Adolescents
- Module 10: Sexual and Reproductive Health Services for Adolescents
- Module 11: Community Linkages and Adolescent Involvement
- Module 12: Supporting the Transition to Adult Care
- Module 13: Monitoring, Evaluation, Quality Assurance, and Supportive Supervision
- Module 14: Supervised Clinical Practicum
- Module 15: Action Planning, Course Evaluation, and Closure

### Exercise 2: Setting Ground Rules and Introducing Daily Activities: Large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To develop and agree on a set of ground rules that will create an environment that facilitates learning</li> <li>• To introduce the Anonymous Question Bowl as a safe space for asking questions</li> <li>• To introduce the "Morning Rounds" as a way to start off each day of the training on the right foot</li> <li>• To introduce the Daily Evaluation Activity as a way to give feedback to the trainers and to make</li> </ul>
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	adjustments DURING the training course.
<b>Instruction</b>	<p><b>Develop and Agree on the Ground Rules</b></p> <ol style="list-style-type: none"> <li>1. Participants will be asked to discuss what rules will help make them feel comfortable speaking during group discussions.</li> <li>2. The ground rules agreed by the group will be recorded on flip chart paper and posted on the wall for reference throughout the training.</li> </ol> <p><b>Introduce the Anonymous Question Bowl</b></p> <ol style="list-style-type: none"> <li>3. The trainer will provide an overview of the “Anonymous Question Bowl”, which is a way for participants to anonymously submit questions about the training or training content.</li> </ol> <p><b>Introduce the “Morning Rounds”</b></p> <ol style="list-style-type: none"> <li>4. Each morning, the group (participants and trainers) will meet in the classroom for “Morning Rounds.” This will be a time to check in with each other, to recap and answer any questions from the previous day, and to review the agenda for the day.</li> <li>5. Participants should feel comfortable discussing, during the “morning rounds, any distractions or events that are on their minds.</li> </ol> <p><b>Introduce the Daily Evaluation</b></p> <ol style="list-style-type: none"> <li>6. At the end of each training day, the group will debrief using the Daily Evaluation Activity called “How did it Go?”</li> <li>7. Participants will be given 2 small sheets of paper. On one of the sheets of paper they should draw a smiley face (☺) and write one thing that was good about the day. On the other sheet they should draw a sad face (☹) and write one thing they did not like about the day.</li> <li>8. Participants should not write their names on the paper so that they are responding anonymously.</li> <li>9. Both papers should be put into the “How did it Go?” envelope.</li> </ol>

## Session 1.3      Training Pre-Test

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### Session Objective

**After completing this session, participants will:**

- Have completed the training pre-test.

### Training pre-test

1. Participants will have about 20 minutes to complete the **pre-test**, which can be found in “Appendix 1B: Pre-Test”.
2. Participants need not write their names on the pre-test. Instead, they should write a number at the top — any number, for example a favourite number or their birth date. But they should remember this number, as they will need to record the exact same number at the top of their **post-test**. Participants may want to record this number on the inside front cover of their Participant Manuals, so that they will not forget it.
3. The objective of the pre-test is not to look at individual scores, but rather, to find out what the group as a whole knows about adolescent HIV care and treatment and the group’s learning needs. The group’s result on the pre-test will guide the amount of time spent on specific modules and highlight learning needs.
4. This test will be re-administered just before the closing session (as the **post-test**). Comparing the answers to the pre- and post-test questionnaires will measure the changes that occur in the group’s (not an individual’s) knowledge between the beginning and the end of the course. The results will provide some indication of whether the material and teaching methods have been successful.
5. The test answers will be reviewed after the post-tests are collected on the last day of training.

## Session 1.4 Values Clarification

### Session Objective

**After completing this session, participants will:**

- Have explored their own values and attitudes around adolescents and adolescent HIV care and treatment.

### Exercise 3: Values Clarification: Large group exercise

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To help participants begin to think about their own values, attitudes, and prejudices, and how these might either positively or negatively impact their work with adolescents.</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will notice that the trainer has posted on opposite sides of the training room flip chart papers that say “AGREE” and “DISAGREE”.</li> <li>2. As the trainer reads statement out loud, participants should move to the “AGREE” or the “DISAGREE” sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.</li> <li>3. Participants will be invited to explain to the group why they agreed or disagreed with a particular statement.</li> </ol>

### Statements for Values Clarification Exercise:

1. Healthcare workers need to tell adolescents living with HIV how to behave.
2. I think it's hard to “get through” to adolescents — they just do as they please.
3. Adolescent HIV care and treatment is really not that different than paediatric HIV care and treatment.
4. If an adolescent tests HIV-positive, it is my duty to tell his or her parents.
5. I feel comfortable demonstrating to adolescent clients how to use a condom.
6. It is important to have adolescents living with HIV as part of the multidisciplinary care team at the clinic.
7. Working with adolescents requires different counselling skills than those needed to counsel adults.
8. Adolescents living with HIV should be discouraged from ever having children.
9. Adolescents living with HIV since birth and those who acquire HIV later on often have different psychosocial support issues and needs.
10. Adolescents are so forgetful — they aren't good at adhering to their care and medicines.

## Appendix 1A: Sample Training Agenda

Suggested agenda:

Day 1	
Morning Session	<ul style="list-style-type: none"> <li>• Official Opening</li> <li>• Module 1: Introduction and Course Overview (2 hours)</li> <li>• Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services (3 hours, 5 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 2 (continued)</li> <li>• Module 3: Clinical Care for Adolescents Living with HIV (3 hours, 25 minutes)</li> <li>• “How did it Go?”</li> </ul>
Day 2	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 3 (continued)</li> <li>• Module 4: Communicating with and Counselling Adolescents (4 hours, 10 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 4 (continued)</li> <li>• Module 5: Providing Psychosocial Support Services for Adolescents (3 hours, 35 minutes)</li> <li>• “How did it Go?”</li> </ul>
Day 3	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 5 (continued)</li> <li>• Module 6: Adolescents, HIV, and Mental Health (2 hours, 55 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 7: Providing Disclosure Counselling and Support (3 hours, 50 minutes)</li> <li>• “How did it Go?”</li> </ul>
Day 4	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 8: Supporting Adolescents’ Retention in, and Adherence to, HIV Care and Treatment (4 hours)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 8 (continued)</li> <li>• Module 9: Positive Living for Adolescents (3 hours, 15 minutes)</li> <li>• “How did it Go?”</li> </ul>
Day 5	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 10: Sexual and Reproductive Health Services for Adolescents (6 hours, 10 minutes)</li> </ul>
LUNCH	
Afternoon Session	<ul style="list-style-type: none"> <li>• Module 10 (continued)</li> <li>• Module 11: Community Linkages and Adolescent Involvement (2 hours, 45 minutes)</li> <li>• “How did it Go?”</li> </ul>
Day 6	
Morning Session	<ul style="list-style-type: none"> <li>• Recap and “Morning Rounds”</li> <li>• Module 12: Supporting the Transition to Adult Care (1 hours, 40 minutes)</li> <li>• Module 13: Monitoring, Evaluation, Quality Assurance, and</li> </ul>



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	Supportive Supervision (2 hours, 15 minutes)
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>Module 14: Supervised Clinical Practicum (2–2.5 days)</li> <li>“How did it Go?”</li> </ul>
<b>Day 7</b>	
Morning Session	<ul style="list-style-type: none"> <li>Module 14: Supervised Clinical Practicum (continued)</li> </ul>
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>Supervised Clinical Practicum (continued)</li> <li>“How did it Go?”</li> </ul>
<b>Day 8</b>	
Morning Session	<ul style="list-style-type: none"> <li>Module 14: Supervised Clinical Practicum (continued)</li> </ul>
<b>LUNCH</b>	
Afternoon Session	<ul style="list-style-type: none"> <li>Module 15: Action Planning, Course Evaluation, and Closure (3 hours)</li> </ul>

## Appendix 1B: Pre-Test

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Participant identification number: \_\_\_\_\_ Score: \_\_\_\_/25

- 1) Which of the following statements are factors in the scale up of adolescent HIV care and treatment services in Zambia? *(select all that apply)*
  - a) Young people are no more vulnerable to HIV than adults.
  - b) Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.
  - c) Healthcare workers need specific knowledge and skills to meet the needs of adolescent clients.
  - d) Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients
  
- 2) Which of the following are characteristics of “youth-friendly” services? *(select all that apply)*
  - a) Special times that allow young people to receive services
  - b) Services are provided anonymously.
  - c) Healthcare workers are friendly to both male and female clients
  - d) Clinic services are affordable or available for no fees
  - e) Healthcare workers create services without the input of adolescents
  
- 3) To be effective, the adolescent package of care must ensure: *(select all that apply)*
  - a) Integration of services
  - b) That services are age and developmentally appropriate
  - c) That the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
  - d) That services are empowering, in other words, they encourage adolescents to take responsibility for their own health
  - e) That the adolescent client receives care in the paediatric clinic for life
  
- 4) The key clinical components of care for ALHIV differ greatly from care of adults.
  - a) True
  - b) False
  
- 5) Adolescent clients should be started on ART when their CD4 cell count is:
  - a) Less than 200
  - b) Less than 250
  - c) Less than 300
  - d) Less than 350
  - e) None of the above

- 6) CD4 cell count should be monitored how frequently?
  - a) Every 12 months; but 6 monthly as CD4 count approaches threshold (to initiate ART)
  - b) Every 9 months; but 4 monthly as CD4 count approaches threshold
  - c) Every 6 months; but 3 monthly as CD4 count approaches threshold
  - d) Every 4 months; but 2 monthly as CD4 count approaches threshold
  - e) Every 2 months; but monthly as CD4 count approaches threshold
  
- 7) Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients. What are the 5 “A’s”?
  - a) Assess, admire, agree, ask, arrange
  - b) Analyze, advise, agree, ask, arrange
  - c) Assess, advise, agree, assist, arrange
  - d) Assess, advise, assert, ask, arrange
  - e) Awake, advise, agree, ask, arrange
  
- 8) Counselling includes which of the following? *(select all that apply)*
  - a) Solving another person’s problems
  - b) Helping people to make informed decisions
  - c) Telling another person what to do
  - d) Respecting everyone’s needs, values, culture, religion, and lifestyle
  - e) Keeping good records
  
- 9) Family-centred care means that healthcare workers can talk openly with caregivers about any information shared between the adolescent and healthcare workers.
  - a) True
  - b) False
  
- 10) Which of the following are coping strategies that healthcare workers should suggest to clients and caregivers to help them reduce stress and promote psychosocial well-being? *(select all that apply)*
  - a) Talk with a Peer Educator
  - b) Join a support group
  - c) Exercise
  - d) Disclose HIV status to all people in the community
  - e) Change your environment and take a walk
  
- 11) Adolescence is a unique stage of life that is characterised by:
  - a) Challenging caregivers or elders
  - b) Focus on body image
  - c) Sense of immortality
  - d) Significant physical, emotional, and mental changes
  - e) All of the above
  
- 12) Which of the following are signs or symptoms of depression? *(select all that apply)*
  - a) Hopelessness

- b) Shaking and sweating
  - c) Really tired with no energy
  - d) Heart pounding fast
  - e) Do not enjoy the things you used to (loss of interest or pleasure)
  - f) Sleep too much or not enough
  - g) Cannot eat or eat too much
  - h) Cannot breathe or shortness of breath
- 13) Disclosure is a one-time event, rather than an ongoing process.
- a) True
  - b) False
- 14) The process of disclosing HIV status to an adolescent with HIV should include discussion of the following:
- a) The diagnosis, the infection and disease process, and health changes that could occur.
  - b) Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
  - c) How to cope with the possible negative reactions of others.
  - d) A and C
  - e) All of the above
- 15) The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommends a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- a) True
  - b) False
- 16) The only reliable way to assess client adherence is with pill counts.
- a) True
  - b) False
- 17) What is positive prevention? *(select all that apply)*
- a) Partner disclosure and testing
  - b) Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
  - c) Sexual risk reduction and sexual health
  - d) Prevention and treatment of STIs
  - e) Bathing regularly
  - f) PMTCT
  - g) Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.

- 18) What questions would you ask to screen for alcohol dependency?  
(select all that apply)
- a) Have you ever felt that you should cut down on your drinking?
  - b) Have people annoyed you by criticising your drinking?
  - c) Have you ever found it difficult to wake up for school or work?
  - d) Have you ever felt bad or guilty about your drinking?
  - e) Have you ever experienced rapid heartbeat after drinking?
  - f) Have you ever had an eye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?
- 19) Which of the following statements is correct?
- a) Healthcare workers need to stress that only heterosexual behaviour is NORMAL
  - b) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL
  - c) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is ABNORMAL
  - d) Healthcare workers need to stress that transsexual/transgendered should not be tolerated
- 20) The following sexual activities are considered **high** risk for transmitting HIV: (select all that apply)
- a) Unprotected (no male or female condom) anal or vaginal intercourse
  - b) Sharing sexual toys (rubber penis, vibrators) without cleaning them
  - c) Using a male or female latex condom for every act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
  - d) Mutual masturbation
  - e) Oral sex without a latex barrier
- 21) The adolescent female genital tract is more biologically susceptible to STIs than that of older women.
- a) True
  - b) False
- 22) What advice would you give an ALHIV who wanted to get pregnant?  
(select all that apply)
- a) It is safest to wait until adulthood to become pregnant
  - b) Do not eat eggs while pregnant
  - c) Talk to your provider and ask for his/her advice
  - d) Make sure you do not have any opportunistic infections
  - e) Make sure you are adhering to your ART regimen

- 23) Which of the following are good family planning options for ALHIV? *(select all that apply)*
- a) Condoms
  - b) Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills
  - c) Spermicides and diaphragms with spermicides
  - d) Male and female sterilisation
  - e) Hormonal implants
- 24) In reference to transitioning to adult care, which of the following statements is true? *(select all that apply)*
- a) Clients should be transitioned to adult care by 18 years of age
  - b) In preparing to transition, the healthcare worker should support the adolescent to develop self-care and self-advocacy skills
  - c) In preparation to transition, adolescents should visit and tour the adult clinic
  - d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure they adherence to their ART regimen
- 25) Which of the following are examples of indicators? *(select all that apply)*
- a) Number of adolescents who initiated ART
  - b) Number of adolescents currently receiving ART
  - c) To ensure that 95% of eligible adolescent clients initiate ART.
  - d) To ensure that at least 120 new clients initiate ART in the next 3 months
  - e) To ensure loss to follow up is no more than 5%



## References and Resources

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<sup>1</sup> UNICEF. 2007. Zambia Statistics.

[http://www.unicef.org/infobycountry/zambia\\_statistics.html?q=printme#66](http://www.unicef.org/infobycountry/zambia_statistics.html?q=printme#66)

<sup>2</sup> Zambia Department of Health Services, Central Statistics Office. 2007.

<http://www.measuredhs.com/pubs/pdf/FR211/FR211%5Brevised-05-12-2009%5D.pdf>

<sup>3</sup> UNAIDS. 2009. [Epidemiological Fact Sheet on HIV and AIDS](#).

<http://www.unaids.org/en/regionscountries/countries/zambia/>

<sup>4</sup> UNAIDS. 2009. [Epidemiological Fact Sheet on HIV and AIDS](#).

<http://www.unaids.org/en/regionscountries/countries/zambia/>

<sup>5</sup> United Nations Population Fund. Young People: The Greatest Hope for Turning the Tide.

<http://www.unfpa.org/hiv/people.htm>





## Module 2

### The Nature of Adolescence and Provision of Youth-Friendly Services

**Session 2.1: Stages and Changes of Adolescence**

**Session 2.2: Adolescent Vulnerabilities, Risk-Taking Behaviours, and their Consequences**

**Session 2.3: Providing Youth-Friendly Services to Adolescents**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Define adolescence.
- Identify some of the physical changes that occur during adolescence.
- Define the stages of adolescent development.
- Describe how adolescents living with HIV are different from children and adults living with HIV.
- Discuss the ways in which adolescents are a heterogeneous group.
- Discuss risk-taking as a normal part of adolescence; discuss the consequence of negative risk-taking.
- Discuss some of the vulnerabilities faced by adolescents.
- Describe the characteristics of youth-friendly HIV care and treatment services.

## Session 2.1      Stages and Changes of Adolescence

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### Session Objectives

**After completing this session, participants will be able to:**

- Define adolescence.
- Identify some of the physical changes that occur during adolescence.
- Define the stages of adolescent development.
- Describe how adolescents living with HIV are different from children and adults living with HIV.
- Discuss the ways in which adolescents are a heterogeneous group.

### Who Are We Talking About?

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Who are we referring to when we talk about “adolescents”? In general, the term “adolescent” refers to people in their second decade of life, that is, those between the ages of 10 and 19 years. Other commonly used terms are “youth” and “young people”, which have slightly different definitions (see Table 2.1), but are sometimes used interchangeably with the term “adolescent”.

**Table 2.1: Key definitions**

Group	Age range (according to WHO)
Adolescents	10–19 years
Youth	15–24 years
Young people	10–24 years



Adolescence has many dimensions: physical, psychological, emotional, and sociological. Adolescence is a PHASE of an individual’s life that is defined differently across cultures and communities.

### Key Changes During Adolescence

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There are a number of physical and sexual changes that occur during adolescence.

#### **In females:**

- Menarche
- Development of breasts
- Widening of the hips
- Appearance of pubic and underarm hair
- Development of the vulva and pelvis

#### **In males:**

- Growth of the penis, scrotum, and testicles
- Night-time ejaculation
- Morning erection
- Development of back muscles
- Appearance of pubic and underarm, chest, and leg hair

The staging system used most frequently to categorise these changes is referred to as "Tanner stages", and is described in "Appendix 2A: Tanner Scale". The first stage in each section represents the pre-pubertal child and the final stage represents the "mature" or adult stage. The Tanner scale is also used to determine maturity when deciding whether an adolescent should receive an adult or paediatric ARV regimen and dosage, as discussed in the next module.

### **In both females and males:**

- Accelerated growth
- Increased perspiration
- Presence of acne
- Face has characteristics of young adult
- Change in tone of voice
- Sexual desire activated
- Initiation of sexual activities

There are also a number of psychological and emotional changes that occur during adolescence<sup>1</sup>:

- Mood swings
- Insecurities, fears, and doubts
- Behavioural expressions of emotion, which may include withdrawal, hostility, impulsiveness, non-cooperation
- Self-centeredness
- Feelings of being misunderstood and/or rejected
- Fluctuating self-esteem
- Interest in physical changes, sex, and sexuality
- Concern about body image
- Concern about sexual identity, decision-making, and reputation
- Need to feel autonomous and independent

## **The Stages of Adolescent Development**

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Adolescence can be categorised into 3 overlapping developmental stages:

- The ages listed are approximate; maturation is more important than specific ages when discussing adolescent development.
- Maturation occurs in fits and starts and is not always coordinated.
- Growth in each of the categories listed in Table 2.2 can occur at different rates. For example, an adolescent girl may look like an adult physically (a characteristic of late adolescence), but not yet capable of abstract thinking (a characteristic of early adolescence). Another adolescent may appear small and stunted, but show advanced intellectual maturity.
- HIV disease impacts maturation in a number of ways (as discussed in the next section).

**Table 2.2: Stages of adolescence**

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 advanced</li> <li>Growth slows down; reached approximately 95% of adult size</li> </ul>	<ul style="list-style-type: none"> <li>Physically mature</li> </ul>
<b>COGNITION</b> (ability to get knowledge through different ways of thinking)	<ul style="list-style-type: none"> <li>Concrete thinking (“here and now”)</li> <li>Does not understand how actions affect 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 long-term results of own actions</li> </ul>	<ul style="list-style-type: none"> <li>Abstract thinking now established</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>Worries about rapid physical growth and body image</li> <li>Frequent mood changes</li> </ul>	<ul style="list-style-type: none"> <li>Established body image</li> <li>Thinks about fantasy or impossible dreams</li> <li>Feels very powerful</li> <li>May experiment with sex, drugs, friends, risks</li> </ul>	<ul style="list-style-type: none"> <li>Plans and follows long-term goals</li> <li>Established sense of identity (who he or she is)</li> </ul>
<b>FAMILY</b>	<ul style="list-style-type: none"> <li>Still defining comfort with independence/dependence</li> </ul>	<ul style="list-style-type: none"> <li>Conflicts with people in authority</li> </ul>	<ul style="list-style-type: none"> <li>Moving from a child-parent/ guardian relationship to more adult-adult relationships</li> </ul>
<b>PEERS</b>	<ul style="list-style-type: none"> <li>Important for 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 that help to affirm self image</li> <li>Peer groups define right and wrong</li> </ul>	<ul style="list-style-type: none"> <li>Decisions/values less influenced by peers in favour of individual friendships</li> <li>Selection of partner 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> </ul>	<ul style="list-style-type: none"> <li>Preoccupation with romantic fantasy</li> <li>Tests how he or she can attract others</li> <li>Sexual drives emerging</li> </ul>	<ul style="list-style-type: none"> <li>Forms stable relationships</li> <li>Mutual and balanced sexual relations</li> <li>More able to manage close and long-term sexual relationships</li> <li>Plans for the future</li> </ul>

**Sources:**

WHO. 2003. Orientation Programme on Adolescent Health for Health-care Providers.

WHO. 2010. IMAI One-day Orientation on Adolescents Living with HIV.

## **Effects of HIV Infection on the Changes of Adolescence<sup>2,3</sup>**

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### **Growth:**

- If HIV disease is fairly advanced, an adolescent may experience delays in physical development, including the physical changes of puberty (for example, delayed or irregular menstrual cycles in girls). As a result, ALHIV may appear younger and smaller than other adolescents because they have not begun the physical process of becoming adults.
- ALHIV may be shorter than their peers, either because of stunting early in life or slowed growth throughout childhood and adolescence. This may lead to a negative sense of self-image and affect how other people view the adolescent — as sick and younger than their actual age.
- ALHIV may experience drug-related side effects including those that change physical appearance, such as lipodystrophy (changes in fat distribution on the body).

### **Cognition:**

- ALHIV experiencing HIV infection of the brain will often have developmental delays and learning problems.

### **Psychological and social:**

- A study of Zambian youth in 2007<sup>4</sup> found that adolescents with HIV were nearly 4 times more likely to experience emotional difficulties than a control group who did not have HIV. The study did not identify the cause of the emotional difficulties, but suggested that it was not necessarily due to health status, but possibly due to the pressures of life and history of loss — less than a fifth of the children surveyed lived with both parents, most were cared for by another family member.
- Interestingly, the same study also found that knowledge of HIV status (that is, adolescents who knew their HIV status) were 2.5 times LESS likely to experience emotional difficulties than the adolescents who did not know their HIV status. This finding contradicts the assumption amongst many caregivers that disclosure is bad for a child's mental health.
- Illness may prevent ALHIV from going to school regularly, making friends, learning sports and hobbies, in short, reducing the number and range of activities that adolescents need to define their identity.
- Managing a chronic disease, including taking multiple medications daily, can have an impact on ALHIV's mental health and sense of fitting in and being like their peers.
- Many ALHIV are not living with one or either birth parent. Although they may be living with extended family, in some cases the adolescent may not feel "attached" or a part of their adopted home, leading to a sense of isolation or that "nobody loves me".

**Peers:**

- A study found that Zambian adolescents with HIV were 7 times more likely to be experiencing peer problems. The study acknowledged that peer problems may be exacerbated by stigma associated with HIV.
- Adolescents may feel unable to identify with their peers or may feel singled out due to stigma and discrimination.
- ALHIV may have to regularly miss school to attend clinic appointments, which can impact their educational attainment and sense of fitting in with peers.
- If adolescents feel different from their peers, they have a harder time bonding with them. This has an adverse effect on their attachments, making it difficult for them to separate from their parents or caregivers.

**No Longer Children, Not Yet Adults<sup>5</sup>**

There are a number of characteristics that distinguish adolescents from both children and adults. However, these are generalisations, some even stereotypes, and are not applicable to every adolescent client. These characteristics may include:

- Energetic, open, spontaneous, or inquisitive
- Unreliable
- Desiring independence
- Influenced by friends
- Less influenced by family
- Looking for role models (often outside of the family)
- Embarrassed to talk to adults about personal issues
- Desire to be different from parents and previous generation

HIV prevention, care, treatment and support services need to be tailored to meet the needs and the characteristics of their adolescent clients. This is referred to as “youth-friendly services” and is discussed further in Session 2.3.

**Exercise 1: Adolescents, Not Big Children or Little Adults: Small group work and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To understand some of the important things healthcare workers should consider about the special needs of adolescent clients</li> <li>• To understand how and why adolescents are a heterogeneous (diverse) group and what implications this has for their care</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will be asked to break into 3 small groups.</li> <li>2. The small groups will have about 20 minutes to discuss <b>any 1</b> the following questions:             <ul style="list-style-type: none"> <li>• <i>What are some of the special characteristics of adolescents that healthcare workers need to consider when providing HIV care and treatment?</i></li> </ul> </li> </ol>

	<ul style="list-style-type: none"> <li>• <i>How and why do the needs of adolescent clients differ from those of paediatric and adult clients?</i></li> <li>• <i>We can say that adolescents are a heterogeneous or diverse group. What are some of the differences healthcare workers may see among adolescents? What are the implications for their HIV care?</i></li> </ul> <p>3. A notetaker should record key discussion points on flip chart paper in preparation for the large group discussion.</p>
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## Special Considerations of Adolescent Clients<sup>6</sup>

### Adherence to medication:

- Although younger adolescents may still rely on a parent or caregiver to remember to take their medicine, older adolescents need to take some — or all — responsibility for taking their medicine every day as directed by the healthcare worker.
- Adolescents often struggle with adherence at different points in their development, as they strive to form their own identity and fit in with peers.

### Adherence to care:

- Adolescent clients often have less disciplined/structured lives and may have less stable relationships outside of the family (in comparison to adults), which makes adherence to care and treatment more difficult.
- Adolescent clients are more likely to lack the skills to negotiate health services and understand side effects, treatment options, and regimen requirements than adults.
- Outreach is more difficult for adolescents because they are scattered and it is harder to bring them into care (while children are accessible through their parents and caregivers).
- Adolescents can be lost in the system when in transition from childhood to adolescence, and there is often no follow up or extra support for adolescents when in transition to adult services.

### Stigma and discrimination:

- Often, blame is placed on adolescents living with HIV (especially those who acquire HIV behaviourally) because of their “risky behaviour,” resulting in stigma and discrimination.
- The stigma and discrimination associated with HIV prevents many adolescents from disclosing HIV status. This is an issue when the adolescent decides to become involved in a sexual relationship.

### **Counselling adolescents:**

- Adolescents have different cognitive abilities and skills than adults, which require different counselling approaches as well as longer counselling sessions.
- Conflicts between cultural or parental expectations and adolescents' emerging values can present serious challenges for adolescents.
- Adolescent clients often depend on their parents or caregivers (for example, for money and housing) and therefore cannot always make independent decisions.
- Adolescent clients have a range of future decisions to make, such as whether to have children or get married.
- Adolescents face strong peer pressure and are more dependent on peers for lifestyle guidance.

### **Safer sex:**

- Adolescents may not understand risk-taking behaviour and the importance of risk reduction and are vulnerable to unintended pregnancy and sexually transmitted infections.
- There is a widespread belief that adolescents living with HIV are “not supposed” to be having sex. Since it is taboo, adolescents often hide their sexuality. They also may have limited access to condoms and other contraceptives; even when they do have access to condoms or other contraceptives, they may lack the skills to negotiate their use or to use them correctly.
- For young women with HIV, gender inequality may further reduce their ability to negotiate condom use.

### **How Adolescents Differ from One Another**

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Adolescents are a heterogeneous group. By definition, adolescents range in age from 10 years old to 19. The personality and expectations of a person who is 10 years old is very different than that of a 19 year old, even though both are adolescents. Adolescents differ by stage of development, gender, sexual orientation\*, home and family situation, and educational level; some are rich, others poor; some are from urban areas, others from rural areas. Some adolescents will be in a relationship, some married, and others will have not yet entered a relationship. Some adolescents will know their HIV status, others will not; some will have never experienced stigma or discrimination, while others may face it every day.

Healthcare workers need to assess an adolescent's care, treatment and support needs and ensure that the plan to meet those needs is tailored to that unique adolescent. Counselling and education, in particular, need to “meet the adolescent where he or she is”.

\* Sexual orientation is further discussed in Module 10.



## Session 2.2      **Adolescent Vulnerabilities, Risk-Taking Behaviours, and their Consequences**

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### **Session Objectives**

**After completing this session, participants will be able to:**

- Discuss risk-taking as a normal part of adolescence; discuss the consequence of negative risk-taking.
- Discuss some of the vulnerabilities faced by adolescents.

### **Risk-Taking as a Normal Part of Growing up**

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Risk-taking, whether healthy or unhealthy, is simply part of an adolescent's struggle to test out an identity by providing self-definition and separation from others, including caregivers.

#### **Healthy risk-taking**

- Healthy risk-taking can include participation in sports, the development of artistic and creative abilities, travel, making new friends, constructive contributions to the family or community.

#### **Unhealthy risk-taking**

- New social relationships, especially with peers, begin to gain greater importance as family influence decreases.
- Adolescents must attain social autonomy during their second decade of life. This involves moving away from dependence on the family.
- Curiosity, sexual maturity, a natural inclination toward experimentation, and peer pressure can lead to negative, or unhealthy, risk-taking — risk-taking that can be dangerous or appear rebellious — includes drinking, smoking, drug use, reckless driving, unsafe sexual activity, self-mutilation, running away and stealing.
- A sense of omnipotence, feelings of invulnerability, and impulsiveness can lead to a lack of future planning and thereby compromise protective behaviour.
- Lack of knowledge about life's risks. As an example, adolescents may know little about sexually transmitted infections, they may find it difficult to use condoms consistently and correctly, or lack communication and negotiation skills, making condom use difficult.
- In some cultures, young men are encouraged to take risks as a way of proving their masculinity.

#### **Role of the healthcare worker**

- Advise caregivers to seek help if they notice psychological problems such as persistent depression or anxiety which goes beyond more typical adolescent "moodiness"; problems at school; or engaging in

illegal activities (mental health issues are discussed further in Modules 5 and 6).

- Healthcare workers can encourage caregivers to:
  - Encourage and help their adolescents find healthy risks, which may prevent unhealthy risk-taking.
  - Share with their children lessons learned from their own histories of risk-taking and experimenting.
  - Help their adolescent to evaluate risks, anticipate the consequences of their choices, and develop strategies for diverting their energy into healthier activities when necessary.

## **Types and Consequences of Negative Risk-Taking Behaviour<sup>7,8</sup>**

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Negative risk taking can include:

- Impulsive decision-making
- Reckless behaviour
- Provoking, arguing, and testing limits with peers and adults

Negative risk taking can result in:

- Poor adherence to HIV-related medication or HIV care and treatment, resulting in a drop in CD4 count, disease progression, opportunistic infections, greater chance of passing HIV to a sexual partner, and drug-resistance.
- Unprotected sex, resulting in unwanted pregnancy, putting partners at risk of HIV infection, unsafe abortion, and a risk of contracting sexually transmitted infections, including re-infection with different strains of HIV.
- Experimentation with substances, such as alcohol and marijuana, resulting in short- and long-term consequences:
  - Substance use and abuse can interfere with judgement and adherence; poor medication adherence will cause a decline in immune-system function.
  - For adolescents on ART, substance use and abuse can adversely interact with HIV medications. For example, alcohol and other psychoactive drugs can magnify the central nervous system side-effects (such as anxiety, nightmares, psychosis, depression) of certain ARVs.
  - Like many ARVs, illegal substances are often processed through the liver. Combining the two may lengthen the time that illegal substances stay in the bloodstream, increasing toxicity and the chance of overdose.
  - Alcohol reduces inhibitions and affects decision-making. Alcohol also can cloud a person's judgement and give courage to do something he or she would not normally do. A study from Botswana (the study focused on people age 15–49, but findings are most likely applicable to adolescents) found that people under the influence of alcohol were more likely to have unprotected sex, have multiple

- partners, pay for sex with money or other resources. In addition, intergenerational sex was strongly associated with heavy drinking.
- There is more on adolescents and substance abuse in Module 9.

## **Physical Vulnerabilities<sup>9</sup>**

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- Young people are more vulnerable to sexually transmitted infections for many reasons (see section entitled “Psychological and Emotional Vulnerabilities” below). Young women (in comparison with adult women) are particularly susceptible, because the cells that normally line the inside of the adolescent cervical canal are more vulnerable to infections than the cells that line the normal cervical canal of the adult female. The prevention or early treatment of sexually transmitted infection in people living with HIV is important to:
  - Avoid increased risk of HIV transmission to partners — many sexually transmitted infections are known to facilitate HIV transmission.
  - Improve survival — sexually transmitted infections can change the natural history of HIV.
- Adolescence is a time of rapid growth and development, creating the need for a nutritious and adequate diet. ALHIV, like all people living with HIV, are particularly vulnerable to nutritional deficiencies due to the increased energy demands that HIV imposes on the body<sup>10</sup>.
- HIV can contribute to compromised physical and psychological development, including stunting and slower than normal growth.

## **Psychological and Emotional Vulnerabilities<sup>11</sup>**

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- Psychological factors that put many adolescents at increased risk of physical harm — which may include anything from an automobile accident to infection with sexually transmitted infections — include a general sense of invulnerability, the desire to try new experiences (including drugs and alcohol), and the willingness to take risks, reckless behaviour, including unsafe sex (for example, changing sexual partners often or having a partner who has multiple partners).
- Mental health problems can increase during adolescence due to the hormonal and other physical changes of puberty, along with changes in adolescents’ social environment. Mental health issues of ALHIV are discussed further in Module 6.
- Adolescents often lack assertiveness and good communication skills, thereby rendering them unable to articulate their needs and withstand pressure or coercion from peers or adults.
- Adolescents may feel pressure to conform to stereotypical gender roles.
- Adolescents are more vulnerable than adults to sexual, physical, and verbal abuse because they are less able to prevent these shows of power.
- Often there are unequal power dynamics between adolescents and adults since adults may still view adolescents as children.

- Adolescents may lack the maturity to make good, rational decisions.

## **Socioeconomic Vulnerabilities<sup>12</sup>**

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- During adolescence, young people's need for money often increases, yet they typically have little access to money or gainful employment. This may lead adolescents to steal or take work in hazardous situations. Girls, in particular, may be lured into transactional sex.
- Poverty and economic hardships can increase health risks, particularly if accompanied by poor sanitation, lack of clean water, and an inability to afford/access healthcare and medications.
- Adolescents are more likely to experiment with drugs and alcohol; disadvantaged adolescents are at greater risk for substance abuse.
- Young women face gender discrimination that affects food allocation, access to health care, adherence to care, the ability to negotiate safer sex, and opportunities for social and economic well-being.
- In many societies, a girl's status is only recognised when she marries and has a child. Some young women marry very young to escape poverty, but as a result may find themselves in another difficult and challenging situation.
- Many young people are at risk for other socioeconomic and political reasons. These especially vulnerable youth include street children, sex workers, child labourers, refugees, young criminals, those orphaned because of AIDS and other circumstances, and other neglected and/or abandoned youth. Most-at-risk adolescents are discussed further in Module 5.

## Session 2.3

## Providing Youth-Friendly Services to Adolescents

### Session Objective

**After completing this session, participants will be able to:**

- Describe the characteristics of youth-friendly HIV care and treatment services.

### Characteristics of Youth-Friendly Services

**Table 2.3: Characteristics of youth-friendly services**

Healthcare worker characteristics	Health facility characteristics	Programme design characteristics
<ul style="list-style-type: none"><li>• Specially trained/oriented staff</li><li>• All staff display respect for youth</li><li>• Privacy and confidentiality</li><li>• Enough time for healthcare worker-client interaction</li></ul>	<ul style="list-style-type: none"><li>• Separate space for young people</li><li>• Special times when young people can receive services</li><li>• Convenient hours</li><li>• Convenient location</li><li>• Adequate space and privacy</li><li>• Comfortable, youth-friendly surroundings</li><li>• Availability of Peer Educators</li></ul>	<ul style="list-style-type: none"><li>• Youth involvement in programme design and monitoring</li><li>• Drop-in clients welcomed</li><li>• Short waiting times</li><li>• Set up to provide chronic disease management, including multiple appointments and medications</li><li>• Appointment systems in place and tracking systems for clients who miss appointments</li><li>• Affordable or no fees for services</li><li>• Publicity, marketing or recruitment materials that inform and reassure youth</li><li>• Friendly to both male and female clients</li><li>• Wide range of services available — “one-stop shopping”</li><li>• Referrals available to clinical and community-based services</li><li>• Youth-friendly educational materials available to take away</li><li>• Youth support groups</li><li>• Peer educators available</li></ul>

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.

### Organising Youth-Friendly Services

There are many things healthcare workers, health facility managers, and youth can do to improve the youth-friendliness of comprehensive HIV care and treatment services. Sometimes, even the smallest adjustments or changes can help, without creating additional workload, or incurring additional costs. A step-by-step guide for developing an action plan to make services more youth-friendly is listed in Table 2.4. This topic will be revisited in Module 15.

**Table 2.4: Making services more youth-friendly**

Step	How
<p>Assess clinic needs: figure out what needs to be done to make services more youth-friendly.</p>	<ul style="list-style-type: none"> <li>• Conduct an assessment using a tool such as that in “Table 2.3: Characteristics of youth-friendly services” and “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services”.</li> <li>• Ask clients what they like about the clinic and what needs improvement. Interview clients who have dropped out of care, ask them why they decided not to attend and what can be done to make the clinic more friendly.</li> <li>• Ask parents what could make services more welcoming for their children.</li> <li>• Ask colleagues what they think needs to change to ensure services are more accessible and meet the needs of young people.</li> <li>• Review national or local reports on the topic or manuals from other clinics or programmes to find out what they have done to attract and retain young people.</li> <li>• Visit a neighbouring clinic that has been very successful in welcoming the youth.</li> </ul>
<p>Design an action plan that will respond to the needs identified in the assessment. This plan should list the most important activities first. For each activity it should include a timeline and list the person responsible.</p>	<ul style="list-style-type: none"> <li>• Based on interviews and research during the assessment phase, list the areas that need improvement, and how they can be improved. For example, if several clients mentioned that they are scared of the receptionist because she’s rude, then one of the areas for improvement might read “Ensure that the person who registers clients makes them feel welcome”. Then suggest ways to address this need, for example, one-to-one training and support for the current receptionist, relieve the receptionist of other duties so that she can focus solely on welcoming clients, recruit a new receptionist, etc. Be sure to include the date by when this activity will be completed and the person who is going to make it happen. See Module 15 for an example of an action planning template.</li> </ul>
<p>Identify existing human and material resources needed to make the plan happen.</p>	<ul style="list-style-type: none"> <li>• Where an activity requires funds, identify the budget from which these funds might be found. Remember, making services youth-friendly does not need to be expensive.</li> </ul>
<p>Present the action plan to stakeholders.</p>	<ul style="list-style-type: none"> <li>• To gain general agreement and support for the action plan, present it first to the</li> </ul>

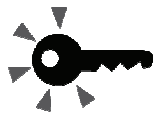
	<p>manager/supervisor. Work with others in management to ensure the support needed to implement recommended changes. The action plan may need to be revised several times to incorporate their suggestions and ensure their support. Once management has approved the plan, present to healthcare workers and youth that will be involved in the programme.</p>
Implement, monitor and evaluate.	<ul style="list-style-type: none"> <li>• Start implementing the activities recommended in the action plan. Provide support to the people responsible for each activity. Revisit the action plan monthly at first to see what progress has been made and where adjustments are needed. A year after implementation, evaluate: find out if the action plan has had an affect on the number of clients retained in care by comparing this year's figures with last year's.</li> </ul>

It is important to remember that setting up youth-friendly HIV care and treatment services is the start — but quality, evidence-based HIV care must be provided within the context of youth-friendly services to meet the needs of ALHIV.

### Exercise 2: Making Services Youth-Friendly: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To learn more about the characteristics of youth-friendly HIV care and treatment services</li> <li>• To begin to assess gaps, challenges, and next steps to provide youth-friendly HIV care and treatment services at participants' health facilities</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will be asked to break into 3 (or more) small groups, ensuring that healthcare workers from the same facilities are grouped together.</li> <li>2. Working in their small groups, participants should take about 10–15 minutes to read through “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” and then discuss how this tool might be useful in their clinic setting.</li> <li>3. Small groups should note key points on flip chart and then select 2 sections of the Tool, go through each question in that section, reflect on their own clinic, record answers, and then discuss and record comments and recommendations.</li> <li>4. When the large group is reconvened, each small group will be asked to give a brief (2–3 minute) presentation on their discussion.</li> <li>5. As this discussion will be re-visited in Module 15,</li> </ol>

	participants are recommended to keep their notes for that discussion.
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## Module 2: Key Points

- Adolescence, the years between the ages of 10 and 19, is characterised by rapid growth and development as well as psychological and emotional changes. Social relationships move from being family-centred to more peer- and community-centred. It is also a time when new skills and knowledge are acquired and new attitudes are formed.
- Young people with HIV can experience adolescence differently; most notably, if HIV disease is advanced the adolescent may have delays in physical development. Social development may be atypical as well, particularly if the adolescent has spent much time ill or if he or she has felt alienated from peers because of HIV-related discrimination or because he or she feels different.
- As part of growing up, adolescents take risks. Risk-taking is the tool an adolescent uses to define and develop his or her identity, and healthy risk-taking is a valuable experience. Sometimes, negative risk-taking can have lifelong consequences. For ALHIV, this can include poor adherence to medications or discontinuing care. ALHIV may also take sexual risks, which can lead to re-infection and/or the further spread of HIV to sexual partners or children.
- Healthcare workers should remember the reasons that clients may be vulnerable, and how these vulnerabilities relate to risk-taking behaviour and participation in and adherence to their own HIV care and treatment. An understanding of their adolescent clients' lives can support healthcare workers to assist adolescents to transition safely into adulthood.
- In order to serve adolescent clients with HIV-related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients.



## Appendix 2A: Tanner Scale

### Boys — development of external genitalia

<b>Stage 1</b>	Pre-pubertal, testes small in size with childlike penis
<b>Stage 2</b>	Testes reddened, thinner and larger (1.6–6cc) with childlike penis
<b>Stage 3</b>	Testes larger (6cc–12cc) and scrotum enlarging; increase in penile length
<b>Stage 4</b>	Testes larger (12cc–20cc) with greater enlargement and darkening of the scrotum; increase in length and circumference of penis
<b>Stage 5</b>	Testes over 20cc with adult scrotum and penis

### Girls — breast development

<b>Stage 1</b>	Pre-pubertal, no breast tissue with flat areola
<b>Stage 2</b>	Breast budding with widening of the areola
<b>Stage 3</b>	Larger and more elevated breast extending beyond the areola
<b>Stage 4</b>	Larger and even more elevated breast; areola and nipple projecting from the breast contours
<b>Stage 5</b>	Mature stage: adult size with nipple projecting above areola

### Boys and girls — pubic hair

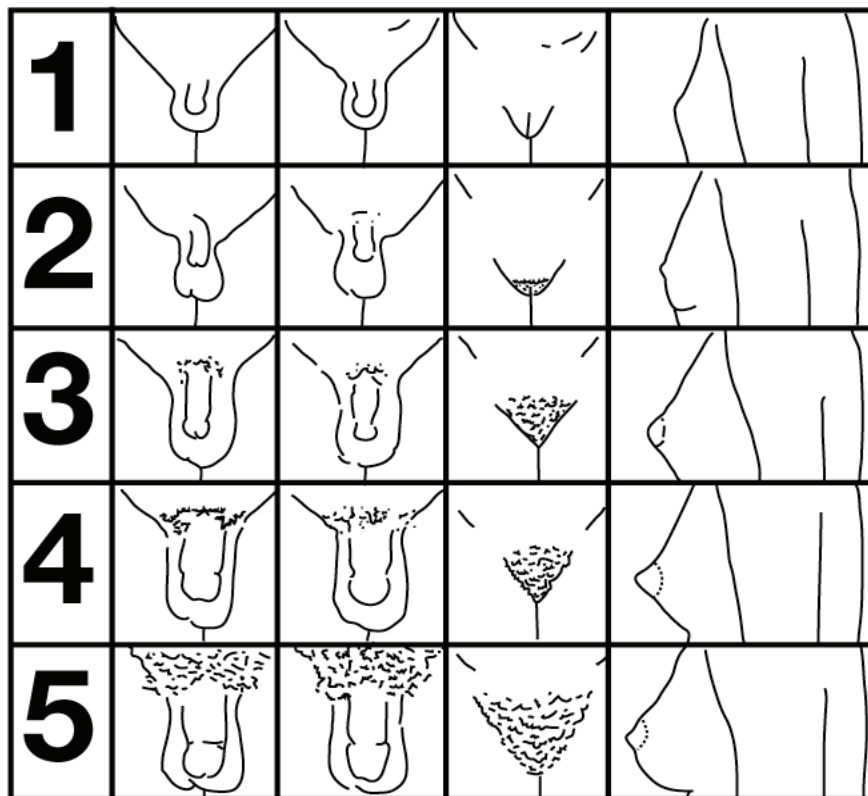
<b>Stage 1</b>	Pre-pubertal, no hair
<b>Stage 2</b>	Small amount of long hair at base of male scrotum or female labia majora
<b>Stage 3</b>	Moderate amount of curly and courser hair extending outwards
<b>Stage 4</b>	Resembles adult hair but does not extend to inner surface of thigh
<b>Stage 5</b>	Adult type and quantity extending to the thigh surface

**Tanner staging system**

Male genitalia

Pubic hair

Female breast



Adapted from: WHO. 2006. Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a public health approach.

## Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services

Facility name: \_\_\_\_\_ Type of facility/clinic: \_\_\_\_\_

Location	Answer	Comments/Recommendations
How far is the facility from public transportation?		
How far is the facility from places where adolescents spend their time?		
How far is the facility from local schools?		
<b>Facility hours</b>		
What time is the clinic open?		
Does the clinic have separate hours/days for youth?		
Is there a sign listing services and clinic working hours?		
What times are convenient for adolescents to seek services?		
<b>Facility environment</b>		
Does the facility provide a comfortable setting for young clients?		
Does the facility have separate space to provide services to adolescent clients?		
Does the facility have a separate waiting area for adolescent clients?		
Is there a counselling area that offers both visual and auditory privacy?		
Is there an examination room that provides both visual and auditory privacy?		

Are both young men and young women welcomed and served at the clinic?	+	
<b>Staffing</b>		
Are all healthcare workers trained in paediatric HIV care and treatment?		
Are all healthcare workers trained in adolescent HIV care and treatment?		
Did all staff members (including data clerks, pharmacists, receptionists, etc.) receive orientation about adolescent services?		
Do healthcare workers show respect for adolescent clients during counselling sessions and group sessions?		
Are there job aides available to help healthcare workers in their daily work with adolescents?		
<b>Services provided</b>		
Is one-stop shopping provided to adolescent clients? Describe.		
Are the following services provided to adolescent clients directly (note if through referral):		
• HIV testing and counselling		
• Comprehensive care, including the prevention and treatment of OIs		
• Malaria prophylaxis and tx		
• ARVs/ART		
• Adherence preparation		
• Ongoing adherence assessment & counselling (at each visit)		
• Pregnancy testing, antenatal care and PMTCT		
• Sexual and reproductive health counselling		
• Condoms and lube		
• Contraception (which methods?)		

• STI screening and treatment		
• Positive prevention counselling		
• Psychosocial counselling & support		
• Nutrition counselling		
• Laboratory tests (CD4, other HIV tests)		
• PEP, as per national guidelines		
Are there outreach services, especially to most-at-risk adolescents? Explain.		
Do adolescent request services other than the ones offered? Which ones?		
Is there a formal referral system for services not provided at the clinic?		
Is there a formal referral system for services required by most-at-risk adolescents (sexual abuse counselling and treatment, drug/alcohol rehabilitation, support for youth-heads of household, etc.)? Which ones?		
Is there a tracking and follow-up plan in place for clients who do not return?		
<b>Peer education and counselling</b>		
Is a peer education programme available?		
How many Peer Educators are working at the facility?		
How many hours/days per week do Peer Educators spend at the facility?		
What are the roles and responsibilities of Peer Educators?		
How are the Peer Educators trained?		
Is there a system for supervising and monitoring Peer Educators?		
<b>Educational activities</b>		
Are educational/information materials available?		

## PARTICIPANT MANUAL

Which ones?		
Are there educational posters displayed?		
Are there posters or brochures that describe clients' rights?		
Are there materials for adolescent clients to take home?		
In what languages are materials available?		
Are group education sessions held with younger adolescents? Describe.		
Are group education sessions held with older adolescents? Describe.		
Are group education sessions held with parents/caregivers? Describe.		
Are adolescent support groups held (younger adolescents)? Describe.		
Are adolescent support groups held (older adolescents)? Describe.		
Are there ways for adolescent clients to access information or counselling off-site (hotline, etc.)?		
<b>Youth involvement</b>		
Are adolescents involved in decision-making about how programmes and services are delivered?		
What ways can adolescents give feedback to the clinic?		
How could adolescents be more involved in decision-making at the facility?		
What other roles can adolescents play in clinic operations or guidance?		
<b>Supportive policies</b>		
Do clear, written guidelines or SOPs exist for adolescent services?		
Do written procedures exist for protecting client		

confidentiality?		
Are records stored so that confidentiality is ensured?		
Is parental/guardian/spousal consent ever required? In what cases?		
Is there a minimum age required for adolescents to receive HIV testing?		
Is there a minimum age required for adolescents to receive contraceptives?		
Are there policies or procedures that pose barriers to youth-friendly services?		
<b>Administrative procedures</b>		
Is the registration process private so that others cannot see or hear?		
Can adolescent clients be seen without an appointment?		
How long would an adolescent client normally have to wait?		
What is the average time allotted for client/healthcare worker interaction?		
<b>Publicity/recruitment</b>		
Does the clinic publicize the services available to adolescents and stress confidentiality?		
Are there staff or volunteers who do outreach activities? Describe.		
<b>Fees</b>		
Are adolescents charged for any services? If so, which ones and how much?		
Are any fees affordable to adolescent clients?		
<b>OTHER?</b>		

Adapted from:  
 Senderowitz, J., Solter, C., & Hainsworth, G. (2002). *Clinic Assessment of Youth Friendly Services: A Tool for Assessing and Improving Reproductive Health Services for Youth*. Watertown, MA: Pathfinder International.

## Appendix 2C: Recommended Reading on Adolescent HIV

### Adolescent HIV — Cause for Concern in Southern Africa

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In 2006, the Society for Adolescent Medicine issued its second position paper on HIV/AIDS in adolescents [1]. It noted that although great progress had been made in the scientific understanding, diagnosis and treatment of HIV, and the prevention of perinatal transmission, there was a growing HIV crisis in the developing world. At least half of all new infections in the developing world were amongst youth and young adults, and a substantial number of teenagers and young adults were already living with HIV/AIDS [2].

As HIV epidemics mature, increasing numbers of children infected perinatally survive and will present with HIV-related symptoms in older childhood and adolescence. Whilst the epidemiology of sexually acquired HIV infection amongst 15–24 year olds is well described in southern Africa [3–5], few data on the prevalence and disease pattern of perinatally acquired HIV infection in older children and adolescence exist. Recent data from a household survey conducted in South Africa in 2008 estimated the prevalence of HIV in children aged 2–14 years to be 2.5% (95% confidence interval 1.9–3.5) [6]. The survey indicates the relatively high prevalence of HIV in children and adolescents in this region. Most of these infections are acquired early in life and are probably undiagnosed.

#### Linked Research Article

This article discusses the following new study published in *PLoS Medicine*:

Ferrand R, Bandason T, Musvaire, P, Larke N, Nathoo K, et al. (2010) Causes of Acute Hospitalization in Adolescence: Burden and Spectrum of HIV-Related Morbidity in a Country with an Early-Onset and Severe HIV Epidemic. *PLoS Med* 7(2): e1000178. doi:10.1371/journal.pmed.1000178

### The Survival of Infected Children

Little is also known about the survival of HIV-infected children in Africa beyond 5 years of age. Some studies have estimated that 38% of children will be slow progressors and that the estimated cumulated mortality at 15 years will be 83% [7]. Others estimate a 67% survival at 1 year, 39% at 5 years, and 13% survival at 10 years [8]. Decreased survival of HIV-infected children in Africa to date is attributed to lack of access to antiretroviral therapy (ART), delayed diagnosis, and inadequate management due to lack of expertise and resources.

There are few data on the impact that HIV has on ill-health, morbidity, and mortality in adolescence in southern Africa. A recent study modeled demographic, HIV prevalence, mother-to-child transmission, and child



survival data in South Africa and Zimbabwe [9]. It estimated that without treatment, the HIV prevalence among 10 year olds in South Africa will increase from 2.1% in 2008, to 3.3% in 2020, whereas in Zimbabwe it will decrease from 3.2% in 2008 to 1.6% in 2020. Deaths among untreated slow progressors will increase in South Africa from 7,000 per year in 2008 to 23,000 per year in 2030, and in Zimbabwe deaths will peak in 2014 at 9,700 per year, from 8,000 per year in 2008. The toll of adolescent HIV on other health outcomes such as hospital admissions in these settings has yet to be quantified.

### **A New Study on Hospitalizations**

In this issue of *Plos Medicine*, Ferrand and colleagues present data on the causes of acute hospitalization in adolescence in Zimbabwe [10]. HIV has become the single most common cause of acute admission and in-hospital death amongst adolescents in Harare. Almost half of all adolescents hospitalized were found to be HIV infected, and most of them were severely immunosuppressed, with the major route of transmission being attributed to perinatal transmission. Those admitted were more likely to be stunted, have pubertal delay, be a maternal orphan, or have an HIV-infected mother as compared to non-HIV admissions. Unlike their HIV-negative counterparts, who were largely admitted for trauma or an acute exacerbation of a chronic medical condition, HIV-infected adolescents were more likely to be admitted for an infection with tuberculosis, pneumonia, cryptococcosis, and septicemia. HIV-infected adolescents were also almost four times more likely to die. The risk of in-hospital death was increased in those HIV-infected adolescents who had underlying chronic complications.

These high rates of in-hospital mortality are also seen in other parts of the region. A study conducted in Zambia amongst HIV-antibody positive children aged 1–14 years found that a single hospitalization for a severe bacterial infection increased the risk of death by 42%, and a further hospitalization doubled this risk again [11]. Interventions to decrease HIV-related deaths that occur in hospitals require urgent investigation.

### **Diagnosis, Clinical Manifestations, and Disease Outcome**

Older children and adolescents are diagnosed late in Africa despite most guardians suspecting their children of being HIV infected before diagnosis [12]. The median age of diagnosis in some studies has been found to be between 11–12 years of age [10,12], with a delay of 3.5 years (interquartile range, 1–6 years) between the first serious illness and diagnosis of HIV infection. In addition, when these adolescents are diagnosed, they are already below average for height and weight, have moderate to severe immunodeficiency, and have had recurrent infections as well as tuberculosis.

Most of the hospital admissions for HIV-infected adolescents in Harare in Ferrand et al.'s study were for infectious diseases [10]. It is unclear whether any data were collected on any underlying depression or other

concomitant mental health diagnoses. Few data from southern Africa are available on the psychological manifestations, depressive symptoms, and psychiatric admissions for children and adolescents infected with HIV.

In contrast, studies from the developed world show high rates of admissions for psychiatric reasons amongst HIV-infected children and adolescents. In the United States, the PACTG 219C study — a prospective cohort study designed to examine long-term outcomes among HIV-infected children and HIV-exposed uninfected infants — found the incidence of psychiatric admissions to be 6.17 cases per 1,000 person-years of follow up, which was significantly higher than that reported in the general population (1.70 cases per 1,000 person-years) [13]. In this study, the most common reasons for psychiatric hospitalization for HIV-infected children were for depression or behavioural disorders. The median age for first psychiatric admission was 11 years (range 4–17 years). Knowledge of HIV status increased the risk of hospital admissions 6-fold, and having experienced a significant life event increased the risk of hospitalization 3-fold. Almost half of the admitted children required multiple psychiatric admissions.

A previous study conducted amongst HIV-infected adolescents in Harare shows the tremendous burden HIV has on the family [12]. More than half of the adolescents participating in the study had lost both parents, and chronic ill health was reported in 44% of the surviving parents. Almost half of the adolescents were caring for sick parents, guardians, and/or siblings. The impact of death and chronic ill-health of a caregiver/and or siblings on the mental health of HIV-infected adolescents in southern Africa requires further description.

### **Response to ART**

Access to ART will improve health outcomes and long-term survival of any child that is infected early on in life, irrespective of setting. In the developed world, the long-term effects of protease inhibitor-based combination therapy have shown greater improvements in CD4% in younger children as compared to older children. These findings may reflect greater thymic productivity in pre-adolescent children than in adolescents and adults [14] or other factors such as poorer treatment adherence in older children.

Kekitiinwa and colleagues examined the impact of ART across different geographical settings [15]. They looked at data describing HIV and early growth responses to ART across childhood, and compared initial responses to ART in the United Kingdom/Ireland and Uganda. They found that although early mortality after ART initiation was 3-fold higher in Uganda as compared to the United Kingdom/Ireland, older children and adolescents in Uganda had a superior virological response to ART compared with those from the United Kingdom/Ireland [15]. This difference was largely attributed to successful adolescent support programs at the Mulago Hospital in Kampala.

Additional data from Uganda, assessing the impact of ART on growth and sexual maturation in HIV-infected adolescents, showed appropriate virological and immunological responses to ART, as well as improvements in growth and to a much lesser extent, sexual maturation [16]. In a cohort of 118 perinatally infected, treatment naïve 10–19 year olds, the effect of antiretroviral was evaluated for a period of 12 months. At enrolment, the median CD4 count was 124, which had increased to 304 by 6 months, and to 370 by 12 months of treatment. ART was virologically suppressive in 79% of adolescents at 6 months, and by 89% at 12 months.

### **Disclosing HIV Diagnosis to Adolescents**

Disclosure issues abound both in the developed and developing world. However, studies suggest that there are medical benefits to disclosure of HIV infection status to children and adolescents. Children and adolescents who know their HIV status appear more likely to accept medical care and have a higher self-esteem as compared to youth that are unaware of their status [17,18]. Nondisclosure can be associated with anxiety and depression, in addition to being excluded from social support. Reluctance of parents and caregivers to disclose the HIV status to a child or an adolescent is usually based on the fear of discrimination and stigma, toward both the adolescent and the family as a whole [19,20].

The American Academy of Pediatrics strongly recommends the disclosure of HIV status to adolescents [21], so that they are fully informed about all aspects of their health, including their sexual behaviour. Ferrand and colleagues document a high rate of disclosure amongst HIV-infected adolescents in their study [10]. Nevertheless, they strongly recommend that health professionals include adolescents in routine provider-initiated testing and counselling, and assist guardians with disclosure as a way to improve early diagnosis and adherence to subsequent ART.

### **Sexual Activity**

Adolescents with moderate or severe immunosuppression are less likely to have adrenarche as compared to HIV-uninfected children of their own age [22]. However, the median age of sexual debut of adolescents who acquired their infection perinatally in southern Africa is unknown. In a study conducted in the US, amongst 40 HIV-positive adolescents/young adults, it was found that 28% of youth (mean age of 16.6 years), reported being sexually active [23]. When re-interviewed about 2 years later, 41% (mean age 18.3 years), were sexually active. Other studies examining sexual behaviour of adolescents infected with HIV as infants report sexually activity ranging from 18% (mean age of 15.5 years) [24], to 59% (mean age 18.5 years) in HIV-infected adolescents with hemophilia who ever reported prior sexual intercourse [25].

Of concern in these studies is that although self-efficacy around condom use was deemed to be high, it was not 100% guaranteed [23]. In various studies, between 63% to 80% of perinatally infected adolescents [24,25]

reported using condoms. HIV knowledge of sexual transmission has been found to be low [23], and these data highlight the need to provide risk-reduction counselling to adolescents who acquire HIV early in life.

### Conclusion

There is a substantial burden of HIV infection in adolescents in southern Africa who acquired HIV perinatally. It is evident that they contribute substantially to hospital admissions and in-hospital deaths. There is an urgent need for services that will be able to provide accessible and appropriate HIV testing, counselling, and support, as well as facilitate access to ART and appropriate sexual risk-reduction interventions. The adolescents admitted to hospitals in Harare could have benefited from early diagnosis and concomitant initiation of ART, and this absence of treatment should not continue to be the plight of similar adolescents in our region.

### Author Contributions

ICMJE criteria for authorship read and met: GEG. Wrote the first draft of the paper: GEG.

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**Competing Interests:** The author declares that she was on the Tibotec Preventing Mother to Child Transmission (PMTCT) advisory board in 2009, for which she was paid, but PMTCT and specific antiretroviral drugs are not discussed in this article. Dr. Gray reports also receiving grant support from GlaxoSmithKline for investigating the prevalence of 3TC resistance in the PETRA and being on an expert panel on HIV for Nestlé Nutrition Institute Africa that assessed interventions to prevent postnatal transmission of HIV.

**Abbreviations:** ART, antiretroviral therapy

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**Provenance:** Commissioned; not externally peer reviewed

### Box 1. Five Key Papers in the Field of Adolescent HIV

**Ferrand RA, Banson T, Musvaire P, Larke N, Nathoo K, et al., 2010 [10].** This paper demonstrates the burden of HIV infection in adolescents who acquired HIV infection in early life and how it contributes significantly to hospital admissions and in-hospital mortality. The article also highlights the need for early diagnosis, which will enable HIV-infected adolescents to benefit from earlier access to treatment and care.

**Shisana O, Rehle T, Simbayi LC, Zuma K, Jooste S, et al., 2009 [6].** This report on a national household survey conducted in South Africa shows the prevalence and incidence

of HIV by age, gender, province, and geographic locality. The report also assesses risk behaviour, such as condom use, multiple concurrent partners, and sexual debut over time.

**Ferrand RA, Corbett EL, Wood R, Hargrove J, Ndhlovu CE, et al., 2009 [9].** This paper models the time course and magnitude of the AIDS epidemic among older children and adolescents in Southern Africa. These data are important for health policy makers and economists who need to evaluate the impact that the HIV epidemic has on health resources in Southern Africa.

**Walker AS, Mulenga V, Sinyinza F, Lishimpi K, Nunn A, et al., 2006 [11].** This study evaluates the determinants of survival of HIV-infected children without ART in Zambia. Data from this study demonstrates that malnutrition and hospitalizations for respiratory or bacterial infections predict mortality independent of immunosuppression.

**Kekitiinwa A, Lee KJ, Walker AS, Maganda A, Doerholt K, et al., 2008 [15].** Few studies have directly compared responses to ART between children living in resource-rich and resource-poor settings. This study showed that irrespective of settings, overall immunological and virological responses to ART were similar.

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## Module 3

# Clinical Care for Adolescents Living with HIV

**Session 3.1: Adolescent HIV Transmission — Modes and Implications for Care and Treatment Session**

**Session 3.2: The Package of Adolescent HIV Care and Treatment Services**

### Learning Objectives

**After completing this module, participants will be able to:**

- Discuss the needs of adolescents who acquired HIV perinatally versus those of adolescents who acquired HIV during childhood or young adulthood.
- Discuss the importance of comprehensive care for ALHIV.
- Define the package of HIV-related care and treatment for adolescents.



## **Session 3.1      Adolescent HIV Transmission — Modes and Implications for Care and Treatment**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Discuss the needs of adolescents who acquired HIV perinatally versus those of adolescents who acquired HIV during childhood or young adulthood.

### **HIV Transmission in Adolescents**

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It is important for healthcare workers to be aware that there are 2 specific groups of ALHIV they will likely serve at the clinic.

#### **Adolescents who acquired HIV perinatally**

- This group of adolescents acquired HIV via MTCT — during pregnancy, labour, delivery, or through breastfeeding.
- As paediatric HIV treatment programmes have become more available and accessed, there will be more and more HIV-infected children who survive into adolescence.
- Adolescents in this group may have been enrolled in HIV care since infancy. Others may have been identified later in life during an acute illness or testing campaign.
- Several recent studies suggest that there are significant numbers of perinatally infected adolescents who have been “missed” by the healthcare system, despite being symptomatic.
- Adolescents in this group may have initiated ART in infancy and have taken various ART regimens by the time they reach adolescence. Others may still be taking the initial regimen they started during early childhood.
- Perinatally infected adolescents may or may not have been fully disclosed to (depending on their age and their caregivers). Unlike adolescents who acquire HIV during adolescence, usually at least one caregiver of a perinatally infected adolescent knows about the adolescent’s HIV status.

#### **Challenges faced by adolescents who acquired HIV perinatally**

Challenges often relate to disclosure of HIV status to the child (the process of disclosure should, ideally, start at an early age and continue as the child grows and develops), mother’s acceptance of her HIV status (including her commitment to “positive living,” that is enrolment in, and adherence to, lifelong care and treatment), disclosure of the child’s HIV status to family

members, acceptance of the child's HIV status (and mother's) by family members, amongst other factors. Challenges can include:

- The demands of caring for a child with chronic HIV infection — juggling multiple appointments, tests, and medications.
- Developmental delays in the child.
- Complexity of adhering to HIV-related medications and care, which can be particularly difficult if the adolescent does not know his or her diagnosis. Children of parents who do not adhere to their own regimens will have more barriers to good adherence as they are unlikely to get the support they need.
- The complexity of living in a home affected by HIV — particularly if the parents are unemployed, unwell, or dead; or if the child was adopted and this has not yet been disclosed to the child.

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

- This group of adolescents likely acquired HIV through sexual intercourse, or less frequently through a blood transfusion or sharing cutting/piercing instruments, or through injecting drug use.
- It is important to recognise that some adolescents in this group will have acquired HIV through child sexual abuse, including rape.
- Adolescents in this group may have only recently learned their HIV status, and generally have not had long contact with the health system. Adolescents in this group are often identified via HIV testing programmes (VCT, PITC, PMTCT, etc.).
- Many adolescents who acquire HIV during adolescence fall into WHO clinical stage 1 or 2 and may not yet feel unwell or need ART. But, it is important that adolescents not eligible for ART receive ongoing care, support, and monitoring for ART eligibility.

### **Challenges faced by adolescents who acquired HIV during childhood or adolescence**

Challenges often relate to acceptance of HIV status; retention of adolescents in care, especially if they are not eligible for ART; disclosure to family, partner, and peers; adherence; and positive living and positive prevention.

There are a number of differences between these 2 groups of adolescents, as summarised in Table 3.1. Keep in mind that these are **generalisations** and may not apply to all adolescents — each person is unique.

**Table 3.1: Differences and similarities between ALHIV based on transmission period**

<b>DIFFERENCES (AND SIMILARITIES) RELATED TO:</b>	<b>PERIOD WHEN HIV WAS ACQUIRED</b>	
	<b>PERINATAL</b> (dependant on current age and stage of development)	<b>ADOLESCENCE</b>
<b>AGE AT PRESENTATION</b>	<ul style="list-style-type: none"> <li>Younger: 10–19 years</li> </ul>	<ul style="list-style-type: none"> <li>Older: 15–19 years</li> </ul>
<b>PHYSICAL DEVELOPMENT</b>	<ul style="list-style-type: none"> <li>Delayed: short stature</li> </ul>	<ul style="list-style-type: none"> <li>Normal physical development</li> </ul>
<b>SEXUAL &amp; REPRODUCTIVE HEALTH</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>Not yet sexually active (or if older, may be thinking about sex or have already had sexual debut)</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>May need SRH services, including safer sex education and support</li> <li>Wants children</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>Probably sexually active</li> <li>May have been sexually abused</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>Need SRH services, including safer sex education and support</li> <li>Wants children</li> </ul>
<b>RELATIONSHIPS/ MARRIED</b>	<ul style="list-style-type: none"> <li>No/maybe</li> <li>Want intimate relationship</li> </ul>	<ul style="list-style-type: none"> <li>Probably in a sexual relationship(s)</li> <li>May want marriage</li> </ul>
<b>DISCLOSURE</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>To adolescent, if he or she does not know status</li> <li>Primary caregiver knows adolescent's HIV status</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>Disclosure to family and peers</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>New diagnosis</li> <li>Disclosure to partner</li> <li>Disclosure to primary caregiver</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>Disclosure to family and peers</li> </ul>
<b>FAMILY SUPPORT</b>	<ul style="list-style-type: none"> <li>Living with parents or caregivers, who typically know adolescent's HIV status so can offer support</li> </ul>	<ul style="list-style-type: none"> <li>Support system for HIV depends on disclosure</li> </ul>
<b>ECONOMIC SUPPORT</b>	<ul style="list-style-type: none"> <li>May be unstable if adolescent has been orphaned</li> </ul>	<ul style="list-style-type: none"> <li>May have few resources (money, information, experience) if adolescent has left home</li> </ul>
<b>ART</b>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>Often on ART for many years</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>Adherence challenges in adolescence</li> </ul>	<p><b>Differences:</b></p> <ul style="list-style-type: none"> <li>May not be needed yet</li> </ul> <p><b>Similarities:</b></p> <ul style="list-style-type: none"> <li>Adherence challenges in adolescence</li> </ul>
<b>STIGMA/"BLAME"</b>	<ul style="list-style-type: none"> <li>Less likely to be blamed</li> <li>Considered "innocent"</li> </ul>	<ul style="list-style-type: none"> <li>More likely to be blamed because of "irresponsible" behaviour</li> </ul>

Source:

WHO. IMAI One-day Orientation on Adolescents Living with HIV, 2010.

Republic of Zambia, MoH, Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010 pg 58.

## Session 3.2      The Package of Adolescent HIV Care and Treatment Services

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### Session Objectives

**After completing this session, participants will be able to:**

- Discuss the importance of comprehensive care for ALHIV.
- Define the package of HIV-related care and treatment for adolescents.

### Overview of the Package of Care for ALHIV<sup>1</sup>

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As discussed in the last session, adolescents with perinatally-acquired HIV have typically — but not always — been in care since they were young. Their experience in HIV care and treatment often started when they were children, under the care of healthcare workers with expertise in paediatrics who were steered by paediatric guidelines. As adolescents, clients with perinatally-acquired HIV have typically been on ART for many years and may even be on a 2<sup>nd</sup> or 3<sup>rd</sup> line regimen. Often these adolescents look young for their age and — due to delays in development and overprotection by caregivers — are often young socially as well.

Whereas young people infected with HIV as adolescents may be quite different, they maybe socially experienced, possibly more so than many of their peers, but relatively inexperienced in terms of dealing with the healthcare system. Adolescents with behaviourally-acquired HIV are typically treated as adults and the treatment is directed by adult guidelines.

Regardless of how long they have been infected or how they acquired HIV, the package of care for all ALHIV is very similar. While the components of the adolescent package of HIV care closely resemble those of the adult package of care, how they are delivered can have an impact on their uptake and success. To be effective, the adolescent package of care must ensure:

- Integration of services
- That services are age and developmentally appropriate
- That they are responsive to the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
- That services are empowering, in other words, that they encourage adolescents to take responsibility

#### **The importance of one-stop shopping for ALHIV**

Increase adolescent clients' ability to access and benefit fully from these services by:

- Ensuring services are integrated or, at least co-located — sometimes called “**one-stop shopping**”
- Ensuring services are youth-friendly (see Module 2)

(as they are developmentally able) for their own health by taking responsibility for their care, treatment and for living positively

- That there is an emphasis on both care and treatment, and retaining adolescents not eligible for ART in care

The goals of comprehensive HIV care are to:

- Reduce HIV-related illness and death,
- Improve quality of life,
- Improve the lives of families and communities affected by HIV, and
- Prevent further spread of HIV.

## **The Importance of Family-focused Care**

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- Family-focused care means that all members of the multidisciplinary care team think about the needs of all family members, and not just those of the adolescent client.
- It also means thinking about the linkages between the individual client, the client's family, and the community as a whole.
- Depending on the client's age and family situation, healthcare workers should make it a normal practice to ask clients about caregivers and other family members and encourage them to bring family members to the clinic for services, if needed. Healthcare workers can provide family members with ongoing education and information on HIV care and treatment, adherence counselling and support, and general support on caring for ALHIV.
- With older adolescents, healthcare workers should also enquire about partners and children. When the adolescent is ready, he or she should be encouraged and supported to bring his or her partner to the clinic for information on HIV, safer sex — including condoms use — and HIV testing.

Remember: Adolescent's day-to-day lives include their families, partners, children, friends and other community members, so it is important to ask about them at every visit!

## **Comprehensive Care for ALHIV**

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The care of the child with HIV is directed by paediatric guidelines, but as the child ages and develops, his or her care transitions to follow the adult HIV guidelines, with the care of adolescents often guided by one or the other or both. Although the paediatric and adult guidelines have many similarities (for example, criteria for ART initiation for the child over 5 years of age is the same as for an adult), it also allows the healthcare worker flexibility to tailor to the child a package of care that meet his or her needs.

Comprehensive care for ALHIV includes the provision of the services listed in the clinical assessment checklists in Table 3.2, Table 3.3, and Table 3.4, below. The first is a listing of steps conducted at the initial, or baseline,

visit, as many adolescents with perinatally-acquired HIV have been in care for years, they will have undergone this baseline assessment as infants or children. As such the checklist in Table 3.2 is more for the young person who acquired HIV as an adolescent. Note that it may take several visits to complete all activities on the baseline clinical assessment.

The 2<sup>nd</sup> (Table 3.3) is the list of steps conducted at follow-up visits for clients **not** on ART, the 3<sup>rd</sup> table (Table 3.4) is a list of steps conducted at follow-up visits for clients on ART.

**Table 3.2: Key steps — baseline visit**

✓	Steps
	<ul style="list-style-type: none"> <li>• Confirm HIV infection status</li> </ul>
	<ul style="list-style-type: none"> <li>• Take a complete medical and social history, including prenatal, birth and family history. Enquire about disclosure to the adolescent (if perinatally infected) or disclosure to others (if HIV was acquired during adolescence) and HIV and treatment status of the mother, father and siblings.</li> </ul>
	<ul style="list-style-type: none"> <li>• Identify concomitant medical conditions (for example, hepatitis B or C infection, other co-infections or OIs, pregnancy in adolescent girls)</li> </ul>
	<ul style="list-style-type: none"> <li>• Enquire about concomitant medication, including cotrimoxazole (CTX), oral contraceptives, and traditional or herbal therapies</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation</li> </ul>
	<ul style="list-style-type: none"> <li>• Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess growth and nutrition (weight, height), as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Review immunisation status of adolescent</li> </ul>
	<ul style="list-style-type: none"> <li>• Undertake a nutritional status assessment, including assessment of the quality and quantity of intake</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct psychosocial assessment, counselling, and support (discussed in Modules 5, 6, and 7). See “Appendix 3B: HEADSS Interview Questions” for guidance.</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess WHO clinical stage. If not on ART, determine whether the adolescent meets the clinical criteria for ART initiation. If already on ART, determine if any new stage 3 or 4 events have occurred since ART was initiated.</li> </ul>
	<ul style="list-style-type: none"> <li>• For those eligible for ART by clinical criteria (WHO stage 3 or 4), consider initiating ART preparation (see “Appendix 8A: Key Points — Adherence Visit 1” in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss findings</li> </ul>

	<ul style="list-style-type: none"> <li>Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>Schedule next visit</li> </ul>

**Table 3.3: Key steps — follow-up visit, clients NOT on ART**

✓	Steps
	<ul style="list-style-type: none"> <li>Assess growth and nutrition (weight, height), as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>Review interim medical history</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation</li> </ul>
	<ul style="list-style-type: none"> <li>Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>Review concomitant medications (consider drug interactions, make dose adjustments if pre-pubescent adolescent)</li> </ul>
	<ul style="list-style-type: none"> <li>If on CTX (discussed in this module) provide refill, monitor adherence, and address the adolescent's and/or caregiver's understanding of and adherence to therapy (discussed in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>Assess WHO clinical stage.</li> </ul>
	<ul style="list-style-type: none"> <li>Review clinical findings at this visit and laboratory findings (include CD4 cell count) from recent visits and consider eligibility for ART and CTX (discussed in this module). If eligible for ART, initiate adherence preparation (discussed in Module 8), which takes 3 visits to cover</li> </ul>
	<ul style="list-style-type: none"> <li>Provide nutrition counselling and support, as indicated (discussed in Module 9)</li> </ul>
	<ul style="list-style-type: none"> <li>Conduct psychosocial assessment, counselling, and support, including for disclosure (discussed in Modules 5, 6, and 7). See "Appendix 3B: HEADSS Interview Questions".</li> </ul>
	<ul style="list-style-type: none"> <li>Discuss positive living and positive prevention (discussed in Modules 9 and 10)</li> </ul>
	<ul style="list-style-type: none"> <li>Provide sexual and reproductive health information, screening, diagnosis, treatment, counselling, and supplies (discussed in Module 10)</li> </ul>
	<ul style="list-style-type: none"> <li>Provide additional support for adolescent clients who are switching providers or transitioning into adult care (discussed in Module 12)</li> </ul>
	<ul style="list-style-type: none"> <li>Provide education, care, and support for family members and/or</li> </ul>

	partner (discussed throughout this curriculum)
	<ul style="list-style-type: none"> <li>• Discuss findings</li> </ul>
	<ul style="list-style-type: none"> <li>• Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule next visit</li> </ul>

**Table 3.4: Key steps — follow-up visit, clients on ART**

✓	Steps
	<ul style="list-style-type: none"> <li>• Assess growth and nutrition (weight, height), as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess development and neurodevelopment, as appropriate for age</li> </ul>
	<ul style="list-style-type: none"> <li>• Review interim medical history</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct physical examination, including Tanner staging, STI screening for sexually active adolescents, skin exam (tattoos, bruises, acne), scoliosis evaluation, evidence of ART side effects or complications (fat redistribution, skin changes)</li> </ul>
	<ul style="list-style-type: none"> <li>• Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis (discussed briefly in this module), diarrhoea, malaria and pregnancy in sexually active adolescents.</li> </ul>
	<ul style="list-style-type: none"> <li>• Review concomitant medications (consider drug interactions, make dose adjustments if pre-pubescent adolescent)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide refills for ART and CTX, monitor adherence, and address the adolescent's and/or caregiver's understanding of and adherence to therapy (discussed in Module 8)</li> </ul>
	<ul style="list-style-type: none"> <li>• Assess WHO clinical stage, determine if any new stage 3 or 4 events have occurred since ART was initiated. Assess CD4 count, determine if treatment failure has occurred.</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide nutrition counselling and support, as indicated (discussed in Module 9)</li> </ul>
	<ul style="list-style-type: none"> <li>• Conduct psychosocial assessment, counselling, and support, including for disclosure (discussed in Modules 5, 6, and 7). See "Appendix 3B: HEADSS Interview Questions".</li> </ul>
	<ul style="list-style-type: none"> <li>• Discuss positive living and positive prevention (discussed in Modules 9 and 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide sexual and reproductive health information, screening, diagnosis, treatment, counselling, and supplies (discussed in Module 10)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide additional support for adolescent clients who are switching providers or transitioning into adult care (discussed in Module 12)</li> </ul>
	<ul style="list-style-type: none"> <li>• Provide education, care, and support for family members and/or partner (discussed throughout this curriculum)</li> </ul>



	<ul style="list-style-type: none"> <li>• Discuss findings</li> </ul>
	<ul style="list-style-type: none"> <li>• Advise and guide (reinforce and support adherence to ART and CTX — if applicable, nutrition, when to seek medical care, medication side effects, adherence, positive living and legal rights; provide referrals for follow up)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule lab tests indicated (discussed briefly below)</li> </ul>
	<ul style="list-style-type: none"> <li>• Schedule next visit</li> </ul>

Further guidance of most of these activities can be found in both the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” and the “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”.

## Laboratory Monitoring

Laboratory assessments should be conducted at baseline (that is, entry into HIV care) and as indicated in “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”. **The unavailability of laboratory monitoring, including CD4 and chemistries, should NOT prevent adolescents from receiving ART.**

Note the following:

- **CD4** should be measured at the time of diagnosis, AND
  - **Adolescents not yet eligible for ART:** monitor every 6 months; but 3 monthly as CD4 count approaches threshold for starting ART.
  - **Adolescents on ART:** measure just prior to starting ART (if previous CD4 was measured more than 3 months ago) and every 6 months thereafter.
  - **All adolescents:** measure CD4 if a new clinical staging event develops, including growth faltering and neurodevelopmental delays.

## Cotrimoxazole (CTX)

CTX prophylaxis, often referred to simply as CTX, is a well-tolerated, cost-effective and life saving intervention for people living with HIV. It should be implemented as an integral component of chronic care for adolescents on ART as well as a key element of pre-ART care.

### Initiating CTX

Indications for CTX

- Clinical criteria: Start CTX when adolescent is in clinical stage 2, 3 or 4 regardless of CD4
- Immunologic criteria: Start CTX when CD4 count is  $<350\text{cells/mm}^3$  regardless of clinical stage

## Discontinuing CTX

- CTX can be discontinued in an adolescent on ART if he or she shows evidence of immune recovery of CD4  $>350$  cells/mm<sup>3</sup> after at least 6 months of treatment.
- In situations where CD4 is not available, CTX can be discontinued when there is evidence of good clinical response to ART (absence of clinical symptoms after at least one year of therapy), good adherence and secure access to ART.
- If CTX is discontinued, it should be restarted if the CD4 falls below 350 cells/mm<sup>3</sup> or if the patient has a new or recurrent WHO clinical Stage 2, 3, or 4 condition.

## Discontinuation of CTX due to adverse events

CTX should be discontinued if the adolescent experiences drug-related adverse events such as jaundice, extensive exfoliative rash, Stevens-Johnson syndrome, severe anaemia or pancytopenia. Such drug-related adverse events are unusual.

## Contraindications to CTX

Contraindications of CTX include:

- Adolescents with history of severe and life-threatening adverse reactions — grade 3 and 4 to CTX or other sulfa drugs — should not be prescribed CTX: dapsone 100 mg/day should be given as an alternative. See “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” additional information, including guidance on desensitising those with history of grade 1 or 2 reaction to CTX.
- Severe liver disease
- Severe renal insufficiency

**Table 3.5: Dosing for CTX**

Recommended once daily dose by age	Suspension	Child tablet (100mg/20mg)	Single strength adult tablet (400mg/80mg)
<b>10–14 years (or 15–30 kg)</b> 400 mg sulfamethoxazole/ 80 mg trimethoprim	10 ml	4 tablets	1 tablet
<b>&gt;14 years (or &gt;30 kg)</b> 800 mg sulfamethoxazole/ 160 mg trimethoprim	N/A	N/A	2 tablets
CTX can be safely continued or initiated during pregnancy, regardless of stage of pregnancy, and breastfeeding.			

Source: Republic of Zambia, MoH, Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010.

## When to Start ART in ALHIV

ART helps HIV-infected adolescents to preserve, and enhance, their immune systems — reducing their risk of OIs, restoring growth, improving

mental functioning, and overall quality of life. By adolescence, most clients with perinatally-acquired HIV will already be on CTX. The decision to start ART in an adolescent client relies on clinical and immunological assessment, as well as evaluation of the adolescent's social environment.

### **Social issues to consider before initiating ART**

Before initiating ART, healthcare workers should also think about:

- **Readiness for ART:** The adolescent understands what ARVs are, how they are to be taken, and is ready to take on this life-long commitment.
- **Ability and willingness of adolescent to return for regular follow up.**
- **How well the adolescent has done taking CTX daily.**
- **Adherence/treatment preparation:** The healthcare worker will have discussed adherence with the adolescent and worked out a plan with the adolescent for him or her to take ARVs every day exactly as prescribed. The “Adult and Adolescent Antiretroviral Therapy Protocols 2010” recommend that all clients initiating ART commit to “perfect” adherence. Given the nature of adolescence, healthcare workers should, upon completion of all three adherence preparation visits, at least get from the adolescent a commitment to excellent adherence, even if that commitment turns out to be easier said than done (see Module 8).
- **Family and peer support:** Ideally, adolescent clients would have family members, parents, caregivers, or peers that understand their HIV diagnosis and the implications of ART, including the importance of adherence for life, and support them to take their ARVs every day.

### **Immunological criteria to start ART**

The criteria to initiate ART is the same in all adolescent patients and adults:

- **CD4  $\leq$  350 or WHO stage 3 or 4**
- **CD4  $>$  350 if:**
  - The adolescent is the HIV positive partner in a discordant couple
  - The adolescent has hepatitis B virus infection (chronic hepatitis B as demonstrated by the presence of HBsAg) **and** elevated ALT or AST **or** has signs of liver cirrhosis. (If the adolescent is HBsAg positive but has normal baseline ALT or AST, recheck both ALT or AST and HBsAg in 6–12 months. If ALT or AST are elevated, or persistent HBsAg then start ART.)

### **Clinical criteria to start ART**

- **All adolescent clients** with stage 3 and 4 disease should start ART, regardless of CD4 count.
- **Asymptomatic or mildly symptomatic adolescents** (i.e. those in stages 1 and 2) should be considered for ART when immunological values fall near the threshold values. A drop below threshold values should be avoided.

**Prior to initiating ART ensure that:**

- Adolescents who know their status have disclosed to someone they trust; adolescents with perinatally-acquired HIV know their HIV status (i.e, have been disclosed to). Ensure that disclosure is documented
- CTX is initiated
- Minimum baseline laboratories are completed (see previous section and “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”)
- The adolescent has none of the following signs of un-resolved opportunistic infections (OIs):
  - Persistent fever (>14 days)
  - Persistent cough (>14 days)
  - Severe persistent headache (>14 days)
  - Anaemia (Hgb < 8 or Hct < 24)
  - Weight loss > 10%

If ANY of the above five symptoms are PRESENT then investigate and treat as appropriate (see “Adult and Adolescent Antiretroviral Therapy Protocols, 2010”).

- Initiate ART 2 weeks after documented response to treatment
- If no clear diagnosis obvious from diagnostic test, then consult an HIV Specialist before initiating ART

For more information, see “Appendix 3A: Clinical and Laboratory Monitoring for ALHIV”, “Appendix 3C: WHO Staging for Children with Established HIV Infection” and “Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents”.

**Recommended First-Line ART Regimens for ALHIV**

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**Introduction to ARV regimen**

ARV regimen and dosing for adolescent clients depend on his or her physical maturity, based on the Tanner scale (see “Appendix 2A: Tanner Scale”). The Tanner scale defines physical measurements of development, based on external primary and secondary sexual characteristics.

- Adolescents who are at **Tanner stages I, II and III** are pre-pubertal; regimens and dosages should be guided by the paediatric guidelines (“Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”). These clients require close clinical monitoring as adolescence is a time of hormonal changes and rapid growth.
- Adolescents who are at **Tanner stages IV and V** are post-pubertal and should be treated according to the adult ARV guidelines.

As a general rule, those who acquire HIV during their adolescent years, are treated according to the adult ARV guidelines, regardless of Tanner stage.

## Pre-pubertal adolescents

For adolescents (Tanner scale I, II or III), first line ART regimens contains NVP or EFV plus a “backbone” consisting of 2 NRTIs. See Table 3.6 for preferred and alternative first line regimens.

**Table 3.6: Regimens for children and pre-pubertal adolescents (Tanner scale I, II or III)**

	Regimen	
	NRTI backbone	NNRTI component
Preferred 1 <sup>st</sup> line	AZT + 3TC +	NVP or EFV <sup>1, 2</sup>
Alternative 1 <sup>st</sup> line <sup>3</sup>	ABC + 3TC +	NVP or EFV <sup>1, 2</sup>
2 <sup>nd</sup> Alternative 1 <sup>st</sup> line <sup>4</sup>	d4T + 3TC +	NVP or EFV <sup>1, 2</sup>
<p>1 The preferred regimen for adolescents with tuberculosis is EFV + the 2 NRTI backbone.</p> <p>2 The use of EFV should be avoided in adolescent girls due to the fact that it may cause foetal harm in the first trimester of pregnancy. If possible, adolescent girls taking EFV should be switched to a NVP-based or other regimen or counselled on and provided with a contraceptive method.</p> <p>3 Use the alternative 1<sup>st</sup> line regimen only if there are contraindications to AZT (for example, severe anaemia, &lt;8g/dl; or neutropenia, &lt;500 cells/mm<sup>3</sup>) or AZT availability cannot be assured.</p> <p>4 Due to its unfavourable toxicity profile and its selection for unfavourable resistance patterns, use of d4T should be minimised; therefore d4T/3TC should only be used as a last resort for initiating infants on ART if the use of AZT or ABC is contraindicated or cannot be assured.</p>		

Note that the 2010 guidelines call for the phasing out of used of d4T-containing regimens, unless AZT or ABC are contraindicated or not assured. The guidelines provide advice on drug substitution for adolescents currently on d4T.

Dosing in pre-pubertal adolescents is usually based on either weight or body surface area. As these change with growth, drug doses must be adjusted at each visit to avoid the risk of under-dosing. For additional information on dosing and regimens for specific scenarios (for example, patients with hepatitis), see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”, Section 6 and Annex G.

## Post-pubertal adolescents and adults

For post-pubertal adolescents (Tanner scale IV and V), the 2010 first line ART regimens includes a TDF + FTC “backbone”. TDF + FTC + EFV is now the preferred first line regimen due to long-term potency, favourable mutation pathway, and lower incidence of anaemia. See Table 3.7 for preferred and alternative first and second line regimens.

**Table 3.7: Regimens for post-pubertal adolescents (Tanner scale IV and V) and adults**

	Regimen	
	NRTI backbone	NNRTI component
Preferred 1 <sup>st</sup> line	TDF + FTC +	NVP <sup>1</sup> or EFV <sup>2</sup>

Alternative 1 <sup>st</sup> line <sup>3</sup>	ABC + 3TC +	NVP <sup>1</sup> or EFV <sup>2</sup>
Preferred 2 <sup>nd</sup> line <sup>4</sup>	AZT <sup>5</sup> + 3TC +	LPV/r
<p>1 Avoid use of NVP either of the following groups of patients:</p> <ul style="list-style-type: none"> <li>• Women who have had exposure to sdNVP without tail coverage with 7 days of AZT + 3TC within the last 12 months (for PMTCT). Instead do not use an Efavirenz containing regimen, instead use LPV/r. If unsure whether tail coverage for sdNVP was provided then use LPV/r</li> <li>• Patients with CD4 greater than 250</li> </ul> <p>2 The use of EFV should be avoided in women due to the fact that it may cause foetal harm in the first trimester of pregnancy. If possible, women taking EFV should be switched to a NVP-based or other regimen or counselled on and provided with a contraceptive method.</p> <p>3 TDF has been associated with renal toxicity: if CrCl &lt;50 ml/min , initiate therapy with ABC/3TC (the alternative 1st line regimen)</p> <p>4 This is the preferred 2nd line regimen for patients failing TDF-based 1st line regimen. Other possible NRTI backbones for 2<sup>nd</sup> line regimens include AZT + TDF <b>or</b> AZT + FTC. The alternative 2<sup>nd</sup> line regimen is d4T + 3TC + LPV/r, but as d4T is associated with long term toxicity, it should be used only if AZT cannot be tolerated.</p> <p>5 AZT is not recommended in patients with Hgb &lt;10. Delay ART until anaemia is treated or use alternative NRTI combination (some of the alternatives are listed in note 4, above).</p>		

#### Recommendations for paediatric patients transitioning to adult care:

- Continue stable patients without signs of toxicity or clinical failure on current regimen: (AZT, ABC or d4T) + 3TC + (NVP or EFV)
- Switch patients with signs of toxicity but not clinical failure to proposed first line regimen: TDF + FTC + either NVP or EFV
- Switch patients with signs of clinical failure from AZT, ABC or d4T-containing regimen to TDF + FTC + LPV/r

See “Appendix 3E: ARV Dosages for Post-pubertal Adolescents and Adults”. For additional information, see “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” or consult a local or provincial HIV specialist for guidance on transitioning to the 2010 recommendations.

### Possible events during the first 6 months

The first six months on ART are critical. In most adolescents, CD4 cell counts rise with the initiation of ART, increase over the course of the first year of treatment, reach a plateau and then continue to rise further over the second year. But, some fail to respond as expected or may even exhibit clinical deterioration.

- Complications in the first few weeks following the initiation of ART are seen most commonly in those with severe immunodeficiency.
- Apparent failure to improve in an adolescent with advanced HIV disease does not

#### Key signs of an adolescent's response to ART include:

- Improvement in growth in adolescents who have been failing to grow
- Improvement in neurological symptoms and development (if the adolescent has experienced delays in the achievement of developmental milestones)
- Decreased frequency of infections (bacterial infections, oral thrush and/or other OIs)

necessarily reflect a poor response to ART; it takes time for HIV viral replication to be controlled by ART and for the youth's immune system to recover.

- As an adolescent with advanced disease recovers immune function, there is risk of immune reconstitution inflammatory syndrome (IRIS). IRIS — which most often occurs within the first weeks to months after initiation of ART — is a complication caused by reactivation of the immune system. IRIS can present as a flare-up of symptoms when the recovering immune system begins to respond to an existing infection, for example, TB. The response is not due to failure of ART, but rather to its success and the resulting immune reconstitution. When IRIS is suspected, consult a clinician experienced in managing adolescents with HIV.
- Allow sufficient time (at least six months on therapy) before judging the effectiveness of a regimen. Supporting adherence during this period is critical and, in such cases, switching of ARV regimen would be inappropriate.
- Persistent failure to see a CD4 response should alert the healthcare worker to potential adherence problems or non-response to ART. In this case, viral load determination can be useful as can consultation with a clinician experienced in managing adolescents with HIV.

## Supporting Adherence to Care and Treatment among ALHIV

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Adherence to both care and medicines are the cornerstones of effective and successful HIV care. Adolescents often face unique challenges with adherence that are different than paediatric or adult clients. Adherence preparation, assessment, and counselling and support for ALHIV is discussed in detail in Module 8.

### Frequency of clinical monitoring

- **Adolescents on ART:** the frequency of clinical monitoring will depend on response to ART. At a minimum, after starting ART, ***follow-up visits should occur at weeks 2, 4, 8, 12, and then every 3 months*** once the adolescent has stabilised on ART.
- **Adolescents not yet eligible for ART:**
  - **Pre-pubescent adolescents:** follow-up visits should occur every 3 months at a minimum
  - **Post-pubescent adolescents:** follow-up visits should occur every 3 months if CD4 count is between 350–500 and every 6 months if CD4 cell count is greater than 500.

## Toxicities

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Toxicity can be monitored clinically, based on adolescent/caregiver reporting and physical examination, and can also be assessed by a limited number of laboratory tests. Drug toxicities generally fall into one of the following 3 categories:

- **Mild toxicities** do not require discontinuation of therapy or drug substitution, and symptomatic treatment may be given (for example, antihistamines for a mild rash).
- **Moderate or severe toxicities** may require substitution with a drug in the same ARV class but with a different toxicity profile, or with a drug in a different class, but do not require discontinuation of all ART.
- **Severe life-threatening toxicities** require discontinuation of all ARV drugs, and the initiation of appropriate supportive therapy until the patient is stabilised and the toxicity is resolved. NNRTIs have a longer half-life than NRTIs, and stopping all first-line drugs simultaneously may result in exposure to sub-therapeutic levels of the NNRTI and subsequently to the development of NNRTI resistance. However, if a child has a life-threatening toxicity, all ARV drugs should be stopped simultaneously until the patient is stabilised.

Refer to the “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” and/or “Adult and Adolescent Antiretroviral Therapy Protocols 2010” for additional information about dealing with toxicities or to a local HIV specialist.

## Considerations for adherence

Regardless of their severity, adverse reactions may affect adherence to therapy. A proactive approach to managing toxicity is recommended:

- Before initiating ART, discuss the potential side-effects.
- During the early stages of treatment, offer support during minor and moderate adverse reactions.

Many ARV drug toxicities are time-limited and resolve spontaneously even when the same ART regimen is continued.

## Treatment Failure

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In the absence of viral load measurement, clinical criteria and CD4 count can be used to identify treatment failure. Therefore, when treatment failure is suspected, confirm that:

- The adolescent has been on ART for at least 24 weeks. The adolescent has been adherent, that is, that he or she has taken nearly all of his ARVs exactly as prescribed. If adherence has not been optimal, then the first course of action is to keep the adolescent on the same regimen, but counsel and support adherence.
- Any inter-current infection or major clinical event has been treated and resolved.
- IRIS has been excluded.



- Before considering a change in treatment because of growth failure, ensure that the adolescent is receiving adequate nutrition.

When treatment failure is confirmed (see box below), switching to a new second-line regimen becomes necessary. In the absence of viral load testing, suspected treatment failure should be referred to the most senior/experienced treatment provider for assessment.

### Treatment failure

Where available, confirm treatment failure with viral load testing. Viral load is the only marker that accurately identifies patients with **virologic failure** or suppression. **Clinical** and **immunologic** criteria can raise the suspicion of virologic failure and be useful to prompt further investigation and help clinical decision making in the absence of viral load monitoring.

**Clinical criteria of treatment failure:** New or recurrent stage 3 or 4 event at least 6 months after starting ART

- Condition must be differentiated from immune reconstitution inflammatory syndrome (IRIS)

**Immunological criteria of treatment failure:**

- Developing or returning to the following immunologic threshold after at least 24 weeks on ART in a treatment-adherent adolescent:
  - CD4 count of <100
- Note: Rule out concomitant infection as a cause of transient CD4 cell decrease or slow increase

**Virological criteria of treatment failure:** According to the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” virologic failure-defined as VL >1000 copies/ml\*.

If viral load is not available, consult the multidisciplinary team or HIV Specialist for joint decision to either initiate 2<sup>nd</sup> line therapy or monitor patient using clinical and immunologic indicators.

\* For additional information on virologic failure, see the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia, Second Edition, 2010”.

## Tuberculosis

People with HIV, including adolescents, are prone to developing OIs and other HIV-related infections, particularly if their CD4 levels drop and they are not on ART. Many OIs can be prevented by ensuring that patients are put on ART and CTX as per guidelines.

Because of its prevalence amongst people with HIV, one OI in particular deserves further discussion: TB. Co-infection with HIV/TB is a major public health threat for people living with HIV and the community. TB threatens the significant health benefits achieved with scale-up of HIV care and treatment. All people living with or at higher risk of HIV in Zambia should be routinely screened for TB and placed on TB treatment if found with to have TB.

### Screening for TB

All ALHIV should be evaluated for contact with a TB source case and for TB symptoms at every visit to a healthcare facility. Key screening questions are included in Table 3.8.

**Table 3.8: TB screening for adolescents in Zambia**

Question	Yes or No
1. Has the patient been coughing for $\geq 2$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Has the patient been having night sweats for $\geq 3$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Has the patient lost $\geq 3$ kg during the last 4 weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4. Has the patient been having fever for $\geq 3$ weeks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
5. Has the patient had contact with someone with TB?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<ul style="list-style-type: none"> <li>• If “Yes” to question 1: do sputum tests and refer to clinician for further investigation of TB.</li> <li>• If “No” to question 1 and “yes” to any other question: Refer to clinic clinician for investigation of TB.</li> <li>• If “No” to all questions: repeat screening at next visit.</li> </ul>	

For information on the diagnosis of TB, see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia”.

### Prevention of TB with isoniazid preventive therapy

- All HIV-infected adolescents exposed to TB through household contacts, but with no evidence of active disease, should begin isoniazid preventive therapy (IPT).
- The recommended dose of isoniazid (INH) for preventive therapy in HIV co-infection is 10 mg/kg daily for 6 months (maximum 300 mg/day; any adolescent weighing more than 25 kg will receive the maximum dose of 300 mg/day).

### Treatment considerations in adolescents with TB and HIV

- Any adolescent with active TB disease should begin TB treatment immediately, and start ART (if eligible) as soon as tolerated — within 2–8 weeks (pre-pubertal adolescents) or 2–3 weeks (post-pubertal adolescents).
- The co-management of TB and HIV, and the treatment of HIV infection, is complicated by drug interactions, particularly between rifampicin and the NNRTI and PI classes of ARVs. These drugs have similar routes of metabolism and co-administration may result in sub-therapeutic drug levels.

See the Government of the Republic of Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” for information on the treatment of TB and HIV.

### **Treatment choices for ALHIV who develop TB before ART**

Choice of first-line ARV regimens in ALHIV receiving rifampicin-containing TB treatment

- Pre-pubertal adolescents: 2 NRTIs + EFV
- Post-pubertal adolescents: TDF/FTC or 3TC + EFV. If renal insufficiency ABC + 3TC + EFV.

### **ART switching for ALHIV who develop TB while on first-line ART**

- ART should continue in ALHIV already on a first-line ARV regimen who are subsequently diagnosed with TB. However, the ARV regimen should be reviewed and may need adjustment to ensure optimal treatment of both TB and HIV and to decrease the potential for toxicities and drug-drug interactions.
- In ALHIV on a standard NNRTI-based first-line regimen who develops TB, make adjustments to ART regimens as follows:
  - Pre-pubescent ALHIV: if on a regimen of 2 NRTI + NVP: change NVP with EFV. If on a PI regimen, consult expert for guidance.
  - Post-pubescent ALHIV: if on a regimen that includes NVP, substitute NVP with EFV and continue ART. NOTE: Where TB is being considered as a sign of treatment failure of the first-line regimen, switching to a second-line regimen should be considered if the adolescent has taken ART for more than 24 weeks, has initially responded to it, and has not responded to anti-TB treatment. Consult an HIV expert for the construction of a second-line regimen.

### **Using the 5 “A’s” in Consultations with Adolescent Clients**

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The 5 “A’s” are part of the WHO IMAI guidelines on working with clients (including adolescents) with chronic conditions, including HIV. Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients.

**Table 3.9: Using the 5 “A’s” during clinical visits with adolescents**

The 5 “A’s”	More Information	What the Healthcare Worker Might Say
<b>ASSESS</b>	<ul style="list-style-type: none"> <li>Assess the client’s goals for the visit</li> <li>Assess the client’s clinical status, classify/identify relevant treatments and/or advise and counsel</li> <li>Assess risk factors</li> <li>Assess the client’s (caregiver’s) knowledge, beliefs, concerns, and behaviours</li> <li>Assess the client’s understanding of the care and treatment plan</li> <li>Assess adherence to care and treatment (see Module 8)</li> <li>Acknowledge and praise the client’s efforts</li> </ul>	<ul style="list-style-type: none"> <li><i>What would you like to address today?</i></li> <li><i>What can you tell me about _____?</i></li> <li><i>Tell me about a typical day and how you deal with _____?</i></li> <li><i>Have you ever tried to _____? What was that like for you?</i></li> <li><i>To make sure we have the same understanding, can you tell me about your care and treatment plan in your own words?</i></li> <li><i>Many people have challenges taking their medicines regularly. How has this been for you?</i></li> </ul>
<b>ADVISE</b>	<ul style="list-style-type: none"> <li>Use neutral and non-judgemental language</li> <li>Correct any inaccurate knowledge and complete gaps in the client’s understanding</li> <li>Counsel on risk reduction</li> <li>Repeat any key information that is needed</li> <li>Reinforce what the client needs to know to manage his or her care and treatment (for example, recognising side effects, adherence tips, problem-solving skills, when to come to the clinic, how to monitor one’s own care, where to get support in the community, etc.)</li> </ul>	<ul style="list-style-type: none"> <li><i>I have some information about _____ that I’d like to share with you.</i></li> <li><i>Let’s talk about your risk _____. What do you think about reducing this risk by _____?</i></li> <li><i>What can I explain better?</i></li> <li><i>What questions do you have about _____?</i></li> </ul>
<b>AGREE</b>	<ul style="list-style-type: none"> <li>Negotiate WITH the client about the care and treatment plan, including any changes</li> <li>Plan when the client will return</li> </ul>	<ul style="list-style-type: none"> <li><i>We have talked about a lot today, but I think we’ve agreed that _____. Is that correct?</i></li> <li><i>Let’s talk about when you will return to the clinic for _____.</i></li> </ul>
<b>ASSIST</b>	<ul style="list-style-type: none"> <li>Provide take-away information on the plan, including any changes</li> <li>Provide psychosocial support, as needed</li> <li>Provide referrals, as needed (support groups, peer education, etc.)</li> <li>Address any problems or challenges the client is facing</li> <li>Help the client come up with solutions and strategies that work for him/her</li> </ul>	<ul style="list-style-type: none"> <li><i>Can you tell me more about any challenges you’ve faced with _____ (for example, taking your medicines regularly, seeking support, practising safer sex)?</i></li> <li><i>How do you think we can solve this problem/challenge?</i></li> <li><i>What questions can I answer about _____?</i></li> <li><i>I want to make sure I explained things well — can you tell me in your own words about _____?</i></li> </ul>
<b>ARRANGE</b>	<ul style="list-style-type: none"> <li>Arrange a follow-up appointment</li> <li>Arrange for attendance in support groups or group education sessions, etc.</li> <li>Record what happened during the visit</li> </ul>	<ul style="list-style-type: none"> <li><i>I would like to see you again in _____ for _____. It’s important that you come for this visit, or let us know if you need to reschedule.</i></li> <li><i>What day/time would work for you?</i></li> </ul>

Sources: WHO. General Principles of Good Chronic Care: IMAI. Guidelines for First-level Facility Health Workers, 2004.

WHO. IMAI One-day orientation on adolescents living with HIV, 2010.

### Exercise 1: The Adolescent Package of Care: Case studies in small groups and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To review clinical care and treatment of ALHIV according to national guidelines</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>Participants will be asked to break into 4 multidisciplinary small groups.</li> <li>Each small group's notetaker should write "Assess", "Advise", "Agree", "Assist", and "Arrange" along the left margin of their flip chart paper.</li> <li>Participants should read the case study assigned to their group and then discuss the following: <ul style="list-style-type: none"> <li>Assess: key points inferred from the assessment (participants may have to make inferences from the case study)</li> <li>Advise: how the client should be advised</li> <li>Agree: key points that should be negotiated with the client</li> <li>Assist: how the client should be assisted</li> <li>Arrange: what services or follow-up appointments need to be arranged and what should be recorded in the notes.</li> </ul> <p>Participants should feel free to refer to Table 3.9: Using the 5 "A's" during clinical visits with adolescents" to guide their case study discussions.</p> </li> <li>Notetakers should take notes on the prepared flip chart paper and be prepared to make a brief presentation to the large group.</li> </ol>

### Exercise 1: The Adolescent Package of Care: Case studies in small groups and large group discussion

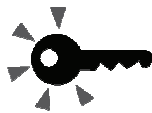
**Case Study 1:** Mehluli is a 17 year old adolescent who became infected with HIV 2 years ago. Mehluli had been attending clinic regularly until he went away to attend college. When he attended clinic — up until 6 months ago — he was taking his ART regularly and doing well in school. He's now been at college for 6 months but has returned for the holidays. During his holiday break he dropped by the clinic. It seems that at college he has become involved in a new church where he was told to stop taking medicine because God will heal. Mehluli states that he feels well and thinks the decision was the right one. How will you proceed with Mehluli?

**Case Study 2:** Katai, who is 16 and acquired HIV through MTCT, went to live with relatives when her parents died three years ago. She has never felt completely welcome at her aunt and uncle's home. Although they do support her to take her ART regularly, she just has never felt "loved". She feels that her uncle is unsupportive of her in general, he makes her do

more chores than his own children are required to do, and he never gives her enough money to buy what she needs. Over the past year or so she has been going to bars and finding the company she craves by having sex with any man she can pick up. How will you proceed with Katai?

**Case Study 3:** Sonkwe is a 12 year old who was infected with HIV perinatally. Although Sonkwe has had his ups and down, in terms of health, as of the past year there has been a definite decline. Sonkwe is small for his age, and has not grown in the past year. He is recently recovered from a WHO Stage 2 illness. During the counselling session with Sonkwe, he stated that his caregivers expect **him** to remember to take his ARVs every day. When he forgets, they do not think to remind him. His caregivers feel that, as he is now 12 that he is old enough to take responsibility for his own health. How will you proceed with Sonkwe?

**Case Study 4:** Trina, who is 17, was diagnosed with HIV 1 year ago. Trina is quite healthy, her CD4 cell count was 500 and at the last visit she was a clinical stage 1. The only reason she was tested last year is because she heard through a girl friend that her old boyfriend was rumoured to have HIV. Today Trina looks thin and tired — much different than she looked the last time you saw her just 6 months ago. When she comes into the exam room you realise that she's been coughing as well. How will you proceed with Trina?



### Module 3: Key Points

- There are 2 specific groups of ALHIV (defined by the mode of HIV transmission), whose histories, experiences and needs may differ significantly — adolescents who acquired HIV perinatally, and those that acquired HIV later in childhood or adolescence.
- While the components of the adolescent package of HIV care closely resemble those of the adult package of care, how they are delivered can have an impact on uptake and success. To be effective, the adolescent package of care must ensure:
  - Integration of services
  - That services are age and developmentally appropriate
  - That they are responsive to the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
  - That there is an emphasis on both care and treatment, and retaining adolescents not eligible for ART in care
  - That services are family-centred
- Key components of comprehensive care for ALHIV include the following:
  - Assess growth, nutrition, and development

- Conduct physical examination and confirm stage of HIV disease
- Prevent, diagnose and treat OIs and other concomitant conditions, including tuberculosis
- If eligible, provide ART (if  $CD4 \leq 350$  or stage 3 or 4) and CTX (if  $CD4 < 350$  or stage 2, 3 or 4) as well as adherence monitoring and support
- Provide the client and his or her family with psychosocial assessment, counselling, education and support, including for disclosure; provide referral for follow up
- Discuss findings, advise and guide

## Appendix 3A: Clinical and Laboratory Monitoring for ALHIV

Laboratory tests for diagnosis and monitoring	Baseline (at entry into care)	At initiation of first- or second-line ART regimen	Every 6 months	As required or symptom directed
HIV Antibody testing	✓			
Haemoglobin <sup>a</sup> (and white cell count, if available) or FBC	✓	✓		✓
LFT <sup>c</sup> and RFT	✓			✓
CD4 cell count <sup>d</sup>	✓	✓	✓	✓
Creatinine Clearance <sup>e</sup>	✓	✓		✓
ALT and/or AST <sup>f</sup>	✓			
Urinalysis	✓			
Pregnancy testing in adolescent girls <sup>gh</sup>		✓		✓
Full chemistry (including, but not restricted to, liver enzymes, renal function, glucose, lipids, amylase, lipase and serum electrolytes) <sup>i</sup>		✓		✓
HIV VL measurement <sup>jk</sup>				✓
Hepatitis B and C status (where available)	✓			
RPR	✓			✓
OI screening (where possible)	✓	✓	✓	✓
Sexually active females: PAP smear (if unavailable, then visualisation with acetic acid screening) or refer to next level of care for PAP smear <sup>l</sup>	✓			✓
If available, chemistry panel to include glucose, cholesterol, triglycerides	✓			

- Monitor haemoglobin at week 4 and 12 after initiation of ART if AZT is used.
- FBC can be repeated at initiation of ART if last FBC was done at least 3 months prior. If FBC is not available at baseline, conduct haemoglobin measurement.
- Liver function tests (LFT i.e. liver enzymes) are recommended during the first few months of treatment in children receiving NVP who have signs of hepatitis or hepatotoxicity, who are co-infected with hepatitis viruses, or who are on hepatotoxic medications. Based on data in adults on ART, routine monitoring of LFTs is unlikely to be cost-effective.
- HIV-infected children not yet eligible for ART should be monitored with CD4 count every six months. For infants and children who develop new or recurrent WHO stage 2 or 3 events, or whose CD4 count approaches threshold values, the frequency of CD4 measurement can be increased. %CD4+ is preferred in children <5 years of age.



- e. Repeat creatinine clearance 12 weeks, 6 months and then yearly after initiating ART. See the Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” for additional information.
- f. Conduct ALT and/or AST in patients initiated on NVP-containing regimen or those testing HBsAg positive. Monitor closely in the first 12 weeks of initiating a NVP-containing regimen.
- g. Pregnancy testing needed for sexually active adolescent girls prior to initiating a regimen containing EFV.
- h. For pregnant adolescent girls, provide prophylaxis or combination ART to those who are in need of it for their own health and/or to prevent vertical transmission. (See WHO PMTCT Guidelines, 2010) [102]
- i. Routine monitoring (every six months) of full chemistry, particularly lipid levels, liver enzymes and renal function, should be considered for infants and children on second-line drugs and LFTs for those on NVP.
- j. At present, VL measurement is not a prerequisite for initiation or regular monitoring of ART in resource-limited settings. VL can be used to diagnose HIV infection, and to confirm clinical or immunological failure prior to switching treatment regimen.
- k. If possible VL should be assessed in infants on NNRTI-based regimens who are known to have been exposed to NNRTIs intrapartum or through breastfeeding every 6 months.
- l. Repeat PAP or visual screen at 6 months and if normal, every 12 months

## Appendix 3B: HEADSS Interview Questions

✓	Topic and key points
	<b>1. Home and environment</b>
	<ul style="list-style-type: none"> <li>Where do you live, and who lives there with you?</li> </ul>
	<ul style="list-style-type: none"> <li>How many brothers and sisters do you have and what are their ages? Are your brothers and sisters healthy?</li> </ul>
	<ul style="list-style-type: none"> <li>Are there any new people living in your home?</li> </ul>
	<ul style="list-style-type: none"> <li>What are the rules like at home?</li> </ul>
	<ul style="list-style-type: none"> <li>How do you get along with your parents, your siblings? What kinds of things do you and your family argue about the most? What happens in the house when there is a disagreement?</li> </ul>
	<ul style="list-style-type: none"> <li>Is there anything you would like to change about your family?</li> </ul>
	<b>2. Education and employment</b>
	<ul style="list-style-type: none"> <li>Are you in school? What are you good at in school? What is hard for you? What grades do you get?</li> </ul>
	<ul style="list-style-type: none"> <li>Which school do you go to? Any recent changes in schools?</li> </ul>
	<ul style="list-style-type: none"> <li>What do you like best and least about school? Favourite subjects? Worst subjects?</li> </ul>
	<ul style="list-style-type: none"> <li>What were your most recent grades? Are these the same or different from the past?</li> </ul>
	<ul style="list-style-type: none"> <li>How many hours of homework do you do daily?</li> </ul>
	<ul style="list-style-type: none"> <li>How much school did you miss last/this year?</li> </ul>
	<ul style="list-style-type: none"> <li>What do you want to do when you finish school? Any future plans/goals?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you work now? How much? Have you worked in the past?</li> </ul>
	<ul style="list-style-type: none"> <li>How do you get along with teachers, employers?</li> </ul>
	<b>3. Activities</b>
	<ul style="list-style-type: none"> <li>What do you do for fun? What things do you do with friends? What do you do with your free time?</li> </ul>
	<ul style="list-style-type: none"> <li>Are most of your friends from school or somewhere else? Are they the same age as you?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you hang out with mainly people of your same sex or a mixed crowd?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you have one best friend or a few friends? Do you have a lot of friends?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you spend time with your family? What do you do with your family?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you see your friends at school and on weekends, too? Are there a lot of parties?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you do any regular sport or exercise? Hobbies or interests?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you have a religious affiliation, belong to a church, or practice some kind of spiritual belief?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you read for fun? What do you read?</li> </ul>
	<ul style="list-style-type: none"> <li>What is your favourite music?</li> </ul>

	<b>4. Drugs</b>
	<ul style="list-style-type: none"> <li>Many young people experiment with drugs, alcohol, or cigarettes. Have you or your friends ever tried them? What have you tried?</li> </ul>
	<ul style="list-style-type: none"> <li>When you go out with your friends or to party, do most of the people that you hang out with drink or smoke? Do you? How much and how often?</li> </ul>
	<ul style="list-style-type: none"> <li>Do any of your family members drink, smoke or use other drugs? If so, how do you feel about this — is it a problem for you?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you or your friends ever tried any other drugs? Specifically, what? Have you ever used a needle?</li> </ul>
	<ul style="list-style-type: none"> <li>Do you regularly use other drugs? How much and how often?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you ever been in a car accident or in trouble with the law, and were any of these related to drinking or drugs?</li> </ul>
	<ul style="list-style-type: none"> <li>How do you pay for your cigarettes, alcohol or drugs?</li> </ul>
	<b>5. Sexuality</b>
	<ul style="list-style-type: none"> <li>Are you involved in a relationship? Have you been involved in a relationship? How was that experience for you?</li> </ul>
	<ul style="list-style-type: none"> <li>How would you describe your feeling towards boys or girls?</li> </ul>
	<ul style="list-style-type: none"> <li>How do you see yourself in terms of sexual preference, i.e. gay, straight, or bisexual?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you had sex? Was it a good experience? Are you comfortable with sexual activity? Number of partners?</li> </ul>
	<ul style="list-style-type: none"> <li>Using contraception? Type and how often (10, 50, or 70% of the time).</li> </ul>
	<ul style="list-style-type: none"> <li>Have you ever been pregnant or had an abortion?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you ever had a discharge or sore that you are concerned about? Knowledge about STDs and prevention?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you ever had a pap smear?</li> </ul>
	<ul style="list-style-type: none"> <li>Have you had an experience in the past where someone did something to you that you did not feel comfortable with or that made you feel disrespected?</li> </ul>
	<ul style="list-style-type: none"> <li>If someone abused you, who would you talk to about this? How do you think you would react to this?</li> </ul>
	<ul style="list-style-type: none"> <li>For females: Ask about menarche, last menstrual period (LMP), and menstrual cycles. Also inquire about breast self examination (BSE) practices.</li> </ul>
	<ul style="list-style-type: none"> <li>For males: Ask about testicular self-examination (TSE) practices.</li> </ul>
	<b>6. Suicide/depression</b>
	<ul style="list-style-type: none"> <li>See “Appendix 6C: Screening Tool for Suicide”</li> </ul>

Adapted from: “H.E.A.D.S.S. — A Psychosocial Interview For Adolescents”

[http://search.phsa.ca/cgi-bin/MsmGo.exe?grab\\_id=0&page\\_id=8144&query=HEADSS](http://search.phsa.ca/cgi-bin/MsmGo.exe?grab_id=0&page_id=8144&query=HEADSS)

## Appendix 3C: WHO Staging for Children with Established HIV Infection

Use this clinical staging for adolescents younger than 15 years of age.

<b>Clinical Stages</b>	
<b>Clinical Stage 1</b>	
<ul style="list-style-type: none"> <li>Asymptomatic</li> </ul>	<ul style="list-style-type: none"> <li>Persistent generalised lymphadenopathy</li> </ul>
<b>Clinical Stage 2</b>	
<ul style="list-style-type: none"> <li>Unexplained persistent hepatosplenomegaly</li> <li>Papular pruritic eruptions</li> <li>Extensive wart virus infection</li> <li>Extensive molluscum contagiosum</li> <li>Unexplained persistent parotid enlargement</li> </ul>	<ul style="list-style-type: none"> <li>Recurrent oral ulcerations</li> <li>Lineal gingival erythema</li> <li>Herpes zoster</li> <li>Recurrent or chronic upper respiratory tract infection (otitis media, otorrhea, sinusitis, tonsillitis)</li> <li>Fungal nail infections</li> </ul>
<b>Clinical Stage 3</b>	
<ul style="list-style-type: none"> <li>Unexplained moderate malnutrition not adequately responding to standard therapy</li> <li>Unexplained persistent diarrhoea (14 days or more)</li> <li>Unexplained persistent fever (above 37.5°C intermittent or constant, for longer than 1 month)</li> <li>Persistent oral Candida (outside first 6–8 weeks of life)</li> <li>Acute necrotising ulcerative gingivitis/periodontitis</li> </ul>	<ul style="list-style-type: none"> <li>Oral hairy leukoplakia</li> <li>Lymph node TB</li> <li>Pulmonary TB</li> <li>Severe recurrent presumed bacterial pneumonia</li> <li>Symptomatic lymphoid interstitial pneumonitis</li> <li>Chronic HIV-associated lung disease including bronchiectasis</li> <li>Unexplained anaemia (&lt;8g/dl), neutropenia (&lt;05 x 10<sup>9</sup>) or chronic thrombocytopenia (&lt;50 x 10<sup>9</sup>/l)</li> </ul>
<b>Clinical Stage 4</b>	
<ul style="list-style-type: none"> <li>Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy</li> <li>Pneumocystis pneumonia</li> <li>Recurrent severe bacterial infections (for example, empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia)</li> <li>Chronic herpes simplex infection; (orolabial or cutaneous &gt; 1 month's duration or visceral at any site)</li> <li>Extra pulmonary tuberculosis</li> <li>Kaposi sarcoma</li> <li>Esophageal candidiasis (or Candida of trachea, bronchi or lungs)</li> <li>Central nervous system toxoplasmosis (outside the neonatal period)</li> <li>HIV encephalopathy</li> <li>Chronic Isosporiasis</li> </ul>	<ul style="list-style-type: none"> <li>Cytomegalovirus (CMV) infection; retinitis or CMV infection affecting another organ, with onset at age &gt;1 month.</li> <li>Extra pulmonary cryptococcosis including meningitis</li> <li>Disseminated endemic mycosis (extra pulmonary histoplasmosis, coccidiomycosis, penicilliosis)</li> <li>Chronic Cryptosporidiosis</li> <li>Disseminated non-tuberculous mycobacteria infection</li> <li>Acquired HIV-associated rectal fistula</li> <li>Cerebral or B cell non-Hodgkin lymphoma               <ul style="list-style-type: none"> <li>Progressive multifocal leukoencephalopathy</li> <li>HIV-associated cardiomyopathy or HIV-associated nephropathy</li> </ul> </li> </ul>

Adapted from: Republic of Zambia Ministry of Health. (2007): *Zambian Guidelines for Antiretroviral Therapy of HIV Infection in Infants and Children*

## Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents

Use this clinical staging for adolescents age 15 years or older.

<b>Clinical Stages</b>	
<b>Clinical Stage 1</b>	
<ul style="list-style-type: none"> <li>Asymptomatic</li> </ul>	<ul style="list-style-type: none"> <li>Persistent generalised lymphadenopathy</li> </ul>
<b>Clinical Stage 2</b>	
<ul style="list-style-type: none"> <li>Moderate unexplained<sup>1</sup> weight loss (under 10% of presumed or measured body weight)<sup>2</sup></li> <li>Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis)</li> </ul>	<ul style="list-style-type: none"> <li>Herpes zoster</li> <li>Angular cheilitis</li> <li>Recurrent oral ulceration</li> <li>Papular pruritic eruptions</li> <li>Seborrhoeic dermatitis</li> <li>Fungal nail infections</li> </ul>
<b>Clinical Stage 3</b>	
<ul style="list-style-type: none"> <li>Unexplained<sup>1</sup> severe weight loss (over 10% of presumed or measured body weight)<sup>2</sup></li> <li>Unexplained<sup>1</sup> chronic Candidiasis for longer than one month</li> <li>Unexplained persistent fever (intermittent or constant for longer than one month)</li> <li>Persistent oral Candidiasis</li> <li>Oral hairy leukoplakia</li> </ul>	<ul style="list-style-type: none"> <li>Pulmonary tuberculosis</li> <li>Severe bacterial infections (for example, pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)</li> <li>Acute necrotising ulcerative stomatitis, gingivitis or periodontitis</li> <li>Unexplained anaemia (below 8 g/dl ), neutropenia (below 0.5 x 10<sup>9</sup>/l) and/or chronic thrombocytopenia (below 50 x 10<sup>9</sup> /l)</li> </ul>
<b>Clinical Stage 4</b>	
<ul style="list-style-type: none"> <li>HIV wasting syndrome</li> <li>Pneumocystis Jiroveci pneumonia</li> <li>Recurrent severe bacterial pneumonia</li> <li>Chronic herpes simplex infection (oro-labial, genital or ano-rectal of more than one month's duration or visceral at any site)</li> <li>Oesophageal Candidiasis (or Candidiasis of trachea, bronchi or lungs)</li> <li>Extra pulmonary tuberculosis</li> <li>Kaposi sarcoma</li> <li>Cytomegalovirus infection (retinitis or infection of other organs)</li> <li>Central nervous system toxoplasmosis</li> <li>HIV encephalopathy</li> <li>Extra pulmonary cryptococcosis including meningitis</li> </ul>	<ul style="list-style-type: none"> <li>Disseminated non-tuberculosis mycobacterial infection</li> <li>Progressive multifocal leukoencephalopathy</li> <li>Chronic cryptosporidiosis</li> <li>Chronic isosporiasis</li> <li>Disseminated mycosis (extra pulmonary histoplasmosis, coccidiomycosis)</li> <li>Recurrent septicaemia (including non-typhoidal Salmonella)</li> <li>Lymphoma (cerebral or B cell non-Hodgkin)</li> <li>Invasive cervical carcinoma</li> <li>Atypical disseminated leishmaniasis</li> <li>Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy</li> </ul>
<sup>1</sup> Unexplained refers to a condition that is not explained by other conditions.	
<sup>2</sup> Assessment of body weight among pregnant women needs to consider the expected weight gain of pregnancy.	

Adapted from: WHO. (2006). Revised WHO clinical staging and immunological classification of HIV and case definition of HIV for surveillance.

## Appendix 3E: ARV Dosages for Post-pubertal Adolescents and Adults

Drug	Usual adult dosage	Notes
Efavirenz (EFV)	600 mg once a day Evening dosing on an empty stomach recommended initially to decrease side effects.	Contraindicated in 1st trimester of pregnancy.
Emtricitabine (FTC)	200 mg once a day, With or without food	Can be administered as a co-formulated product with TDF (Truvada) or with TDF and EFV (Atripla).  Adjust if CrCl <50 ml/min.
Lamivudine (3TC)	300 mg once a day	Can cause pancreatitis. Adjust if CrCl <50 ml/min.
Boosted Lopinavir (LPV/r)	400/100 mg twice a day, With or without food	Can cause hyperlipidemia, insulin resistance, pancreatitis, transaminitis, and/or fat redistribution
Nevirapine (NVP)	200 mg twice a day	Two-week lead-in recommended (200 mg once a day), as it reduces risk of rash and hepatotoxicity.  Can cause Stevens Johnson Syndrome, toxic epidermal necrolysis, hepatotoxicity (monitor ALT/AST first 12 weeks), liver failure, and hypersensitivity
Stavudine (d4T)	<ul style="list-style-type: none"> <li>Wt &gt;60 kg: 40 mg twice-daily</li> <li>Wt &lt;60 kg: 30 mg twice-daily</li> </ul> (WHO recommends and data supports 30 mg twice-daily, less toxic and equally effective.)	Contraindicated with AZT due to in vitro and in vivo antagonism.  Can cause peripheral neuropathy, lipoatrophy, hyperlipidemia, pancreatitis, lactic acidosis.  Adjust if CrCl <50 ml/min.
Tenofovir (TDF)	300 mg once a day, With or without food	Avoid TDF based regimen in patients with renal insufficiency (CrCl <50 ml/min).
Zidovudine (AZT)	300 mg twice a day, With or without food (often better tolerated with food)	Avoid AZT in patients with Hb <10 gm/dl (monitor Hb in the first 12 weeks). Can also cause neutropenia, myopathy, and lactic acidosis.  Adjust if CrCl <15 ml/min.

For information on serious, acute, and chronic toxicities, see “Guidelines for Antiretroviral Therapy for HIV in Infants and Children in Zambia” Annex B and Annex C.

## References and Resources

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<sup>1</sup> WHO/UNICEF. 2008. *Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV*. Geneva, Switzerland: WHO/UNICEF.



## Module 4

# Communicating with and Counselling Adolescents

**Session 4.1: Establishing Trust and Rapport with Adolescent Clients**

**Session 4.2: Effective Techniques for Counselling Adolescents**

**Session 4.3: Challenges and Solutions to Counselling Adolescent Clients**

### Learning Objectives

**After completing this module, participants will be able to:**

- Discuss ways to establish trust and rapport with adolescent clients.
- Demonstrate effective counselling skills.
- Identify and address common challenges in counselling adolescent clients.



## Session 4.1      Establishing Trust and Rapport with Adolescent Clients

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### Session Objective

**After completing this session, participants will be able to:**

- Discuss ways to establish trust and rapport with adolescent clients.

### Strategies for Establishing Trust and Rapport with the Adolescent Client<sup>1</sup>

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ALHIV may have any number of personal concerns related to their diagnosis, disclosure of their HIV status, feelings of isolation, and coping with a chronic condition. In order to provide them with support and information, healthcare workers must first establish trust and rapport. Establishing trust with an adolescent can be difficult because:

- Adolescence is a unique phase of life. The adolescent is going through dramatic biological and emotional changes. Seeking health care may seem challenging because the normal changes of adolescence affect the young person's self-confidence, relationships, social skills, and general thinking.
- Adolescents may feel fearful, embarrassed, or uncomfortable around healthcare workers. They may be reluctant to disclose personal information for fear of being scolded or mocked, especially if a caregiver is present.
- Most adolescents have concerns about confidentiality, which will impact their willingness to discuss personal issues with the healthcare worker. ***Healthcare workers should always reassure adolescents, during one-to-one counselling sessions, that what is discussed in the counselling session will remain confidential.*** Clarify what this means: although the healthcare worker may have to share information with other healthcare workers — if it is critical in making decisions about the client's care — discussions with clients are never shared with anyone outside of the multidisciplinary team. These discussions are not even shared with caregivers or partners, unless the client gives explicit permission.
- Adolescents who are in same-sex relationships may feel that they will face discrimination if they reveal their relationship to others. Instead, they are likely to choose to lie about their relationships or the gender of their current partner, making it impossible for healthcare workers to tailor prevention strategies to their situations.

**When face-to-face with a healthcare worker (or an adult staff member) many adolescents feel:**

- *Shy* about being in a clinic and about needing to discuss personal matters.
- *Embarrassed* that they are seeking assistance on a taboo topic (HIV, sex, sexuality, wanting to have sex, wanting to have a baby).
- *Worried* that someone will see them and tell their parents.
- *Inadequate* at describing their concern and ill-informed about health matters in general.
- *Anxious* that they have a serious condition that has significant consequences.
- *Afraid* that they might die.
- *Intimidated* by the medical facility and/or the many “authority figures” in the facility.
- *Defensive* about being the subject of the discussion or because they were referred against their will.
- *Resistant* to receiving help or engaging in care and treatment because of rebelliousness, a fear of the unknown, or another reason.
- *Unsure* about how to ask for help around living with a chronic condition.

**The following are tips for building rapport with adolescents:**

- Treat everyone equally and with respect.
- Be genuinely open to an adolescent’s questions or need for information.
- Do not use judgemental words or body language. Do not talk down to an adolescent by scolding, shouting, blaming, or getting angry.
- Use words and language that an adolescent can understand, and are appropriate to their age and developmental stage. Use educational materials, like flip charts or pictures, to explain complicated information.
- Do not be critical of an adolescent’s appearance or behaviour.
- If sensitive issues are being discussed, help ensure that conversations are not seen or overheard by others.
- Do not threaten to break an adolescent’s confidentiality “for their own good.”
- Adolescents may be reluctant to disclose personal information if their parents or caregivers are present. Healthcare workers should stress that information entrusted with them will not be shared, unless the client gives permission.
- Allow enough time for the adolescent client to become comfortable enough during the visit to ask questions and express concerns.
- Show an understanding of and empathize with the client’s situation and concerns. Try and put yourself “in the adolescent’s shoes.”
- Understand that they might be uncomfortable; be reassuring when responding to them. Explain that you “*are here to help.*”
- Reassure adolescents that their feelings and experiences are normal.
- Be honest and admit when you do not know the answer to a question.

**Exercise 1: Establishing Rapport and Building Trust: Role play and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To practise establishing rapport and building trust with adolescent clients</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>Participants will be invited to role play or read the case studies below.</li> <li>Upon completion of the role play (or reading), the trainer will facilitate a discussion about the case study.</li> </ol>

**Exercise 1: Establishing Rapport and Building Trust: Role play and large group discussion****Case Study 1**

Mary is 18 years old and has recently found out that she is HIV infected. She has not disclosed her HIV status to anyone and is very concerned that you might tell her partner. How do you proceed with Mary?

**Case Study 2**

Ethel is 15-years-old and living with HIV. She has been living with HIV since she was an infant. Her mother passed away a few years ago and now she lives with her father. She is responsible for caring for her 3 younger siblings. She comes to the clinic today, claiming she has some stomach pains. You suspect the real reason that she has come is because she wants to talk about something. How do you proceed with Ethel?

**Case Study 3**

Katib is a 10-year-old boy with perinatally-acquired HIV infection. He is an orphan and has been brought to the clinic for an appointment by his grandmother. He is very shy and seems uncomfortable being in the clinic and he doesn't talk with the other adolescent children. How do you proceed with Katib?

## **Session 4.2      Effective Techniques for Counselling Adolescents**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Demonstrate effective counselling skills.

### **Overview of Counselling and Communication**

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#### **Why do we do counsel someone?**

- To help people talk about, explore, and understand their thoughts and feelings
- To help people work out for themselves what they want to do and how they will do it

#### **Counselling includes:**

- Establishing supportive relationships
- Having conversations with a purpose (not just chatting)
- Listening carefully
- Helping people tell their stories without fear of stigma or judgement
- Giving correct and appropriate information
- Helping people to make informed decisions
- Exploring options and alternatives
- Helping people to recognise and build on their strengths
- Helping people to develop a positive attitude toward life and to become more confident
- Respecting everyone's needs, values, culture, religion, and lifestyle
- Being willing to trust client's feelings and decisions, which may be the right ones for them in their situation and at that time.

#### **Counselling does NOT include:**

- Solving another person's problems
- Telling another person what to do
- Making decisions for another person
- Blaming another person
- Interrogating or questioning another person
- Judging another person
- Preaching to, or lecturing, another person
- Making promises that cannot be kept
- Imposing one's own beliefs on another person
- Providing inaccurate information

## Communicating with Adolescents

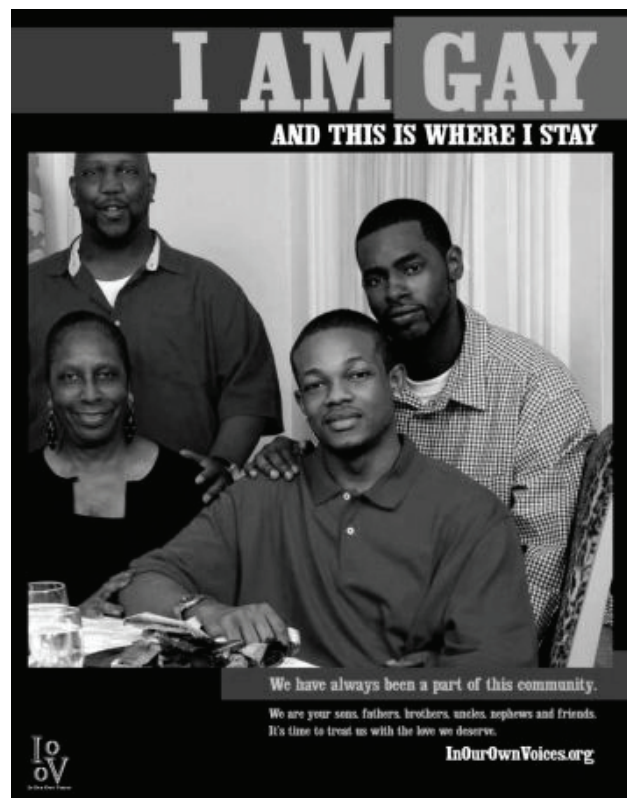
### General tips on communicating with adolescents<sup>2</sup>:

- **Start the counselling session by talking about non-threatening issues:** Begin by establishing rapport (see Session 4.1) and asking questions about the adolescent's home, family, school and even hobbies, before moving on to more sensitive topics, like adherence to medication, disclosure, and sexual or reproductive health issues.

- **Use a third person (indirect questions):** Initially, ask about activities of peers and friends rather than asking direct questions about their own behaviour: *"Do any of your friends smoke pot/dagga?"* *"Have you ever joined them?"*

- **Reduce stigma around an issue by normalising it:** An adolescent who is living with HIV with may feel embarrassed seeking help with various issues, but you can reduce stigma and feeling of shame by saying: *"I have treated a number of young people who are also living with HIV. I'm here to help you."* *"I ask all of my clients if they are having sex so I can make sure they get the information and services you need. Some adolescents are in sexual relationships and others are not. Whether your answer is yes or no, it is OK and I want you to feel comfortable talking with me about these personal things."* Another way to reduce stigma is to use posters in common areas that communicate important messages in an eye-catching, youth-friendly manner, see Figure 4.1: "I am gay" poster," as an example. The logo at the bottom of the poster reads "We have always been a part of this community. We are your sons, fathers, brothers, uncles, nephews and friends. It's time to treat us with the love we deserve." A poster such as this would communicate to a young homosexual man that the clinic is gay-friendly, making him more likely to open up about his sexuality.

Figure 4.1: "I am gay" poster



- **Repeat information through questions:** You can repeat information that sounds irrational and unreasonable back to an adolescent in the form of a question. For example, an adolescent might say, *"I do not care that my cousin stopped talking to me when I told him I had HIV. I do not*

*need him.*" Instead of saying, "*Of course you care,*" and pushing the client away, you could respond by asking, "*So it doesn't bother you that your family is giving you a hard time? How does it make you feel?*" When put into a question, many adolescents re-think and reflect about the statement they just made.

- **Encourage peer support:** Encourage adolescents to discuss issues with peers who are also infected with HIV, either one-to-one or in groups. Peer support helps adolescents recognise that they are not alone in dealing with their problems. An ALHIV may not respond to an adult who tells him to take his medication every day; but he might listen to a peer. Using other adolescents who have struggled with the same problems related to care and treatment, like adherence challenges or disclosure, can be extremely effective motivator (see Session 5.3 for more information about peer support).

### **Considerations when communicating with younger adolescents**

- Younger adolescents need time to feel safe and to trust. Try starting the session by doing something together, like playing a game.
- Younger adolescents understand concrete things that they can touch and see. Drawing, demonstration, or visual aids can be used to make information more concrete.
- They may feel scared and fear being judged.
- They may feel anxious or embarrassed when asking for help
- They need some time to observe you! Do not expect they will instantly talk. Allow plenty of time and be patient.
- Explain things in simple terms.
- Just because the adolescent is not asking questions, does not mean he or she is not thinking about what is being said.
- Do not force the adolescent to share. Positively reinforce the adolescent's effort to express him or herself.
- If a youth is rude or aggressive, remember that it may not be directed at you. He (or she) may be feeling angry with adults for treating him badly or letting him down. Be patient and don't take it personally.
- Give young adolescents as much time as necessary.

### **Activities to promote expression with younger adolescents:**

- **Storytelling or reading together:** The healthcare worker could read or tell a story (such as that in Table 4.1: Monde's story) during a group or individual counselling session. Following the story, the healthcare worker asks key questions to encourage thought and discussion.

**Table 4.1: Monde's story****Monde's story**

*Monde is a 16 year old girl living in Lusaka, the capital of Zambia. Like many teenagers, she goes to school, hangs out with friends and has a boyfriend. However, there is something that people don't know about her: she is HIV positive. Although Monde was born with HIV, because of taking ART she has reached adolescence and is hoping to attend university in a couple years. She lives at home with her mother, who is also HIV positive, and two younger siblings who are not. Her dad died when she was little.*

*None of her friends knows she is HIV positive, and she is scared that if they knew, they wouldn't want to hang around with her anymore. Monde really loves her boyfriend, Bwalya, and spends a lot of time with him. They sometimes kiss, and he often wants to go further but she tells him that she doesn't believe in sex before marriage. Monde is starting to feel this pressure, but she doesn't know what to do. There is a part of her that really does want to sleep with her boyfriend. She really does love him. But she is worried that she will give him HIV. She doesn't know how to get condoms, and she heard that boys don't like using condoms. She doesn't know how to tell him that she has HIV. What if she tells him and he leaves her and tells all her friends? Her whole world would fall apart!*

What do you think Monde should do?

Adapted from: Ross, J. 2010. Needs, Challenges and Opportunities: Adolescents and Young People Living with HIV in Zambia. International HIV/AIDS Alliance and Evidence for Action.

- **Journaling:** Encourage clients to keep a journal or a diary. The journal is a place where the adolescent can write about what is happening in their lives and how they feel about it (for example, *How I would describe myself? Last week I felt.....because....*).
- **Drawing:** Encourage clients to draw a picture of their families or their homes. The healthcare worker should then ask questions about the drawing to communicate interest and encourage expression:
  - “Tell me about your drawing”
  - “What happened here?”
  - “How did you feel then?”
- **Letter writing:** Encourage adolescent clients to write letters to a friends or family members about what is happening or how they are feeling.
- **Doing something fun:** Initiate something fun while you are talking. This could include playing a game, playing cards, taking a walk, pursuing a hobby (making a toy, knitting, hand sewing, etc), or playing a sport. Young people often feel more comfortable talking when discussion is secondary to something else they are doing.

## Listening and Learning Skills<sup>3,4,5</sup>

Good counsellors use verbal and non-verbal listening and learning skills to help clients through their process of exploration, understanding and action. Therefore, when communicating with and counselling clients, healthcare workers should:

- Skill 1: Use helpful non-verbal communication
- Skill 2: Actively listen and show interest in the client
- Skill 3: Ask open-ended questions
- Skill 4: Reflect back what the client is saying
- Skill 5: Empathize — show that you understand how the client feels
- Skill 6: Avoid words that sound judging
- Skill 7: Help the client set goals and summarise each counselling session

For additional information, refer participants to “Appendix 4B: General Tips on How to Talk With Adolescents”, “Appendix 4C: Basic Counselling Guidance for ALHIV”, and “Appendix 4D: Listening and Learning Skills Checklist”.

### Skill 1: Use helpful non-verbal communication

Non-verbal communication refers to all aspects of a message that are not conveyed by the literal meaning of words. It includes the impact of gestures, gaze, posture and expressions capable of substituting for words and conveying information. Non-verbal communication reflects attitude. Helpful non-verbal communication encourages the client to feel that the healthcare worker is listening and cares about what is being said.

The acronym “ROLES”, as shown in Table 4.2: ROLES, can be used to help remind healthcare workers of behaviours that convey caring.

**Table 4.2: ROLES**

Non-verbal behaviour that conveys caring	
<b>R</b>	A <b>relaxed</b> and natural attitude with clients is important. Do not move around quickly or chat nervously.
<b>O</b>	Adapt an <b>open posture</b> . Crossing one’s legs or arms can signal that you are critical of what the client is saying or are not listening. Using an open posture shows that you are open to the client and to what the client is saying.
<b>L</b>	<b>Leaning forward</b> toward the client is a natural sign of involvement.
<b>E</b>	Culturally appropriate <b>eye contact</b> should be maintained to communicate interest; never stare or glare at the client.
<b>S</b>	<b>Sitting squarely</b> facing another person shows involvement. If for any reason this may be threatening, then sitting to the side is an option.



These physical behaviours convey respect and genuine caring. However, these are guidelines, and should be adapted based on cultural and social expectations.

**Table 4.3: Examples of non-verbal communication**

What not to do	What to do
Female adolescent client walks in <b>Healthcare worker (HCW):</b> <i>Hello. My name is _____ (name). (HCW keeps working at computer and sits behind desk.)</i>	Female adolescent client walks in <b>Healthcare worker (HCW):</b> <i>Hello. My name is _____ (name). (HCW keeps working at computer.)</i>
<b>Adolescent:</b> <i>I have a question I wanted to ask you about.</i>	<b>Adolescent:</b> <i>I have a question I wanted to ask you about.</i>
<b>HCW:</b> <i>Please sit down</i> (speaking in a hurried fashion). <i>What is your question</i> (still looking at the computer and keyboard)?	<b>HCW:</b> (looks at adolescent, stops working at her computer and moves chair so that it is not behind the desk) <i>Please sit down. What was your question</i> (leaning forward, not crossing legs).
<b>Adolescent:</b> <i>Well, I just started seeing someone...a boy. And, I was wondering...</i> (her voice trails off)	<b>Adolescent:</b> <i>Well, I just started seeing someone...a boy. I was wondering if you thought it might be OK if I don't tell him I have HIV just yet.</i>
<b>HCW:</b> no response (still typing at computer)	<b>HCW:</b> looks warmly, yet with concern, at adolescent. (Optional: demonstrate appropriate touch.)
<b>Adolescent:</b> clears throat to get HCW's attention	
<b>HCW:</b> <i>Oh sorry</i> (she finally stops typing and looks at watch). <i>Yes, go ahead, you had a question about some girl friend of yours?</i> (HCW's hands are folded, legs crossed and facing away from adolescent, looking across the room, with expression suggesting disinterest.)	<b>HCW:</b> <i>You look concerned, as if you think this may not be the right decision. Tell me a bit more about why you'd prefer to wait to disclose to him</i> (speaking in a warm voice, looking at adolescent, leaning forward, not crossing legs).
<b>Adolescent:</b> <i>Well no, actually it was a boy, not really a boyfriend ... yet, anyhow. Actually it's OK. Don't worry, sorry to have bothered you.</i>	<b>Adolescent:</b> Proceeds to explain her perspective.
Note that in the first skit (Hinders non-verbal communication), the adolescent walked out, giving up on her attempt to get advice on disclosure. In the second skit (Helpful non-verbal communication), the adolescent feels free to ask her questions.	

## Skill 2: Actively listen and show interest in the client

Another way to show that you are interested and want to encourage a client to talk is to use gestures such as nodding and smiling, responses such as “Mmm”, or “Aha” and skills such as clarifying and summarising. These skills, also referred to as attending skills, demonstrate that the healthcare worker is actively listening to the client. These behaviours invite the client to relax and talk about herself or himself.

**Clarifying:** Clarifying prevents misunderstanding and helps sort out what has been said. For example, if an adolescent says: “*All my friends will drop me if they find out I have HIV!*” the healthcare worker may ask “*Tell me more about why disclosing to your friends is a concern for you*”.

**Summarising:** Summarising pulls together themes of the counselling discussion so that the client can see the whole picture. It also helps to ensure that the client and the healthcare worker understand each other.

- Healthcare workers should review the important points of the discussion and highlight any decisions made.
- Healthcare workers can summarise key points at any time during the counselling session, not only at the end.

Summarising can offer support and encouragement to clients to help them carry out the decisions they have made related to their own health and well-being.

**Table 4.4: Example of actively listening and showing interest**

What to do	
<b>HCW:</b>	<i>Hey, you seem down today. What's going on?</i>
<b>Male adolescent client:</b>	<i>It's school, I don't want to go any more.</i>
<b>HCW:</b>	<i>umhumm*</i> (nods understandingly)
<b>Adolescent:</b>	<i>Well, it's not really school, it's the kids at school. I don't have any friends.</i>
<b>HCW:</b>	<i>So, you dread going to school because you feel like you don't fit in?*</i>
<b>Adolescent:</b>	<i>Yea, the other children make fun of me. They call me “shortie” and “crybaby”.</i>
<b>HCW:</b>	<i>umhum*</i>
<b>Adolescent:</b>	<i>Yesterday one of the bigger boys even pushed me to the ground.</i>
<b>HCW:</b>	<i>That's terrible. It seems to me that the other boys are bullying you. What one thing would you like to change to make this situation better?***</i>
*	A gesture that shows interest
**	Clarifying
***	Summarising

### Skill 3: Ask open-ended questions

Asking questions helps identify, clarify and break down problems into smaller, more manageable parts. Open-ended questions begin with “how”, “what”, “when”, “where” or “why”. Open-ended questions encourage responses that lead to further discussion, whereas closed-ended questions tell a client the answer that you expect; responses are usually one-word answers such as, “Yes” or “No”. Closed-ended questions usually start with words like “are you?” “did he?” “has she?” “do you?”

Healthcare workers should try to avoid questions that have a yes or no answer. For example, instead of asking, “Are you concerned about talking to your family about your diagnosis?” you may ask, “What concerns do you have about talking to your family about your HIV test results?” Or, instead of “Are you taking your ARVs?” you may ask, “How many times have you taken your ARVs in the last 3 days?”

**Table 4.5: Examples of open- and closed-ended questions**

What not to do	What to do
Female adolescent client walks in <b>HCW:</b> <i>Hi, how are you? I’m _____ (name), the counsellor. As you will be starting ART soon, I thought that today we could talk about adherence.</i>	Female adolescent client walks in <b>HCW:</b> <i>Hi, how are you? I’m _____ (name), the counsellor. As you will be starting ART soon, I thought that today we could talk about adherence.</i>
<b>Adolescent:</b> <i>OK</i>	<b>Adolescent:</b> <i>OK</i>
<b>HCW:</b> <i>Do you know what we mean by “adherence”?</i>	<b>HCW:</b> <i>What do we mean when we refer to “adherence”?</i>
<b>Adolescent:</b> <i>Yea, I think so.</i>	<b>Adolescent:</b> <i>Well, I’m not sure, is it about sticking to your medicine?</i>
<b>HCW:</b> <i>Great! Do you think you will be able to adhere to your ART regimen?</i>	<b>HCW:</b> <i>Kind-of. It’s about sticking to your ART regimen by taking your ARVs every evening and every morning exactly as recommended. What do you think you can do to remember to take are ARVs every morning and evening?</i>
<b>Adolescent:</b> <i>Yes, probably.</i>	<b>Adolescent:</b> <i>Well, I’ll keep my pills on the table where we eat, that will remind me to take them with breakfast and again at dinner time. I’ll remember because they are right there.</i>
<b>HCW:</b> <i>And will you have an adherence buddy to help you remember?</i>	<b>HCW:</b> <i>That sounds like a good plan, we’ll see how it works. Who will you buddy to help you remember to take your medications?</i>
<b>Adolescent:</b> <i>Yes, I guess so.</i>	<b>Adolescent:</b> <i>My mother will help me remember.</i>
In the first skit (Hinders), the close-ended questions are conversation	

stoppers; this client left the session without a concrete adherence plan and possibly a misunderstanding of what the term “adherence” means. Whereas in the second skit (Helps Open-ended questions), the same client was required to come up with a plan before responding to the HCW’s questions. She left the session with a concrete plan to help her remember to take her medications every day and a named adherence buddy to provide back up. At the follow-up visit the HCW can enquire about how the plan worked.

#### **Skill 4: Reflect back what the client is saying**

"Reflecting back", also referred to as paraphrasing, means repeating back what a client has said to encourage him or her to say more. Try to say it in a slightly different way. For example, if a client says, *“I am not able to tell my boyfriend about my HIV status,”* the healthcare worker may reflect by saying, *“Talking to your partner sounds like something that you are not comfortable doing right now”*. After the client confirms that this is an accurate reflection of what she or he said, the healthcare worker can then say, *“Let’s talk about that some more”*.

For example, the counsellor can use the following formulas for reflecting:

- *“You feel \_\_\_\_\_ because \_\_\_\_\_.”*
- *“You seem to feel that \_\_\_\_\_ because \_\_\_\_\_.”*
- *“You think that \_\_\_\_\_ because \_\_\_\_\_.”*
- *“So I sense that you feel \_\_\_\_\_ because \_\_\_\_\_.”*
- *“I’m hearing that when \_\_\_\_\_ happened, you did not know what to do.”*

Reflecting back shows that the healthcare worker is actively listening, encourages dialogue, and gives the healthcare worker an opportunity to understand the client’s feelings in greater detail. See “Table 4.4: Example of actively listening and showing interest” for an example of reflecting back.

#### **Skill 5: Empathize — show that you understand how the client feels**

Empathy develops when one person is able to comprehend (or understand) what another person is feeling. Empathy, however, is not the same as sympathy; sympathy implies that you feel sorry for (pity) the other person.

Empathy is needed to understand how the client feels and helps to encourage the client to discuss issues further. For example, if a client says, *“I just cannot tell my partner that I have HIV!”* the healthcare worker could respond by saying *“It sounds like you might be afraid of your partner’s reaction.”* Another example is if a visibly upset client says: *“My partner argues with me all the time about using condoms! I’m so sick of fighting with him”* the healthcare worker could respond by saying: *“That must be really*

*upsetting. It sounds like you feel very frustrated with him. ”* If the healthcare worker responds with a factual question, for example, “*How often do you have these kinds of fights about condoms?*” the client may feel that the healthcare worker does not understand because the healthcare worker’s response was not in reference to the underlying feelings.

Empathy is used to respond to a statement that is emotional. When empathizing, the healthcare worker identifies and articulates the emotion behind a client’s statement. Whereas, “Skill 4: Reflect Back what the Client Says” is used to summarise conversation that is primarily factual.

**Table 4.6: Examples of empathy**

What not to do	What to do
<b>HCW:</b> <i>What do you think about asking your partner to use condoms?</i>	<b>HCW:</b> <i>What do you think about asking your partner to use condoms?</i>
<b>Female adolescent:</b> <i>To be honest, I’m scared. I actually think he might hit me.*</i>	<b>Female adolescent:</b> <i>To be honest, I’m scared. I actually think he might hit me.*</i>
<b>HCW:</b> <i>Yea I know what you mean, that happened to my sister. She actually did ask her boyfriend to use condoms and you know what? He hit her then he made her leave the house. He didn’t let her come back for two full days.***</i>	<b>HCW:</b> <i>It sounds like you’re often scared of your boyfriend.**</i>
<b>Adolescent:</b> (Silent, waiting for HCW to continue her story.) <i>So did your sister go back?</i>	<b>Adolescent:</b> <i>You’re right, I am. It’s not just about asking him to use condoms, I’m also fearful that he’ll be upset if I even talk to another boy, if I forget to call him after school, if I’m home even one minute late, or for a lot of other reasons.</i>
<p>* Notice that the client is discussing how she feels; empathy is a skill used to respond to the underlying feelings expressed by the client.</p> <p>** Notes the empathetic response. The empathetic response encourages the client to further discuss the issue.</p> <p>*** This statement is more sympathising rather than empathizing; it changes the subject of the discussion from the client to the HCW’s sister.</p>	

### Skill 6: Avoid judging words

Judging words are words like: *right, wrong, well, badly, good, enough* and *properly*. If a healthcare worker uses judging words when asking questions, adolescent clients may feel that they are wrong or that they should respond in a certain way to avoid disappointing the healthcare worker. Healthcare workers should also avoid phrasing a question in a way that is judging, that is, in a manner that leads the client to respond in a certain way for fear of disappointing the questioner. See examples below.

Examples of what **NOT** to do:

#### Examples of using judging words

<b>Healthcare worker:</b>	<i>Did you listen to me and use a condom?</i>
<b>Client:</b>	<i>Um...yes.</i>
<b>Healthcare worker:</b>	<i>Did you take your medicine correctly (or properly)?</i>
<b>Client</b>	<i>I think so.</i>
<b>Healthcare worker:</b>	<i>Didn't you understand what I told you about taking your medicine?</i>
<b>Client:</b>	<i>I don't know, I think so.</i>
<b>Healthcare worker:</b>	<i>Did you follow my recommendation to talk to your mother about your HIV status? (Or "Did you do the right thing and talk to your mother about your HIV status?")</i>
<b>Client:</b>	<i>Well, yes, I tried to speak with her....</i>

Notice in these examples that the client has not fully responded to the healthcare worker's questions. Instead, the healthcare worker is making the client uncomfortable. It is quite likely that the client may provide the healthcare worker with a misleading response for fear of being judged.

Note that the client may use judging words and this is acceptable (for example, *"I was not brave enough to talk to my mother. I only told my sister."*) When a client does use judging words, do not correct him or her, but do not agree with her either. Instead, the response should aim to build her confidence through praise, for example, *"I was impressed that you were able to talk with your sister. That is a big step."*

More helpful examples, using open-ended questions and avoiding judging words, could be as follows:

#### Examples of using non-judging words

<b>Healthcare worker:</b>	<i>What form of family planning, if any, did you use the last time you had sex?</i>
<b>Healthcare worker:</b>	<i>At about what time yesterday did you take your ARVs? How about the day before yesterday?</i>
<b>Healthcare worker:</b>	<i>What has been your experience with taking ART?</i>

**Healthcare worker:** *Can we go back to our discussion on disclosure?  
Who have you told about your HIV test result since  
your last visit?*

However, sometimes a healthcare worker needs to use “good” judging words to build a client's confidence, and to recognise and praise the client when she or he is doing the right thing.

### Example of using judging words to build confidence

**Healthcare worker:** *You are doing a great job remembering to come to your appointments.*

**Healthcare worker:** *You are doing the right thing for yourself and your baby by taking your ARVs.*

## Skill 7: Help the client set goals and summarise each counselling session

Toward the end of a session, the healthcare worker works with the adolescent client to come up with “next steps” and summarise the session:

- **Develop “next steps”.** The healthcare worker could initiate this part of the discussion by stating, “Okay, now let’s think about the things you will do this week based on what we talked about.” To help the client develop a more specific plan, the healthcare worker could ask:
  - *What do you think might be the best thing to do?*
  - *What will you do now?*
  - *How will you do this?*
  - *Who might help you?*
  - *When will you do this?*
- **Summarise the client’s plan and review next steps.** The healthcare worker could say, “I think we’ve talked about a lot of important things today. (List main points.) We agreed that the best next steps are to \_\_\_\_\_. Does that sound right? Let’s plan a time to talk again soon.”
- **Give the client a chance to ask questions.**
- **Make referrals,** if needed.
- **Make an appointment for return visit:** Discuss when the client will return and make sure she or he has an appointment.

### Next steps and goals should:

- Be developed by the healthcare worker and client together
- Empower the client to achieve what he or she wants by agreeing to realistic short- and long-term goals and actions
- Provide direction and must be results-oriented
- Be clear enough to help the client measure his or her own progress (people feel good when they achieve something they have set out to do)

<b>Exercise 2: Practise Listening and Learning Skills: Case studies in small groups and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with an opportunity to gain experience using listening and learning skills with adolescent clients</li> </ul>
<b>Instruction</b>	<p><b>Part 1: Trainer Demonstration</b></p> <ul style="list-style-type: none"> <li>2 trainers or a trainer and volunteer will role play the following case study.</li> <li>During the role play participant should use “Appendix 4D: Listening and Learning Skills Checklist” as they observe the demonstration.</li> </ul> <div style="border: 1px solid black; padding: 10px; margin: 10px 0;"> <p>Geraldine, who has had HIV since she was a baby, has been coming to your clinic ever since you can remember. Geraldine, who is now 16, has had the same boyfriend since she was 14, and the relationship is starting to get more serious. The “healthcare worker” has suggested that Geraldine consider telling her boyfriend that she has HIV. Geraldine is scared; she just doesn’t know how to break the news after all these years.</p> </div> <ul style="list-style-type: none"> <li>After the role play, the trainer will debrief the training skills demonstration using “Appendix 4D: Listening and Learning Skills Checklist”.</li> </ul> <p><b>Part 2: Small Group Work</b></p> <ol style="list-style-type: none"> <li>Participants will be asked to break into groups of 3 and review the case studies below.</li> <li>Participants should then:             <ul style="list-style-type: none"> <li>Identify a “healthcare worker/counsellor”, “client” and an “observer” for the first case study.</li> <li>Using the first case study, suggest that the “healthcare workers” initiate the discussion as they would in the clinic setting. Give the “healthcare worker” and “client” about 5 minutes for their session.</li> <li>The “healthcare worker/counsellor” will practise as many of the listening and learning skills possible in the 5 minutes provided.</li> </ul> </li> <li>After five minutes, participants should stop the exercise and ask the “observer” to provide feedback on each of the skills and techniques observed using the Listening and Learning Skills Checklist.</li> <li>Repeat this exercise using the remaining 2 case studies so that everyone will have an opportunity to practise each role.</li> </ol>



**Part 3: Large Group Discussion**

5. Each of the small groups will be invited to report key findings on things that the “healthcare workers/counsellors” did well and the things they can do to improve their counselling.

**Exercise 2: Practise Listening and Learning Skills: Case studies in small groups and large group discussion**
**Case Study 1:**

Mwape is an 18-year-old client you see regularly at the ART clinic. He tells you that he has a male partner that he sees on the weekends. He is very worried that his family and friends at school will find out that he is HIV infected and is scared about confiding in you. How do you counsel Mwape?

**Case Study 2:**

Prudence is a 12-year-old girl who acquired HIV perinatally. Her mother died when she was 5 years old and she has been living with her grandmother ever since. Her grandmother does not like to talk about Prudence’s HIV status, and none of her friends know she has HIV. When you speak to Prudence, she doesn’t say anything, and keeps looking at the floor with her arms crossed. How do you counsel her?

**Case Study 3:**

Gabriel is a 16-year-old who tested positive for HIV 4 weeks ago. When you see him at the clinic today, he appears upset. He says that he hasn’t told anyone about his HIV status and that he feels really angry most of the time. His girlfriend is threatening to break up with him because of his moodiness, and he is not doing well in school. When you question him, he gives you short responses in an angry voice. How do you counsel Gabriel?

## Session 4.3      Challenges and Solutions to Counselling Adolescent Clients

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### Session Objective

**After completing this session, participants will be able to:**

- Identify and address common challenges in counselling adolescent clients.

### Communication Challenges with Adolescents<sup>6</sup>

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#### Silence:

- Silence can be a sign of shyness, embarrassment, anger, or anxiety.

**What the healthcare worker can do:**

- If it occurs at the beginning of a session, the healthcare worker can say, *“I realise it’s hard for you to talk. Talking to someone you don’t know can be scary. Many people are scared to share their feelings.”*

#### Anger:

**What the healthcare worker can do:**

- Say, *“You seem angry, it’s OK to be angry, but would you like to talk about it?”* Or, if the healthcare worker thinks he or she knows why the client is angry, he or she can say something like: *“Sometimes when someone comes to see me against his or her will and doesn’t want to be here, it is difficult to speak. Is that what is going on?”*

#### Shyness:

- Adolescents may not volunteer information about a health problem or a concern because they are not comfortable with the healthcare worker or the situation.

**What the healthcare worker can do:**

- Legitimise the feeling by saying, *“I would feel the same way in your place. I understand that it’s not easy to talk to a person you have just met.”*
- Use books, brochures or posters to encourage discussion or refer to a story or anecdote so the adolescent can talk about others rather than him or herself (see “Activities to promote expression with younger adolescents:” on page 7). Some adolescents simply need time to become comfortable with someone new.
- If the adolescent cannot or will not talk, the healthcare worker should propose another meeting.

#### Crying:

**What the healthcare worker can do:**

- Try to evaluate what provoked the tears and assess if it makes sense in the given situation.
- If the client is crying to relieve tension, the healthcare worker can give the adolescent permission to express his or her feelings by saying, *“It’s okay to cry since it’s the normal thing to do when you’re sad.”*
- If the client is using crying as manipulation, the healthcare worker can say, *“Although I’m sorry you feel sad, it’s good to express your feelings.”*
- The healthcare worker should allow him or her to freely express emotions and not try to stop the feeling or belittle its importance.

### **Threat of suicide:**

#### ***What the healthcare worker can do:***

- Take all suicide threats very seriously! Refer the adolescent to a qualified counsellor, psychiatrist or psychologist, and accompany him or her to the appointment. Work together with relevant members of the multidisciplinary care team to form an appropriate plan of action.

### **Refusal of help:**

#### ***What the healthcare worker can do:***

- Discreetly try to find out why the adolescent feels this way. If the underlying feeling is anger, he or she may want to refer to some of the suggestions under “Anger:” on page 19.
- If the client has been sent against his or her will, the healthcare worker can say, *“I understand how you feel. I’m not sure I can help you, but maybe we could talk for a minute and see what happens.”*

### **Need to talk:**

#### ***What the healthcare worker can do:***

- Challenges in counselling may also include a situation where the client is very vocal and wants an outlet to express other concerns that may not be directly related to the immediate counselling need as perceived by the healthcare worker. In this situation, the healthcare worker should give the client the opportunity to express his or her needs and concerns. The healthcare worker should then summarise the discussion thus far and identify the key issues that need to be discussed further today. This then sets the agenda for the rest of the meeting and gives the healthcare worker permission to pull the session back on track if the client starts discussing tangential issues.
- If the healthcare worker cannot help the client, he or she should listen to the client’s concerns (using the listening and learning skills), but clarify that he or she will have to refer the client to another professional for assistance. When appropriate, the healthcare worker should direct the client to someone who can help with the problem. The healthcare worker may say, *“I can see that you are really concerned about this problem. I wish that I could do something to help you. Have you discussed this with . . .”*
- Sometimes the key issue from the healthcare worker’s perspective is simply not enough time to devote to a particularly needy or talkative

client. In this case, the healthcare worker should, about half way through the session, summarise the session so far, identifying the key points that require further discussion. Assuming the client agrees that the summary is accurate, the healthcare worker then tries to prioritise the client's issues, suggesting that they talk about the first 2 or 3 issues in the time remaining today and that the other issues will be tackled at the next session. Assuming the client agrees with this listing of priorities, the healthcare worker then makes a note of the agenda items for the next session so they are not forgotten.

### **Talking about sex and sexuality:**

- ALHIV do not lose their desire to have sex and children. Communicating with ALHIV about sexuality can be challenging because it is a sensitive topic about which adolescents often feel emotional, defensive, and insecure.

#### ***What the healthcare worker can do:***

- Consider the adolescent's age, understanding of HIV (the healthcare worker may ask "*What do you know about HIV?*") and of other sexual and reproductive health in general.
- Show patience and understanding of the difficulty adolescents have in talking about sexual and reproductive health issues.
- Be accepting of sexual orientation.
- Assure privacy and confidentiality.
- Use third-person questions: *Do your friends have boyfriends? How about you?*
- Respect the adolescent and his or her feelings, choices, and decisions.
- Be direct. Use clear language that is not too technical, complex or above ability to understand. Candidly discuss transmission of HIV to partners, correct condom use, and safer sex practices (for example, reduction of partners, safer ways of giving sexual pleasure): *What do you know about condoms?*
- See Module 10 for more information about Sexual and Reproductive Health.

### **Talking about disclosure:**

- In adolescents who acquired HIV behaviourally, disclosure of HIV status to parents or others who can give support can be a challenge. Ideally, the adolescent will have the support of a parent or a guardian. Often, however, young people do not want their parents or caregivers to know about the medical consultation or its outcome.

#### ***What the healthcare worker can do:***

- Discuss the value of disclosure, as a way to build a support network. At the same time, the healthcare worker should respect the young person's wishes, views, and confidentiality, should he or she not want family involvement.

- Volunteer to role play the disclosure scenario. The healthcare worker should first take the role of the adolescent client (so that the client can hear how the healthcare worker discloses). Then, the client should practise disclosing and the healthcare worker takes the role of the parent or friend (to whom the client is disclosing).
- Offer to meet with the caregiver either with or without the client.
- Identify sources of support for the client.
- See Module 7 for more information on supporting the disclosure process.

### **Talking about adherence to care and treatment:**

- After a certain period, adherence may decrease, or the patient may experience side-effects or develop a toxic reaction, become resistant or suffer treatment failure. Treatment change may be required. The caregiver and adolescent need intensified support in any of these circumstances. Re-motivation is required.

#### ***What the healthcare worker can do:***

- Ensure an open and trusting relationship with the client.
- Maintain a non-judgemental attitude to encourage the client to discuss any problems.
- Give ongoing encouragement and re-motivation, despite any adherence challenges.
- Refer the client to a support group, which can provide emotional, practical and problem-solving support from others who face similar adherence challenges.
- Ensure ongoing and regular contact with the adolescent and caregiver to help with any adherence challenges that may arise.
- See Module 8 for more information on adherence.

### **Concern about confidentiality:**

#### ***What the healthcare worker can do:***

- In order for clients to trust healthcare workers with their feelings and problems, it is important for them to know that anything they say will be kept confidential. This means that members of the multidisciplinary care team will not tell other people any information about the client, including what the client says or that the client is living with HIV.
- Confidentiality is especially important for adolescents and in HIV programmes because of the stigma surrounding HIV and discrimination against ALHIV in the home, at work, at school, and in the community.

### **To avoid communication challenges, healthcare workers should be aware of the following:**

- Involve adolescents in their care! Of course, their involvement should be appropriate to their interest and developmental stage.
- Assess the adolescent's emotional and developmental level (including level of understanding, capacity to express him/herself, and capacity

for self-care) at every visit. This will help to ensure that expectations of the adolescent are appropriate.

- Keep in mind the changing capacities of the adolescent. With very young adolescents, the focus of counselling is generally on the caregiver. The older the adolescent, the better the adolescent's understanding and ability to express him or herself. However, because of differences between adolescents, counselling must always be adapted to the needs of the particular adolescent.
- Find out what the adolescent knows and be guided by the questions he or she asks.
- Listen to ALHIV, reflect their feelings, offer empathy, and show that you care about what they are going through. ALHIV, especially after learning about their diagnosis, might be angry, depressed, or afraid. They might feel betrayed or refuse to accept the diagnosis.
- Encourage questions to check understanding.
- Be aware of the adolescent's attention span. (A younger adolescent will lose interest more quickly than an older adolescent.)
- Watch the adolescent's body language to determine whether he or she is taking in the information (for example, fidgeting, slumping, changing the subject, falling asleep.) If the adolescent is inattentive, stop and try again at a later stage.

### **Exercise 3: Overcoming Communication Challenges: Large group discussion using case studies**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To bring together information discussed in Session 4.3</li> <li>• To give participants an opportunity to problem solve and discuss strategies to overcome communication challenges with adolescent clients</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will be asked to review the case studies below.</li> <li>2. The trainer will facilitate a discussion about each case study.</li> <li>3. If there is sufficient time, the trainer will invite 2 or 3 volunteers to role play one of the case studies in front of the large group.</li> </ol>

### **Exercise 3: Overcoming Communication Challenges: Large group discussion using case studies**

#### **Case Study 1:**

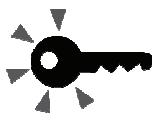
Francis, a 14-year-old boy, meets with you for the first time after testing positive for HIV. He seems very angry and irritated. When you ask him how he is feeling, he pauses for long time, then rolls his eyes and finally tells you, in an annoyed tone, that the test must be wrong because he has only had sex with 2 people in his whole life and they were very healthy and not "bad girls." How do you proceed?

#### **Case Study 2:**

Nora is 18-years-old and has been living with HIV and on ART for many years. She just found out that she is pregnant. She is very upset and can't stop crying. How do you proceed?

**Case Study 3:**

Vincent is a 12-year-old boy who acquired HIV through mother-to-child transmission. He is brought to the clinic by his Auntie, because he has not been taking his ARVs. Auntie would like you to convince him to take his medicines and “stop his bad behaviour.” When you sit down and talk to Vincent, he remains completely silent and will not respond to your questions. How do you proceed?



#### **Module 4: Key Points**

- Establishing a comfortable and open relationship is the foundation for communication and education, and increases the chances that the client will return for treatment.
- When asked by healthcare workers about sensitive issues, like sexual activity, adolescents may be reluctant or embarrassed to disclose information for fear of being scolded or mocked.
- When communicating with adolescent clients, it is important to be respectful, ensure privacy, maintain confidentiality, be honest, use language that they understand, and be open to their ideas and choices, even if they are not the ones you would have wanted them to make.
- Some communication and counselling tips for adolescents are: starting the conversation by building rapport and non-threatening issues, asking indirect questions about a third person, and trying to reduce stigma around an issue by normalising it. Younger adolescents will sometimes require a more activity-based approach to counselling than older adolescents, such as storytelling, games, reading, and art.
- Good communication is the key component to effective counselling. These are the 7 key listening and learning skills healthcare workers should always use:
  - Use helpful non-verbal communication.
  - Actively listen and show interest in the client.
  - Ask open-ended questions.
  - Reflect back what the client is saying.
  - Empathize — show that you understand how the client feels.
  - Avoid words that sound judging.
  - Help the client set goals and summarise each counselling session.
- The healthcare worker's strategy for a particular counselling session is determined by the adolescent's needs as well as his or her behaviour (silent or talkative), mood (sad, angry or happy), and attitude (I love being here, I hate having HIV).



## Appendix 4A: Common Counselling Mistakes<sup>7</sup>

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**The “Listening and Learning Skills” are easy to learn but difficult to apply. Some common mistakes include:**

- Not allowing enough time for counselling, making it hard for the client to take in all the information and react.
- Conducting counselling in a non-private space, such as in a corridor or waiting area or allowing interruptions during the counselling session.
- Controlling the discussion, instead allowing the client to control the session by asking questions and expressing their feelings and needs.
- Judging the client — making statements that show that the client does not meet the healthcare worker’s standards.
- Preaching to a client — telling clients how they should behave or lead their lives, for example, saying: *“you never should have trusted that guy, now you have created a big problem for yourself”*.
- Labelling a client instead of finding out their individual motivations, fears or anxieties.
- Reassuring a client without even knowing her or his health status — for example, telling a client, *“you have nothing to worry about”*.
- Not accepting the client’s feelings — saying *“you shouldn’t be upset about that”*.
- Advising, before the client has collected enough information or taken enough time to arrive at a personal solution.
- Interrogating — asking accusatory questions. Questions that start with *“why...?”* can sound accusatory, though the tone is important, as *“why”* questions may also be a way of getting an open-ended response.
- Encouraging dependence — increasing the client’s need for the healthcare worker’s guidance.
- Persuading or coaxing — trying to get the client to accept new behaviour by flattery or fakery. *“I know you are a good girl and you will take your ARVs like I have told you.”*

## Appendix 4B: General Tips on How to Talk With Adolescents<sup>8</sup>

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This section presents general guidelines on interacting with adolescents, either when providing testing or ongoing care and treatment. Establishing a comfortable and open relationship (using the listening and learning skills discussed in Session 4.2) is the foundation for communication, and increases the chances that a client (and his or her caregivers) will return.

The age and developmental stage of the adolescent is critical to the way in which the healthcare worker communicates with him or her. Some basic principles about working with adolescents include:

- Make the young person feel comfortable from the beginning; create a comfortable environment by encouraging the adolescent to talk about general things that interest him or her before going on to discuss specific issues in their personal lives. (*for example, Did you hear about the football match last night? How is school going? I like the blouse you're wearing, did you sew that as well?*)
- Engage and take an interest in the adolescent and not just in her or his physical condition.
- Meet the young person at her or his level; this might mean using creative methods to help adolescents, especially younger ones, to feel comfortable and express their feelings as well as making the information more concrete.
- Maintain eye contact.
- Do not ask too many questions.
- Listen attentively.
- Use language that is developmentally appropriate. Be direct. Use clear language that is not too technical, complex or above ability to understand.
- Avoid false reassurances and do not impose your personal beliefs on the situation.
- Younger adolescents will need the presence of a trusted adult to feel secure. Try involving caregivers and other family members in the counselling process.
- Explain confidentiality; note that there are some situations in which it may be necessary to breach confidentiality.
- Act appropriately and with authority without being an authoritarian.
- Use an interactive, participatory style of communicating. Allow time and opportunity for the adolescent to educate and inform you about his or her ideas and decisions.

## Appendix 4C: Basic Counselling Guidance for ALHIV

The previous appendix provided general guidance for healthcare workers when speaking with ALHIV. This appendix provides suggested conversational cues or prompts for introducing some of the core topics related to HIV care and treatment. This appendix is meant to be a simplified framework outlining main discussion points around care and treatment — not a comprehensive counselling script.

<b>Counselling an adolescent living with HIV, Ages 10–12</b>	
<b>Guidance</b> <ul style="list-style-type: none"> <li>• Give realistic information about health status.</li> <li>• At this age, depending on his or her developmental level, it may be appropriate to begin discussions about HIV.</li> <li>• Emphasize that people with HIV can live meaningful lives and have normal relationships.</li> <li>• Help the adolescent deal with possible stigma.</li> </ul>	
<b>Objectives</b>	<b>Script</b>
<b>Tell the client that you are here to address his or her specific questions and concerns.</b>	<p>I want to talk with you about any questions you have about your HIV result. OR</p> <p>I want to talk with you about any questions you have about your health and clinic visits. (Use the term “HIV” only if the adolescent knows his or her diagnosis; otherwise substitute a word such as “a germ” or “your health” for “HIV” and continue working with caregivers on disclosure. If the adolescent does not know his or her diagnosis, the following script will need to be adapted, or covered over a span of many visits.)</p>
<b>Talk about HIV in age-appropriate terms.</b>	HIV is a sickness that lives in your blood and makes it easier for you to get other sicknesses. That means that you will get sick very often if you don’t take your medicines and take them correctly. You should know that even if you have HIV, you can still grow up to live a good life.
<b>Discuss ART and adherence.</b>	It is important for you to take your medicine every day and not skip any doses, even if you don’t feel like taking them. These medicines will help you to stay healthier. Are you having any problems remembering to take or problems taking your medicines?
<b>Talk about ways to stay healthy.</b>	Knowing that you have HIV will let you take control of your health. To stay healthy you should always take your medicines. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.
<b>Discuss confidentiality. Encourage the adolescent to decide with his or her caregivers who it is okay to talk to about HIV.</b>	While knowing your HIV status is necessary for taking good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help to take care of you. You and your caregivers, together, can decide who else you feel comfortable talking to about your HIV status.
<b>Ask about HIV-related discrimination.</b>	Some people have the wrong information about HIV and might treat you differently if they think you have HIV because they just don’t know any better.

	Has this happened to you? Some of the things you can do are: talk to someone you trust who can help you to manage the bad feelings; know that you have friends and family who love and care for you; and understand that HIV is just a sickness. Having it does not make you a bad or different person. You just have to take care of your health. You will be able to live a healthy life, just like others.
<b>Provide referrals.</b>	There are doctors who are experts in taking care of people just like you. There are also support groups and services in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.
<b>Comfort the adolescent.</b>	There are a lot of ways you can stay healthy and we are here to help you.
<b>Address any questions and concerns.</b>	What questions do you have? If you think of any questions later on, I am available to answer them. Let's talk about how you can contact me if you have any more questions.

### Counselling an adolescent living with HIV, Ages 13–19

#### Guidance

- Give realistic information about health status; answer all questions.
- The adolescent should know her or his HIV status by this stage. Waiting to disclose makes learning about HIV much more difficult for the adolescent to accept.
- Emphasize that people with HIV can live meaningful lives and have normal relationships.
- Help the adolescent deal with possible stigma.
- Include prevention information in pre- and post-test counselling.

Objectives	Script
<b>Tell the client that you are here to address his or her specific questions and concerns.</b>	I want to talk with you about any questions you have about your health and clinic visits.
<b>Talk about HIV in age-appropriate terms.</b>	HIV is a sickness that lives in your blood and makes it easier for you to get other sicknesses. That means that you will get sick very often if you don't take your daily medicines and take them correctly. You should know that even if you have HIV, you can still have a good life, even get married if you want to.
<b>Discuss ART and adherence.</b>	It is important for you to take your medicine every day and not skip any doses, even if you don't feel like taking them. These medicines will help you to stay healthier. What are you doing now to remember to take your medicines every day? How many times have you forgotten to take your medicines in the past three days?  If appropriate: Tell me a bit more about why you missed some doses of your medicine? What are your ideas to improve adherence (that is, to remember to take your medicine every day at about the right time)?
<b>Talk about ways to stay healthy.</b>	Knowing that you have HIV will let you take control of your health. To stay healthy you should always take your medicines. You can also stay healthy by eating healthy foods, exercising and getting enough sleep.
<b>Discuss confidentiality.</b>	While knowing your HIV status is necessary for taking

<b>Encourage the adolescent to decide with his or her caregivers who it is okay to talk to about HIV.</b>	good care of yourself, it is not something you have to share with everyone. Your test results are confidential. That means that they are only shared with doctors and nurses who help to take care of you. You and your caregiver, together, can decide who else you feel comfortable talking to about your HIV status.
<b>Ask about HIV-related discrimination.</b>	<p>Some people have the wrong information about HIV and might treat you differently if they know you have HIV because they just don't know any better. You should be ready in case you run into someone like this.</p> <p>Has this happened to you? Some of the things you can do are: talk to someone you trust who can help you to manage your reaction; know that you have friends and family who love and care for you; and understand that HIV is just a sickness. Having it does not make you a bad or different person. You just have to take care of your health. You will be able to live a healthy life, just like others.</p>
<b>Provide referrals.</b>	<p>There are doctors who are experts in taking care of young people with HIV. There are also support groups and services in the community, such as _____, _____ and _____. Our referral team can help you get in touch with these services.</p>
<b>Talk about the responsibility to protect others.</b>	<p>Now that you know your HIV status, you have the power to stay healthy. It is also your responsibility to prevent the spread of HIV. HIV can spread through blood, breast milk, pregnancy and unprotected sex (sex without a condom).</p> <p><b>If you are not yet having sex</b>, it is important that you stay abstinent until you are at an age when you are ready for what may happen if you have sex, for example, getting pregnant or getting a sexually transmitted infection.</p>
<b>When age-appropriate, talk about safer sex.</b>	<p>You can pass on HIV to your partner if you have sex without a condom. That means that you should always use a condom when you have sex. This will also help prevent against unwanted pregnancies. Having sex without a condom is the most common way that HIV is spread. If you are having sex, it is important that you stay with only one partner and talk to your partner about being only with you.</p>
<b>Comfort the adolescent.</b>	There are a lot of ways you can stay healthy and we are here to help you.
<b>Address any questions and concerns.</b>	What questions do you have? If you think of any questions later on, I am available to answer them. Let's talk about how you can contact me if you have any more questions.

Adapted from: Zambia MoH. 2010. National Training Package on Provider-Initiated Paediatric HIV Testing & Counselling in Zambia.

## Appendix 4D: Listening and Learning Skills Checklist

Listening and Learning Skills Checklist		
Skill	Specific Strategies, Statements, Behaviours	(√)
<b>SKILL 1: Use helpful non-verbal communication</b>	• Make eye contact	
	• Face the person (sit next to him or her) and be relaxed and open with posture	
	• Use good body language (nod, lean forward, etc.)	
	• Smile	
	• Do not look at your watch, the clock or anything other than the client	
	• Do not write during the session	
	• Other (specify)	
<b>SKILL 2: Actively listen and show interest in your client</b>	• Use gestures that show interest (nod and smile), use encouraging responses (such as “yes,” “okay” and “mm-hmm”).	
	• Clarify to prevent misunderstanding	
	• Summarise to review key points at any time during the session	
	• Other (specify)	
<b>SKILL 3: Ask open-ended questions</b>	• Use open-ended questions to get more information	
	• Other (specify)	
<b>SKILL 4: Reflect back what your client is saying</b>	• Reflect back or paraphrase	
	• Encourage client to discuss further (“Let’s talk about that some more”)	
	• Other (specify)	
<b>SKILL 5: Show empathy, not sympathy</b>	• Demonstrate empathy: show an understanding of how the client feels by naming the emotion expressed	
	• Avoid sympathy	
	• Other (specify)	
<b>SKILL 6: Avoid judging words</b>	• Avoid judging words such as “bad,” “proper,” “right,” “wrong,” etc.	
	• Use words that build confidence and give support (for example, praise what a client is doing right)	
	• Other (specify)	
<b>SKILL 7: Help your client set goals and summarise each counselling session</b>	• Work with the client to come up with realistic “next steps”	
	• Summarise the main points of the counselling session	
	• Set next appointment date; discuss availability of clinic services outside of clinic visits	

Adapted from: World Health Organization. 2008. Prevention of Mother-to-Child Transmission of HIV Generic Training Package. Available at:  
[http://www.womenchildrenhiv.org/pdf/p03-pi/pi-60-00/Intro\\_PM\\_2-05.pdf](http://www.womenchildrenhiv.org/pdf/p03-pi/pi-60-00/Intro_PM_2-05.pdf)

## References and Resources

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- <sup>1</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents. Watertown, MA: Pathfinder International.
- <sup>2</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents. Watertown, MA: Pathfinder International.
- <sup>3</sup> Zambia MoH. 2010. National Training Package on Paediatric Provider-initiated HIV Testing & Counselling in Zambia.
- <sup>4</sup> World Health Organization. 2008. Prevention of Mother-to-Child Transmission of HIV Generic Training Package.
- <sup>5</sup> ICAP. 2010. “Improving Retention, Adherence, and Psychosocial Support within PMTCT Services, Implementation Workshop Curriculum for Health Workers, Trainer’s Manual. Available at: <http://www.columbia-icap.org/resources/pmtct/index.html>
- <sup>6</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2004. Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents. Watertown, MA: Pathfinder International.
- <sup>7</sup> World Health Organization. 2008. Prevention of Mother-to-Child Transmission of HIV Generic Training Package.
- <sup>8</sup> REPSSI. 2008. Mainstreaming Psychological Care and Support within Paediatric HIV and AIDS Treatment.



## Module 5

### Providing Psychosocial Support Services for Adolescents

- Session 5.1: The Psychosocial Needs of Adolescent Clients**
- Session 5.2: Assessing Psychosocial Support Needs**
- Session 5.3: Providing Psychosocial Support Services for the Most-At-Risk Adolescent**
- Session 5.4: Peer Support in Psychosocial Services for Adolescents**

#### Learning Objectives

**After completing this module, participants will be able to:**

- List common psychosocial needs of adolescent clients.
- Conduct a psychosocial assessment with adolescent clients and caregivers, to better determine their specific psychosocial needs and types of support required.
- Provide ongoing, age-appropriate psychosocial support services, including referrals, for adolescents and caregivers.
- Identify strategies to support adolescent clients and caregivers to deal with stigma and discrimination.
- Provide psychosocial support services, including referrals, to most-at-risk ALHIV.
- Understand the importance of peer support in meeting adolescents' psychosocial support needs.



## **Session 5.1      The Psychosocial Needs of Adolescent Clients**

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### **Session Objective**

**After completing this session, participants will be able to:**

- List common psychosocial needs of adolescent clients.

### **Overview of Psychosocial Support**

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#### **Definition of psychosocial support and well-being:**

- **Psycho** refers to the mind and soul of a person. This involves internal aspects such as feelings, thoughts, beliefs, attitudes, and values.
- **Social** refers to a person's external relationships and environment. This includes interactions with others, social attitudes, and values (culture) and social influences of family, peers, school, and community.
- **Psychosocial support** addresses the ongoing emotional, social, and spiritual concerns and needs of people living with HIV, their partners, and their caregivers.
- **Psychosocial well-being** is when these internal and external needs are met and a person is physically, mentally, and socially healthy.

### **Psychosocial Support Needs of ALHIV**

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All adolescents have unique psychosocial needs, which are different than those of children and adults, because adolescence is a unique stage of life that is characterised by:

- Significant physical, emotional, and mental changes
- Risk taking behaviour and experimentation
- Sexual desires, expression, and experimentation
- Insecurity/confusion
- Anxiety
- Reactive emotions
- Criticism of caregivers or elders
- Focus on body image
- Sense of immortality
- Need to challenge authority figures while nonetheless still needing their support

#### **ALHIV have additional psychosocial needs, which may include:**

- Support in understanding and coming to terms with their own HIV-status and the effect it has on their own and their family's lives.
- Support in understanding and coming to terms with family members' HIV status, especially in the case of perinatally infected youth.
- Support with grieving the loss of parents and/or siblings.

- Support with the increased responsibilities at home and/or a need to generate income as a result of having a deceased or an ill parent(s)
- Support with responsibility for the care of younger siblings.
- Help to manage problems with school fees or having time to attend school, etc.
- Support with the disclosure process.
- Help coping with their diagnosis.
- Help maintaining connections to important adults including immediate family, extended family, adults who can serve as mentors.
- Support with discussing sexual and reproductive health issues, including disclosure to partners, safer sex or delaying sexual debut.
- Discussion of views about taking medication when they may not be feeling sick and they just want to fit in and be “normal”.
- Help with developing self-esteem and confidence.
- Sense of belonging, acceptance or fitting in with peers, community, etc.
- Strategies to disclose their HIV-status to their peers, family and community members.
- Strategies to deal with stigma and discrimination.
- Strategies to encourage their partners and family members to test and, if appropriate, enrol into care and treatment programmes.
- Access to education and training — and work opportunities once they have completed school/training.
- Access to higher education.
- Access to social welfare services.
- Spiritual support and referrals to spiritual counselling.
- Knowledge about their legal issues and rights.
- Support around planning for the future and issues such as having children.
- Support for mental health, including strategies for managing anxiety and depression (see Module 6 for more information about Mental Health and ALHIV).
- Substance abuse management.
- Strategies to best utilise support networks.
- Support for their anxiety about having children; or for others, support to delay pregnancy until they are old enough to accept the responsibility of raising a child.

**Providing psychosocial support is important for ALHIV and their caregivers because:**

- HIV affects all parts of a person's life: physical, mental, social and spiritual dimensions.
- Perinatal HIV is often associated with a series of family adversities for which emotional and material supports are needed to achieve good outcomes for adolescents.
- Relationships with parents and caregivers may become more conflicted as the adolescent tests limits and moves towards independence, resulting in disruptions that reduce the adolescent's access to needed support.

- Psychosocial support can help clients and caretakers gain confidence in themselves and their skills (dealing with long-term illness, dealing with stigma or discrimination, dealing with taking medications every day, caring for an HIV-exposed or HIV-infected child, etc.).
- Psychosocial well-being is related to better adherence to HIV care and treatment.
- Good mental health is closely linked to good physical health.
- All adolescents need support coping with normal developmental issues as well, such as wanting to feel normal and fit in with peers.
- Psychosocial support will increase clients' understanding and acceptance of all HIV comprehensive care and support services.
- Psychosocial support from healthcare workers and other members of the multidisciplinary team can help prevent ALHIV from entering most-at-risk category.

## Session 5.2      Assessing Psychosocial Support Needs

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### Session Objectives

**After completing this session, participants will be able to:**

- Conduct a psychosocial assessment with adolescent clients and caregivers, to better determine their specific psychosocial needs and types of support required.
- Identify strategies to support adolescent clients and caregivers to deal with stigma and discrimination.

### Conducting a Psychosocial Assessment

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**Tips to remember during the psychosocial assessment process:**

- Emphasize that all information is confidential and private, but that healthcare workers may share some of the information with other providers in the clinic to ensure the best care for the client.
- Conduct the assessment in a space that has visual and auditory privacy.
- Involve the adolescent at all phases of the assessment process.
- Respect the dignity and worth of the adolescent at all times.
- Do not talk down to an adolescent. Use good listening and learning skills, as discussed in Session 4.2.
- Always be positive! Offer lots of encouragement and praise throughout the assessment.
- Be patient! Allow an adolescent to speak for himself/herself. Allow the client to express his or her views and describe his or her experiences.
- Respect the adolescent's coping skills and their ideas and solutions to the problem.
- Do not judge! Make adolescents feel comfortable and not fearful that they will be punished or judged, especially if they openly discuss challenges.
- Offer to include caregivers' and/or family members' input into the assessment as needed and agreed upon by the adolescent, while simultaneously protecting the confidentiality of information.
- Keep good records. Always keep a copy of the psychosocial assessment in the client's file.

#### **Family-centred care versus client confidentiality**

It is important to ensure the inclusion of caregivers and other family members in care. But it is equally important that private information discussed during an individual session with an ALHIV remain confidential and is not shared with caregivers. Clients will be unwilling to discuss personal issues unless they have a guarantee of confidentiality.

## Overview of Coping Strategies

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**Healthcare workers should** use the 5 “A’s” when conducting a psychosocial assessment with clients: **ASSESS, ASSIST, ADVISE, AGREE** and **ARRANGE**.

- **Assess** the client's psychosocial needs, ideally using a standardised assessment tool (see Appendix 5-A).
- **Advise** and guide, and schedule next visit.
- **Assist** — provide take-away information on the plan, provide psychosocial support and referrals, address any problems or challenges the client is facing, help the client come up with solutions and strategies that work for him/her, offer to talk to family members and caregivers about the situation if the adolescent is in agreement with this.
- **Agree** on an action plan for the situation.
- **Arrange** a follow-up appointment and arrange for attendance in support groups or group education sessions, etc.
- Refer to clinical checklist in Module 3 for more information on the 5 “A’s”.

Healthcare workers can suggest coping strategies to clients and caregivers to help them reduce stress, deal more effectively with challenges, and promote their psychosocial well-being. Coping strategies might include:

- Talk about a personal problem with someone you trust, such as a friend, family member, counsellor or Peer Educator
- Seek assistance in resolving the problems that you are having with your family/caregiver
- Join a support group
- Exercise
- Change your environment and take a walk
- Seek spiritual support
- Attend a cultural event, like traditional dancing or singing
- Join in recreational activities, like sports or youth clubs
- Return to your daily routine, like cooking or going to school
- Do something to make yourself feel useful, like helping a sibling with homework
- Seek professional help from the clinic if you are sad, depressed, anxious, etc for a long period of time (see Module 6 for more information about Mental Health and ALHIV)

Helping clients express themselves and encouraging them to tell their stories and share their problems also helps them to:

- Feel a sense of relief
- Reduce feelings of isolation
- Think more clearly about what has happened
- Feel accepted, cared, and valued by the person who listens

- Develop confidence
- Build self esteem
- Explore options or solutions to make better decisions
- Prevent bad feelings from coming out as aggressive behaviour
- Maintain needed support from family members and other adults

Lastly, healthcare workers can plan in advance and counsel the adolescent to help them with caregiver transitions (for example, if a mother is becoming too ill to care for her children, family counselling to reduce the likelihood of an adolescent being abandoned or running away, help with reconciliation if the adolescent is already estranged from the family, etc.).

### Exercise 1: Assessing Psychosocial Support Needs: Case studies and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss the adolescent psychosocial assessment, using “Appendix 5A: Psychosocial Assessment Tool” and applying the 5 “A’s”</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will be asked to review the case studies below. They should also refer to “Appendix 5A: Psychosocial Assessment Tool” and the 5 “A’s” in Table 3.6 in Module 3.</li> <li>2. For each of the case studies below, participants will be asked to identify, as a large group, the important issues in relation to each of the 5 “A’s”: “<b>Assess</b>”, “<b>Advise</b>”, “<b>Agree</b>”, “<b>Assist</b>”, and “<b>Arrange</b>”.</li> <li>3. If there is sufficient time, 2 participants will be invited to role play in front of the large group a psychosocial assessment, using the 3<sup>rd</sup> case study.</li> </ol>

### Exercise 1: Assessing Psychosocial Support Needs: Case studies and large group discussion

#### Case Study 1:

You meet with a young 13-year-old girl named Lesiana whose mother has just passed away from an HIV-related infection. Lesiana is enrolled in the ART programme and generally comes to all of her appointments and adheres to her medicines. Yesterday, Lesiana missed an appointment and today, she arrives late. She tells you that she is depressed about school — she used to be ranked first in her class and now she is ranked last. She also tells you that she never feels like hanging out with her friends anymore. How do you proceed with Lesiana?

#### Case Study 2:

A 17-year-old woman named Taonga tested positive for HIV 6 months ago. She is caring for her 3 younger sisters with the help of her grandmother. She is so busy that she has missed a couple of appointments at the ART clinic. Her partner is the only one who knows she is HIV-positive, and he himself has not been tested. How do you proceed with Taonga today?

**Case Study 3:**

A 10 year-old boy named Mumba, who comes to clinic today with his mother, looks like he is “feeling down.” You sense that “he wants to talk to someone” but seems very quiet and won’t make eye contact with anyone. How do you proceed with Mumba?

## Overview of Stigma and Discrimination

**Table 5.1: Definitions of Stigma and Discrimination**

**Stigma:** Having a negative attitude toward people that we think are not “normal” or “right.” For example, stigma can mean not valuing PLHIV or people associated with PLHIV.

**To stigmatise someone:** Seeing them as inferior (less than, below) because of something about them. A lot of times people stigmatise others because they do not have the right information or knowledge. People also stigmatise others because they are afraid.

**Discrimination:** Treating someone unfairly or worse than others because they are different (for example, because someone thinks a person has HIV). Discrimination is an action that is typically fuelled by stigma.

### There are different kinds of stigma:

- **Stigma towards others:** Having a negative attitude about others because they are different or assumed to be different (for example, the girl with HIV felt isolated at school because of the stigmatising attitudes of her peers).
- **Self-stigma:** Taking on — or feeling affected by — the cruel and hurtful views of others. Often, self-stigma can lead to isolating oneself from family and community (for example, Helen is HIV-positive and is afraid to “give the disease” to her family, so she keeps to herself and eats her meals alone.).
- **Secondary stigma:** People, such as community healthcare workers, doctors and nurses at the HIV clinic, children of parents with HIV, caregivers and family members, are stigmatised by their association with PLHIV (for example, when May’s male acquaintance found out that she was seeing an HIV doctor, he ended their budding relationship).

### There are different forms of discrimination:

- Facing violence at home or in the community
- Being kicked out of school
- Not being able to attend school
- Not being able to get a job
- Being isolated or shunned from the family or community
- Not having access to quality healthcare or other services
- Being rejected from a church, mosque or temple

- Police harassment
- Verbal discrimination: gossiping, taunting, scolding
- Physical discrimination: insisting the person uses separate eating utensils or occupies separate living space

**Stigma and discrimination deter access to HIV prevention, care, and treatment services for many people. Stigma and discrimination can prevent people — including adolescents — living with HIV and their families from living a healthy and productive life.**

## **Effects of Stigma and Discrimination**

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### **Stigma and discrimination can also:**

- Keep ALHIV from accessing care, treatment, counselling and community support services, because they want to hide their status.
- Make adolescents feel isolated and as if they do not fit in with peers.
- Make it difficult for ALHIV to succeed in school.
- Motivate ALHIV to stop taking their ARVs, so that they can feel “normal”.
- Keep people from testing for HIV.
- Motivate people with HIV to have sex without disclosing their HIV status.
- Make it hard for people to tell their partner(s) their test result.
- Make it hard for people to discuss safer sex with partners.
- Cause a great deal of anxiety, stress or depression.
- Make it hard for parents to disclose their own HIV status to their children; make it difficult for caregivers to tell HIV-infected children their HIV diagnosis.
- Discourage pregnant women from taking ARVs or accessing other PMTCT services.
- Prevent people from caring for PLHIV in their family, in the community and in healthcare settings.
- Can impact some adolescents more than others. For example, orphans who are HIV-positive may encounter hostility from their extended families and community, and may be rejected, denied access to schooling and healthcare, and left to fend for themselves.

## **Strategies to Deal with Stigma and Discrimination**

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### **Individual strategies for dealing with stigma:**

- Stand up for yourself and talk back.
- Educate others.
- Be strong and prove yourself.
- Talk to people whom you feel comfortable with.
- Ignore people who stigmatise you.
- Join a support group.
- Try to explain the facts.



- Avoid people who you know will stigmatise you.
- Taking and adhering to medicines and ART reduces stigma around HIV, helps normalise HIV and allows the community to see HIV as a chronic disease. People who openly taking ART can reduce stigma around the disease.

**Strategies for dealing with stigma within healthcare settings:**

- Make sure young people and young people living with HIV, such as Peer Educators, are part of the care team. This includes making sure they attend regular staff meetings, trainings and other events.
- Make sure young people are given opportunities to evaluate clinical services and that feedback is formally reviewed by managers and healthcare workers.
- Ensure there are linkages with community based youth groups and support groups for ALHIV; refer adolescents to these groups.
- Talk openly with other healthcare workers about your own attitudes, feelings, fears, and behaviours. Support each other to address fears and avoid burnout.
- When you witness discrimination in the healthcare setting, challenge it. For example, if you see a colleague being rude to a client with HIV, after the client leaves, talk to this colleague on a one-to-one basis. Tell her what you saw and how the situation could have been handled differently.
- Report to the clinic manager discrimination in the clinic setting that is directed towards people living with HIV or their families.
- Listen to clients when they talk about their feelings and concerns about stigma and discrimination, and report these back to other healthcare workers.
- Work with other members of the multidisciplinary team to identify where stigma and discrimination exist in the clinic and work together to make changes.

## Session 5.3      Providing Psychosocial Support Services for the Most-At-Risk Adolescent

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### Session Objective

**After completing this session, participants will be able to:**

- Provide psychosocial support services, including referrals, to most-at-risk ALHIV.

### Overview of Most-at-Risk ALHIV<sup>1,2</sup>

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Most-at-risk ALHIV include young people who are HIV positive and particularly vulnerable or at risk, such as young people who are homeless, homosexual, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, gang members, sex workers, and injecting drug users. Most-at-risk adolescents may live in especially difficult circumstances and typically experience enormous challenges in meeting their own basic needs for food, shelter, and safety.

“Most-at-risk” refers to behaviours, while “vulnerability” refers to the circumstances and conditions that make most-at-risk behaviours more likely.

Young people who most need support often have the most difficulty accessing services and adopting behaviours that protect them from HIV. The behaviours that put them at risk (for example, exchanging sex for money, food, or shelter) are usually heavily stigmatised and take place secretly, often illegally.

Existing policies and legislation, lack of political support, and other structural issues often prevent most-at-risk adolescents from receiving the services that they need. Such factors contribute to marginalising these young people further, which then contributes to undermining their confidence in health and social services, and their willingness to make contact with service providers.

Worldwide, all adolescents are vulnerable and at-risk because:

- Young people’s behaviour is less fixed than adults’ behaviour. Drug use and particular sexual practices are sometimes experimental and might or might not continue.
- Young people are less likely than older adults to identify themselves as drug users or sex workers. This makes them harder to reach with programmes and less responsive to communication addressed to groups with specific identities.
- Young people are more easily exploited and abused.
- Young people have less experience coping with marginalisation and illegality.

- Young people might be less willing to seek out services, and service providers might be less willing to provide services to them because of concerns about the legality of behaviours in some settings and informed consent.
- Young people are often less oriented toward long-term planning and thus might not think through the consequences of the risks that are related to the choices they make.
- Many adolescents are living without parental guidance and support.
- There is a lack of accessible health, social, educational, and legal resources for adolescents.
- Adolescents might live in societies or communities where laws, cultural practice, or social values force young people to behave in ways that place them at risk, for example, homophobia, female genital cutting, or norms that encourage adolescent girls to have sex with older men.

Most-at-risk ALHIV may require more psychosocial support because they are experiencing extreme challenges such as:

- Displacement.
- Severe social exclusion/isolation/stigma/discrimination (young women can face additional gender discrimination, which can affect access to healthcare, food allocation, access to education, and other social and economic opportunities).
- Exploitation.
- Substance abuse.
- Having parents, siblings or peers who abuse drugs or alcohol.
- Migration (internal and external).
- Trafficking.
- Not being connected to the usual community supports such as schools, faith-based organisations, or the formal workplace.
- Poverty due to the poor economic climate or because they are part of a child-headed household.
- Physical or sexual abuse and violence. Adolescents working on the street are subject to the everyday risk of being sexually abused and experiencing violence at the hands of both adults (caregivers, police and others) and their peers. Many of them do not have access to health services. Their major concern is survival, and they are often involved in theft or prostitution because they do not have other means of earning money.
- Young men who have sex with other males may be unsure about their sexuality and not have anyone to talk to because of the stigma surrounding homosexuality and bisexuality.
- Chronic mental health issues, psychiatric disorders, and learning disorders: research indicates that most-at-risk adolescents are at greater risk for anxiety, depression, and anger. Studies have concluded that vulnerable youth, such as those orphaned by AIDS, experience high levels of psychological distress and material support alone is not sufficient.
- Disabilities.

- Stressful past: many situations and events that pushed these youth into vulnerable circumstances in the first place (like parental illness and death, lack of substitute parental care, physical and sexual abuse and adverse external circumstances) may have a lasting impact on their well being.

## **Providing Psychosocial Services to Most-at-Risk ALHIV<sup>3,4</sup>**

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### **Identifying most-at-risk ALHIV**

**Identification of most-at-risk ALHIV is a complicated task.** A review of services for most-at-risk young people found that outreach by peers has often proven to be the best way of making contact with them.

ALHIV who are especially vulnerable may show distress through feelings of suffering or difficult behaviours. This difference is sometimes referred to as having internal symptoms or external symptoms. To recognise or better identify ALHIV who are especially vulnerable, healthcare workers should pay attention to the following behaviours when conducting a clinical assessment or exam:

Internal symptoms and behaviours include:

- Unresolved grief
- Anxiety and/or depression (see Module 6 for more information about Mental Health and ALHIV)
- Poor self esteem and feelings of unworthiness
- Poor self care, including not adhering to HIV care and treatment
- Lack of self-protective behaviours, for example staying involved with sexual partners who are violent
- Inability to accept help and support from other people
- Feelings of being numb and detached
- Loss of motivation about working toward goals for the future

External symptoms and behaviours include

- Easily frustrated or impatient with simple and reasonable rules
- History of truancy
- History of stealing
- Destroys property
- Initiates physical fights
- Justifies hurting others
- Exhibits signs of substance abuse (or suspected by friends and family)
- History of physical aggression to people or animals
- Threatens caregivers or family with self-harming, self destructive behaviour, or violence
- History of running away from home
- Refuses to acknowledge impact of behaviour on others
- Exhibits emotional or mental cruelty to others

Of course an adolescent can demonstrate both types of symptoms and behaviours, but the ones that are external tend to be more troublesome to others and therefore more likely to be recognised. In addition, hazardous alcohol and substance use, suicide risk, difficulties trusting adults and mental illnesses can be seen with both types of symptoms and behaviours.

### **Providing support to most-at-risk ALHIV**

All young people should receive information, psychosocial support, and HIV care and treatment services, including services related to sexual and reproductive health. For especially vulnerable young people or those ALHIV who are most-at-risk, programmes should include all of the activities and services provided to the general population of adolescents, plus actions that are designed to reduce the risk and related harm of their behaviours, as well as support to stop these behaviours.

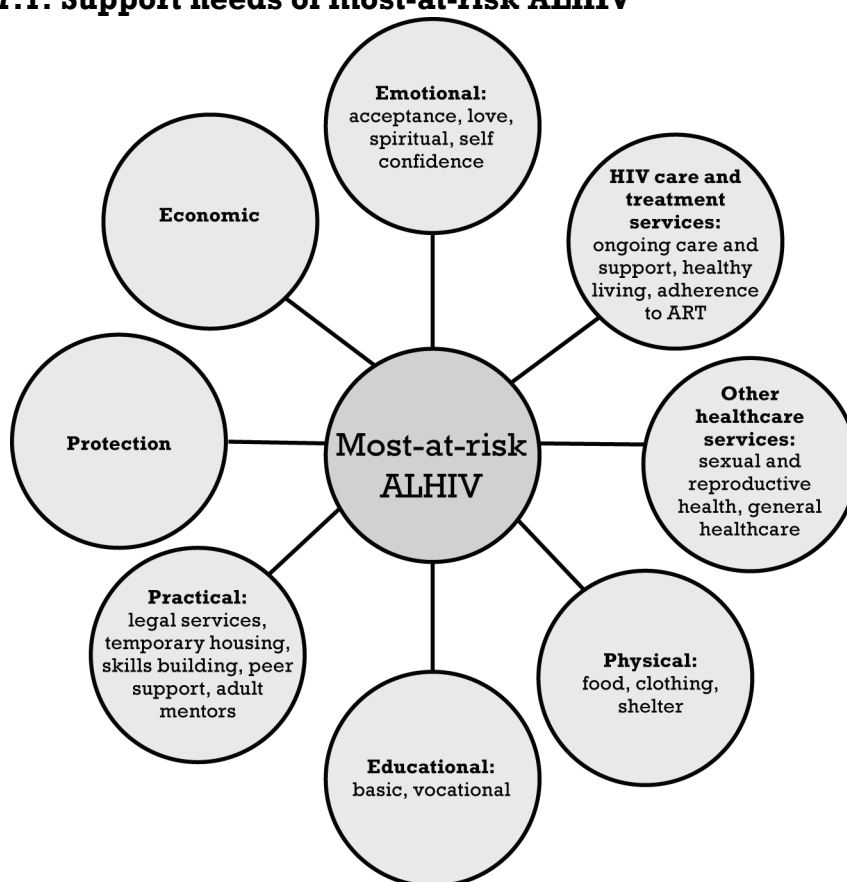
Key psychosocial interventions with most-at-risk ALHIV include:

- Promoting behaviour change, such as the use of condoms and reduction in number of sexual partners.
- Promoting positive behaviours associated with HIV treatment, care and support, including adherence to ART and the diagnosis and treatment of sexually transmitted infections (STIs).
- Teaching risk-reduction skills to help them negotiate condom use, develop strategies for refusing unprotected sex and avoiding clients who are alcohol/drug affected and potentially violent.
- Encouraging enrolment in a peer support group; peer support is particularly useful in bringing information to most-at-risk adolescents, who do not have access to teachers, parents, or other supportive adult mentors.
- Asking about and encouraging supportive relationships in the adolescent's life (for example, extended family members, friends, supportive neighbours).
- Exploring the possibility of reconnecting the adolescent to immediate or extended family, if this is appropriate and feasible. This can be done by clinic staff or by referral to an organisation that does such work in the community.
- Remember that all adolescents have wishes to be helped and supported by adults as well as peers, although they often do not want to show this. Adolescents refusing adult help are often waiting to see if the adults will persist and thereby prove that they care and are trustworthy.
- Developing an effective referral system with follow up and linkages to social, legal, NGO, faith-based organisations, and community-based youth services, to help most-at-risk adolescents meet their basic needs. Helpful services can include: assistance with school fees and supplies; child care for younger siblings so that adolescents can attend school; adult mentors that help adolescents with such skills as vocational development, income generating activities, parenting skills, and household maintenance; and general emotional support.

- Using adolescent-friendly approaches: art, drama, music, and dance often involve youth more easily than more traditional educational materials. Youth friendly services are particularly important for most-at-risk adolescents, because they are the most difficult to engage in care, are the most fearful of healthcare workers, and have the least access to services.
- Ensuring that young people participate in the planning and decision making around clinic services. Involving young people as advocates and as peers to make contact with, and provide outreach to, vulnerable and most-at-risk young people.

The support needs of most-at-risk adolescents is presented schematically in Figure 7.1.

**Figure 7.1: Support needs of most-at-risk ALHIV**



### Transactional sex: putting young women at risk

Transactional sex can include occasional exchange of sex for money, goods, or services. Significant age disparities are common in transactional sex. Among other factors, concern about HIV has prompted older men to seek younger sexual partners under the assumption that they are less likely to be infected. Young women are often willing to participate in these partnerships for emotional reasons; perceived educational, work, or marriage opportunities; monetary and material gifts; or basic survival.

These young women may fail to realise their vulnerability to abuse, exploitation, reproductive health risks and HIV. Transactional sex puts girls and young women at risk of HIV because of low condom use and the likelihood that the male partner is older and HIV positive.

### Exercise 2: Psychosocial Support to the Most-at-Risk Adolescents: Large group discussion using case studies

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To discuss how healthcare workers can meet the psychosocial needs of most-at-risk-adolescents</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>Participants will be asked to review the case studies below and to refer to “Appendix 5A: Psychosocial Assessment Tool” and revisit the 5 “A’s” in Table 3.6 (Module 3).</li> <li>For each of the case studies below, participants will be asked to identify, as a large group, the important issues in relation to each of the 5 “A’s”: “<b>Assess</b>”, “<b>Advise</b>”, “<b>Agree</b>”, “<b>Assist</b>”, and “<b>Arrange</b>”.</li> </ol>

### Exercise 2: Psychosocial Support to the Most-at-Risk Adolescents: Large group discussion using case studies

#### Case Study 1:

Patrick a 16-year-old homeless youth, with no recent family contact and a history of alcohol abuse. Patrick was diagnosed with HIV 6 months ago. During his visit with you, Patrick appears dishevelled and in need of a wash. He says he has difficulty taking his medications; he forgets his schedule, often loses medication. He says that he has not told anyone that he is living with HIV. How would you proceed with Patrick?

#### Case Study 2:

Kasonde is a 15-year-old girl who acquired HIV perinatally. Her mother died when she was 3 years old. She doesn’t know her father and, for the last year, has been living with her 28-year-old boyfriend. She comes to the clinic today because she thinks she is pregnant. How would you proceed with Kasonde?

#### Case Study 3:

Sonkwe is 16 years old. He comes to the clinic and starts shouting and

banging on your desk. He claims someone from this clinic told his mother that he is HIV-positive and she has kicked him out of the house. Sonkwe says that he has “nowhere to go” and that he has been living in a street camp since the fight with his family. How would you proceed with Sonkwe?



## Session 5.4      Peer Support in Psychosocial Services for Adolescents

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### Session Objective

**After completing this session, participants will be able to:**

- Understand the importance of peer support in meeting adolescents' psychosocial support needs.

### Importance of Peer Support for ALHIV

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Adolescents generally depend on peers for information, approval, and connection. This is particularly true for most-at-risk adolescents — such as, street children — who do not have guidance from parents, teachers and other adults. In addition to the other psychosocial support strategies described in this Module, peer support can help ALHIV to counter stigma and discrimination, to cope with fear and hopelessness after diagnosis, to improve adherence to care and treatment services, and to deal with issues such as disclosure to partners, friends and family.

**The engagement of ALHIV as Peer Educators can play an important role in improving adherence and service quality.**

### Peer Educators can help improve services for ALHIV

Full participation of Peer Educators in the health facility and outreach services can expand the clinic's ability to provide quality care by allowing the already overburdened healthcare workers to concentrate on more technical tasks. Depending on the context and programme, Peer Educators can play a number of important roles in HIV service delivery, including but not limited to:

- Providing individual counselling and long term support (adherence preparation, adherence follow up, disclosure, positive living, positive prevention, etc.) at ART clinics.
- Providing psychosocial support to clients and family members enrolled in HIV care and treatment.
- Leading health talks and group education sessions with ALHIV, caregivers, treatment supporters and others.
- Assisting clients with disclosure.
- Linking young pregnant women living with HIV to ANC and PMTCT services.
- Assisting clients with referrals from place to place within or between health facilities.
- Providing referrals and linkages to community-based services and support.
- Tracing clients who miss appointments or who have been lost to follow up.

- Serving as a communication link between clients and healthcare workers.
- Participating in outreach and education activities related to HIV in the community.
- Assisting with the design and delivery of peer support groups for ALHIV and their caregiver.

Peer support for ALHIV can help address adolescents' psychosocial support needs by:

- Helping youth feel they are accepted and valuable members of the group and reduce their sense of isolation.
- Helping clients solve their own problems.
- Providing emotional support.
- Promoting learning, sharing, and skill building around disclosure, adherence, and dealing with stigma and discrimination.
- Maintaining a youth's motivation and commitment to HIV care and treatment, since peer support can be stronger than adult support or personal desire alone.
- Effectively engaging most-at-risk adolescents, who tend to lack positive support networks.

## **Peer Support Groups for ALHIV**

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Peer support groups are groups of people who come together because they share a common situation. In peer support groups, members help each other to improve and better manage their situation, share challenges and discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical and medical needs.

- Very often people living with HIV feel isolated and alone. Meeting other people living with HIV can reduce isolation and provide encouragement to live more fully and positively.
- Support groups can help increase the uptake of healthcare services, such as HIV testing, PMTCT and HIV care and treatment. Support groups can help members to better understand clinical services, give them support to seek and adhere to care, and provide support for integrating family members into care.
- Support groups also offer ways to link members to healthcare services and community-based services. For example, healthcare workers or leaders of community-based organisations can talk about the range of services their organisations offer during support group meetings. Support group members typically share with each other their experiences with local service providers and swap advice on how to navigate each programme (for example, ideal time to arrive to reduce wait time, which documents to bring to the initial appointment, etc).
- Depending on the specific programme, Peer Educators may play an important role in starting support groups, facilitating support group meetings and/or helping others organise them and recruit members for

them. Peer Educators in these roles will benefit from support and mentoring.

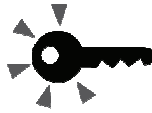
### **A sampling of the range of support groups:**

- **Adolescent support groups:** ALHIV may want to form their own support groups to discuss some of the special challenges that they face. These groups may involve recreational activities (sports, crafts, drama, etc.), as well as time for discussion. It is best if they are led by an adolescent enrolled in care and treatment, such as a Peer Educator. Peer Educators in this role will benefit from support and mentoring to help them problem solve difficulties that may arise (for example dealing with withdrawn or disruptive members).
- **Playgroups for younger adolescents:** Children living with HIV and their caregivers may benefit from groups where children of similar ages can play together and where caregivers have a chance to share and talk. These groups often involve child-friendly activities, such as games, drawing, art and music.
- **Young mothers support groups:** Young mothers living with HIV and those with HIV-exposed or HIV-infected children may want to have their own support group. Young mothers support groups can provide needed psychosocial and emotional support and help mothers understand and access key HIV and PMTCT services. These groups can address concerns specific to mothers, such as safer infant feeding, care of HIV-exposed babies, and the importance of adherence to PMTCT and ART services.
- **Adolescent grief group:** The loss of a loved one is an extremely painful experience for anyone, including adolescents. Loss can be particularly difficult if it is the loss of a parent, children expect their parents to always be able to protect them from harm. One way that adolescents can cope with the loss of a loved one is to join a bereavement group.
- **Couples support groups:** Couples, including those where both people are living with HIV as well as discordant couples, may wish to form support groups. Couples can share common concerns and challenges and support one another to live positively with HIV.
- **Post-test clubs:** These groups are for anyone who has been tested for HIV. Therefore, they do not require participants to identify their status when joining. They often focus on promoting HIV information and education in the community, but they also provide a social environment for the members to meet each other and discuss any important issues, including how to stay negative, being in a discordant relationship, etc.
- **Groups for other specific populations:** Other groups of people with common characteristics may wish to form their own support groups. This could include sex workers support groups, support groups for men who have sex with men or others. In some places, there are

support groups just for single people to meet other singles living with HIV. In areas with a diverse population, groups of people that have the same ethnicity or speak the same language may wish to form their own support groups.

**Ideas for health education topics that can be incorporated into support group meetings:**

- Positive living
- Navigating the healthcare system
- Disclosure
- Coping with school
- Relationships and sexuality
- Dealing with stigma
- Adherence
- Preventing opportunistic infections
- Nutrition
- Domestic violence
- Family planning and dual protection
- Preventing new HIV infections
- Dealing with death and dying of a friend or family member



## Module 5: Key Points

- Psychosocial support addresses the ongoing emotional, social and spiritual concerns and needs of people living with HIV, their partners, their family and caretakers of children living with HIV.
- Healthcare workers play a key role in assessing clients' psychosocial needs. Healthcare workers can use a Psychosocial Assessment Tool to help assess clients' psychosocial needs and help counsel them to come up with their own solutions.
- Healthcare workers should remember the 5 "A's" when conducting a psychosocial assessment: **ASSESS** the client's needs, **ASSIST** with referrals and support, **ADVISE** the client and help him/her make an informed decision, **AGREE** on goals, and **ARRANGE** a follow-up appointment.
- Stigma means having a negative attitude toward people that we think are not "normal" or "right." For example, stigma can mean not valuing PLHIV or people associated with PLHIV. Self-stigma is when a person is affected by the cruel and hurtful views of others, which can lead to isolating oneself from family and community.
- Most-at-risk adolescents include ALHIV who are vulnerable, such as young people who are injecting drug users, homeless, sex workers, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, and gang members. Health services for young people need to be adapted to meet the needs of most-at-risk.
- Good psychosocial support can reduce the number of adolescents who are in the most-at-risk category.
- Offer to include caregivers' and/or family members' input into the assessment as needed and agreed upon by the adolescent, while simultaneously protecting the confidentiality of information.
- Healthcare workers and peers can engage and help support the psychosocial needs of ALHIV, especially those who are most-at-risk, and can help them to have better access and adherence to HIV prevention, care and treatment services.

## Appendix 5A: Psychosocial Assessment Tool

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### How to Use this Tool

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This psychosocial assessment guide was developed to support a range of providers (trained counsellors, lay counsellors, healthcare workers, and others) who work with ALHIV and their families. Conducting a psychosocial assessment with each client (and caregiver, if applicable) helps to learn more about his or her specific situation, to prioritise needs, and to give direction to ongoing counselling and psychosocial support. This includes referrals for needed community and home-based services.

A psychosocial assessment should be conducted with **each adolescent client after enrolment in HIV care and treatment services**. Healthcare workers may want to conduct another psychosocial assessment or revisit specific psychosocial issues when a client's situation changes in a significant way, such as when a client reaches a new developmental stage or starts to show signs that there are new challenges/problems. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Key information from the psychosocial assessment should be recorded on the form and the form kept in the client's file for reference during follow-up visits. A template to record follow-up counselling notes is also included.

**Basic information:** Write down the client's name and file number. Be sure to sign and date the form at the end of each session.

**Questions to ask the client/caregiver:** The questions in these sections allow the healthcare worker to discuss and assess the client's psychosocial issues and needs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished. Write down any important information from their responses, as this will help decide on effective next steps, important areas for follow up, and in supporting the client's psychosocial wellbeing over the long term.

**Questions, summary, and next steps:** Ensure that the client has time to ask questions and that the healthcare worker has time to summarise the session and agreed upon next steps. Record key next steps in the space provided.

**Additional notes:** Write any additional notes about the session or the client's psychosocial needs in the space provided.

**Referrals made:** Linkages and referrals to psychosocial support services are important elements of HIV care and treatment programmes and the ongoing support of adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as Peer Educators, adherence supporters, ALHIV associations, food support,

education and job training programmes, legal support, etc.) and formal two-way referral systems to these organisations and services. Clients with severe psychosocial and psychological issues (such as depression, use of drugs and alcohol, feeling suicidal) will require careful follow up and immediate referrals to ongoing professional counselling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these services.

**Date of next counselling session/clinic appointment:** Schedule a follow-up counselling appointment with the client and record this date, as well as any clinic appointments in the space provided.

**REMEMBER:**

- Do not talk down to an adolescent.
- Allow an adolescent to speak for himself/herself. Respect their opinions.
- Be patient! Allow the adolescent to express her views and describe her experiences.

## ALHIV Psychosocial Assessment Guide and Recording Form

Client Name: \_\_\_\_\_

Client File#: \_\_\_\_\_

<b>Coping, Support System, and Disclosure</b>	
1. Smile, introduce yourself and give a short explanation of your role. Explain that this discussion will be confidential.	
2. Can you tell me how things have been going since you learned your HIV-status? How are you coping? <b>Explore and discuss client's coping strategies</b>	
3. Let's talk about your living situation. Who are you living with? How long have you lived with them? How well do you get along you're your caregiver? Who else is in your household? Which of them have HIV infection? How are they doing? <b>Assess living situation</b>	
4. <i>If not living with parents, ask:</i> Where are your parents? When did this happen? How did this affect your living situation? What other caregivers have you lived with?	
5. Who do you feel close to? Who can you go to for emotional support? <b>Counsel on importance of social support</b>	
6. Tell me what you do. Do you, for example, go to school or work outside the home?	
7. How often in the last week have you used cigarettes, alcohol, or other drugs? <b>Assess for harmful coping strategies, such as drug/alcohol use, and provide counselling and referrals</b>	
8. To whom have you disclosed your HIV-status? What was their reaction? Do you want to disclose to anyone else to get the support you need? If so, how will you do this? What support do you need? <b>Counsel on full and partial disclosure</b>	Yes   No
9. Do you belong to a community/religious organisation or support group that gives you the support you need? Would you be willing to join a support group, to meet other ALHIV?	Yes   No Name/location of organisation or group:
10. We have all felt rejected or isolated at some point in our lives. Have you experienced negative attitudes or treatment because of your HIV-status or other reasons? Has anyone caused you harm in the past; for example, hurt you physically or unwanted sexual encounters?	Yes   No Details:



<b><i>Counsel and discuss available support services</i></b>	
11. How is your mood now? Do you feel sad or depressed? What changes have you noticed in your mood? What about in your eating habits? In your sleeping pattern? Do you have less energy than usual? Have you lost interest or pleasure in things you usually enjoy? <b><i>Assess risk of depression and need for referral to a mental health expert, etc.</i></b>	
12. Do you have financial support from your family or partner, a regular source of income, or do you receive help, such as social grants, food parcels, or anything else? <b><i>Counsel and refer to social worker and community-level support</i></b>	Yes    No Sources of income/support:  Receiving social grant?    Yes    No
13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?	
14. Many adolescents have sex with their partners. Are you having sex? If so, what family planning method did you use the last time you had sex? (If client is sexually active and did not use condoms the last time, ask) When was the last time you used a condom? <b><i>Screen for sexual risk taking and counsel on safer sex and family planning</i></b>	
15. How do you/will you remember to take your medications every day? How will you remember when to come back to the clinic? Who can help you? <b><i>Counsel on adherence to care and medicines and briefly discuss:</i></b> <ul style="list-style-type: none"> <li>• <b><i>WHO will give or manage medicines?</i></b></li> <li>• <b><i>WHAT will you do to remember?</i></b></li> <li>• <b><i>WHEN will you take them?</i></b></li> <li>• <b><i>WHERE will you store your medicines?</i></b></li> <li>• <b><i>HOW will you remember to take your medicines (review use of reminders, like calendars, pill boxes, etc)</i></b></li> </ul>	
<b>Questions, Summary, and Next Steps</b>	
16. What other questions or concerns do you want to discuss today?	
17. Summarise the session and review immediate plans and next steps, including the next clinic visit date	Note next steps here and in the space below:

Notes:

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**Referrals made:**

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**Date of next counselling session/clinic appointment:** \_\_\_\_\_

**Healthcare worker signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. Improving retention, adherence, and psychosocial support within PMTCT services: A Toolkit for Health Workers. New York, NY: Columbia University/ICAP.

## **Appendix 5B: Starting/Planning a Peer Support Group**

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### **Key steps to think about when starting/planning a support group**

**First, find out what HIV-related support groups already exist in the area. Then, try to understand what support groups are needed:**

- Work in partnership with clients, counsellors, social workers, and/or Peer Educators to determine what types of support groups are needed.
- Ask adolescents who attend the clinic when they could come to a meeting, where they would like the meeting to be held and what they would like to talk about (for example, adherence strategies, stigma, disclosure).

### **Decide WHO the support group is for:**

- Who will be invited to attend? Generally, it is best to have different support groups for younger and older adolescents.
- What is the ideal number and type of participants? It is recommended that support groups not have more than 10–15 people in the same meeting so that everyone can participate.

### **Define the overall goals of the support group:**

- What is the purpose of the support group?
- What will members gain from the support group?
- Is the support group meant to go on indefinitely, or will it cover a certain number of topics and then come to an end?

### **Recruit support group members:**

- How will you let people know about the support group?
- Will members of the multidisciplinary team refer people to the support group? How will it be advertised?

### **Decide on the location of the support group meetings:**

- Can it be held at the health facility? Is this convenient for adolescents or should it be located in the community?
- If support group meetings are held at a health facility, will members be able to get HIV services before/after the meeting?

### **Decide how often the group will meet:**

- What time and how often will the groups be held? Do most participants go to school during the day or do they have household chores at certain times of the day? Is 1 hour enough or is 2 hours better?
- Will the group meet once each month? More often? Less often?

### **Develop the meeting agenda**

- Who will run the support group?

- Who will be invited to speak? What is the topic?
- Will there be guest speakers?

**Think about venue, food, and other logistics:**

- Is there privacy at the meeting space?
- Are there enough places for people to sit?
- Can the room be arranged so participants are in a semi-circle (instead of in rows)?
- Will you arrange for tea or snacks for the meeting? Who will get them? How will they be paid for? Who will keep attendance and other records of the support group?

**Suggested agenda items for support group meetings**

- Registration/sign-in
- Refreshments (tea, coffee, snacks, etc.)
- Welcome/opening (song, prayer, dance)
- Introductions
- Overview of the agenda
- Reminder about confidentiality and other ground rules
- Main group learning activity (game, health talk, etc)
- Questions and answer session (make use of an anonymous question box)
- Plan for the next meeting
- Closing (song, prayer, dance, etc.)

**Most support group meetings last between 1–2 hours.**

**Make sure to suggest and plan new learning opportunities and fun activities for support group members:**

- Keep everyone busy and having fun! Use games and participatory activities (refer to suggestions in “Appendix 5D: Ideas for Peer Support Group Activities”)
- Consider including a health talk as a part of each support group meeting. The health talk can be focused on a different topic area at each of the meetings. Health talks should be kept short and simple (about 15–20 minutes) so that support group members have time to discuss their feelings, questions and concerns.
- Plan an activity or ongoing project for each group meeting that relates to the overall theme of the group.
- Get feedback from support group members on topics they would like to discuss during the meetings and incorporate these into the agenda. This can be done through an anonymous questions box.

## Appendix 5C: Facilitating a Peer Support Group

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### **Set up the room so that everyone can participate:**

- Encourage participants to sit in a semi-circle to make it more comfortable to talk and less like a classroom.
- The person leading the meeting should be part of the semi-circle.
- If possible, provide tea or a light snack for members, facilitators and invited guests.

### **Remind participants about confidentiality:**

- Support group members will only feel open to discuss their experiences and feelings if they know others will ensure the discussion is kept confidential.
- It is always a good idea to remind support group members at the start of each meeting that what is said during the meeting is not repeated in the community.

### **Ask participants to establish ground rules:**

- During the first group meeting, ask the participants to brainstorm the group's ground rules. Ground rules might include any of the following: we respect others' opinions, we will not interrupt, we will allow everyone a chance to speak, we will not tolerate homophobic comments, etc.

### **Offer participants ongoing support and referrals:**

- Encourage participants to speak with you or another facilitator in private afterwards if they have concerns they do not want to share with the group.
- Know what support and services are available in the community and at nearby health facilities so you can provide referrals.
- If the meeting takes place at a health facility, try to time it so members can seek services before or after the meeting.
- Seek input from multidisciplinary team members and other experts on topics beyond your area of expertise.
- Create a plan for situations where support group members need assistance right away (for example, if they are mentally distressed, suicidal, violent or the victim of violence).

### **Keep records of the meeting:**

- Always keep an attendance record. Remember, this information is confidential.
- Ask someone to take simple notes during the meeting. Note what topics were discussed, key concerns of members, and any next steps. Also note the date, time and location of the next meeting.

- All meeting records must be stored in a locked cabinet to ensure confidentiality.

**Be a good facilitator or co-facilitator:**

- Partner with a Peer Educator, social worker or counsellor as a co-facilitator. Decide what role the co-facilitator will play during the meeting.
- Create a safe and welcoming environment for support group members. Support groups should not feel like health education sessions or lectures. Instead, members should feel that this is “their” meeting.
- Be sure to plan the meeting agenda ahead of time and practise what you are going to say.
- Lead an introductory activity (have people introduce themselves or say something about their family) so participants feel more comfortable with one another.
- Review the agenda with support group members and ask if there are questions. Always ask for suggestions for the next meeting agenda.
- Stick to the agenda and keep time!
- Use the 7 listening and learning skills when leading a support group meeting:

**7 Listening and learning skills**

- Skill 1: Use helpful non-verbal communication.
- Skill 2: Actively listen and show interest in the client.
- Skill 3: Ask open-ended questions.
- Skill 4: Reflect back what the client is saying.
- Skill 5: Empathize — show that you understand how the client feels.
- Skill 6: Avoid words that sound judging.
- Skill 7: Help the client set goals and summarise each session.

## Appendix 5D: Ideas for Peer Support Group Activities

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### Charades

Players try to act out terms or concepts without speaking.

- **Materials:** Watch or timing device, pieces of paper (cut a sheet of A4 paper into eights; papers can be blank or already containing health terms), two baskets, hats or other containers for the paper, scorekeeping method.
- **Play:** Form teams. Divide the paper between the two teams. If the paper is blank, allow the teams to privately consult and fill in the blanks with terms, phrases or concepts related to material they are learning. Choose a neutral timekeeper/scorekeeper, or have the teams take turns. Review the gestures and hand signals and invent any others as needed.

To play, teams take turns having a player choose a piece of paper from another team's basket. Without speaking, the player has 3 minutes to use gestures and actions to help his or her team members guess what is written on the piece of paper.

Normally the game continues until every player has had a chance to "act out" a phrase. Scoring may be based on one point for every paper correctly guessed. Another scoring option is based on the total time that each team needed for all of the rounds; with this system, the team with the lowest score wins the game.

### Sculpturing

Participants put themselves in certain poses using their whole body, including gestures and facial expression, to communicate an image of an issue or relationship. The 'sculpture' is then discussed.

- **Play:** Ask participants to get in pairs then ask the pairs to make a sculpture showing how people treat orphans. Ask them to decide on roles. One person is the orphan, the other is a community member. Then ask some pairs to show their sculptures in the centre of the circle. After each demonstration, ask:
  - *What do you think this person is saying?*
  - *How do you think these people are feeling?*

Ask the people in the sculpture:

- *What are you thinking?*
- *Why are you doing that?*
- *How are you feeling?*

## **Journaling**

Ask participants to create “All About Me” journals using magazines, markers, and other materials, which can be used for decorating the journal. Ask participants to think of the special characteristics (hobbies, traits, etc) that make up their identity. Also include future goals and dreams. A counsellor or Peer Educator at the clinic may want to write back/respond to client’s journal entries in writing.

## **Question box**

Create a box at the health facility for anonymous questions. Ask clients to drop in questions any time. These questions can then be picked out of the box at random during one portion of the support group meeting and discussed by everyone.

## **Songs**

Ask participants to work in small groups to create a song about a health topic, positive living or reducing stigma.

## **Plays/drama**

Ask participants to work in small groups to create a play about, for example, combating stigma in schools or the community.

## **Arts and crafts games**

These games help adolescents to think about themes in their lives in new ways — and can be quite useful for appealing to younger adolescents who enjoy doing activities that are hands-on, participatory and creative. One technique for slowing down youth who rush through art projects is to tell them that within the time frame, the LAST artists to finish are the winners.

**Example:** Create a painting or drawing of a scene where participants were discriminated against; ask participants to discuss their feelings about this.



## References and Resources

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<sup>1</sup> WHO/UNICEF. 2008. Global Consultation on Strengthening the Health Sector Response to Care, Support, Treatment and Prevention for Young People Living with HIV. Geneva, Switzerland: WHO/UNICEF.

<sup>2</sup> Working Group, U.S. Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People, and FHI. 2010. *Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth*, Research Triangle Park, NC: FHI, 2010.

<sup>3</sup> FHI. 2010. *Young People Most at Risk of HIV: A Meeting Report and Discussion Paper from the Interagency Youth*, Research Triangle Park, NC: FHI.

<sup>4</sup> Working Group, U.S. Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter-Agency Task Team on HIV and Young People.



## Module 6

### Adolescents, HIV, and Mental Health

**Session 6.1: Importance of Mental Health Services for ALHIV**

**Session 6.2: Assessing Mental Health and Providing Basic Mental Health Support to ALHIV**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Identify their own beliefs and attitudes about mental health and ALHIV.
- Discuss why ALHIV need access to mental health services.
- Describe common mental health issues faced by adolescents.
- Distinguish between mental health problems and mental illness.
- Discuss ways to screen and treat some common mental health issues and neuropsychiatric disorders affecting ALHIV.

## Session 6.1      Importance of Mental Health Services for ALHIV

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### Session Objectives

**After completing this session, participants will be able to:**

- Identify their own beliefs and attitudes about mental health and ALHIV.
- Discuss why ALHIV need access to mental health services.

### Exercise 1: Values Clarification: Large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss attitudes, values, beliefs, and prejudices about ALHIV and mental health issues</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. The trainer will read out loud to the large group each one of the “<b>Statements for sentence completion</b>” (which participants will see below).</li> <li>2. For each statement, the trainer will ask participants to offer their responses and their reactions to others’ responses.</li> </ol>

### Exercise 1: Values Clarification: Large group discussion

#### **Statements for sentence completion:**

1. Mental illness is...
2. Mental health services in this country are...
3. The way people with mental health issues are treated is....
4. Some of the traditional/cultural beliefs about mental illness in this community are...
5. ALHIV who suffer from depression and other mental health diagnoses are...
6. An adolescent with a mental health problem should...
7. Providing mental health care at our facility is...
8. When an ALHIV shows signs or symptoms of a mental health problem, the role of the healthcare worker should be...

## Overview of ALHIV and Mental Health<sup>1,2,3,4</sup>

### Overview of mental health and mental illness

- Given the enormous amount of biological and psychological change associated with adolescence, most adolescents will experience some type of fluctuation in mood or behaviour and/or problems that affect their emotional and mental functioning.
- The task of evaluating whether an adolescent is experiencing a milder mental health problem versus a mental illness is complicated and requires extensive training.
- Although the symptoms of **mental illness** can range from mild to severe and are different depending on the type of mental illness, a young person with an untreated mental illness often is unable to cope with life's daily routines and demands.
- **Mental illness** is not a single disease but a broad classification for many disorders. Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many of these conditions are caused by a combination of factors, including genetics or family history of a disorder, chemical imbalances in the brain, or stressors in the environment.
- Many **mental health disorders** of adulthood begin in childhood or adolescence.

### Definitions

- **Mental health** refers to a psychological or emotional state of an individual.
- **Mental health problem** describes the normal fluctuation in mood or behaviour that has minimal effect on life's daily routines and demands
- **Mental illness** is any disease or condition affecting the brain that significantly influences or disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning.
- **Mental disorder** is when a problem or symptom disrupts daily functioning in 1) home, 2) school, and/or 3) community. If an adolescent is able to function well in at least two of those three areas, it is unlikely that he or she has a serious mental disorder.

### Importance of mental health services

Providing mental health services to ALHIV is important because:

- Both mental health problems and mental illness are common among ALHIV.
- Mental health status influences the course of HIV disease in various ways. For example, depression can limit the energy required to keep focused on staying healthy, and research shows that depression may accelerate progression to AIDS.
- A person's mental health significantly influences his or her adherence to HIV care and treatment. Mental health problems can prevent people from taking their medications correctly. Studies have shown that 2 of the

major factors causing non-adherence are mental health problems and substance abuse. Studies in adults have found that when depression is treated, clients with HIV are more likely to adhere to their ART, experience improved CD4 cell count and lower viral load.

- People who experience mental health problems (for example, depression), are more likely to abuse drugs or alcohol and to engage in risky sexual behaviours, such as improper or no condom use.
- Our mental health and our physical health are closely related — which is why helping people deal with mental health problems can help them live positively.
- Access to mental health services has been shown to decrease HIV disease progression and death.

## **Stressors**

In addition to the normal developmental challenges of adolescence, ALHIV also have to cope with multiple HIV-related conflicts and stressors in their lives. Stressors, such as the following, can be risk factors for mental health and social problems:

- Anxiety about medical prognosis
- Anger at parents about being HIV positive (ALHIV who were perinatally infected)
- Loss and bereavement
- Loss of caregivers, particularly when caregiver is not replaced by an adequate substitute (adolescents who are heads of household and those who are homeless are at risk of mental health problems due to hardship and lack of traditional support systems)
- Anxiety over physical appearance and body image (for example, delayed development, wasting, and dermatologic conditions)
- Emotional pain related to social stigma, isolation and hopelessness, forced disclosure
- Social and emotional isolation (lesbian/gay/bisexual/transgender youth are particularly vulnerable to a range of physical and mental health problems)

## **ALHIV need extra support with their mental health:**

- When they first learn about their HIV diagnosis (symptoms of depression may be common immediately after learning HIV status).
- When feeling rejected or as if they don't fit in with their peers.
- When feeling upset, frustrated or angry about living with HIV (for example, having to take medicines every day, having to hide medicines when at school or around people that don't know their HIV status, coming to the clinic and missing out on opportunities with friends).
- After learning a family member is living with HIV.
- When preparing to disclose to friends or family members.
- When worrying about dating, having sex, or fantasizing about having children in the future.
- When starting ART or changing regimens.

- When having problems with personal relationships with friends or partners.
- When grieving the loss of a loved one.
- When facing stigma, discrimination, or violence in school, at home, or in the community.
- When experiencing any significant any physical illness.
- Upon recognising new symptoms/progression of disease (for example, major drop in CD4 cells, rise in viral load).
- When hospitalised (particularly the first hospitalisation).
- When exhibiting signs or symptoms of persistent mental illness, such as depression, anxiety, drug and alcohol abuse, or other behavioural problems.

These are all important times for healthcare workers and members of multidisciplinary care team to provide extra emotional support, but ongoing mental health support is also needed to help people live positively with HIV in the long term.

### **Common mental health problems or disorders in adolescents**

Many mental health problems emerge in late childhood and early adolescence. ALHIV are especially susceptible to many mental health challenges, such as:

- Depression (a feeling of intense sadness — including feeling helpless, hopeless, and worthless — that lasts for days to weeks).
- Anxiety (a feeling of nervousness, fear, or worry that interferes with the ability to sleep or otherwise function).
- Behavioural disorders, such as violent behaviour, aggression, and impulsivity (the tendency to do things without adequate forethought).
- Eating disorders (for example, overeating, not eating enough, dieting to the point of starvation, binge eating and then purging).
- Neurocognitive impairments (HIV-infected children and adolescents are at increased risk of developing central nervous system disease characterised by cognitive, language, motor, and behavioural impairments).
- Somatic complaints (complaints relating to the body, not the mind or spirit): Anxiety and depression affect the mind and the body and, when severe, are routinely accompanied by physical (or somatic) complaints. These may include fatigue, headaches/migraines, abdominal pain/gastrointestinal problems, back aches, difficulty in breathing/chest pain. Somatic symptoms can also occur as indicators of distress in the absence of obvious depression and anxiety. Among ALHIV it is always important to rule out medical causes.
- Suicidal ideation (thinking about suicide).
- Other behavioural problems or risky behaviours, such as drug and alcohol abuse.
- Problems resulting from side effects of ARVs or negative experiences with medications: some ARVS, like efavirenz, are known for their effect

on the central nervous system, resulting in sleep disturbance and mood changes. Symptoms usually resolve but clients still need encouragement and support.

- General problems coping with HIV diagnosis, including social withdrawal, loneliness, anger, confusion, fear, and guilt.

The more common mental health problems and/or mental health disorders are discussed further in the next session.

## Session 6.2 Assessing Mental Health and Providing Basic Mental Health Support for ALHIV

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### Session Objectives

**After completing this session, participants will be able to:**

- Describe common mental health issues faced by adolescents.
- Distinguish between mental health problems and mental illness.
- Discuss ways to screen and treat some common mental health issues and neuropsychiatric disorders affecting ALHIV.

### Recognising Common Mental Health Problems in ALHIV

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- Symptoms of depression and anxiety are very common among adolescents. They are often transient and respond to support from friends, family and healthcare workers. The presence of a mental illness should be suspected when symptoms:
  - Are persistent, unresponsive to simple support, and/or
  - Cause severe distress or result in reduced ability to carry out ordinary activities such as self-care, maintaining social relationships and attending to schoolwork or other activities.
- Diagnosing a mental illness by interviewing an adolescent is difficult and requires years of specialised training, but all healthcare workers should be able to screen for major signs and symptoms of basic mental health problems. An example of a basic, routine mental health screening tool for use with clients or caregivers during routine check ups can be found in Table 6.1.
- It is important to assess a client's mental health needs at every visit and to ask caregivers about the clients' moods, general behaviour, and any changes they have observed — at home, at school, with friends, and with family members.
- It is also important to consider environmental factors, such as poverty, education, employment, and factors related to the family/ caregivers (for example, a change in caregiver, caregiver skill in raising an ALHIV) — all of which can be risk factors for the development of mental illness.

**Remember:** The way mental health problems present in clients will vary from culture to culture and person to person. They will also be different for younger and older adolescents. For example, it is common for younger children to manifest mental health issues through acting out behaviours or by complaining about stomach pain or other unexplained somatic problems. Older adolescents may demonstrate more pronounced difficulties with schoolwork, truancy, running away from home, and



substance abuse. Significant mental health problems interfere with a sense of well-being and/or the ability to carry out usual activities. Use the Assessment of Well-being screening tool to determine if mental health problems are likely to be present.

**Table 6.1: Assessment of well being screening tool**

✓	Topic and key questions
	<b>1. General mood and energy level</b>
	<ul style="list-style-type: none"> <li>How are you feeling today?</li> <li>Would you say that you are feeling better or worse than the last time you were here?</li> </ul>
	<b>2. Eating, sleeping, and daily functioning</b>
	<ul style="list-style-type: none"> <li>How you have been sleeping?</li> <li>What types of foods have you been eating?</li> <li>Can you tell me about any changes in your eating and sleeping habits in the last month?</li> </ul>
	<b>3. Family and home</b>
	<ul style="list-style-type: none"> <li>Can you tell me more about any problems you are having at home? With your family?</li> </ul>
	<b>4. School or work</b>
	<ul style="list-style-type: none"> <li>Can you tell me more about how you are doing at school/work?</li> <li>During the last month, how often have you missed or skipped full days at school/work?</li> </ul>
	<b>5. Alcohol and drug use</b>
	<ul style="list-style-type: none"> <li>Can you tell me how often you used alcohol or recreational drugs in the last month?</li> <li>(Ask caregiver) Have you noticed any changes in _____ (name) behaviour at home, with friends, and/or at school?</li> </ul>
	<b>6. Support network and coping mechanisms</b>
	<ul style="list-style-type: none"> <li>Who supports you at home?</li> <li>Do you have any activities that you enjoy?</li> <li>How do you cope when you feel depressed or sick?</li> </ul>
<b>If the client/caregiver reports any problems that are interfering with their relationships, school/work performance, and/or ability to manage responsibilities at home, this may indicate a mental health problem that warrants further assessment (see next section).</b>	

### Behaviour during clinic visits

The healthcare workers should also pay close attention to the client's behaviour during clinic visits, as this may provide important information about a person's mental health. Healthcare workers should observe the following:

- Appearance:** How is the client's hygiene and grooming?
- Behaviour:** Is the client behaving normally? Or, is the client behaving restless, "jumpy," or slow?
- Attitude:** Is the client's attitude cooperative or belligerent?

- **Speech:** Is the client's speech normal? Or is the client's speech overly loud, slow, rapid, or slurred?

## **Common Mental Health Problems in ALHIV<sup>5,6</sup>**

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The client who is exhibiting signs or symptoms of mental health problems based on the mental health screening tool (see “Table 6.1: Assessment of well being screening tool”), needs further assessment. Healthcare workers should develop and maintain the necessary skills to recognise, address, and in some cases prevent, the major mental health problems commonly associated with HIV.

The signs, symptoms, and treatment options of common disorders are summarised below. This content is based on guidelines from the American Psychiatric Association in the United States. Although these tools for screening and treatment of mental health disorders have not been tested in Zambia, they can at least provide some guidance for clinicians.

## **Anxiety**

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Anxiety disorders, which can cause enormous distress and/or disability, are different from everyday, normal anxiety. Anxiety disorder:

- Is more intense (for example, panic attacks),
- Lasts longer (anxiety that may persist for months instead of going away after a stressful situation has passed), or
- Leads to phobias (irrational fears) that interfere with daily life.

In adolescents, anxiety is a common reaction to learning their HIV diagnosis.

### **Signs and symptoms of anxiety:**

- Cannot eat
- Cannot breathe or shortness of breath
- Shaking and sweating
- Heart pounding fast
- Tingling in the hands or feet
- Headaches
- Trouble sleeping
- Cannot concentrate on anything
- Feel “jumpy”, “stressed”, or restless
- Feel worried about many things
- Can present differently for younger and older adolescents, for example younger adolescents may exhibit acting out behaviours

Anxiety can also present as panic disorders and posttraumatic stress disorder. Healthcare workers should screen and assess clients for anxiety according to the guidelines in “Appendix 6A: Screening and Management Tool for Anxiety”.

### **Management and treatment for anxiety:**

- Counselling, including support groups
- Teach client relaxation techniques
- If there is no improvement, refer to a psychiatrist at the nearest hospital

## **Depression**

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Depression is the most common mood disorder seen in ALHIV.

### **Signs and symptoms of depression:**

- Feel like you just do not know what to do (depressed mood, helpless or hopeless)
- Really tired with no energy
- Cannot find good in anything
- Do not enjoy the things you used to (loss of interest or pleasure)
- Sleep too much or not enough
- Get angry for no reason
- Cannot eat or eat too much
- Do not feel like being social with friends or family
- Feelings of guilt or low self-worth
- Poor concentration.
- Desire for sex decreases
- Talk about running away
- Think about suicide
- Talk of self injury or prior episode(s)
- Prior attempts or expressions of suicide

These problems can become chronic or recurrent, and lead to impairments in the person's ability to take care of his or her everyday responsibilities. At its worst, depression can lead to suicide.

### **Risk factors for depression in an ALHIV:**

- Family history of depression or previous episode(s) of depression
- Dropping out of school or not accomplishing a significant goal
- Diagnosis of an illness, disease progression or hospitalisation
- Disclosure of a diagnosed illness to family and friends
- Low adaptive/coping ability
- Family financial difficulties, neglect/abuse, parental alcohol or substance abuse
- Difficulties in a romantic relationship
- Stress or trauma (including natural disasters)
- Having other behavioural or learning disorders
- Questioning sexual orientation
- Previous suicide attempt
- Loss of a parent or loved one, divorce of parents, or other losses

Healthcare workers should screen clients for depression:

- Upon enrolment into care,
- At routine check ups, AND
- Whenever symptoms of depression are reported

Healthcare workers can use the guidelines in “Appendix 6B: Screening and Management Tool for Depression” to screen and assess for depression.

### **Management and treatment for depression:**

- Family and individual counselling
- Medications
- Diet, exercise, and sleep modifications with family involvement to increase compliance
- Psychosocial counselling for problem resolution (see Module 5)
- Combination of counselling and medications
- Some things to consider before initiating medication: Consider possibility of substance use and ensure that standard medical assessment includes CD4 count. In clients with severe immunosuppression, depression can indicate a new OI. If client recently began efavirenz, wait to see if symptoms spontaneously improve. If not, treat depression or consider ARV regimen change.

### **Screening for and management of suicide risk**

#### **Clients require urgent intervention if:**

- They indicate they might hurt themselves or another person or show any evidence of self-harm (for example, cut marks on the wrists/body)
- They are thinking about, threatening, or have attempted to kill themselves
- Their families cannot cope with them anymore and want to throw them out.

#### **Role of family and friends:**

- When clients are suicidal, caregivers, family, and friends are crucial sources of support who can reduce isolation and hopelessness.
- If family and friends are unwilling or unable to assist, provide organised support through community-based services.

See “Appendix 6B: Screening and Management Tool for Depression” and “Appendix 6C: Screening and Management Tool for Suicide Risk”. **Ensure clients assessed as high risk for suicide, are put under constant observation and hospitalised, if possible.**

## **Disruptive Behavioural Disorders**

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Disruptive behavioural disorders are marked by poorly regulated and socially unacceptable behaviours that interfere with the adolescent's ability to carry out daily activities and negatively affect school performance. Symptoms are typically observed in younger adolescents.

### **Signs and symptoms of disruptive behavioural disorders**

The signs and symptoms of disruptive behavioural disorders (will vary depending on the type of disorder) include:

- Frequent defiance of the authority of parents, teachers and others
- Arguing and refusing to obey rules at home and school
- Failure to take responsibility for bad behaviour or mistakes
- Resentment and looking for revenge
- Regular temper tantrums

Older children and adolescents with disruptive behavioural disorders may exhibit the following behaviours as well:

- Aggressive behaviours that threaten or harm people or animals
- Behaviours that destroy property such as fire setting, breaking windows or graffiti
- Stealing, bullying or lying to get something
- Serious violations of rules, including school truancy and running away from home

Adolescents with attention deficit hyperactivity disorder (ADHD), which can co-occur with disruptive behavioural disorders, exhibit the following symptoms:

- Trouble paying attention and concentrating
- Difficulty organising activities
- Easily distracted
- Failure to finish most tasks
- High activity level
- Cannot sit still
- Impulsivity, acting without thinking
- Cannot wait for a turn
- Interrupt

### **Management and treatment for disruptive behavioural disorders:**

- Counselling with the client focusing on self-regulation
- Counselling with caregivers focusing on improvements in parenting skills and giving advice on how to create a structured home environment
- Medication
- Referral to any local support services

## Neurocognitive Disorders

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HIV in children is associated with developmental delays and cognitive impairments. Some children have normal development, some have mild impairment and others have severe impairment. Factors that affect the degree of impairment include the timing of HIV infection and the use of ART.

### Signs and symptoms of neurocognitive disorders:

- Delayed expressive language skills (problems expressing him or herself using spoken language)
- Slowed psychomotor speed (taking longer than normal to understand what someone else is saying and then respond)
- Memory deficits (experiencing a loss of memory)
- Poor attention (difficulty concentrating or paying attention)
- Developmental impairment (not developing as expected, developmental impairment is most common among children who experience severe immunodeficiency during the first few years of life)

### Management and treatment for neurocognitive disorders:

- Provide client and family tailored supportive counselling that meets the unique strengths, disabilities and needs of the adolescent
- Ensure that the adolescent is on an adequate ARV regimen to prevent or slow further progression of neurocognitive impairment
- Encourage caregivers to follow this general principal: reward effort, not results
- Link client and family to community based resources for children and adolescents with intellectual and developmental disabilities
- Look for areas of strength that can be developed to promote social and occupational skills
- Provide extra guidance to manage sexual impulses
- Provide the caregivers of older, stronger adolescents who are severely impaired with assistance and support to manage behavioural disturbances

## Severe Mental Illness

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Severe mental illness usually refers to schizophrenia, schizoaffective disorder, and other mental illnesses that can have psychotic features (in other words, loss of contact with reality). Psychotic illnesses are assumed to be primarily the result of neurotransmitter imbalances in the brain; however, psychotic disorders can also result from reactions to outside stressors or medications. In talking with clients, healthcare workers may discover psychosis exhibited by clients' bizarre ideas or delusions, or by their disorganised thinking and language.

### Signs and symptoms of serious mental illness:

- Bizarre delusions

- Auditory and visual hallucinations (client reports hearing or seeing things)
- Paranoia
- Agitation
- Suspiciousness
- Hostility
- Exaggerated sense of self

Healthcare workers can use the guidelines in “Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders” to screen and assess for psychotic disorders in clients.

### **Assessment of serious mental illness:**

First rule out delirium, a serious *medical* (i.e., not psychological) condition that can also present with delusions, hallucinations (to see or perceive something that is not there) and agitation. Many serious medical conditions can cause delirium, which is characterised by rapid onset and changes in consciousness, confusion and inattention. Head trauma can cause delirium, as can alcohol and other drugs intoxication or withdrawal. Always check for fever — an agitated adolescent who is febrile should always be presumed to be medically ill.

#### **Delirium**

A rapid change in mental state associated with confusion and varying degrees of alertness (for example agitated one minute and drowsy the next) suggests the serious medical condition known as delirium.

**Adolescents suspected of delirium should be referred for urgent medical evaluation and treatment.**

### **Management and treatment of serious mental illness:**

- If delirium is *not* suspected, refer to a psychiatrist or mental health nurse for assessment and treatment (generally using prescribed antipsychotic medications)
- Clients with severe mental health disorders should not be discriminated against when ARV treatment is considered. Stabilisation of psychiatric symptoms and directly observed treatment by a caregiver or treatment supporter will likely improve adherence.

## **Providing Mental Health Support to Clients and Caregivers<sup>7,8</sup>**

### **Challenges**

Barriers and challenges to providing mental health services include the following:

- Insufficient number of mental health specialists to provide effective training and supervision of primary care workers

- Limited information on prevalence of mental health disorders in African countries
- Lack of validated and context-appropriate screening tools
- Few treatment options (for example, therapy, medication)
- Little data are available on the treatment of psychiatric disorders in ALHIV
- Social stigma of people living with persistent mental illness
- Little is known about the links between depression and other specific behavioural disorders in this population

### **Important components of mental health services for ALHIV**

The treatment for mental health problems in ALHIV is generally similar to the treatment approaches among non-infected clients. Healthcare workers providing mental health services for ALHIV should:

- Use a solution-focused counselling approach aimed at: enhancing problem-solving, brainstorming together on ways of coping including lifestyle changes, identifying choices and evaluating the value and consequences of choices.
- Include the family. If the client gives permission, ensure the inclusion of the family when providing mental health services. The advantages of family-focused services include the following: they give families a chance to discuss issues together, learn new things about each other, explore problems and then work on solutions together — ensuring a wider commitment for plans that come out of the counselling session. Family counselling can provide the building blocks for a more functional and communicative household, enhancing the wellness of the entire family.
- Encourage peer contact and support. Identify other ALHIV in the community who have adjusted to their life and are willing to talk about it. Arrange for them to meet the client and his or her family so that they can give support and inspiration.
- Refer the client to support groups for ALHIV, so he or she can meet other ALHIV who are living healthy, positive lives.
- Ensure that the basic needs (for example, food, shelter, clothing, etc.) of the ALHIV are met.
- Identify other community resources and support groups and link the client and family with them. These could be groups to help with finances, spiritual counselling, childcare, transport, or other needs.
- Provide referrals to mental health providers (for example, mental health specialists, psychologists and/or psychiatrists, if available).
- Discourage use of recreational drugs and alcohol because they can make mental health problems worse.
- Prescribe medications, when appropriate. But if not prescribed by a doctor, discourage the use of antidepressant medicines because they can have serious side effects. Even if prescribed, the caregiver must supervise their use. It can take a few weeks before antidepressants begin to improve depression, although the side effects appear right



away. To be safe and effective, antidepressants need to be used consistently and in the exact doses that are prescribed.

- Be managed by a doctor AND a mental health professional — for example, a psychiatrist, psychologist, or social worker — who is in close communication with the physician or nurse providing the HIV treatment.
- Respect and listen to clients' beliefs on the origin and healing of mental health problems. Beliefs concerning the treatment of mental health conditions vary among members of different cultural groups. Some clients will reject conventional Western methods of treating mental health disorders. Others, particularly those from communities where there is a strong sense of spirituality, may consult spiritual leaders for help. Yet other clients and caregivers will feel comfortable with interventions grounded in their own cultural traditions and practices.

### **Treating mental health problems with medication**

- Prescription antidepressant medications are generally well-tolerated and safe for people living with HIV. But like all medications, they can have side effects and require careful monitoring.
- Healthcare workers should learn about antidepressants and their interactions with HIV-related medications.
- It is important to be aware that the use of antidepressants in adolescents is sometimes associated with an increased risk of suicide.
- Any behavioural changes in a client require further assessment for possible medical problems, including drug-drug interactions.
- If medication is prescribed to a client for a mental health problem, it should, whenever possible, be combined with counselling.
- An important consideration for patients who are mentally ill is adherence to both HIV and any other medication regimens. Healthcare workers should assess a client's adherence to ALL prescribed medications at every visit.

### **Healthcare workers can support adolescent clients experiencing mental health problems by:**

- Reminding them that feelings of depression and anxiety are common, but should be managed as much as possible: *"Recognising the problem is the first step in dealing with it, therefore please ask for help if you have symptoms such as crying, loss of appetite, excessive anxiety, or feel panicked."*
- Helping them set goals around living positively, like eating well, getting good medical care, and practising safer sex.
- Reminding them that sometimes caregivers may also be tired and discouraged. This is not necessarily directed at the client personally, but is a result of the situation.

## Encourage caregivers

An important part of helping adolescents cope with mental health issues is to encourage caregivers to strengthen their relationship with the adolescent. Healthcare workers can suggest that the caregivers:

- Spend time with and listen to the adolescent.
- Let the adolescent know that their painful feelings are common. Encourage them to talk and express feelings and thoughts. Listen actively.
- Communicate unconditional love and acceptance by using appropriate nonverbal gestures and verbal communication. This will give them an opportunity to understand and help them to overcome their negative feelings.
- Help the adolescent plan daily or weekly activities. This encourages them to be active and retain control of their life.
- Involve the adolescent in family activities as much as possible.
- Relax. It is important for both the adolescent and the family to learn to relax both physically and mentally.
- Get enough rest and eat well.
- Get professional help from a counsellor.
- Be aware that when emotional distress is persistent and interferes with daily activities, a mental illness may be present, and evaluation by a doctor or mental health provider is needed.
- Talk to someone; family members may also be depressed and need help.
- Get help from a support organisation in the community.
- Continue their regular religious or spiritual practices.

### Exercise 2: Mental Health Assessment and Support: Role play and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss mental health assessment and provision of support to ALHIV and their caregivers</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Two participants will be invited to role play each of the case studies below. The role plays will be conducted, one at a time, in the front of the room.</li> <li>2. For each role play, the trainer will stop the role play to ask participants about the main mental health concerns for this client, tools that should be used to screen this client, and how the client should be managed.</li> <li>3. Throughout the role plays, participants should refer to “Table 6.1: Assessment of well being screening tool”, and then to either “Appendix 6A: Screening and Management Tool for Anxiety”, “Appendix 6B: Screening and Management Tool for Depression”, “Appendix 6C: Screening and Management Tool for Suicide Risk”, or Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders”.</li> </ol>

## **Exercise 2: Mental Health Assessment and Support: Role play and large group discussion**

### **Case Study 1:**

Mary is a 16-year-old client living with HIV. Mary tells you that her mother died last year. She says that she feels “stressed out” most of the time. She tells you that managing her schoolwork and taking care of her siblings is overwhelming, and she thinks that she will need to drop out of school. Mary also reports that she is often consumed by a sense of panic and feels like “her heart is leaping out of her chest.”

### **Case Study 2:**

Namwene is 13 years old and has been coming to the ART clinic since she was a small child. As a young child, she maintained good grades in school, and was described by her mother and grandmother as being helpful around the house. Recently, however, Namwene's relationship with her family has deteriorated, she is not eating or sleeping regularly, and she has run away from home twice in the past year. Namwene's mother suspects that she is using alcohol and possibly other drugs.

### **Case Study 3:**

Mumba is a 15-year-old boy who is perinatally infected with HIV. Accompanied by his grandmother, he comes to the clinic for a routine 3-month HIV visit with chronic fatigue, "difficulty remembering things," and gastrointestinal complaints. When you ask how he is feeling, he shrugs his shoulders but does not say anything. Mumba has a few friends, none of whom knows that he is living with HIV. His grandmother says he does not like to play and is withdrawn, preferring to just spend time alone. How would you proceed?

### **Case Study 4:**

Peter, a 14-year-old boy who is perinatally infected with HIV, and his aunt arrive at the clinic for a routine check up. Peter is described by his aunt as being temperamental, hard to handle, and high-strung. His aunt also reports that he was suspended from school due to fighting with his classmates. She says he is also violent with his cousins at home and she does not know what to do to manage his behaviour. Peter was living with his mother until she died two years ago. He has not made a good adjustment to living with his aunt and feels she treats him differently than her own children. How would you proceed?

### **Case Study 5:**

Jane is an 18-year-old young woman who has been coming to the ART clinic for 2 years. Recently, she had missed a couple of visits and has appeared withdrawn and even tearful at the clinic. She also reports "drinking a little" and "not being very good at remembering to take all of her medications." You know that Jane has recently broken up with her boyfriend of 4 years, and she complains to you of sleep problems, having no energy, and says she has “lost hope” about her life. You notice that

Jane has cut marks on her wrists. How would you proceed?



### Module 6: Key Points

- ALHIV face stressors associated with their disease, including loss and bereavement, cycles of wellness and poor health, barriers to care and community-based/social services. These stressors, combined with the normal stress of adolescence, means that ALHIV are especially susceptible to mental health problems.
- Healthcare workers should conduct a basic screening of mental health problems at every clinic visit, and ask caregivers about any changes in the client's behaviour at home, with friends, and/or at school. Healthcare workers should also observe behaviour during clinic visits to validate findings from the screening. Systematic screening for mental health problems and mental illness makes it possible to detect and treat problems early, potentially preventing the more serious issues.
- ALHIV may be at greater risk for mental health problems, such as depression. Anxiety is also very common in people living with HIV. Some clients will show signs and symptoms of both depression and anxiety. Anxiety and depression are common reactions to living with HIV, especially when people are not feeling well and do not get the support they need from family, friends, healthcare workers, and their community. Other common mental health issues include disruptive behavioural disorders, neurocognitive disorders, and "severe mental illness", which includes schizophrenia.
- Although there are barriers to providing mental health services in many settings (for example, insufficient resources, few treatment options, little data on ALHIV and mental health prevalence in sub-Saharan Africa), there are many concrete steps healthcare workers can do to support clients and caregivers.
- Healthcare workers can help clients and caregivers stay mentally healthy by offering counselling and emotional support, practical suggestions about how to positively cope with life, and referring them to support groups, spiritual counsellors, mental health professionals (if indicated), and other groups.

## Appendix 6A: Screening and Management Tool for Anxiety

✓	Screening and management of anxiety in adolescents	
	<b>1. Screen clients for anxiety by asking:</b>	
	<ul style="list-style-type: none"><li>Do you experience palpitations (for example, heartbeat that is too fast)?</li><li>Do you have a choking sensation or shortness of breath (hyperventilate)?</li><li>Do you have clammy hands and sweat profusely?</li></ul>	
	<b>2. If client responds YES TO 1 OR MORE of the above questions, ask:</b>	<b>3. If client says YES to this question:</b>
	1. Do the above symptoms last for more than 6 months on and off?	⇒ Client may have generalised anxiety disorder.
	2. Do you have a feeling of impending doom?	⇒ Client may have panic disorder.
	3. Do you experience intrusive thoughts (obsessions or repeated thoughts that always come back to your mind)?	⇒ Client may have obsessive compulsive disorder.
	4. Do you have repeated behaviour (compulsion or unwanted behaviours that seem impossible to stop or control) in an attempt to relieve the intrusive thoughts (obsessions or repeated thoughts that always come back to your mind)?	
	5. Do you have an unexplained or irrational fear or worry?	⇒ Client may have a phobia.
	6. Do you have vivid recollection or nightmares of a past trauma?	⇒ Client may have post-traumatic stress disorder.
	<b>4. Provide care and referrals:</b>	
	<ul style="list-style-type: none"><li>Refer to a psychologist, psychiatrist, and mental health nurse if available, or provide basic counselling:</li><li>Explain that these symptoms are part of an illness called anxiety, which is common and treatable.</li><li>Recognise the client's distress by stating that you understand, and want to help.</li><li>Identify current life problems and stressors, and focus on small steps the client might take to manage these problems.</li><li>If client is taking efavirenz, make sure he or she is taking at bedtime. Symptoms usually resolve within first month of treatment.</li><li>Advise client to discontinue use of substances that promote anxiety such as cigarettes and caffeinated beverages or stimulant drugs of abuse (e.g. chat)</li></ul>	
	<b>5. Teach interventions to use during an anxiety attack (an episode of acute anxiety and feelings of panic):</b>	
	<ul style="list-style-type: none"><li>Relaxation techniques: Sit upright in a chair with the feet flat on the ground and hands on the knees. Relax the whole body.</li><li>Controlled breathing: When seated (as above), breathe in and hold breath for 10 seconds then breathe out and hold breath for 10 seconds. Repeat this until the palpitations stop and person feels relaxed.</li><li>Re-breathing: If too agitated to sit still, then obtain a paper bag, cover nose and mouth with the bag, and breathe in and out of the paper bag until relaxed.</li></ul>	
	If there is no improvement, refer to a psychiatrist at the nearest hospital.	

Adapted from: American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6B: Screening and Management Tool for Depression

✓	<b>Screening and management of depression in adolescents</b>	
	<b>1. Screen clients for depression by asking:</b>	
	<ul style="list-style-type: none"> <li>Do you feel sad or depressed?</li> </ul>	
	<ul style="list-style-type: none"> <li>Have you felt little interest or pleasure in doing things you usually enjoy?</li> </ul>	
	<ul style="list-style-type: none"> <li>Do you have less energy than usual?</li> </ul>	
	<b>2. If client responds YES TO 1 OR MORE of the above questions, ask:</b>	
	<b>Questions for client</b>	<b>Assessment</b>
	<ul style="list-style-type: none"> <li>Over the past month, how would you say you've been sleeping: about the same as usual, better than usual or worse than usual?</li> <li>Is your sleep disturbed?</li> <li>When do you go to bed? When do you wake up? Do you sleep during the day?</li> </ul>	Experiencing disturbed sleep or sleeps most of the day? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, would you say that you have been eating about the same amount as usual, more than usual or less than usual?</li> </ul>	Experiencing appetite loss or increase? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, would you say your weight has been steady, or do you think you've gained or lost weight? (If possible, verify changes in weight with medical record.)</li> </ul>	Experiencing weight loss or gain? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the last month, would you say your <b>interest</b> in day-to-day activities has been about the same as usual, or have you been more interested or less interested than usual?</li> </ul>	Experiencing reduced interest in day-to-day activities? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the last month, would you say your <b>pleasure from</b> day-to-day activities has been about the same as usual, or have you received more pleasure or less pleasure from these activities than usual?</li> </ul>	Experiencing reduced pleasure in day-to-day activities? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, has your desire for sex been about the same as usual, or has it increased or decreased? Or is this question not applicable to you?</li> </ul>	Experiencing decreased desire for sex? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, would you say your ability to concentrate is about the same as usual, or is it better or worse?</li> </ul>	Experiencing poor concentration? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, would you say that you have felt hopeless or helpless?</li> </ul>	Feelings of hopelessness and helplessness? <input type="checkbox"/> Yes <input type="checkbox"/> No
	<ul style="list-style-type: none"> <li>Over the past month, have you considered killing yourself?</li> </ul>	Thoughts of suicide or death?

	<ul style="list-style-type: none"> <li>Over the past month, would you say that you have been thinking a lot about death?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No
If client has suicidal thoughts, administer the screening tool for suicide.		
	<ul style="list-style-type: none"> <li>Do you hear voices inside your head or ears (auditory hallucinations)?</li> <li>Do you see things others do not see (visual hallucinations)?</li> <li>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</li> </ul>	Delusions or hallucinations? <input type="checkbox"/> Yes <input type="checkbox"/> No
If client is experiencing delusions or hallucinations, administer the screening tool for psychotic disorders.		
<b>Total number of "yes" responses:</b>		
<b>3. If the client responded "yes" to 5 OR MORE of the above questions, and symptoms have lasted MORE THAN 2 WEEKS, then the person may have Major Depression.</b>		
Refer to counselling services if available, or provide basic counselling: <ul style="list-style-type: none"> <li>Explain that these symptoms are part of an illness called depression, which is common and treatable.</li> <li>Recognise the client's distress by stating that you understand and want to help.</li> <li>Identify current life problems and stressors, and focus on small steps the client might take to positively cope and manage these problems.</li> <li>Refer to peer support group, if available.</li> </ul> <p>If client is taking efavirenz, make sure he or she is taking it at bedtime. Symptoms usually resolve within first month of treatment.</p>		
<b>4. If the client responded "yes" to LESS THAN 5 of the above symptoms or has experienced MORE THAN 2 MONTHS OF BEREAVEMENT with functional impairment:</b>		
<ul style="list-style-type: none"> <li>Offer ongoing supportive counselling to counter depression.</li> <li>Follow up in 1 week.</li> </ul>		
<b>5. If the client responded "yes" to LESS THAN 5 of the above symptoms, but is ABLE TO FUNCTION day-to-day:</b>		
<ul style="list-style-type: none"> <li>Counsel and assure psychosocial support.</li> </ul>		

Adapted from: American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6C: Screening and Management Tool for Suicide Risk

The **SAD PERSONS** scale is an acronym used as a mnemonic device for a suicide risk clinical assessment tool. This tool that appears below was adapted by Gerald A. Juhnke in 1996 for use with children and adolescents.

✓	Screening tool for suicide	
	Questions for client	Response
<b>S</b>	<b>1. Sex</b>	
	Tick “yes” if client is male.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>A</b>	<b>2. Age</b>	
	<ul style="list-style-type: none"> <li>How old are you?</li> </ul> Tick “yes” if client is older than 15 years.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>D</b>	<b>3. Depression or affective disorder</b>	
	Tick “yes” if client is depressed. (See Screening Tool for Depression.)	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>P</b>	<b>4. Previous suicide attempt or psychiatric care</b>	
	<ul style="list-style-type: none"> <li>Have you ever tried to commit suicide?</li> </ul> Tick “yes” if client has previously tried to kill him or herself.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>E</b>	<b>5. Ethanol or drug abuse</b>	
	<ul style="list-style-type: none"> <li>How often do you drink alcohol? How many drinks do you have?</li> <li>What other recreational drugs do you use? How often do you use them?</li> </ul> Tick “yes” if client abuses alcohol or drugs.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>R</b>	<b>6. Rational thinking loss (psychosis)</b>	
	<ul style="list-style-type: none"> <li>Do you hear voices inside your head or ears (auditory hallucinations)?</li> <li>Do you see things others do not see (visual hallucinations)?</li> <li>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</li> <li>Do you have periods of abnormal (disorganised) behaviour that cause concern to the people around you?</li> </ul> Tick “yes” if client has experienced psychosis.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>S</b>	<b>7. Social support lacking</b>	
	<ul style="list-style-type: none"> <li>Have there been any major changes in your family over the past 3–5 years? (parental death, death of another family member, divorce, re-marriage)</li> <li>Have you currently broken up with a partner or close friend?</li> </ul> Tick “yes” if client either lacks social support, or has experienced recent losses to their support system.	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>O</b>	<b>8. Organised plan or attempt</b>	
	<ul style="list-style-type: none"> <li>Do you have a plan for how you want to commit suicide?</li> </ul>	<input type="checkbox"/> Yes <input type="checkbox"/> No



	Tick “yes” if client has a plan.		
<b>N</b>	<b>9. Negligent parenting, significant stressors, suicidal modelling by parents or siblings</b>		
	<ul style="list-style-type: none"> <li>How is your relationship with your parents? Did your parents ever hit you?</li> <li>Has anyone else in your family committed suicide?</li> </ul> Tick “yes” if client has a history of neglect, abuse, trauma, chaotic lifestyle, or history of suicidal behaviours in the family.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>S</b>	<b>10. School problems</b>		
	<ul style="list-style-type: none"> <li>How is school going?</li> <li>How many friends would you say you have at school?</li> <li>Is there anyone at school that bullies you, that is, makes fun of you, hits or threatens you?</li> </ul> Tick “yes” if client has a history of chronic conflict with peers and problems associated with school.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
<b>Total number of “yes” responses:</b>			
<b>11. Interpreting scores</b>			
Total number of “yes” responses:			
0–2	No real problems, provide counselling*, send home but set appointment for follow up		
3–4	Provide counselling*, send home but check frequently		
5–6	Provide counselling*, refer to psychologist or consider inpatient depending on safety level and follow-up capability		
7–10	Refer for hospitalisation (voluntary or involuntary)		
*Counselling: <ul style="list-style-type: none"> <li>Recognise the client’s distress by stating that you want to help.</li> <li>Identify current life problems and stressors, and focus on small steps the client might take to manage these problems.</li> <li>Encourage client to resist being pessimistic and self-critical.</li> <li>Do not leave the client alone.</li> <li>Remove any harmful objects from the home.</li> <li>If the underlying problem is depression, manage according to the guidelines in “Appendix 6B: Screening and Management Tool for Depression”.</li> <li>Before giving medication, ensure relatives are available to store the medication and administer it to the client — at least during the first 2 weeks of treatment. Be aware that tricyclic antidepressants are quite dangerous in overdose.</li> <li>Frequent consultations and counselling are advised when there is no other social support.</li> </ul>			

Adapted from: American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## Appendix 6D: Screening and Management Tool for Primary Psychotic Disorders

✓	<b>Screening and management of psychotic disorders in adolescents</b>
	<b>1. Rule out delirium</b>
	<p>Delirium is a serious medical condition that can also present with delusions, hallucinations (often visual) and agitation. Suspect delirium if any the following are present:</p> <ul style="list-style-type: none"> <li>• Rapid onset and changes in consciousness (for example agitated one minute and sleepy the next).</li> <li>• Confusion and inattention</li> <li>• Poor orientation to time, place or person</li> <li>• Patient appears to be physically ill</li> <li>• History of recent head trauma</li> <li>• History of alcohol and/or other drug intoxication or withdrawal</li> <li>• History of seizure disorder</li> <li>• Fever — an agitated adolescent who is febrile should always be presumed to be medically ill.</li> </ul> <p>Adolescents suspected of delirium should be referred for urgent medical evaluation and treatment.</p>
	<b>2. If delirium is not suspected, screen clients for psychotic disorders by asking:</b>
	• <i>Do you hear voices inside your head or ears (auditory hallucinations)?</i>
	• <i>Do you see things others do not see (visual hallucinations)?</i>
	• <i>Do you have suspicions (paranoid delusions) that people around you feel are excessive?</i>
	• <i>Do you have periods of abnormal (disorganised) behaviour that cause concern to the people around you?</i>
	<b>3. If the client responded “yes” to 1 OR MORE of the above questions, observe whether:</b>
	<ul style="list-style-type: none"> <li>• The client is unkempt</li> <li>• The behaviour is bizarre</li> <li>• The thoughts do not make sense or are completely unrealistic</li> <li>• The patient is angry, agitated or suspicious</li> <li>• The client talks to him/herself, or appears to be talking to people who are not there.</li> </ul>
	<b>4. If the client has symptoms of any one of the above:</b>
	<ul style="list-style-type: none"> <li>• Consider giving antipsychotic medications.</li> <li>• Provide basic counselling</li> </ul>
•	<b>5. If symptoms get worse :</b>
	<ul style="list-style-type: none"> <li>• Reassess for delirium</li> <li>• Refer to a psychiatrist or mental health nurse for assessment</li> </ul>

Adapted from: American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.

## References and Resources

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- <sup>1</sup> Bush-Parker, T. 2000. *Perinatal HIV: Children with HIV Grow Up*. Focus: A Guide to AIDS Research and Counseling; 15(2):1–4.
- <sup>2</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>3</sup> Mellins, C., Brackis-Cott, E., Leu, C., Elkington, K., Dolezal, C., Wiznia, A., McKay, M., Bamji, M., Abrams, E.J. 2009. *Rates and Types of Psychiatric Disorders in Perinatally Human Immunodeficiency Virus-Infected Youth and Seroreverters*. Journal of Child Psychology and Psychiatry ; 50(9):1131–1138.
- <sup>4</sup> Mellins C.A., Brackis-Cott, E., Dolezal, C., Abrams, E.J. 2006. *Psychiatric Disorders in Youth with Perinatally Acquired Human Immunodeficiency Virus Infection*. Pediatric Infectious Disease Journal; 25(5):432–437.
- <sup>5</sup> American Psychiatric Association. 1994. *Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV)*.
- <sup>6</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>7</sup> Frank, L. 2006. *Adolescents, HIV, and Mental Health*. AETC National Resource Center and AETC Adolescent HIV/AIDS Workgroup.
- <sup>8</sup> Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.



## Module 7

# Providing Disclosure Counselling and Support

**Session 7.1: The Disclosure Process: A Developmental Approach**

**Session 7.2: Disclosure Preparation, Counselling, and Support for Caregivers**

**Session 7.3: Disclosure Counselling and Support for Adolescents Who Know Their Status**

### Learning Objectives

**After completing this module, participants will be able to:**

- Apply a developmental approach to the process of disclosure preparation.
- Support caregivers to understand the importance of disclosure and to continue to move through the disclosure process with adolescents.
- Provide counselling and support to adolescents on disclosing their HIV status to others.

## Session 7.1      The Disclosure Process: A Developmental Approach

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### Session Objective

**After completing this session, participants will be able to:**

- Apply a developmental approach to the process of disclosure preparation.

### Overview of Disclosure and ALHIV<sup>1,2</sup>

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#### What is disclosure?

Disclosure should be seen as a process — not a one-time event — of telling an adolescent that he or she has HIV, and helping the young person to understand what this means. It can also mean helping an ALHIV to disclose his or her HIV status to others. It is a 2-way conversation that involves:

- Speaking truthfully with the adolescent (and sometimes the caregiver), over time, about his or her illness,
- Disclosing the specific diagnosis at a time appropriate to the young person's needs or helping the caregiver to do so, and
- Helping the young person prepare to disclose to others and providing follow-up support during the process.

#### Through the process, the young person should come to know about:

- The diagnosis, the infection and disease process, and health changes that could occur.
- Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
- How to cope with the possible negative reactions of others.

#### Developmental approach to disclosure for adolescents

- Decisions about when to start talking to children about their health will be determined by the readiness of the caregiver, as well as by the developmental stage of the child.
- Each phase of an adolescent's development (from early to late adolescence) has characteristic features. Understanding an adolescent's developmental stage and needs is vital to disclosure. An adolescent's understanding of the process will evolve as their brain becomes more equipped to absorb complex material and as emotional maturity level increases.
- Understanding adolescent development will help healthcare workers and caregivers better guide the disclosure process for adolescents, ensuring that appropriate information is presented when the young person is able to cope with it.
- It is important to note that developmental stages are associated with approximate ages; however, just because a young person is a certain

age does not necessarily mean that their development is the same as those of others in that age group. Therefore, it is also essential to follow up with questions to assess the young person's understanding.

See “Appendix 7A: Guidance for Developmentally Appropriate Disclosure” for additional information.

## Session 7.2      Disclosure Preparation, Counselling, and Support for Caregivers

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### Session Objective

**After completing this session, participants will be able to:**

- Support caregivers to understand the importance of disclosure and to continue to move through the disclosure process with adolescents.

### Disclosure of HIV Status to ALHIV

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To improve the chances that the disclosure process proceeds as smoothly as possible, healthcare workers should start talking about disclosure with caregivers WELL before the child is an adolescent (it is recommended that partial disclosure — see “Partial and Full Disclosure” on page 8 — begin by the time the child is 6 years old). Ideally, the young person will already know about their HIV status by the time he or she is an adolescent. However, there are challenges associated with the disclosure process and healthcare workers play an important role in helping families work through these barriers.

What are the reasons to disclose a child's HIV status?

- All children/adolescents have a right to know about their own health care.
- Adolescents often want and ask to know what is wrong. Adolescents are observant, smart, and curious.
- ALHIV who have not been disclosed to may have frightening or incorrect ideas about their illness, feel isolated and alone, learn their HIV status by mistake, or have poor adherence.
- Disclosure may help improve social functioning and school performance due to a decrease in stress.
- When adolescents learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, adolescents overhear healthcare workers and caregivers talking about their health as if they are not in the room.
- Children and adolescents are exposed to unintended “clues” of their diagnosis, for example, HIV-related signs on the walls of the clinics they attend, etc.
- Disclosure for orphaned or other vulnerable and most-at-risk adolescents is especially critical, because they may wonder why they have lost a parent or been rejected by the family. Disclosure will also help them seek the services they need, especially those who do not have regular caregivers.
- Adolescents who know their HIV status can access HIV care and treatment, take an active role in their care and treatment plan and, when old enough, take steps to live positively, adhere to treatment, and prevent new infections.

- Disclosure affects the mental health of the adolescent and caregiver. Non-disclosure does not protect the young person. Levels of anxiety, depression and low self-esteem have been shown to be higher in adolescents who have not been disclosed to. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression than those who do not).

## Barriers to Disclosure

### Healthcare worker barriers

Healthcare workers may also find it difficult to discuss HIV infection and disclosure with caregivers and adolescents. Healthcare workers experience some of the same barriers experienced by caregivers, such as not knowing where to start or being concerned about harming the adolescent (see next section). Training is essential to equip healthcare workers to support caregivers and adolescents throughout the disclosure process. Additionally, asking the advice of other healthcare workers who have been through this process with caregivers and observation of more experienced healthcare workers is important. Additionally, knowing the backgrounds, limitations and resources of caregivers will help to improve healthcare workers' sense of mastery and comfort assisting and supporting the disclosure process. Other barriers are listed in Table 7.1 along with suggested solutions for each barrier.

**Table 7.1: Solutions to healthcare worker barriers to disclosure**

Healthcare worker barrier	Suggested solution
<b>Healthcare worker may be unsure about their role or think that the process of disclosure is not their responsibility</b>	All members of the multidisciplinary team can support the process of disclosure in various ways. Discussing and defining healthcare workers' roles in the process of disclosure can promote effective coordination among the team members involved.
<b>Differences of opinion between healthcare workers and caregivers — or among healthcare workers.</b>	It can be challenging when the healthcare worker thinks that the adolescent needs to understand their HIV diagnosis but the caregiver is not ready to start or move ahead with the disclosure process.  When conflicts about disclosure arise, it is helpful to remember that disclosure is a process that takes time. Careful assessment of barriers to disclosure and working with the caregiver is often required to agree on what, when and how to disclose to the adolescent. It is always important to remember that the decision of the caregiver should be respected.



## Caregiver barriers

Caregivers may not want to disclose their children's HIV status for a number of reasons, all of which are valid. Healthcare workers should never judge a caregiver for their unwillingness to disclose, for their fears about disclosure, or their “performance” during the disclosure process. Table 7.2 includes a partial listing of caregiver barriers alongside suggested healthcare worker responses for each barrier.

**Table 7.2: Addressing caregiver barriers to disclosure**

Caregiver barrier	Suggested healthcare worker response
<b>Fear that disclosure will cause psychological harm</b>	<p>Those who fear that disclosure will cause psychological harm, may assume that disclosure could:</p> <ul style="list-style-type: none"> <li>• Reduce the adolescent's will to live</li> <li>• Make the adolescent think they are not normal</li> <li>• Strip adolescents of their happiness — an unconscionable gamble for caregivers who believe that children/adolescents are supposed to be happy</li> </ul> <p>Healthcare workers can:</p> <ul style="list-style-type: none"> <li>• Reassure caregivers that contrary to common assumptions, studies have shown that there are positive psychological benefits when they are appropriately aware of their illness. Studies suggest that young people who know their HIV status have higher self-esteem than young people who are unaware of their status. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression than those who do not).</li> <li>• Connect caregivers to others who have gone through the process of disclosure (peer support) and are willing to share their experiences.</li> </ul>
<b>Concern that topic is too complicated for the adolescent to understand</b>	<p>Reassure caregivers that the healthcare worker will work with them to ensure that all disclosure-related conversations are appropriate to the adolescent's age and developmental status (for example, understanding, emotional maturity, etc). The aim of these many conversations, that will take place over many years, is to help the adolescent become “appropriately aware of his or her illness”, not to explain everything all at once.</p>
<b>Unsure of where to start or how to respond to questions</b>	<p>The healthcare worker can begin talking to the caregiver very early about the disclosure process — long before anything is said to the adolescent. This will help the caregiver make a plan for where, when and how to begin the process of disclosure.</p>

<b>Lack of knowledge/comfort with topic</b>	<p>The healthcare worker should:</p> <ul style="list-style-type: none"> <li>• Provide caregivers with the background information they need to discuss HIV with their children. Ensure the caregiver's questions are answered throughout the disclosure process.</li> <li>• Provide the caregiver with possible answers to the adolescent's anticipated questions.</li> <li>• Role play various disclosure scenarios to give the caregiver practise.</li> <li>• Decide with the caregiver what is appropriate/necessary to tell the adolescent at each stage of development, given the adolescent's level of understanding.</li> </ul>
<b>Fear of stigma and discrimination against adolescent and other family members</b>	<p>Disclosure of HIV status is complicated by the fact that HIV infection brings with it stigma and discrimination that are rarely associated with other diseases. Healthcare workers can reduce this stigma and discrimination within family systems by:</p> <ul style="list-style-type: none"> <li>• Supporting caregivers to provide guidance to their adolescents about disclosure, and with whom they may safely speak about their illness (confidentiality within the home and community).</li> <li>• Suggesting to caregivers that they identify one or more trustworthy people with whom the adolescent is regularly in contact (other than the healthcare worker) to be a "safe" person — one with whom the child can discuss his or her HIV status, concerns and treatment. If adolescents have one "safe" person they will be less likely to disclose inappropriately.</li> <li>• Involving caregivers and other family members early in the disclosure process, to ensure misinformation about HIV is corrected early on.</li> <li>• Referring the adolescent and caregivers to support groups where others can provide advice on dealing with stigma.</li> <li>• Maintaining a continuous open line of communication with the adolescent to help him or her deal with their changing feelings about HIV and negative reactions from society.</li> </ul>
<b>Parent guilt regarding transmission</b>	<p>Healthcare workers should remember that disclosure of HIV status to adolescents is often a family issue as it is related to one or both of the parents' infection status. Healthcare workers can help parents deal with the shame or guilt of passing on HIV to their children by encouraging them to:</p> <ul style="list-style-type: none"> <li>• Understand that they should not blame themselves for getting HIV.</li> </ul>

	<ul style="list-style-type: none"> <li>• Take care of themselves, for example, go to the clinic regularly and take their medication. Taking specific actions to improve their health will reduce the sense of powerlessness that may accompany feelings of guilt.</li> <li>• Model positive living for their children. Healthy behaviours reflect a positive attitude towards life, thereby encouraging children to also see life with optimism.</li> </ul>
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Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François-Xavier Bagnoud Center, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

## Partial and Full Disclosure

Disclosure to adolescents depends on their stage of development: Young children may only need to know that they are sick and have to go to the doctor and take medicines to feel better (partial disclosure); older children/adolescents should know that they have HIV, understand the disease and the medications, and actively participate in their own care and treatment (full disclosure). As an adolescent develops, caregivers and healthcare workers should eventually move from partial to full disclosure, gradually helping the young person to understand and cope with knowing their diagnosis.

### Partial disclosure:

Children develop the ability for logical thinking around 6 years of age. It is at this time that they are able to begin to understand the concept of illness and what causes it; partial disclosure may therefore be considered around this age, particularly if the child has started asking questions related to his or her health. Partial disclosure:

- Refers to giving a child information about his or her illness without using the actual words "HIV" or "AIDS".
- Helps move the disclosure process forward and prepares the child/adolescent and caregivers for full disclosure later on.
- Is an effective strategy to help caregivers who do not yet feel ready to use the terms "HIV" and "AIDS" or for caregivers of young children who are not ready for full disclosure.
- Is useful for building a context in which full disclosure can be more meaningful for a child.

### Full disclosure:

"Full disclosure" is when a child/adolescent is specifically told that he or she is HIV-infected and given more HIV-related details, for example, how it is transmitted, how the child might have contracted it. Families and caregivers must decide at what point full disclosure is necessary. It is generally recommended that children are fully disclosed to when they are developmentally ready to receive the information, typically between the

ages of 10–14<sup>3</sup>. A particularly important indication that full disclosure should be considered is when the child starts asking specific questions about his or her illness, for example, how did he or she get the sickness, and no longer seems satisfied with the responses previously received.

Full disclosure is easier for the child/adolescent if they have been partially disclosed to over time, understand some basics about their health and their care and medicines, and have been supported throughout the disclosure process.

## Providing Disclosure Support to Caregivers

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General considerations when disclosing to adolescents:

- All adolescents have a right to know about their own health. We must work with caregivers to encourage disclosure.
- When we disclose to adolescents, we must consider the needs, feelings and beliefs of the adolescents, caregivers, as well as the specific family situation.
- We need to involve all of the adolescent's caregivers and make sure everyone has the same messages. Everyone should know how and when the young person will be disclosed to and what the ongoing disclosure plan is. There are challenges when a young person has many caregivers or when the caregivers change. Healthcare workers help by asking about all of the caregivers and family members, and by making sure they are given support throughout the disclosure process.
- Keep in mind that disclosure to adolescents depends on their stage of development:
  - Young adolescents may only need to know that they are sick, and must go to the doctor and take medicines to feel better.
  - Older adolescents should know that they have HIV, understand the disease and the medications, and actively participate in their own care and treatment.
- Plan for follow-up support to the family, including the young person, after disclosure.
- Healthcare workers should work with caregivers to develop a disclosure plan that incorporates the concerns and meets the individualised needs of all family members, including siblings and other relatives, if applicable.
- Healthcare workers should never make judgements about how the caregiver 'performs' during the disclosure process.
- Healthcare workers should always apply the principle of shared confidentiality within the multidisciplinary care team when discussing disclosure with clients and caregivers.
- **Remember: Disclosure to adolescents is not a one-time event and will require many conversations over time.**

## Healthcare Worker Role in Disclosure

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The role of the healthcare worker in the disclosure process:

- Usually, the primary caregiver should be the person to disclose to the child. Sometimes, caregivers ask for help with the process. A healthcare worker can assist, first by preparing the caregiver and then, if asked, being present when the caregiver talks with the child. In some cases, the healthcare worker may be asked to take a more active role in the disclosure process.
- Healthcare workers may or may not be involved in the discussions during which the adolescent is disclosed to — some caregivers prefer to do this at home, but some may prefer to come to the clinic where they can get assistance from the healthcare worker.
- The role of the healthcare worker is to encourage open dialogue about disclosure and offer practical strategies that are tailored to the individual family situation. They can help caregivers decide what information to give to the adolescent and when, given their child's age and development.

Supporting the caregiver in the disclosure process begins with the initial visits to clinic. The healthcare worker should:

- Build trust by getting to know the caregiver; find out what HIV means to him or her.
- Assess the caregiver's psychosocial situation, ability to cope, answer questions, and establish their sources of support.
- Discuss the implications of disclosure with the caregiver and the family to help them consider in advance the reactions of the child, family members, friends, and teachers.
- Help the caregiver develop a plan of disclosure for the child. The plan will:
  - List any preparations they need to make before disclosure,
  - Include what they will say, how and where they will disclose, and
  - Include plans for ongoing support.
- Arrange to see the caregiver (and the adolescent) again, to review this process.
- If there is disagreement between family members about timing and process of disclosure, assess all family members' concerns, and discuss benefits and risks of disclosure, potential harm of long-term non-disclosure. Collaborate with caregivers to make a plan tailored to the needs of the entire family.
- Always respect and try to understand caregivers' reasons for fearing or resisting disclosure. Validation of caregivers' concerns can foster a partnership and prevent the development of an adversarial relationship between the members of the healthcare team and caregivers.

**Remember: If the caregiver is not ready to disclose, the process cannot be forced.** If the family or community situation is such that disclosure is not currently an option, the healthcare worker may assist the caregiver in determining which factors are within their control to change and which are not. The safety of the caregiver, infected child/adolescent, and other children in the household, as well as their need for continuing

source of livelihood, are vitally important. If any of these issues will pose a potential risk, careful consideration should be given before disclosure discussions are initiated.

If the adolescent is not ready for the disclosure process, the caregiver and healthcare worker should try to determine the reasons:

- If the adolescent is not yet mature enough, the healthcare worker may suggest giving information to the adolescent a bit at a time, in language that the adolescent can accept, to allow him or her time to understand the information.
- If the adolescent appears to be emotionally unprepared, the healthcare worker may suggest that the caregiver let the adolescent know that both caregiver and healthcare worker are available to answer questions. A healthcare worker should always reassess the adolescent's readiness for disclosure over time.
- If the adolescent appears fearful of getting information, it may be that the client has overheard conversations and understands only a part of what has been heard. In this case, the healthcare worker should discuss with the caregiver how to encourage the young person to ask questions.

**An important task for the healthcare worker to assess is whether the caregiver is ready for disclosure.** The questions in Table 7.3 can be used to assess the readiness of the caregiver, prepare for the process, and determine the level of support that he or she may require from the multidisciplinary care team:

**Table 7.3: Questions to assess caregiver disclosure support needs**

1. Educating and preparing caregivers
<ul style="list-style-type: none"> <li>• What do they (the caregiver) think are the important points to communicate to the young person?</li> <li>• How do other family members feel about disclosing? Do some family members feel that it is the right time for disclosure and others feel that it is not?</li> <li>• What do they think will be the hardest part of the disclosure process?</li> <li>• What do they think will be the hardest questions to answer?               <ul style="list-style-type: none"> <li>• Acknowledge that disclosure is difficult.</li> <li>• Help caregivers anticipate the young person's questions and responses.</li> </ul> </li> <li>• What are their feelings about their child's health (address any guilt or shame)?               <ul style="list-style-type: none"> <li>• Affirm the caregiver's commitment to disclosing to the child.</li> <li>• Answer the caregiver's questions about HIV.</li> <li>• Plan how the young person will receive support after disclosure.</li> </ul> </li> </ul>
2. Planning for disclosure
<ul style="list-style-type: none"> <li>• When and where will disclosure start?               <ul style="list-style-type: none"> <li>• Ideally when the adolescent is in a comfortable place, such as the home.</li> </ul> </li> </ul>

<ul style="list-style-type: none"> <li>• With younger adolescents, encourage the caregiver to begin by playing with him or her, or conversing about the adolescent's day.</li> <li>• Who will lead the discussion and what is that person's relationship to the adolescent? Will there be other people involved, for example if the adolescent becomes angry and withdrawn or has questions that the caregiver may have trouble answering?</li> <li>• How will they start the conversation?</li> <li>• How will they provide support to the adolescent after disclosure?</li> <li>• How might disclosure impact family members, friends, school, and community members?</li> <li>• What support does the caregiver/family need?</li> </ul>
<b>3. Planning ongoing follow up and support for caregiver</b>
<ul style="list-style-type: none"> <li>• What support does the caregiver need to talk about the process and get answers to questions?</li> <li>• Who does the caregiver have to talk with if he or she has questions? <ul style="list-style-type: none"> <li>• Offer support to the caregiver to cope with their emotions and feelings after disclosure. Refer to a support group if possible.</li> </ul> </li> <li>• When will the healthcare worker and caregiver meet again? <ul style="list-style-type: none"> <li>• Plan for a follow-up counselling session with the adolescent and caregiver at the clinic.</li> </ul> </li> </ul>
<b>4. Planning ongoing follow up and support for client</b>
<ul style="list-style-type: none"> <li>• What support does the client need to talk about the process and get answers to questions?</li> <li>• Who does the adolescent have to talk with if he or she has questions? <ul style="list-style-type: none"> <li>• Offer support to the adolescent to cope with his or her emotions and feelings after disclosure. Refer to an ALHIV support group if possible.</li> <li>• Make sure the adolescent is given a chance to express their feelings — through talking, through role play, or through drawing, for example.</li> </ul> </li> <li>• When will the healthcare worker and client meet again? <ul style="list-style-type: none"> <li>• Plan for a follow-up counselling session with the young person and caregiver at the clinic.</li> </ul> </li> <li>• What are the adolescent's next steps to support him or herself to live positively with HIV (for example, ALHIV support group)?</li> <li>• To whom is the adolescent planning to disclose? <ul style="list-style-type: none"> <li>• Plan for disclosure to others (other family members, teacher, or peers), as agreed appropriate with the caregiver.</li> </ul> </li> </ul>

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

## Ongoing Disclosure Support to Caregivers and Clients

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Disclosure does not begin or end with a single conversation. As adolescents grow and develop, they need to be able to continue to ask questions and discuss their feelings. Caregivers will also need ongoing support as the process proceeds over time.

Healthcare workers should remember to use a developmental approach to disclosure, incorporating some of the techniques in “Appendix 7A: Guidance for Developmentally Appropriate Disclosure”.

In general, 3 levels of ongoing support are needed for adolescents and caregivers coping with HIV-related disclosure:

- **Support by the healthcare worker:** The role of the healthcare worker and caregiver is to continue talking to the adolescent and to assess if the adolescent has further needs. New needs might include, for example, to understand more about the diagnosis, to have someone to talk to, or to make friends who are experiencing the same challenges that they are, or to try to reduce risk behaviours and live positively.
- **Support in the household:** As part of ongoing disclosure support, healthcare workers should specifically review the level of support within the household and who knows the adolescent’s diagnosis. It is also important to discuss when siblings will be told about the HIV status of an infected family member. Disclosure to siblings may provide an ongoing and positive source of support for adolescents living with HIV.
- **Support through peers:** Peer support for ALHIV and/or their caregivers can be very important. Peer support can be one-to-one, in small groups or in larger groups. Healthcare workers could approach caregivers who have successfully navigated the disclosure process and encourage them to start a peer group for other caregivers. Healthcare workers can also seek permission from one adolescent to pair him or her with another ALHIV who is going through or has just gone through similar life events.

The role of the healthcare worker is to facilitate an ongoing, truthful conversation about disclosure with the adolescent and caregiver over time. Once the disclosure process has begun (ideally well before the child reaches adolescence), at each visit, healthcare workers should ask the **client**:

- *Why do you think you take these medications? What do you know about HIV?*
- *How have you been feeling since you learned about your HIV status?*
- *Who else knows about your illness? Who else do you talk to about HIV?*
  - Refer the adolescent to a peer support group.
- *What other questions do you have?*
- *How are you doing with your medications?*



Once the disclosure process has begun (ideally well before the child reaches adolescence), at each visit, healthcare workers should ask the **caregiver**:

- *Have you noticed any changes in your child's behaviour after he or she learned about their HIV status?*
- *What kind of help, support, or information do you still need?*
- *What other questions do you have?*
- *What feelings or concerns do you have about the disclosure process with your child?*
- *Who does the adolescent have to talk with if he or she has questions?*
  - Remind caregiver to offer support to the adolescent to cope with their emotions and feelings after disclosure.
- *When will we meet again?*
  - Plan for a follow-up counselling session with the adolescent and caregiver at the clinic.

#### **Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To give participants an opportunity to develop the knowledge, skills, and confidence to support caregivers and clients in the disclosure process</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. 2–3 volunteers will be asked to role play, in front of the large group, each of the case studies below (one at a time).</li> <li>2. Participants should refer to “Appendix 7A: Guidance for Developmentally Appropriate Disclosure”.</li> <li>3. During the role plays, the trainer will stop (“freeze”) the actors from time to time so that the large group can discuss what is going on.</li> </ol>

#### **Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion**

##### **Case Study 1:**

A mother named Ethel has been caring for her HIV-infected 10-year-old son, Tylor. Tylor keeps asking you why he has to take these pills and wants to know when he will finish taking them. When you ask the mother what Tylor knows about his health, she becomes quiet. How would you proceed with Ethel?

##### **Case Study 2:**

Amukusana is 11 years old. She has lived with her grandmother since her mother died three years ago. Amukusana and her grandmother have been visiting the clinic since Amukusana started to become symptomatic. The doctor wants her to start ART soon. Grandmother is having problems giving Amukusana her CTX. You believe that Amukusana would cooperate better if she understood more about the medication and why she needs it, especially since ART is now about to become part of their lives.

Grandmother thinks Amukusana is too young to know her status and insists

she does not need to know. How do you proceed?

**Case Study 3:**

Gabriel is a 12-year-old boy living with HIV and taking ART. He lives with his mother, maternal uncle, and 5 older half-siblings and cousins. Each time Gabriel comes to the clinic he gets very agitated when he gets blood drawn, and recently has been asking *“Why do I need to take medicines?”* and *“Why am I always coming here?”* Today, Gabriel seems very upset that he has to come to the doctor instead of playing with his cousins. When you ask, his mother has not told Gabriel anything about his HIV status or the reasons she has to come to the clinic so much. She asks your advice about what to do and asks for your help disclosing to Gabriel. How do you proceed?

## **Session 7.3      Disclosure Counselling and Support for Adolescents Who Know Their Status**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Provide counselling and support to adolescents on disclosing their HIV status to others.

### **Providing Disclosure Support to ALHIV**

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Healthcare workers can work with ALHIV to help them understand why disclosure is important and to whom they should disclose, based on the advantages and disadvantages. Healthcare workers can also help ALHIV to prepare for disclosure and provide follow-up support.

#### **Advantages of disclosure may include:**

- Avoid the burden of secrecy and feeling of hiding
- Avoid anxiety about accidental or unwanted disclosure
- Access to emotional and practical support from peers or family members, including the freedom to talk about symptoms and concerns
- Easier access to health care
- Enhanced adherence to care and medication
- Ability to discuss safer sex and family planning choices with one's partner(s)
- Ability to refer partner for HIV counselling and testing, and to care and treatment, if needed
- Freedom to ask a friend or relative to be a treatment buddy
- Access to peer support groups and community organisations
- Serve as a role model for other people on disclosure

#### **Disadvantages of disclosure may include:**

- Blame by partner or family for “bringing HIV into the household”
- Distancing, fear, rejection or abandonment by partner, family or friends/classmates
- Discrimination at school
- Discrimination in the community
- Discrimination at work, including possible loss of job
- Assumptions made about sexuality, promiscuity or lifestyle choices
- Rejection in the community
- Reluctance on the part of partner to enter into intimate relationships or have children
- Physical violence
- Self-stigma
- Loss of economic/subsistence support from family members or partners

## Helping ALHIV with the Disclosure Process

Disclosure counselling:

- Should not include pressure to disclose.
- Is a confidential conversation that assists clients to work through the issues related to telling others about their HIV status.
- Is important to reduce stigma, enhance adherence to care and treatment, and reduce the spread of HIV.
- Is intended to promote informed decisions about whether or not to disclose HIV status and, if so, to whom.
- Assists and supports clients who have decided to disclose their status.
- Enhances coping strategies following disclosure.
- Uses a tailored and developmental counselling approach, as each adolescent is unique.
- Is an ongoing process that requires preparation, practise and follow-up support.

Adolescents should make their own decisions about disclosure, but healthcare workers can assist ALHIV in the disclosure process by:

- Using good communication and counselling skills (for example, the 7 Listening and Learning Skills from Module 4).
- Talking about the client's fears and feelings around disclosure.
- Discussing the advantages and disadvantages of disclosure specific to the person's life.
- Supporting clients to make their own decisions about disclosure.
- Helping clients decide whom to disclose to, when and where.
- Helping the adolescent identify barriers to and fears about disclosure.
- Exploring possible options to overcome barriers.
- Providing accurate and detailed information in response to questions.
- Assisting the adolescent to anticipate likely responses, including possible negative reactions to disclosure.
- Talking about current and past sexual partners who need to be notified of their risk of HIV.
- Offering reassurance and emotional support.
- Identifying sources of support and referring clients to peer support groups.
- Encouraging the client to take the time needed to think things through.
- Practising disclosure through role plays with clients, including practical suggestions about how they will start the conversation. For example, you can suggest the

### Peer support and disclosure

Peer support can be an excellent resource for adolescent clients who are deciding about disclosure:

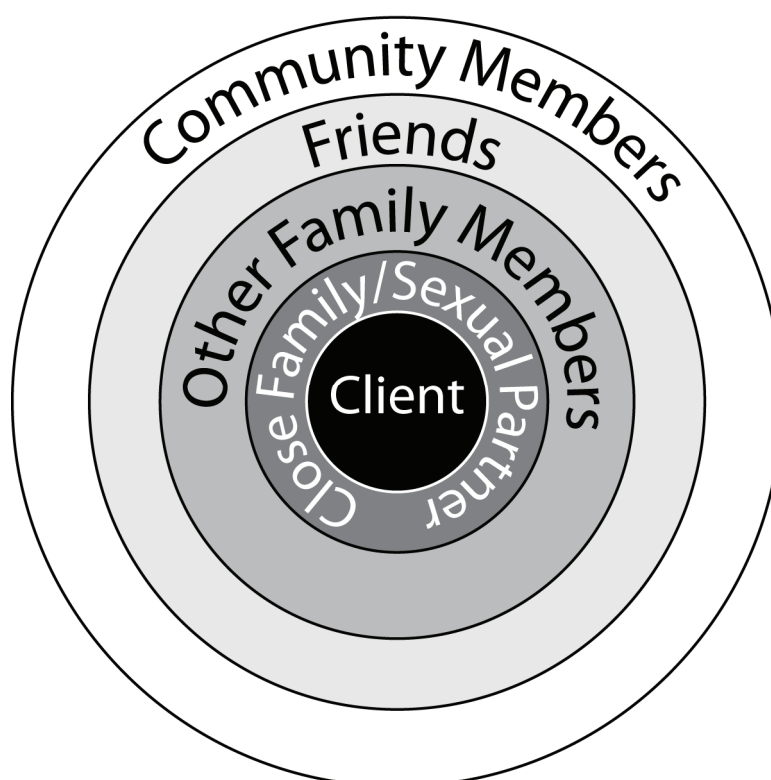
- **Peer Educators and peer support groups:** Adolescents may find it helpful to meet each other for mutual support.
- **Groups for caregivers of ALHIV:** Family members of ALHIV may also benefit from talking with other families or with a healthcare worker in a support group setting.

following “conversation starters” to clients who are confused about what to say to family or friends:

- *“I wanted to talk to you about something because I know you can help and support me.”*
- *“I went to the clinic today for a check-up and they talked to me about how it is important for everyone to get an HIV test because you cannot tell if someone has it by looking at them.”*
- *“I want to talk with you about something very important. I am talking to you about it because I love you and I trust you.”*
- *“I need to talk to you about something that is very difficult for me to discuss.”*
- Providing ongoing follow up and support through the disclosure process

## **Deciding about disclosure**

- A good way to understand disclosure and help adolescents decide who they will disclose to is by creating “disclosure circles” with your client, see Figure 7.1: Disclosure circle.
- The centre of the circle is the adolescent (self).
- The next circle out is a person or people the adolescent is very close to, such as a mother, siblings or partner (give the adolescent a piece of paper so that he or she can write the names of the people at this and the next layers of his or her own disclosure circle) .
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many layers to the circles of disclosure.
- Each layer of disclosure represents a process in itself — preparing for disclosure, the disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure. There will probably be ongoing discussions between the client and the person she or he has disclosed to over time.
- The goal is NOT that all people will eventually disclose to all of the people in the circles. Instead, the circles provide a way to discuss the disclosure process, consider the risks and benefits of disclosing to different people, and help prioritise disclosure activities.

**Figure 7.1: Disclosure circle**

Source: Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009.  
*Comprehensive Peer Educator Training Curriculum, Trainer Manual, Version 1.0.*,  
 International Center for AIDS Care and Treatment Programs.

### Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with an opportunity to discuss strategies for providing ALHIV assistance with the disclosure process</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>2 participants will be invited to volunteer to role play, in front of the large group, the first of the case studies below.</li> <li>During the role play the “healthcare worker” and “client” should incorporate into the dialogue the material discussed in this module, including material on creating a “disclosure circle”.</li> <li>Participants will role play or simply discuss the remaining 3 case studies.</li> </ol>

### Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion

#### Case Study 1:

Chabala is 15 years old and found out that he is HIV-infected at a VCT clinic 2 months ago. He returned for a second visit to the ART clinic, and says that he has not yet told anyone about his HIV status because he is too

ashamed and scared to tell his family. How would you help Chabala?

**Case Study 2:**

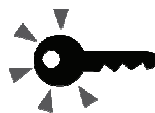
Lelemba is a 16-year-old girl who was perinatally infected with HIV. Lelemba mentions that she really wants to disclose her status to one of her male friends at school. Lelemba likes this boy very much and she knows that he likes her, but she is nervous about her friend's reaction. They have been arguing recently because Lelemba has been avoiding him. She asks your opinion about what to do. How do you proceed?

**Case Study 3:**

Josephine is a 14-year-old female orphan with HIV that lives with her maternal aunt and uncle. Josephine just started a new school and is afraid that she will be thought of as different from the other kids if anyone finds out she is living with HIV. She has not disclosed her status to anyone at school. How would you proceed with Josephine?

**Case Study 4:**

An 18-year-old named Isaac tested positive for HIV about 2 years ago. He takes good care of himself and feels fine. He got tested because his girlfriend at that time found out she was HIV-infected. He has since changed girlfriends and has not told his new girlfriend about his HIV status. He comes to the clinic for his regular appointment, but wants to talk with you about how to tell his girlfriend that he is living with HIV. How would you help Isaac prepare for the disclosure process to his girlfriend?



**Module 7: Key Points**

- Disclosure is an ongoing process, not a one-time event. Most adolescents and their caregivers need support with planning disclosure, the actual disclosure conversation and post-disclosure follow up.
- Disclosure can help a person access prevention, care, treatment and support; improve adherence; help reduce stigma and discrimination by bringing HIV out into the open; and slow the spread of HIV by helping people protect themselves and their partners.
- Healthcare workers can work with caregivers and adolescents to help them to understand why disclosure is important, help them overcome their barriers to disclosure, assist them with preparing for disclosure, assist them with the disclosure process, and provide follow-up support.

## Appendix 7A: Guidance for Developmentally Appropriate Disclosure

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
<b>Younger adolescents (approx 10–13 years old)</b>			
<ul style="list-style-type: none"> <li>Beginning to understand cause and effect, but still struggles with abstract concepts</li> <li>Growing vocabulary, but struggles to express ideas and feelings in words</li> <li>Enjoys activities that give a chance to control, organise and order things</li> <li>May regress and want help from adults if feeling insecure or unsure</li> </ul>	<ul style="list-style-type: none"> <li>Be truthful</li> <li>Ideally, the disclosure process will have already started by this age</li> <li>Give more detailed information, with concrete examples.</li> <li>If a child asks for more information (for example, “<i>What’s the germ called?</i>” or “<i>How did the germ get in my body?</i>”) give short, clear answers.</li> <li>Help the child deal with possible stigma.</li> <li>Reassure the child that he or she can ask further questions or share any concerns now or later.</li> </ul>	<ul style="list-style-type: none"> <li><i>Why do I have to go to the clinic?</i></li> <li><i>Why am I sick?</i></li> <li><i>Why do I have to go to the clinic so much?</i></li> <li><i>Why do I have to take medicine?</i></li> <li><i>Am I going to die?</i></li> <li><i>How did I get HIV?</i></li> <li><i>Who knows that I have HIV?</i></li> <li><i>Do I have to tell people I have HIV?</i></li> <li><i>What will happen if people know I have HIV?</i></li> </ul>	<ul style="list-style-type: none"> <li><i>Going to the clinic will help you stay well.</i></li> <li><i>You have a virus in your blood called HIV. It attacks the germ fighters in your body. This is why you get sick sometimes.</i></li> <li><i>You and I (if mother or caregiver is also HIV-infected) both have HIV in our bodies.</i></li> <li><i>You have to take medicine so the germ fighters can work and you won’t get sick so much.</i></li> <li><i>You (and I, if appropriate) take medicine to keep us strong.</i></li> <li><i>The medicines that we have to treat this virus are very good. If you take your medicine the right way, every day and never miss a dose, you can stay healthy for a very long time.</i></li> <li><i>HIV is nothing to be ashamed of, but it is something private. You don’t have to tell other people if you don’t want to.</i></li> <li><i>You can always talk to me about it at any time.</i></li> <li><i>Maybe we should keep this in the family for now?</i></li> </ul>



Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
<b>Older adolescents (approx 14–19 years old)</b>			
<ul style="list-style-type: none"> <li>Early adolescents beginning to be able to think in more abstract terms</li> <li>Want solid, well-thought-out explanations</li> <li>Body changes can create feelings of insecurity</li> <li>Forming a sense of identity — peer approval and social acceptance very important</li> </ul>	<ul style="list-style-type: none"> <li>Ideally, the adolescent will have been fully disclosed to by this age.</li> <li>Accurate and more detailed information can be given in response to questions.</li> <li>Realistic information about health status should be given, and all questions should be answered.</li> <li>Be sure to ask about and discuss the adolescent's feelings and fears about HIV.</li> <li>Ask questions about their understanding and address misperceptions, for example, "What have you heard about HIV?"</li> <li>Ways to live meaningfully with HIV, including having relationships, are a common concern. Issues like risk reduction and living positively with HIV should be discussed.</li> <li>Being assured that their status and what they say is</li> </ul>	<ul style="list-style-type: none"> <li>What is HIV?</li> <li>Why do I have it?</li> <li>Can I give HIV to my (girl/boy) friends? How?</li> <li>Why do I have to go to the clinic so often?</li> <li>What are the healthcare workers looking at in my blood?</li> <li>What if I want to get married and have children? Is that possible for people living with HIV?</li> <li>Who should I tell that I have HIV?</li> <li>Why are people mean to people with HIV?</li> </ul>	<ul style="list-style-type: none"> <li>You have the HIV virus. A virus is something that gets into your blood and can make you sick. Having HIV does not mean that you are sick all the time.</li> <li>Healthcare workers look at your blood to see how many healthy cells, called CD4 cells, are in it. The higher your CD4 count, the better.</li> <li>You can control the virus by taking your medication every day, at the same time and never missing a dose. But there is no way you can get rid of HIV completely.</li> <li>If you stop taking your medicine, the virus will get stronger and damage all of your healthy CD4 cells. If that happens you can get sick.</li> <li>Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and not pass HIV to other people.</li> <li>People with HIV can and do live long lives, have relationships and get married.</li> <li>If you have sex, it is important for you and your partner that you use condoms. Taking your ARVs the right way, every day also lowers the amount of virus in your body and makes it less likely that you will pass HIV to your partner during sex.</li> <li>You can have a baby in the future, but there</li> </ul>

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent might have	Possible responses to questions or ways of explaining things to the adolescent
	<p>confidential is very important.</p> <ul style="list-style-type: none"> <li>• Normal adolescent striving for independence may complicate the response to disclosure (for example, result in a decline in adherence).</li> <li>• Issues of disclosure to others should be discussed, but the adolescent should make his or her own decisions on this matter.</li> <li>• Assurance of support and willingness to help should be given without seeming intrusive.</li> </ul>		<p>are risks of passing HIV to your partner or to the baby. There are many things you could do to lower the chances that your baby would get HIV. Taking your ARVs the right way, every day will help lower the chance of passing HIV. We can talk more about this whenever you like.</p>

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

## References and Resources

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<sup>1</sup> Adherence Networking Group. 2006. Kids Count: Guide for Trainers, Children's ART Adherence Resource Pack.

<sup>2</sup> The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV.

<sup>3</sup> The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; International Center for AIDS Care and Treatment Programs; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. 2010. "HIV Care & Treatment Training Series", Module 6: Disclosure Process for Children Ages 3 to 18 Living with HIV. Pages 6-19.



## Module 8

### Supporting Adolescents' Retention in, and Adherence to, HIV Care and Treatment

**Session 8.1: Introduction to Retention and Adherence**

**Session 8.2: Supporting Retention and Adherence to Care**

**Session 8.3: Providing Adherence Preparation Support to ALHIV and Caregivers**

**Session 8.4: Assessing Adherence and Providing Ongoing Adherence Support**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Define retention in, and adherence to, HIV care and treatment.
- Identify common barriers to retention in care and adherence to treatment among adolescent clients.
- Discuss ways that healthcare workers and health facilities can support adolescents' retention in and adherence to care.
- Conduct adherence preparation sessions with adolescents who are starting ART, and their caregivers.
- Assess adolescent clients' (and caregivers) adherence.
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers) adherence.

## Session 8.1 Introduction to Retention and Adherence

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### Session Objectives

**After completing this session, participants will be able to:**

- Define retention in, and adherence to, HIV care and treatment.
- Identify common barriers to retention in care and adherence to treatment among adolescent clients.

### Overview of Retention and Adherence

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#### Definition of retention:

- Retention refers to keeping (or “retaining”) clients in the care programme; in this case, the continuation with lifelong HIV care and treatment services.
- A goal of all HIV care and treatment programmes is to retain clients in care and treatment. The onus of retention is on healthcare workers and managers, as they can offer quality services and set up systems that support the retention of ALHIV.
- For ALHIV, this also means supporting their transition to adult care and treatment (see Module 12).

#### Definition of adherence:

The standard clinical definition of adherence has been taking at least 95% of medications the right way, at the right time. Over time, this definition has been broadened to include more factors related to continuous care, such as following a care plan, attending scheduled clinic appointments, picking up medicines on time, and getting regular CD4 tests.

#### Key concepts of adherence:

- Includes active participation of the client in his or her care plan (and, if applicable, the active participation of caregivers in the client’s care plan)
- Includes adherence to both medications and care
- Depends on a shared decision-making process between the client (and caregivers) and healthcare workers
- Determines the success of HIV prevention, care, and treatment programmes
- Is not static — in other words, it changes over time and as ALHIV age and go through different developmental stages and life changes

#### Adherence

Adherence describes how faithfully a person sticks to and participates in his or her HIV prevention, care, and treatment plan.

**Adherence to care includes:**

- Entering into and continuing on a lifelong care and treatment plan
- Attending appointments and tests, such as regular CD4 tests, as scheduled
- Taking (or giving) medicines to prevent and treat opportunistic infections
- Participating in ongoing education and counselling
- Picking up medications when scheduled and before running out
- Recognising when there is a problem or a change in health and coming to the clinic for care and support
- Adopting a healthy lifestyle and trying to avoid risky behaviours, as much as is possible given the client's life situation

**Adherence to treatment includes:**

- Taking (or giving) ARVs correctly, as prescribed, for the person's whole life, even if the person feels healthy ("every pill, every day")
- Taking (or giving) other medicines, such as CTX, as prescribed
- Not taking any treatment "breaks"

**Non-adherence includes:**

- Missing one or many appointments at the hospital or health centre, lab, or pharmacy
- Not following the care plan
- Missing a dose or doses of medicine
- Sharing medications with other people
- Stopping medicine for a day or many days, or taking a "treatment break" or "holiday"
- Taking medicines at the wrong times
- Taking medicines without following instructions about timing or food intake

**Why is excellent adherence to HIV care and medicines important?**

- To ensure that ART and other medications do their job — which is, to increase the CD4 cell count and decrease the amount of HIV in the body
- To make sure people get all the benefits that ARVs have to offer, such as feeling better, not getting sick as often or as badly, living a longer life, etc.
- To keep people looking and feeling good so they can get back to "normal" life, including going to school, working, socialising, and being an active family and community member
- To help adolescents grow and develop into healthy adults
- So the virus does not become resistant to certain medicines
- To prevent mother-to-child transmission of HIV
- To reduce the risk of spreading the virus to others
- To keep families and communities healthy and productive

**Remember, no one is perfect. It is important not to judge adolescent clients (and caregivers) if they are non-adherent. Instead, we should try to understand why people do not adhere and help clients and caregivers find ways to resume good adherence as soon as possible.**

## **Factors Affecting ALHIV Adherence**

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The following is a listing of some of the common factors that can affect adherence for adolescents.

### **Health service factors:**

The following health service factors can affect client adherence to treatment and retention in care.

- Availability of youth-friendly services
- Lack of confidentiality
- Provider attitudes
- Drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Patient record and tracking systems
- Number and type of healthcare workers
- Provider language
- Waiting times
- Space for private counselling
- Linkages between services, including linkages to social and material support in the community and home-based care
- Referral systems
- Support groups
- PLHIV involvement, including ALHIV
- The cost of health services or medicines

### **Individual factors:**

Adolescence can bring with it some new issues that can affect adherence. Some adolescents — when going through a rebellious or risk-taking stage — want to define who they are, take more risks, and have a desire to “fit in” with peers and appear “normal”, all of which can negatively affect their adherence to care and medicines. Sometimes, young adolescents who have been managing well with HIV and adhering to their care and treatment (when their parents or caregivers took primary responsibility for their care) have new adherence challenges as they progress through adolescence and take on more responsibility for their own care.

The following are additional individual factors that can affect client adherence to treatment and retention in care.

- Feeling self-conscious about taking medication (particularly older adolescents).

- Forgetting to take their medicine; or, sometimes, forgetting because of alcohol or drug use.
- Side effects:
  - If a person feels sick from the medicine, then he or she is more likely to stop taking it.
  - If a person begins to notice unwanted body changes caused by the medicine (such as lipodystrophy — changes in fat distribution on different parts of the body), he or she may stop taking the medicine.
- Running out of tablets, forgetting to go to pharmacy at end of the month
- Having difficulty accepting his or her HIV status
- Stigma and discrimination from peers, family and/or others in community can affect willingness to take HIV medications or go to an HIV clinic, for fear that these behaviours might disclose their HIV status
- How far along they are in the disclosure process
- Whether or not they have adequate family or social support (i.e. no treatment “buddy” or supporter)
- How sick or well people feel
- Migration or relocation — disrupting continuity of care
- Time away from home, school, or work because of clinic appointments
- Mental illness, like depression

### **Community and cultural factors:**

The following are environmental factors (for example, families, communities, and culture) that can affect an adolescent client’s adherence to treatment and retention in care.

- Lack of family support or help with decision making from caregivers, particularly for younger adolescents
- Poverty
- Lack of food
- Stigma and discrimination
- Caregiver’s availability, health, and understanding of adherence
- Societal discomfort with youth and issues related to HIV, like sexuality
- Disclosure within the family, or at school or work — either not disclosing so there is a lack of peer support or the fear that taking medications or leaving early to go to the clinic will inadvertently disclose one’s HIV status
- Social support at home and in the community, including at school
- Unable to find child care for younger siblings (if youth-headed household) or for one’s own children (if a young parent)
- Unable to take time off from school or work to attend clinic
- Gender inequality: In some places, young women are less likely to have access to adequate nutrition to support their treatment, they can be more dependent on others economically, they can sometimes be forced to share their treatment with others, and it may be harder for them to travel to clinics to access treatment.
- Violence
- Distrust of the clinic/hospital



- Use of traditional medicine — which can replace perceived need for ART or negatively interact with HIV-related medications
- Political instability or war
- Physical environment (for example, mountains, seasonal flooding, etc.)

### **Medicine factors**

The following are things about ARV medicines that can affect an adolescent client's adherence to treatment and retention in care.

- Side effects
- Changing paediatric doses
- Changing regimens
- Number of pills in regimen
- Dose timing
- Availability of reminder cues — pill boxes, calendars, alarms, etc.
- Taste
- Changes in drug supplier — labelling, pill size, colour, formulation

## Session 8.2      Supporting Retention and Adherence to Care

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### Session Objective

**After completing this session, participants will be able to:**

- Discuss ways that healthcare workers and health facilities can support adolescents' retention in and adherence to care.

### Improving Retention in and Adherence to Care

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The following are suggestions for healthcare workers to improve retention in and adherence to care among ALHIV.

- Ensure HIV services are youth-friendly and that adolescent clients are treated respectfully and non-judgementally by healthcare workers
- Ensure that HIV services are provided on days and times that are convenient to adolescent clients
- Use a developmental, youth-friendly approach to counselling and education that corresponds to the adolescent's maturational stage
- Build a relationship of trust and respect with clients
- Ensure linkages to adolescent Peer Educators and adolescent support groups
- Make time for private counselling and adherence support sessions and ensure adolescent client's privacy and confidentiality.
- Ensure that there are appointment systems in place.
- Ensure that all clients are given reminder cards to help them remember their upcoming appointments.
- Ensure that there are systems to track adolescent clients who miss clinic appointments or pharmacy refills.
- Track client attendance. When adolescent clients miss an appointment, contact them through phone calls or SMS messaging. If that does not work, or isn't available as an option, send an outreach worker to their homes (or to the home of their treatment buddy; treatment buddies are discussed in Session 8.3) to provide counselling and education and to set an appointment for their next visit.\*
- Check in with clients frequently after starting or changing medications — if not medical visits then by phone or outreach.
- If possible, provide transportation stipends to clients who are unable to pay for their own transportation to the clinic.
- Consider establishing a formal mechanism to facilitate feedback from clients through the establishment of an adolescent consumer (or client) advisory board (CAB). CABs are autonomous bodies that advise the clinic on quality of services, gaps in care and make recommendations to improve service provision. CABs are discussed further in Module 11.

See also “Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” in Module 2, which is an audit of

services. The outcome of this assessment tool can provide additional suggestions to make a clinic friendlier for adolescents.

**\*Permission to call or visit home**

During the baseline intake and at key times thereafter, perhaps annually, ensure personal client information — such as address and phone numbers — are updated. At that time, request permission to follow up by phone or home visit should the client miss a clinic visit. Clients who have not disclosed their HIV status to others in the home may give special instructions at that time regarding what to say to caregivers or siblings regarding the nature of the visit.

## Session 8.3      **Providing Adherence Preparation Support to ALHIV and Caregivers**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Conduct adherence preparation sessions with adolescents who are starting ART, and their caregivers.

### **Adolescent-Friendly ART Adherence Preparation**

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Overview of adherence preparation and support for clients and caregivers:

- The “Zambia Adult and Adolescent Antiretroviral therapy Protocols, 2010”, recommend a total of 3 adherence preparation visits. Although the 1<sup>st</sup> and 2<sup>nd</sup> adherence preparation visits may be conducted within a group session, the 3<sup>rd</sup> of the 3 visits should include an individual counselling session. Another member of the multidisciplinary care team, like a Peer Educator or counsellor, can assist the healthcare worker during these sessions.
- ALHIV initiating care and treatment should have time to speak to a counsellor, healthcare worker, and/or Peer Educator alone, and in private.
- The counselling session should include talking with the client (and caregiver or treatment buddy) about any adherence challenges they may face and making an individual adherence plan.
- Group education/peer support sessions are useful in giving many people information at one time.
- An individual session can be used to find out what the client (and caregiver) has learned from any group education sessions, and in which areas they need extra support.
- While providing as much support as possible, the multidisciplinary care team should be flexible when addressing ART readiness. The preparation process should facilitate ART initiation and should never be a barrier.

### **What is a treatment buddy?**

A **treatment buddy** or **treatment supporter** is someone who is chosen by a client about to start ART to provide ongoing support for adherence to care and treatment.

A treatment buddy is usually a client's caregiver, friend, family member, or another ALHIV who is also enrolled in care and is a trusted person to whom a client can disclose her or his status. Younger adolescents may have one of their primary caregivers as a treatment buddy. Older adolescents may prefer to have a friend or peer as their treatment buddy, but it depends on the client.

Generally, a treatment buddy receives some basic education on HIV, adherence, and positive living, and can then provide psychosocial and adherence support to an adolescent client. It is important for healthcare workers, including Peer Educators, to explain to ALHIV the importance of having a treatment buddy and to make sure that treatment buddies have the information and skills needed to support adherence and positive living. **Remember, not having a treatment buddy should not act as a barrier to any client initiating ART.**

## **ART Adherence Preparation**

The Zambia "Adult and Adolescent Antiretroviral Therapy Protocols, 2010" recommend a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART. These adherence preparation visits are designed for the adolescent client who was diagnosed with HIV as a young adult (i.e., not as an infant or child). Young adolescents, where and when possible should be accompanied by a caregiver, or someone else who can provide support, during these sessions.

### **Adherence preparation visit 1**

The 1<sup>st</sup> adherence preparation visit is typically attended by the client who has recently received a positive HIV test and has enrolled in care. It is during this visit that the client will learn about HIV and AIDS, how HIV is transmitted/prevented, disclosure, partner referral and testing, CD4, viral load, CTX and ART.

The topics and key points for Adherence preparation visit 1 can be found in “Appendix 8A: Key Points — Adherence Preparation Visit 1”.

## Adherence preparation visit 2

The 2<sup>nd</sup> adherence preparation visit is for clients who have undergone clinical and laboratory assessment and found to qualify for ART. Adherence preparation visit 2 may take place weeks, months or years after adherence preparation visit 1. During this visit clients will learn about ART, starting ART, benefits of ART, resistance, preventing resistance and the importance of excellent adherence.

### Adherence preparation visits 1, 2 and 3

- These sessions can be conducted by any qualified trained personnel (medical officer, medical licentiate, clinical officer, nurse, adherence counsellor, community worker).
- The key points for the adherence preparation visits can be covered in an individual or group session. If utilising a group session format, establish ground rules emphasizing the importance of keeping the discussion and names of other group members confidential.

The topics and key points for Adherence preparation visit 2 can be found in “Appendix 8B: Key Points — Adherence Preparation Visit 2”.

## Adherence preparation visit 3

The 3<sup>rd</sup> adherence preparation visit is for the client who is free of any opportunistic infections or is on treatment for OIs and has been prescribed ART. During this visit the client will learn more about resistance and how to develop a successful adherence plan. They should also take the “Patient Readiness Questionnaire” as either part of the group session or in the individual counselling session.

The topics and key points for Adherence preparation visit 3 can be found in “Appendix 8C: Key Points — Adherence Preparation Visit 3”. Appendix 8C also includes the “Patient Readiness Questionnaire”.

## Personal adherence plan

### Tips for developing a personal adherence plan

During the individual counselling session, work with clients to develop a personal adherence plan. This plan should address the ARE YOU COMMITTED and then the WHO, WHAT, WHEN, WHERE, and HOW of the medications:

- **ARE YOU PLANNING TO TAKE YOUR MEDICATIONS?** If the response to this question is no, then consider delaying ART initiation.
- **WHO** will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?

- **WHAT** medicines are you taking? What is the dose and how often will you take it? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
- **WHEN** will you take your medication? Establish a routine.
- **WHERE** will you take your doses of ARVs (for example, school, home, work, etc.)? Where will you store your ARVs?
- **HOW** will you remember to take your medicines at the same time, every day? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends?

### **Assessing clients' and caregivers' readiness for ART**

Use the plan agreed during the WHO, WHAT, WHEN, WHERE, and HOW discussions when completing the "Guide for Assessing Adolescents'/Caregivers' Readiness for ART" questionnaires in Appendix 8D: Adherence Preparation and Support Guides". These assessment guides are standardised tools that can help healthcare workers assess a client's and caregiver's readiness for ART. The guides can also:

- Support healthcare workers to increase their clients' understanding of the importance of lifelong adherence to HIV care and treatment.
- Ensure a shared understanding of the care and medications plan.
- Identify potential adherence challenges and brainstorm practical solutions.

Instructions for administering the guides are also included as part of Appendix 8D.

Note that it may take 1, 2, or more individual counselling sessions before the client is ready to start ART. Upon completion of the 3 adherence preparation visits and the individual counselling session or sessions, the client should be ready to initiate ART. If the client is not ready, the multidisciplinary teams can advise if the client should delay initiation until the next visit, or discuss their reservations with the client and/or the caregiver and give them the choice to start now or delay temporarily.

Keep in mind that, as with any other one-to-one counselling session, the client will need to be reminded that the session is confidential. When counselling adolescents, also remind them that the commitment to confidentiality also means that the healthcare worker will not share with a caregiver or partner the information discussed in the individual counselling session.

**Exercise 1: Developing an Adherence Plan: Case studies in small groups and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To practise conducting adherence preparation counselling, including an adherence readiness assessment, with adolescent clients and caregivers.</li> </ul>
<b>Instruction</b>	<p><b>Part 1: Trainer Demonstration</b></p> <ol style="list-style-type: none"> <li>The trainer will start this exercise by role playing Case Study 1, below, with 2 volunteers. The other participants are asked to observe the counselling session and ask questions.</li> <li>Participants should refer to “Appendix 8A: Key Points — Adherence Preparation Visit 1”, “Appendix 8B: Key Points — Adherence Preparation Visit 2”, “Appendix 8C: Key Points — Adherence Preparation Visit 3”, and “Appendix 8D: Adherence Preparation and Support Guides”.</li> </ol> <p><b>Part 2: Small Group Work</b></p> <ol style="list-style-type: none"> <li>Participants will be asked to break into 4 small groups and assigned a case study. Working in their small groups, participants should respond to the questions at the end of their case study.</li> </ol> <p><b>Part 3: Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>The small groups will be reconvened into a large group where they will be invited to summarise their case study discussion. If time allows, some of the groups will be invited to conduct a short role play in front of the large group.</li> </ol>

**Exercise 1: Conducting an Adherence Readiness Assessment: Case studies in small groups and large group discussion**
**Case Study 1:**

Bupe is 11 years-old and will begin taking ART today. Today is her 3<sup>rd</sup> adherence preparation visit and she and her Auntie have gone through the 3 group presentations. Auntie is her primary caregiver and will be responsible for giving Bupe her medicines every day. Bupe understands that she has HIV and needs to take medicines everyday, but Auntie is worried how she will manage. How should you help Bupe and her caregiver prepare for adherence at the clinic today? What questions would you ask to assess their understanding of adherence and readiness for Bupe to start ART?

**Case Study 2:**

Saasa is 16 years old and lives on his own. He needs to start taking ART and the doctor asks you to help prepare him for adherence, now that he has attended the 3 adherence preparation visits. Saasa works during the day as a taxi assistant and you sense that it might be challenging for him to take



his medicines the right way because he has not disclosed to anyone and he works long hours. How do you help Saasa prepare to start taking ART? What questions would you ask to assess his readiness for ART?

**Case Study 3:**

Lumamba is 17 years old and lives with her mother and father. She is going to start taking ART and, now that she has attended the 3 adherence preparation visits, you have been asked to help prepare her and make an adherence plan. Lumamba is at the clinic with her older cousin and says she and her mother and father do not talk much about HIV. Her cousin has agreed to be her treatment supporter. How would you prepare Lumamba and her cousin to start taking ART? What questions would you ask to assess their readiness and understanding?

**Case Study 4:**

Jane is 14 years old and, based on her CD4 results, is eligible to start ART. She is at the clinic for adherence preparation (she has already attended adherence preparation visits 1, 2 and 3) and initiation, accompanied by her father. Her mother recently passed away, so her father will be her main treatment supporter. While conducting adherence preparation counselling with Jane and her father, he expresses some concern that ART is bad for children and that his daughter feels fine without medicine. He also says that he works long hours away from the house, so Jane spends a lot of time at home with her older brother. How would you proceed in preparing Jane and her father for ART?

**Case Study 5:**

Noah is 15 years old and lives with his mother and 4 younger siblings. Noah is still in school, but only because his mother requires him to go. Noah would prefer to spend his time with his friends, which he does do as soon as school ends. He is rarely home before 21.00hrs. He is failing nearly half of his classes. He has not told his mother or siblings of his HIV status, but he has told his best friend and partner, Aaron. Aaron is 21 and also has HIV. How do you help Noah prepare to start taking ART? What questions would you ask to assess his readiness for ART?

## Session 8.4      Assessing Adherence and Providing Ongoing Adherence Support

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### Session Objectives

**After completing this session, participants will be able to:**

- Assess adolescent clients' (and caregivers) adherence.
- Provide ongoing, age-appropriate support to improve adolescent clients' (and caregivers) adherence.

### Assessing Adherence

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Assessing adherence is very challenging and there is no perfect way to do so. Only through ongoing, individual adherence assessment and counselling, coupled with other adherence measures and review of the client's response to ART over time can we really learn about adherence. It is very important to assess adherence at each visit, but we must also take the next steps after assessment to offer clients ongoing, individual adherence support.

- The purpose of ongoing adherence monitoring and support is to encourage the client (or caregivers) to express challenges and to be open about any problems they may be facing so that the multidisciplinary team can provide them with ongoing support.
- Assess adherence at every visit. If the caregiver or treatment buddy is available, ask him or her about adherence as well. Adolescents and caregivers may have different reports and understanding of adherence, so it is important to conduct separate adherence assessment sessions with older adolescent clients and their caregivers. Where answers to parallel questions differ greatly, discuss the divergent responses when client and caregiver are together to see if they can explain. When asking for an explanation of divergent responses, ensure the question is appropriate and non-accusatory, for example: *"Interestingly, in response to my question 'How did the medicines make your child feel?' you said that the medicine was responsible for daily headaches, but your mother responded that the medicine had no effect on how you feel. I am sure you're both right, but maybe either of you can explain further how your responses can seem, on the surface, to be so different?"*
- Make adherence assessment and support a normal part of every clinic visit. Remember, adherence and psychosocial support need to be adapted to the needs of the adolescent as they age.
- Do not judge! Make clients feel comfortable, let them know that they will not be punished or judged if they openly discuss adherence challenges.
- Share that everyone has problems taking medicines the right way all the time.

- Build a trusting relationship and encourage clients to be completely honest with you about adherence. Remember: the job of a healthcare worker is to work WITH clients, not against them!
- Refer the client to a peer support group or link him or her to a Peer Educator
- Talk about clients' adherence at multidisciplinary team meetings.
- Use tools to help assess and improve adherence, such as:
  - Pill counts
  - Review of clinical findings and laboratory tests
  - Reviewing medicine diaries or calendars with clients

### **Adherence Red Flag**

Missing pharmacy refills or clinic appointments is a RED FLAG to poor adherence and should be addressed immediately in any client on ART.

Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. "Appendix 8E: Adherence Assessment Guides" includes two standardised adherence assessment tools which can be used at every follow up and refill visit to ensure that the adolescent client (and caregiver) understands the care and medication plan. The assessment questions should be used to identify areas where the client and/or caregiver may need additional information and support.

### **How to ask clients (and caregivers) about their adherence:**

- *I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late?*
- *How many pills did you miss in the last 7 days? What were the main reasons you missed them?*
- *How did the medications make you feel?*
- *Can you tell me about any changes you noticed (such as in your health) lately?*
- *Can you tell me about any challenges you had with your medicines lately?*
- *What support or reminders do you have to take your medicines at the same time, every day?*
- What questions do you have about your care or your medicines?

### **Providing Ongoing Adherence Support**

When providing adherence support, it is important that healthcare workers build on their trust and rapport with the client and caregiver, maintain a safe space to discuss any problems, and give ongoing encouragement and motivation. If, after discussing adherence with clients, the healthcare workers feels they are adhering well:

- Praise them (and the caregiver, if present) for good adherence.
- Remind them to come back if there are any problems.
- Talk about how important it is to be open with providers and healthcare workers and to solve challenges together.

If the healthcare worker or multidisciplinary team has determined that an adolescent client is experiencing challenges with adherence, provide individual counselling. During individual counselling:

- Praise the client for sharing his or her challenges.
- Identify the specific challenges and how these challenges affect adherence.
- Help resolve each of the challenges.
- Discuss the importance of adherence.
- Refer to the Peer Educator, adolescent support groups and other organisations.
- Refer difficult cases to a counsellor, social worker or other available mental healthcare worker.
- Plan for next steps, including the clinic return date.
- Record the session on the patient record.
- Follow up at the next visit.
- Share this with the multidisciplinary team and review the client's clinical status to determine if poor adherence is impacting treatment outcomes.

### **Exercise 2: Assessing Adherence and Providing Support: Role play and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To practise conducting an adherence assessment with adolescent clients and caregivers, and providing ongoing adherence support.</li> </ul>
<b>Instruction</b>	<p><b>Part 1: Small Group Work</b></p> <ol style="list-style-type: none"> <li>1. Participants will be asked to break into 4 small groups, The small groups should identify a “healthcare worker”, “client”, and “caregiver”.</li> <li>2. Each of the 4 “clients” and “caregivers” (in the 4 small groups) will be assigned one of the case studies (below).</li> <li>3. <b>Small groups should note that the first bullet point in the case study is shared with the “healthcare worker” the remaining bullet points are for the “client” and “caregiver”.</b> The “healthcare workers” should not look at the case studies!</li> <li>4. To start the role play, the “clients” should introduce themselves to the “healthcare worker” by reading aloud the 1<sup>st</sup> bullet point in their case studies. They should NOT read aloud the 2<sup>nd</sup> or 3<sup>rd</sup> bullet points!!!</li> <li>5. After the introduction the “healthcare workers” should go ahead and take the lead. The “clients” and “caregivers” should feel free to act and respond to the “healthcare worker” as they think their character might behave.</li> <li>6. The “healthcare workers” should provide adherence counselling and support as discussed in this session, ensuring that they use the adherence assessment in</li> </ol>

	<p>“Appendix 8E: Adherence Assessment Guides”.</p> <ol style="list-style-type: none"> <li>7. Participants who do not have roles may advise those who are role playing. Actors and non-actors may switch places during the role play.</li> <li>8. After the role play, participants should answer the following questions: <ol style="list-style-type: none"> <li>a. <i>What are the client’s/caregiver’s main adherence challenges? What are some possible solutions?</i></li> <li>b. <i>What are some age-appropriate techniques and/or approaches a healthcare worker could use to build the client’s/caregiver’s confidence and knowledge about adherence?</i></li> <li>c. <i>Are there any community outreach/services that might help the client? What suggestions or referrals would you make?</i></li> </ol> </li> </ol> <p><b>Part 2: Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>9. Once the trainer reconvenes the large group, one representative from each of the small groups will be asked to summarise their case study and the answers to the 3 questions (above).</li> </ol>
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### Exercise 2: Assessing Adherence and Providing Support: Role play and large group discussion

#### Case Study 1: Jonathon

- **At beginning of role play, “Client” (Jonathon) introduces himself to the “healthcare worker”:** I am Jonathon, I am 17 years old and have perinatally acquired HIV. My parents died many years ago, I live with my uncle and his family. My uncle came with me today.
- **When asked by the “healthcare worker”: Uncle (the “Caregiver”)** says that Jonathon is often out all night and comes home drunk. The family is upset with his behaviour and is afraid for him. The uncle says that Jonathon used to be a good student and did well in school. Recently he has not been taking his ARVs regularly, maybe he hasn’t taken his ARVs at all. Uncle is angry with his nephew and says that he found medication thrown away in the outhouse. He wants the healthcare worker to frighten Jonathon into taking his medication. Uncle discloses that he also has HIV.
- **When asked by the “healthcare worker”: Jonathon** states that he thinks that he has taken about half of his ART doses over the past week, mostly because he’s just been too busy.

#### Case Study 2: Nicholas

- **At beginning of role play, “Client” (Nicholas) introduces himself to the “healthcare worker”:** I am Nicholas, I am 12 years old and have and have been on ART for the last 6 years. My mother is here with me.
- **When asked by the “healthcare worker”: Mother (the “Caregiver”)** complains that Nicholas always used to cooperate and take his

medicines with no problem. But now he is fighting her with every dose, runs away, and spits out his ARVs. Although Mother is planning to tell Nicholas his diagnosis, she actually has not used the term “HIV” just yet.

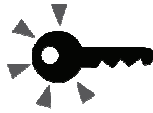
- **When asked by the “healthcare worker”:** **Nicholas** states that his mother forces him to take his medicine every morning and every evening. But he does not want to take them anymore because he just wants to be normal and not take medicine, his friends do not take medicine, so why does he have to?

### Case Study 3: Mana

- **At beginning of role play, “Client” (Mana) introduces herself to the “healthcare worker”:** I am Mana, a 14-year-old female. I’ve come in today because I am feeling bad and I want to stop taking ART. I am here today with my best friend.
- **When asked by the “healthcare worker”:** **Mana** states that she’s missed 3 doses of her ART in the last month but thinks that taking the doses most of the time is good enough. She tells you that she thinks the pills are making her look fat and she feels self-conscious about her body. She also tells you that she really likes this boy in her class but is afraid he thinks she is ugly. She says she is teased when she goes to school and only has one friend (the girl who accompanied her today).

### Case Study 4: Mary

- **At beginning of role play, “Client” (Mary) introduces herself to the “healthcare worker”:** I am Mary, I am 16 years old and have come in today for my routine visit. As always, my mother is here with me. The doctor told me to give this to you (Mary should hand over her pretend medical record with the results of her last 2 CD4 tests — which show a decrease in her CD4 count).
- **When asked by the “healthcare worker”:** **Mother** (the “Caregiver”) reports that Mary has taken 100% of her medicines on time this month.
- **When asked by the “healthcare worker”:** **Mary** states that she has taken 100% of her medicines on time this month.



## Module 8: Key Points

- Retention refers to keeping (or “retaining”) clients in the care programme, in this case continuing with lifelong HIV care and treatment services. For adolescents, this also means transitioning them to adult care and treatment.
- In the context of ART, studies have shown that clients must take over 95% of the necessary doses to achieve the conditions for therapeutic success, i.e. clients should adhere or “stick” to at least 95% of their drug schedule. Therefore, as healthcare workers our aim is to support clients to achieve and sustain this rate of adherence to their regimens.
- Although it is ultimately the responsibility of clients to adhere to their care plans, there are many steps healthcare workers can take to make it easier for clients to adhere to care. One of the most important steps to improve retention in care is to ensure that services are youth friendly. Services that are youth friendly increase the likelihood of attendance and therefore the likelihood of perfect, or near-perfect adherence to treatment.
- The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommend a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- In addition, the healthcare worker can help the client to develop a personal adherence plan by:
  - Asking the ARE YOU COMMITTED and then the WHO, WHAT, WHEN, WHERE and HOW of the medications.
  - Administering a standardised assessment tool to help determine a client and caregiver’s readiness for ART and help them to form an adherence plan.
- Assessing adherence and providing adherence support to clients and caregivers are important tasks, but can be challenging. There is no one particular way of assessing adherence. The best way is to use many a number of methods, such as a standardised adherence assessment combined with patient/caregiver self-report, pill count and review of clinical and laboratory records.
- Adherence support services should be ongoing — not one-time events — and the entire multidisciplinary team, not just counsellors or Peer Educators, is responsible for providing these services.
- Ongoing adherence support is especially important for adolescents. This is because their adherence to care and medications will not be static — meaning it changes over time — especially for ALHIV who are going through different phases of life and different life situations.

## Appendix 8A: Key Points — Adherence Preparation Visit 1

### Checklist for adherence preparation visit 1

✓	Topic and key points
	<b>1. What is HIV?</b>
	<ul style="list-style-type: none"> <li>HIV is a virus that attacks the body</li> <li>It damages your ability to fight germs and disease</li> <li>The virus makes many copies of itself every day if you are not on treatment</li> <li>Without treatment people progress from no symptoms to minor illness to severe life threatening illness and death</li> </ul>
	<b>2. What is AIDS?</b>
	<ul style="list-style-type: none"> <li>AIDS occurs when the body is overcome by the HIV virus and becomes weak due to other illnesses</li> <li>HIV causes AIDS months to years after infection</li> </ul>
	<b>3. How is HIV spread?</b>
	<ul style="list-style-type: none"> <li>Unprotected sex is the most common method</li> <li>Sharing needles or blood contaminated sharp objects (razors, knives, etc)</li> <li>Mother-to-child either before, during or after delivery (in the womb, during delivery, or while breastfeeding)</li> <li>Infected body fluids in contact with:               <ul style="list-style-type: none"> <li>Soft moist skin in the mouth, nose, vagina or rectum</li> <li>Cuts in the skin</li> </ul> </li> <li>Traditional beliefs that facilitate HIV transmission (sexual cleansing, wet nursing, dry sex, pre-coital pubic shaving with shared razor, etc)</li> <li>HIV is NOT spread through sharing food or utensils, touching, kissing, mosquitoes, or curses</li> </ul>
	<b>4. How can HIV be prevented?</b>
	<ul style="list-style-type: none"> <li>Abstaining from sex</li> <li>Knowledge of sexual partner's HIV status</li> <li>Being faithful to one partner/spouse</li> <li>Using condoms when engaging in sexual contact</li> <li>Becoming circumcised if an HIV negative male</li> <li>Taking ARVs perfectly or near-perfectly (discuss how they can prevent re-infecting themselves or infecting others)</li> </ul>
	<b>5. Which of your partners or family members need to be referred for HIV testing? Review how a person gets tested for HIV.</b>
	<ul style="list-style-type: none"> <li>A simple blood test</li> <li>HIV test may not be positive for up to 3–6 months after infection (window period)</li> <li>Retest every 3–6 months if you are at risk</li> </ul>



	<ul style="list-style-type: none"> <li>The standard test looks for an immune system reaction to HIV</li> </ul>
<b>6. Who will you tell that you have HIV? It is important to disclose your status to someone you trust and notify your sexual partner.</b>	
	<ul style="list-style-type: none"> <li>Sharing your test results with someone you trust who can support you is associated with better success in managing HIV</li> </ul>
	<ul style="list-style-type: none"> <li>Your family should become a source of support and help in your HIV care and treatment</li> </ul>
	<ul style="list-style-type: none"> <li>Notifying your sexual partners so they can be tested also can help stop HIV spreading. If any of your partners are HIV infected, they can seek early care.</li> </ul>
<b>7. What is the meaning of CD4 cells?</b>	
	<ul style="list-style-type: none"> <li>The immune system works in your body to fight infections and keep you healthy</li> </ul>
	<ul style="list-style-type: none"> <li>CD4 cells are the “soldiers” of your immune system army</li> </ul>
	<ul style="list-style-type: none"> <li>CD4 cells recognise germs in your body, and they work with other cells to destroy them</li> </ul>
	<ul style="list-style-type: none"> <li>HIV attacks and destroys your CD4 cells</li> </ul>
	<ul style="list-style-type: none"> <li>When CD4 cells are destroyed by HIV, the immune system does not know how to fight germs</li> </ul>
<b>8. What is viral load?</b>	
	<ul style="list-style-type: none"> <li>Viral load is the amount of HIV virus in the blood</li> </ul>
	<ul style="list-style-type: none"> <li>The lower the amount of HIV virus in the blood the better</li> </ul>
	<ul style="list-style-type: none"> <li>When the amount of HIV virus increases, eventually you don’t have enough CD4 cells to fight HIV and other germs that enter your body, and you progress to AIDS. You want to have more CD4 cells in your body and little HIV virus in your body</li> </ul>
<b>9. What is cotrimoxazole (also referred to as “CTX”)?</b>	
	<ul style="list-style-type: none"> <li>CTX can help prevent illnesses before you start HIV treatment. Taking CTX everyday can help your body fight off germs that can cause pneumonia, diarrhoea, toxoplasmosis and malaria</li> </ul>
	<ul style="list-style-type: none"> <li>Your healthcare worker will tell you if you should be taking CTX</li> </ul>
	<ul style="list-style-type: none"> <li>Taking CTX before HIV treatment is good practice for adhering to HIV treatment</li> </ul>
<b>10. What are the benefits of starting HIV treatment (also known as antiretroviral therapy or “ART”)?</b>	
	<ul style="list-style-type: none"> <li>Starting HIV treatment before you become sick and have AIDS will make it easier to lower the HIV virus in your blood and increase your CD4 cells faster</li> </ul>
	<ul style="list-style-type: none"> <li>It will also make the potential side effects from treatment easier to tolerate</li> </ul>
	<ul style="list-style-type: none"> <li>It will prevent you from developing more serious infections, and improve your chance of living a normal life with HIV</li> </ul>
<b>Summary of visit 1</b>	
	<ul style="list-style-type: none"> <li>HIV is a disease of the immune system:             <ul style="list-style-type: none"> <li>HIV is a virus that infects blood</li> <li>HIV is passed from one person to another through blood or</li> </ul> </li> </ul>

	<p>certain body fluids</p> <ul style="list-style-type: none"> <li>• HIV reproduces very fast and attacks and kills CD4 cells</li> <li>• CD4 cells are needed to fight HIV and other germs</li> <li>• Viral load measures how much HIV is in your blood and predicts how well you will do</li> <li>• CD4 cells measure how well your immune system fights germs</li> <li>• Disclosing your results to someone you trust is very important</li> <li>• Your examination and laboratory results will help determine whether you need treatment now:</li> <li>• Soft moist skin in the mouth, nose, vagina or rectum</li> </ul>
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**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Appendix 8B: Key Points — Adherence Preparation Visit 2

### Checklist for adherence preparation visit 2

✓	Topic and key points
	<b>1. What is ARV?</b>
	<ul style="list-style-type: none"> <li>ARV stands for <b>Anti-Retro Viral</b></li> <li>ARVs are medicines that help control the HIV virus in the blood</li> <li>ART is <b>Anti-Retroviral Therapy</b>, and refers to the combination of ARVs that are used to fight HIV</li> </ul>
	<b>2. Who should start ART?</b>
	<ul style="list-style-type: none"> <li>You cannot always tell by looking at someone if they need ART</li> <li>Even if you look and feel healthy, your immune system may already be weakened (low CD4 cell count), and you may benefit from starting ART to prevent you from getting sick</li> <li>You should start ART if you are experiencing illnesses or your immune system is weakened (low CD4 cell count)</li> <li>An HIV-positive person does not always need to start ART immediately, and some people may have no illnesses and a healthy immune system (high CD4 cell count) and can delay ART, but should remain in care with regular follow up</li> </ul>
	<b>3. What are the other considerations before starting ART?</b>
	<ul style="list-style-type: none"> <li>Several considerations are associated with success when starting ART               <ul style="list-style-type: none"> <li>Disclosing your status to someone that you trust is associated with better success on ART</li> <li>Identifying a treatment supporter or buddy that can help you with ART is very important</li> <li>Identifying linkages to the community through home based care, treatment support groups, and other community services will help you be more successful with your treatment</li> <li>Discuss fears and questions with your health care team members</li> <li>Always keeping a supply of medication with you and NEVER running out</li> <li>Heavy drinking of alcohol and depression can lower your adherence and reduce your success when taking ART</li> </ul> </li> <li>Medication issues that will be discussed in visit 3</li> </ul>
	<b>4. Starting ART is never an emergency</b>
	<ul style="list-style-type: none"> <li>Starting ART is an individual decision and one that is not forced</li> <li>Those who are already sick with AIDS will need ART, however <b>STARTING ART IS NEVER AN EMERGENCY</b></li> <li>Opportunistic Infections and other illnesses should be identified and treated before starting ART</li> <li>ARVs may cause side effects, however most people tolerate ART</li> </ul>

	well, and specific potential side effects will be discussed prior to starting ART
	<b>5. What are the benefits of starting ART?</b>
	<ul style="list-style-type: none"> <li>• ART increases the CD4 cell count</li> </ul>
	<ul style="list-style-type: none"> <li>• ART allows the body to better fight infections by restoring the immune system</li> </ul>
	<ul style="list-style-type: none"> <li>• A healthy immune system will lead to fewer hospitalisings</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can allow you to live longer so that you can marry and start a family if that is what you want</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can help you gain weight, feel more energetic, and improve your sexuality</li> </ul>
	<ul style="list-style-type: none"> <li>• ART can decrease the risk of transmitting HIV to others</li> </ul>
	<b>6. What are the benefits of delaying ART?</b>
	<ul style="list-style-type: none"> <li>• You have more time to prepare yourself to be successful with ART</li> </ul>
	<ul style="list-style-type: none"> <li>• You don't have to take medication or risk experiencing side effects</li> </ul>
	<b>7. What is resistance?</b>
	<ul style="list-style-type: none"> <li>• Resistance is when the HIV virus changes itself and the ARVs can no longer work</li> </ul>
	<b>8. How does resistance occur?</b>
	<ul style="list-style-type: none"> <li>• Resistance can occur when you miss doses of your medicine or take them incorrectly. HIV virus uses this chance to make more and more copies of itself that are so different that your medicines stop working</li> </ul>
	<ul style="list-style-type: none"> <li>• Resistance can also occur if you get infected with an HIV virus that is already resistant to the medications that you are taking, or if you get re-infected with an type of HIV virus that is already resistant to the medications that you are taking (always practise safe sex to avoid infection or re-infection)</li> </ul>
	<b>9. How do you prevent resistance?</b>
	<ul style="list-style-type: none"> <li>• You can prevent resistance through excellent adherence</li> </ul>
	<ul style="list-style-type: none"> <li>• Excellent adherence requires that you take your medicines every day at the right time and in the right way (dose and combination)</li> </ul>
	<ul style="list-style-type: none"> <li>• It also means always collecting your medicines on time so that you never run out of ART, and making sure that you take them when travelling away from home (funerals, holidays, other emergencies) or while away at work (miners, truck drivers, etc)</li> </ul>
	<b>10. Why is excellent adherence necessary?</b>
	<ul style="list-style-type: none"> <li>• The best way to live a long life with HIV is too keep the first ART combination working as long as possible</li> </ul>
	<ul style="list-style-type: none"> <li>• When ART is not taken properly the virus can change (viral mutation) and then the medicines quit working and resistance has developed</li> </ul>
	<ul style="list-style-type: none"> <li>• Once resistance occurs, it is NOT reversible and will last forever</li> </ul>
	<ul style="list-style-type: none"> <li>• When resistance develops you are no longer able to fight the HIV</li> </ul>

	in your body and you risk getting sick and dying
	<ul style="list-style-type: none"> <li>• It will then become necessary to find a different combination of ART medicines to treat your HIV virus. The second ART combination may not work as well as the first ART combination and it may have more side effects, and is very expensive</li> </ul>
	<ul style="list-style-type: none"> <li>• Without excellent adherence eventually you run the risk of having no treatment options for HIV</li> </ul>
	<b>Summary of visit 2</b>
	<ul style="list-style-type: none"> <li>• ART are medicines that help control the HIV in the blood             <ul style="list-style-type: none"> <li>• Starting ART is never an emergency</li> <li>• Not all HIV-positive persons need to start ART immediately</li> <li>• Consider medical and social factors before starting ART</li> <li>• ART helps the immune system get healthy (higher CD4 cell count)</li> <li>• Resistance is when the HIV virus changes itself and ART can no longer work</li> <li>• ART requires excellent adherence for life</li> </ul> </li> </ul>

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Appendix 8C: Key Points — Adherence Preparation Visit 3

### Checklist for adherence preparation visit 3

✓	Topic and key points
	<b>1. Can resistant virus be transmitted from one person to another?</b>
	<ul style="list-style-type: none"> <li>A resistant virus can be transmitted to another person through sex and other high risk exposures</li> </ul>
	<ul style="list-style-type: none"> <li>Someone who is not taking their ARVs correctly and develops resistant virus can pass the virus to:               <ul style="list-style-type: none"> <li>An uninfected person (then they will start their HIV infection with virus that is already resistant to ART)</li> <li>An infected person who is taking their ARVs correctly, and then develops resistance to the new resistant HIV virus that was passed on to them</li> </ul> </li> </ul>
	<ul style="list-style-type: none"> <li>Practise safe sex even if you and your partner are both HIV-positive to avoid passing on resistant virus</li> </ul>
	<b>2. How can resistance be prevented?</b>
	<ul style="list-style-type: none"> <li>Resistance can be prevented by excellent adherence</li> </ul>
	<ul style="list-style-type: none"> <li>Partial adherence puts your virus at risk for resistance</li> </ul>
	<ul style="list-style-type: none"> <li>Excellent adherence requires a person to take their ART medicines every day at the right time and in the right way, and NEVER run out of medication</li> </ul>
	<b>3. Can I feel resistance when it happens?</b>
	<ul style="list-style-type: none"> <li>Resistance is like a silent side effect and you will not feel any different at first when your HIV virus becomes resistant to your ART</li> </ul>
	<ul style="list-style-type: none"> <li>Resistance will make your ART become less effective, and eventually the number of HIV viruses in your blood increases then your CD4 cells decrease and eventually you will get sick and feel worse</li> </ul>
	<b>4. How can I ensure the success of my treatment plan?</b>
	<ul style="list-style-type: none"> <li>Keep all scheduled appointments and pharmacy refills</li> </ul>
	<ul style="list-style-type: none"> <li>Make sure the health facility knows how to contact you and your buddy (up to date phone numbers and address) and contact your health care facility or healthcare worker for any problems with medications (side effects, lost medicine, unable to make appointment, etc) or new illnesses</li> </ul>
	<ul style="list-style-type: none"> <li>Use a defined schedule for taking your ARVs and use helps such as calendars, pill boxes, checklist to ensure that doses are not missed</li> </ul>
	<ul style="list-style-type: none"> <li>Involve family members or a treatment supporter (buddy) in your care and keep them up to date with your progress</li> </ul>
	<ul style="list-style-type: none"> <li>Stay healthy with good nutrition and exercise</li> </ul>

	<ul style="list-style-type: none"> <li>Plan for emergencies before they happen (rainy season, floods, funerals, holidays, lost medicine) so that you do not run out of medication</li> </ul>
	<ul style="list-style-type: none"> <li>Do not STOP your medicines without discussing with a healthcare worker</li> </ul>
	<ul style="list-style-type: none"> <li>Do not take other herbal or over the counter medicines without discussing with your healthcare worker</li> </ul>
	<b>5. Should I learn the names of my ART medications?</b>
	<ul style="list-style-type: none"> <li>Yes, you should remember the names of the medicines you take and how they are to be taken</li> </ul>
	<ul style="list-style-type: none"> <li>Know the potential side effects and what to do if they occur</li> </ul>
	<ul style="list-style-type: none"> <li>Know about potential drug interactions between your medicines</li> </ul>
	<b>Summary of visit 3</b>
	<ul style="list-style-type: none"> <li>Resistance is not reversible and compromises treatment success             <ul style="list-style-type: none"> <li>Patients should not start ART if they cannot commit to excellent adherence</li> <li>Develop a successful treatment plan</li> <li>Review ART medication side effects</li> <li>Patients should understand the Patient Readiness Questionnaire and answer correctly</li> </ul> </li> </ul>

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Patient Readiness Questionnaire

Prior to dispensing, healthcare workers should review the Patient Readiness Questionnaire with the client to make sure he or she understands ART.

Question	Mark the correct answer	
1. ART can cure HIV/AIDS.	<input type="checkbox"/> True	<input type="checkbox"/> False
2. People taking ART should still abstain from sex or use condoms when having sex to be sure not to pass HIV to their sexual partners.	<input type="checkbox"/> True	<input type="checkbox"/> False
3. ART works well as long as at least half the doses are taken correctly.	<input type="checkbox"/> True	<input type="checkbox"/> False
4. What would you do if you think you are having a bad side effect from the ART?	a. Continue taking your ART and go to the clinic b. Stop the one that you think is making you feel bad, but continue the others c. Stop all the ART medicines and resume taking them when you feel better	
5. What is HIV resistance?	a. When you don't like your medicines b. When your body "resists" your medicines c. When the HIV virus changes in a way that stops your medicines from working to keep your HIV virus under control d. When your medicine changes in a way that stops them from keeping your HIV under control	
6. What can cause resistance?	a. When you forget to take your HIV medicines b. When the amount of medicine in your body is too low from missed doses c. When HIV makes copies of itself that are different from the original d. All of the above	
7. If my HIV virus develops resistance it will go away once I become adherent to my medications and I can continue with my current ART.	<input type="checkbox"/> True	<input type="checkbox"/> False
8. I can be re-infected with HIV that is already resistant to my ART.	<input type="checkbox"/> True	<input type="checkbox"/> False



9. There is no cure for HIV. If I stop ART after someone says that I am cured (faith healing, herbal medicines, etc) the HIV will come back, and I may develop resistance and the ART will not work.	<input type="checkbox"/> True	<input type="checkbox"/> False
10. I agree to identify a treatment supporter or buddy, and allow home visits.	<input type="checkbox"/> True	<input type="checkbox"/> False
11. I understand that herbal medicines can work against ART.	<input type="checkbox"/> True	<input type="checkbox"/> False
12. I understand that ART, if taken correctly, will help prolong my life.	<input type="checkbox"/> True	<input type="checkbox"/> False

**Source:**

Government of the Republic Of Zambia, Ministry Of Health. 2010. *Adult and Adolescent Antiretroviral Therapy Protocols 2010*.

## Appendix 8D: Adherence Preparation and Support Guides

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### How to use these guides:

These adherence preparation and support guides were developed to assist a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community healthcare workers, and others) who work with adolescents living with HIV (ALHIV) and their caregivers. These guides can help providers work with their clients (and caregivers) to understand the importance of adherence to HIV care and treatment throughout their life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. The adherence guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used, including the age and situation of the individual adolescent client. It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of adolescents and, in some cases, adolescents are referred to adult ART clinics, which may not be youth-friendly, for adherence counselling and preparation. Many programmes stipulate that clients participate in a series of group and individual counselling and preparation sessions before starting ART.

Included is one adherence preparation and support guide to assess adolescents' readiness for ART and one to assess the readiness of caregivers. The forms should be adapted as needed and used during adherence counselling sessions, according to the client's (and caregiver's) needs and situation. Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

### Basic information:

Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

### Questions to ask the client/caregiver:

The questions in this section allow the healthcare worker to discuss specific care, medication, and adherence issues with the adolescent client/caregiver. The questions should be used to identify areas where the client/caregiver may need additional information and support, but should not be used to "score" a client's knowledge and readiness to take ARVs. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel

comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, important areas for follow up, and in supporting the client's adherence over the long term.

**Client/caregiver requires more counselling and support in these areas:**

Write down specific areas in which the adolescent client/caregiver needs ongoing adherence counselling and support. Refer to this section of the form during follow-up counselling appointments and clinic visits. Even if a client has questions about his or her care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ARVs/ART. Instead, these issues should be viewed as important areas for ongoing counselling and support.

## Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART

Client's Name: \_\_\_\_\_ Client's Age: \_\_\_\_\_ Client's File#: \_\_\_\_\_  
 Caregiver and/or Treatment Buddy's Name: \_\_\_\_\_

Questions to ask the adolescent client:	Notes
1. Can you tell me what peer support group or group education sessions you have attended here at the clinic?	
2. Can you explain why you need to take ARVs?	
3. Who have you spoken to/who knows about your HIV status?	
4. What do you expect from taking ARVs?	
5. How do you feel about taking medicines every day for your lifetime?	
6. Can you tell me the names of the ARVs you will be taking and when you will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your ARVs? What will you do if you have side effects?	
8. Can you explain what happens if you do not take all of your ARVs every day, at the same time?	
9. Who can help you come to the clinic for appointments and help you take your medicines every day? What is their name and contact information?	
9a. Has he or she been to the clinic with you?	
9. What might make it difficult to come to this clinic for your appointments?	
10. How will you remember to come for your clinic appointments?	
11. How will you remember to take your medicines the right way, at the same time, every day?	
12. Are you taking any medicines — other than the ones prescribed to you by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store your medicines?	
14. What will you do if you are about to run out of your medicine(s)? What about if you are going to be away from home, such as when you are at school??	
15. What will you do if you miss a dose of your medicine?	
16. What questions do you have about the plan for your care or your medicines?	
17. Do you feel ready to start taking these medications?	

**Client requires more counselling and support in these areas (LIST):**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*

## Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART

Client's Name: \_\_\_\_\_ Client's Age: \_\_\_\_\_ Client's File#: \_\_\_\_\_  
 Caregiver and/or Treatment Buddy's Name: \_\_\_\_\_

Questions to ask the caregiver:	Notes
1. Can you tell me what support group or group education sessions you and your child have attended here at the clinic?	
2. Can you explain why your child needs to take ARVs?	
3. Who knows about your child's HIV status?	
4. What do you expect from your child taking ARVs?	
5. How do you feel about your child taking medicines every day for his or her lifetime?	
6. Can you tell me the names of the ARVs your child will be taking and when he or she will take them (how many pills, what times of day)?	
7. Can you tell me some possible side effects of your child's ARVs? What will you do if your child has side effects?	
8. Can you explain what happens if your child does not take all of his or her ARVs every day, at the same time?	
9. Who will help your child come to the clinic for appointments and help him or her take his or her medicines every day? What is your contact information/other supporters' contact information?	
9a. If someone other than the caregiver, has he or she been to the clinic with your child?	
9. What might make it difficult for your child to come to this clinic for his or her appointments?	
10. How will your child remember to come for his or her clinic appointments?	
11. How will your child remember to take his or her medicines the right way, at the same time, every day?	
12. Is your child taking any medicines — other than the ones prescribed to him or her by the doctor or nurse (including traditional or herbal medicines)?	
13. Where will you store the medicines?	
14. What will you do if you are about to run out of medicine(s)? What about if you or your child will be away from each other, or away from home, such as when he or she is at school?	
15. What will you do if the child misses a dose of the medicine?	
16. What questions do you have about the plan for your child's care or medicines?	
17. Do you feel that you and your child are ready to start taking these medicines?	

**Caregiver requires more counselling and support in these areas (LIST):**

**Signature of person completing assessment:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*

## Appendix 8E: Adherence Assessment Guides

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### How to use these guides:

These adherence assessment guides were developed to support a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community healthcare workers, and others) who work with ALHIV and their caregivers. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. The adherence assessment guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used and for different ages of adolescent clients. It may be helpful to translate the guides into the local language.

**Included is one adherence assessment guide for adolescents enrolled in HIV care and treatment and one to be used with caregivers.** The guides should be used at every follow-up and refill visit to ensure that the adolescent client and caregiver understand the care and medication plan and that the client is taking his or her medicines the correct way, every day and/or that the caregiver is giving the client his or her medicines the correct way, every day. Completed adherence assessment forms should be kept in the client's file and referred to at follow-up visits.

### Basic information:

Write the client's name, age, and file number, as well as the caregiver or treatment buddy's name, at the top of the form. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and keep in the client's clinic file.

### Questions to ask the client/caregiver:

The questions in this section allow the healthcare worker to discuss and assess adherence. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, know important areas for follow up, and support the clients' adherence over the long term. If possible, the healthcare worker should meet with the client and caregiver separately to identify and address and discrepant responses. Meeting separately is especially important as young clients age into middle and late adolescence.

### Other assessment measures and next steps:

This is the section where healthcare workers will plan with the adolescent client/caregiver to ensure that the client keeps up good adherence or develops strategies to improve adherence.




- **Other adherence assessment measures:** Depending on standard procedures at the clinic, the healthcare worker may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- **Specific adherence challenges identified by the adolescent client, caregiver, and healthcare worker:** Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organising, such as a youth support group or a home-based care programme, that could help support the client (and the caregiver and family) to overcome his or her challenges to adherence, refer the adolescent client (and/or caregiver) to that organising or service and indicate the name and specific service in this part of the form. In some cases, the client (or caregiver) may need to be referred for other facility-based services, such as an appointment with a trained counsellor or a session with the pharmacist to explain dosing.
- **Next steps and follow-up plan:** Together with the adolescent client/caregiver identify which solutions and next steps he or she thinks are feasible and manageable. For each solution, list the necessary steps the client or healthcare worker will need to take and a time line for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for the adherence assessment during follow-up visits.

## Adherence Assessment for Adolescents Taking ART

**Client's Name:** \_\_\_\_\_ **Client's Age:** \_\_\_\_\_ **Client's File#:** \_\_\_\_\_

**Caregiver and/or Treatment Buddy's Name:** \_\_\_\_\_

**Tick one:** ☐ 2-week follow up   ☐ 1-month follow up   ☐ monthly refill   ☐ 3-month refill

Questions to ask the adolescent client:	Notes
1. Can you tell me more about how you took your medications this past month (or 2 weeks)? (Do you know the names of the medicines? How many pills do you take? At what time of day do you take them?)	
2. I would like you to think about the last 7 days. How many pills did you take late in the last 7 days? What were the main reasons you took them late?	
3. How many pills did you miss in the last 7 days? What were the main reasons you missed them?	
4. If we put all the pills you had to take in the last 2 weeks into one cup, this is what you would see. If you took all of them the cup would be empty. If you forgot to take all of them the cup would be full. Which of these pictures best shows how many of your doses you took in the last month (or 2 weeks)? (circle one)	
5. How did the medicines make you feel?	
6. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
7. What support or reminders do you have to help you take your medicines at the same time, every day?	
8. What questions do you have about your care or your medicines?	

Other assessment measures and next steps:	Notes
Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by the adolescent client, caregiver, and healthcare worker: (discuss possible solutions to each)	

## PARTICIPANT MANUAL

Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

**Notes:**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_


Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*

## Adherence Assessment for Caregivers of Adolescents Taking ART

**Client's Name:** \_\_\_\_\_ **Client's Age:** \_\_\_\_\_ **Client's File#:** \_\_\_\_\_

**Caregivers Name:** \_\_\_\_\_

**Tick one:** ☐ 2-week follow up ☐ 1-month follow up ☐ monthly refill ☐ 3-month refill

Questions to ask the caregiver:	Notes
1. Can you tell me more about how your child took his or her medications this past month (or 2 weeks)? (Do you know the names of the medicines? How many pills does he or she take? At what time of day does he or she take them?)	
2. I would like you to think about the last 7 days. How many pills did your child take late in the last 7 days? What were the main reasons he or she took them late?	
3. How many pills did your child miss in the last 7 days? What were the main reasons he or she missed them?	
4. If we put all the pills your child had to take in the last 2 weeks into one cup this is what you would see. If he or she took all of them the cup would be empty. If he or she forgot to take all of them the cup would be full. Which of these pictures best shows how many of your child's doses he or she took in the last month (or 2 weeks)? (circle one)	
5. How did the medicines make your child feel?	
6. Can you tell me about any changes you or your child noticed (such as in your child's health) or challenges your child had with his or her medicines?	
7. What support or reminders does your child have to help him or her take his or her medicines at the same time, every day?	
8. What questions do you have about your child's care or your medicines?	

Other assessment measures and next steps:	Notes
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _____

**Notes:**

**Signature of person completing assessment:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Adapted from: ICAP. 2010. *Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for health workers.*



## Module 9

### Positive Living for Adolescents

**Session 9.1: Supporting ALHIV to Live Positively and Maintain a Healthy Mind**

**Session 9.2: Supporting ALHIV to Live Positively and Maintain a Healthy Body**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Define positive living and describe the key components of positive living for adolescent clients.
- Describe the role of the healthcare worker in supporting ALHIV to achieve and maintain a healthy mind.
- Provide ongoing support and counselling to adolescent clients on maintaining a healthy body.
- Recognise signs of alcohol and drug use and abuse in adolescent clients and provide counselling and referrals.

## Session 9.1      Supporting ALHIV to Live Positively and Maintain a Healthy Mind

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### Session Objectives

**After completing this session, participants will be able to:**

- Define positive living and describe the key components of positive living for adolescent clients.
- Describe the role of the healthcare worker in supporting ALHIV to achieve and maintain a healthy mind.

### What is Positive Living?

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- Positive living includes:
  - Keeping the mind healthy (having a positive outlook toward living and life),
  - Keeping the body healthy,
  - Keeping the soul and spirit healthy (for example, the things we do to feel good on the “inside” and feel a sense of peace and contentment), and
  - Living responsibly with HIV and preventing new HIV infections.
- ALHIV can live full and healthy lives if they take care of themselves, access care and treatment, and feel supported to make healthy choices. This includes feeling supported by healthcare workers at the clinic.
- Caregivers and family members also play an important role in supporting ALHIV to live positively with HIV and prevent new HIV infections.
- Healthcare workers play a key role in helping ALHIV live positively and follow the “**recipe for positive living**” (see box below).

<p style="text-align: center;"><b>Recipe for positive living</b></p> <p style="text-align: center;"><b>KNOWLEDGE + DETERMINATION TO LIVE</b></p> <p style="text-align: center;"><b>with actions for a</b></p> <p style="text-align: center;"><b>HEALTHY MIND + HEALTHY BODY + HEALTHY SOUL</b></p> <p style="text-align: center;"><b>= A LONG, HEALTHY LIFE</b></p>
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Source: Orr, N.M. 2004. Positive health. Cape Town: Double Storey Books.

Healthcare workers play an important role in helping adolescent clients learn about positive living. Because their questions and understanding of living with HIV changes over time, it is helpful to talk to adolescents on an ongoing basis about this topic. Information on positive living should be communicated repeatedly and through multiple channels, such as:

- Individual counselling sessions

- Individual health education sessions
- Group health education sessions (with adolescents alone, caregivers alone, or mixed groups)
- Support group meetings
- Youth-friendly written materials (such as flyers, brochures, books)
- TV shows or films about living positively
- Internet

A list of information web-based resources on positive living, geared towards young people, can be found in “Appendix 9A: Web Resources for ALHIV”.

## **Supporting Adolescents to have Healthy Minds**

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### **Ensure that adolescent clients have access to adolescent-specific support groups and peer support (see Module 5)**

- Healthcare workers should take part in creating and facilitating peer support groups in the clinic and should also link ALHIV with any existing support groups.
- Peer support can engage and help support the psychosocial needs of ALHIV, and can help them improve access and adherence to HIV prevention, care, and treatment services.

### **Ensure that psychosocial support and mental health services are part of comprehensive HIV care and treatment (see Modules 5 and 6)**

- ALHIV face additional challenges and stressors as a result of living with a chronic, highly stigmatised disease. They are also more susceptible to many mental health challenges, which often emerge in late childhood and early adolescence. Adolescents need support not only with mental health issues but also with everyday issues such as the desire to be normal to accept HIV-related care.
- It is important to provide ALHIV with routine psychosocial and mental health assessments and support as an integral part of their care. They will likely need extra support during challenging times, such as when they are preparing to disclose their status, when they lose a loved one, when they face discrimination, etc.

### **Ensure that adequate attention is paid to ongoing disclosure support for caregivers and for adolescent clients (see Module 7)**

- Disclosure is a process, and not a one-time event. Both ALHIV and caregivers need ongoing support on issues related to disclosure.
- Healthcare workers can help adolescents overcome their fear of disclosure to others by helping them see the advantages to having trusted people know their status. They can also help them decide whom to disclose to, when and where, to weigh the advantages and disadvantages, and to help them anticipate likely responses.

### **Ensure that adolescent clients (and caregivers) receive ongoing adherence support (see Module 8)**

- There are many barriers and challenges to retaining adolescents in care and to supporting adolescents to adhere to their ART regimen. Although healthcare workers may not be able to address all of the client's barriers to adherence, there are many factors that can be addressed, such as minimising health service barriers by improving the quality of counselling and ensuring access to youth-friendly services.
- There is no one specific way to monitor adherence. The best way is to use many different methods, such as routine adherence assessment, ongoing adherence counselling, review of clinical and laboratory records, pill count, etc. When helping clients and caregivers prepare for ART, always address the WHO, WHAT, WHEN, WHERE, and HOW of the medications.

**Encourage adolescents to go to and stay in school**

- Adolescents who stay in school will have more opportunities in the future.
- In addition to building academic skills, school also provides a chance for adolescents to make friends and to develop life skills.

**Talk with adolescents about their spiritual and/or religious beliefs and practices**

- Healthcare workers should encourage both ALHIV and their families to continue their regular religious or spiritual practices.
- For those who have grown up with a spiritual and/or religious element in their family or community, this can be a further source of support and counselling to help them face issues related to mental health, disclosure, and positive living.

**Encourage adolescent clients to develop life skills and to help them live positively with HIV (see below).**

**Supporting Adolescents to Develop Life Skills<sup>1</sup>**

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Having life skills helps adolescents to be confident, knowledgeable, and able to take responsibility for their own lives. Life skills education can help adolescents develop into stronger, more aware, and more caring human beings equipped to cope with the demands and pressures of everyday life and living with HIV. Life skills can also help adolescents assess risks and make decisions that will lead to positive outcomes and a better, healthier life.

There is no definitive list of life skills, but a sample list is included in Table 9.1, below. This list encompasses psychosocial and interpersonal skills that are generally considered important for adolescents as they grow, develop, and manage their chronic illness.

Healthcare workers are not responsible for teaching adolescent clients all of these life skills, but should keep them in mind when working with adolescents and providing psychosocial support. They should also



encourage life skills trainings and discussions as part of peer activities and support groups. When possible, healthcare workers can link their adolescent clients with formal or informal life skills trainings, for example, trainings offered by youth groups, schools, or community organisations.

**Table 9.1: Examples of adolescent life skills**

Communication and Interpersonal Skills	Decision-making and Critical Thinking Skills	Coping and Self-Management Skills
<p><b>Interpersonal communication skills:</b></p> <ul style="list-style-type: none"> <li>• Verbal communication</li> <li>• Non-verbal communication</li> <li>• Expressing feelings</li> <li>• Giving and receiving feedback</li> </ul> <p><b>Negotiation/refusal skills:</b></p> <ul style="list-style-type: none"> <li>• Negotiation and conflict management</li> <li>• Assertiveness skills</li> <li>• Refusal skills</li> </ul> <p><b>Empathy:</b></p> <ul style="list-style-type: none"> <li>• Ability to listen and understand another's needs and circumstances and express that understanding</li> </ul> <p><b>Cooperation and Teamwork:</b></p> <ul style="list-style-type: none"> <li>• Expressing respect for others' contributions and styles</li> <li>• Assessing one's own abilities and contributing to the group</li> </ul> <p><b>Advocacy skills:</b></p> <ul style="list-style-type: none"> <li>• Influencing skills and persuasion</li> <li>• Networking and motivation skills</li> </ul>	<p><b>Decision-making and problem solving skills:</b></p> <ul style="list-style-type: none"> <li>• Information gathering skills</li> <li>• Evaluating future consequences of present actions for self and others</li> <li>• Determining alternative solutions to problems</li> <li>• Analysis skills related to the influence of values and attitudes on motivation (of self and others)</li> </ul> <p><b>Critical thinking skills:</b></p> <ul style="list-style-type: none"> <li>• Analysing peer and media influences</li> <li>• Analysing attitudes, values, social norms, and beliefs and factors affecting these</li> <li>• Identifying relevant information and sources of information</li> </ul>	<p><b>Skills for increasing internal locus of control:</b></p> <ul style="list-style-type: none"> <li>• Self-esteem/confidence building skills</li> <li>• Self awareness skills, including awareness of rights, influences, values, attitudes, strengths, and weaknesses</li> <li>• Goal setting skills</li> <li>• Self-evaluation, self-assessment, and self-monitoring skills</li> </ul> <p><b>Skills for managing feelings:</b></p> <ul style="list-style-type: none"> <li>• Anger management</li> <li>• Dealing with sadness, grief, and anxiety</li> <li>• Coping skills to deal with loss, abuse, illness, and trauma</li> </ul> <p><b>Skills for managing stress:</b></p> <ul style="list-style-type: none"> <li>• Time management</li> <li>• Positive thinking</li> <li>• Relaxation techniques</li> </ul>

Source: UNICEF. 2004. "Which skills are life skills?" Available at: [http://www.unicef.org/lifeskills/index\\_whichskills.html](http://www.unicef.org/lifeskills/index_whichskills.html)

## Session 9.2      Supporting ALHIV to Live Positively and Maintain a Healthy Body

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### Session Objectives

**After completing this session, participants will be able to:**

- Provide ongoing support and counselling to adolescent clients on maintaining a healthy body.
- Recognise signs of alcohol and drug use and abuse in adolescent clients and provide counselling and referrals.

### Key Points for Positive Living

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#### Healthy behaviours

Healthcare workers should actively encourage ALHIV to live healthy. Some of the activities that constitute “living healthy” or “living positively” are summarised in Table 9.2.

**Table 9.2: Positive living**

<b>“Living positively” with HIV includes...</b>	
<b>Healthcare</b>	
•	Going to the hospital or clinic for checkups, lab tests, and to pick up medicines. Never miss an appointment.
•	Taking medicines the right way (at the right time, the right number, etc.).
•	Informing healthcare workers if taking any traditional remedies or supplements.
•	Telling a nurse or doctor if there are any health-related changes, even small ones.
<b>Sexual health</b>	
•	If sexually active, using condoms and practising safer sex every time; using a family planning method in addition to condoms (dual protection).
•	Getting screened for STIs and, if infected, getting treatment immediately and referring partners for treatment.
<b>Staying active and socially engaged</b>	
•	Taking physical exercise (walking, jogging, and light household chores) to build muscles, reduce stress, and improve appetite.
•	Staying socially engaged: making new friends and accessing peer support through youth clubs, sports teams, and/or after-school clubs; joining an ALHIV association; talking about things openly.
•	Staying in school/at work and prioritising education/career.
<b>Rest</b>	
•	Getting enough rest.

<ul style="list-style-type: none"> <li>• Sleeping and resting under an insecticide-treated mosquito net if in a malarial area.</li> </ul>
<b>Personal hygiene</b>
<ul style="list-style-type: none"> <li>• Washing hands with soap often, especially:             <ul style="list-style-type: none"> <li>• After using the toilet, touching the genitals, or touching any body fluid.</li> <li>• Before preparing food or eating.</li> <li>• After sneezing or coughing.</li> <li>• After handling garbage.</li> <li>• After touching animals.</li> </ul> </li> </ul>
<ul style="list-style-type: none"> <li>• Bathing regularly.</li> </ul>
<ul style="list-style-type: none"> <li>• Practising good hygiene during the menstrual period:             <ul style="list-style-type: none"> <li>• Changing sanitary pads or cloths regularly.</li> <li>• Washing hands before and after changing sanitary products.</li> <li>• Bathing daily during the monthly period (note: there is never a need to clean inside the vagina, not even during the monthly period).</li> <li>• Safely disposing (by putting into a pit latrine or burning) or washing used sanitary pads/clothes.</li> </ul> </li> </ul>
<b>Oral health</b>
<ul style="list-style-type: none"> <li>• Keeping your mouth clean by brushing teeth, mouth, and tongue at least twice a day.</li> </ul>
<ul style="list-style-type: none"> <li>• Treating severe oral lesions with gauze soaked in salt water to clean the mouth.</li> </ul>
<b>Nutrition</b>
<ul style="list-style-type: none"> <li>• Eating enough healthy food and taking multivitamins.</li> </ul>
<ul style="list-style-type: none"> <li>• Drinking at least 8 glasses (250 mls/glass) of clean water each day. People with HIV should always drink water that has been boiled or treated with chlorine liquid or tablets (for example, “WaterGuard”).</li> </ul>
<b>Food hygiene</b>
<ul style="list-style-type: none"> <li>• Washing food preparation, cooking, eating, and storage utensils with soap and hot water.</li> </ul>
<ul style="list-style-type: none"> <li>• Washing raw fruits and vegetables well with clean water.</li> </ul>
<ul style="list-style-type: none"> <li>• Covering food to prevent both flies and dust from contaminating it; not storing raw and cooked foods together.</li> </ul>
<ul style="list-style-type: none"> <li>• Eating food as soon as it is cooked. Not storing leftovers unless they can be kept in a refrigerator or a cool place.</li> </ul>
<ul style="list-style-type: none"> <li>• Cooking food thoroughly, particularly meat, poultry, and fish. Meat should have no red juices; however, remember that overcooking vegetables causes them to lose nutritional value.</li> </ul>
<ul style="list-style-type: none"> <li>• Keeping the house and compound clean — getting rid of any still water, keeping garbage covered, and disposing it at least daily.</li> </ul>
<ul style="list-style-type: none"> <li>• Keeping all food preparation surfaces clean. Use a germ-killing bleach solution (like Jik, or Gentian Violet) diluted with water to keep household surfaces clean. If using Jik for home disinfecting, mix one part Jik to 10 parts water. When using Jik in healthcare settings (for example, disinfecting instruments such as blades and needles), use one part Jik to six parts of water and soak at least 10 minutes.</li> </ul>

## Unhealthy behaviours

Healthcare workers should talk with ALHIV about avoiding practices or behaviours that are not healthy. These include:

- Drinking alcohol
- Using drugs
- Smoking cigarettes
- Having unsafe sex
- Avoiding social contact and staying alone too much
- Sharing medicines, stopping medicines without talking to the doctor, or missing medication doses
- Missing appointments at the clinic
- Taking traditional medicines that have not been discussed with the doctor or nurse
- Not eating enough healthy foods or eating too many sugary or fatty foods

## Helping Clients Practise Positive Prevention

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Positive prevention is a key component of positive living. Healthcare workers are responsible for discussing with ALHIV ways to prevent the further spread of HIV to sexual partners and children. Positive prevention includes:

- Partner disclosure and testing,
- Sexual risk reduction and sexual health (see Module 10),
- Prevention and treatment of STIs (see Module 10),
- PMTCT (see Module 10), and
- Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.

## Review of General Nutrition Information<sup>2</sup>

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### Common nutritional issues for adolescents:

- Many adolescents — especially the most vulnerable adolescents, such as orphans, street youth, and others — face food insecurity.
- Many adolescents develop bad eating habits — such as eating a lot of “junk food” (see box, below), skipping meals, and having erratic eating patterns given their busy lifestyles.
- Some ARVs may cause adolescents to lose their appetite and some may cause weight changes, such as lipodystrophy.

#### **Junk food**

Sometimes when adolescents are very busy or do not have time to prepare food, they (and their families) eat pre-prepared foods and “junk foods”. Healthcare workers should help clients understand why they should avoid “junk foods” like soft drinks, sweets, and potato chips/crisps — they cost a lot of money and have little nutritional value. Fresh, natural foods are always the best and are usually cheaper than packaged and pre-prepared foods.

**It is critically important to provide regular weight and nutrition monitoring as part of routine care for ALHIV.**

### **Eating a “balanced diet”**

Eating a “balanced diet” means eating a variety of foods from each of the 3 food groups (see “Appendix 9B: Basic Food Groups”) and eating enough food every day. It is always best to eat foods that are grown at home or produced locally instead of imported or processed foods, which do not have as many nutrients.

For additional information on healthy eating for people living with HIV, see the Zambia Ministry of Health’s *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*.

## **Helping ALHIV to Eat Well**

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### **The relationship between nutrition and HIV**

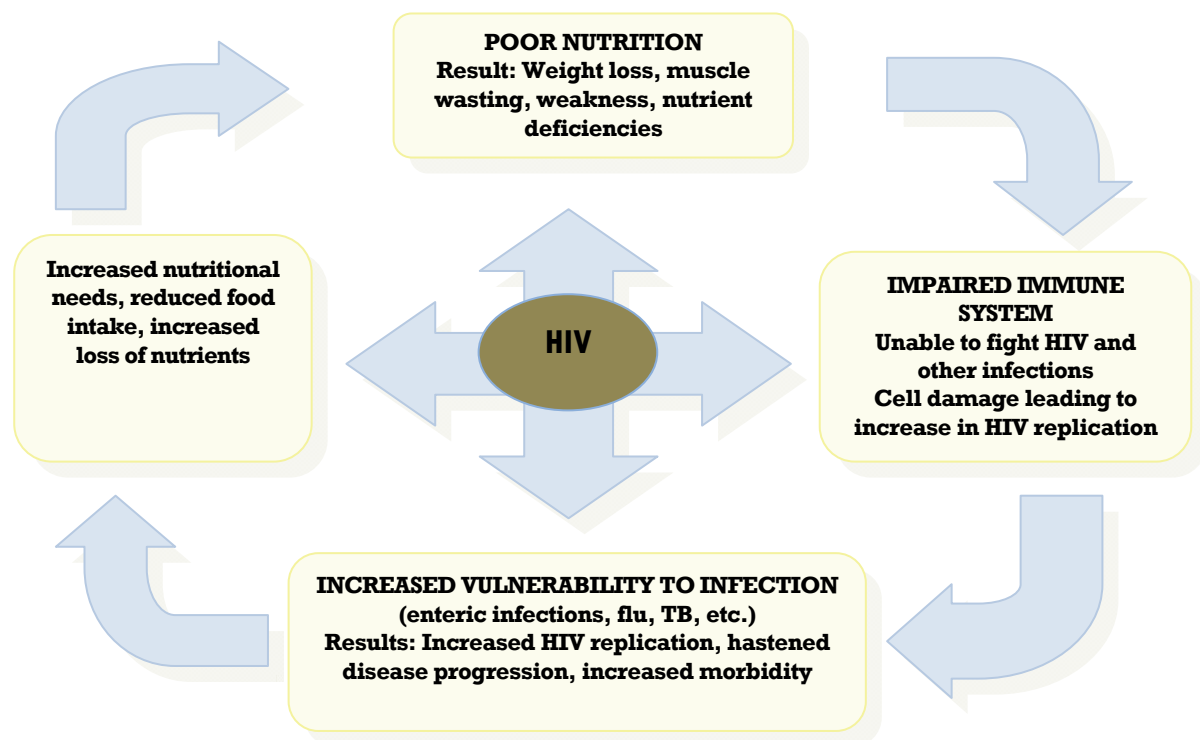
Good nutrition can play an important role in the care and management of HIV. The effect of HIV on the body’s nutritional status begins early in the course of the infection, even before symptoms are seen. Conversely, good nutrition has the greatest impact at the early stages of HIV, strengthening the immune system to fight OIs and delaying disease progression.

The relationship between nutrition and HIV is cyclical:

- HIV infection increases nutrient requirements and reduces nutrient intake and absorption.
  - This increases the risk of malnutrition.
    - Malnutrition increases the risk of opportunistic infections and speeds the progression of HIV to AIDS.

Poor nutrition and HIV together create a vicious cycle that weakens the immune system, as illustrated in Figure 9.1 below.

**Figure 9.1: Cycle of malnutrition and infection in the context of HIV**



Source: Zambia Ministry of Health, National Food and Nutrition Commission. 2004. *Nutrition Guidelines for Care and Support of People Living with HIV/AIDS*. Available at: [http://www.fantaproject.org/publications/zambia\\_guide2005.shtml](http://www.fantaproject.org/publications/zambia_guide2005.shtml)

## **The goals of providing nutritional support to ALHIV**

The goals of nutrition support include:

- Preventing weight loss and maintaining optimal nutrition status.
- Restoring nutritional status for severely malnourished patients in order to optimise health.
- Supporting overweight patients to lose weight and reduce the associated health risks.

## **General nutrition recommendations for ALHIV:**

- Eat a well-balanced diet that includes a variety of fresh foods, based on what is locally available and affordable.
  - Make “energy giving foods” (starches) the biggest part of every meal.
  - Eat “body building foods” with every meal. Whenever possible, a meal should contain some meat, fish or other foods from animals as often as the client can afford them. Plant proteins (beans, peas, soya beans, peanuts, and other nuts), when properly combined, also provide good quality protein.
  - Eat fruits and vegetables every day.
  - Use fats and oils in moderation.

- Avoid junk food and processed foods.
- Increase caloric intake, especially with “energy giving” and “body building” foods.
  - Asymptomatic ALHIV require between 10–15% more energy intake than people without HIV. They require an extra snack or additional small meal each day just to maintain their current weight.
  - Symptomatic ALHIV require between 20–30% more energy intake. This translates to another full meal each day or 2–3 additional snacks.
- Try to eat small meals frequently and have a regular meal schedule (remember, adolescents often have erratic eating patterns given their busy lives)
- Have their weight routinely monitored and recorded. If there are changes, or other indications of nutritional problems, the healthcare worker should conduct a nutritional assessment (see next section).
- Receive nutritional education and counselling (along with their caregivers) as a part of all HIV care appointments.
- Receive a daily multivitamin supplement as a routine part of care in order to prevent micronutrient deficiencies.

Many of the activities listed in “Table 9.2: Positive living” will enhance appetite (for example, taking exercise), aid digestion (for example, drinking plenty of water) and prevent food-related illness (for example, practising good food hygiene).

## Conducting a Nutritional Assessment

Healthcare workers should follow national guidelines on nutrition assessment and be sure to:

### Weight monitoring

It is important to weigh **EVERY** client at **EVERY** visit. Their weights should be charted, or at least recorded in a table, for easy comparison with previous weights. **Even adolescents who have stopped growing and adults need to be weighed at every visit!**

- Weigh adolescent clients at each visit, record their weight in the patient chart, and look for and ask about changes.
- Conduct anthropometric, clinical, and dietary (and biochemical, where available) assessments regularly.

A summary of key anthropomorphic assessments and their interpretation is included as “Appendix 9C: Key Components of a Nutritional Assessment”.

The goal of nutritional assessment is to determine if nutritional problems exist and if so, the severity of nutritional problems and probable causes. Healthcare workers should consider the high incidence of food insecurity for families in Zambia, especially those affected by HIV. Every nutritional assessment should include a discussion of the ability of the client and his or her family to buy or grow enough healthy foods to eat. Nutritional counselling,

education, and advice should always be adapted to the realities of clients' situations.

## **Common Nutritional and Eating Problems and Advice for Adolescent Clients and Caregivers**

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Many health-related symptoms can be prevented or even treated through food-based interventions. Healthcare workers should try to support adolescent clients with nutritional problems and work with them and or their caregivers to address them with home-based nutrition interventions. Prompt treatment of symptoms can support clients to adhere to their care and treatment plan, including ART, which, in turn, can prevent or reduce many symptoms. See “Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection” for more information.

## **What to Do When Clients and Families Do Not Have Enough Food**

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One of the most common challenges ALHIV and their families face is lack of food. Some ways healthcare workers can help ALHIV and their families get or grow enough good foods to eat include the following:

- Provide practical counselling and education on good nutrition, gardening, purchasing locally available foods, and how to store and prepare food.
- Make sure clients take multivitamins.
- Work with the rest of the multidisciplinary team to have formal linkages between the clinic and agricultural and food support organisations, including food distribution to clients at the health facility level.
- Link clients with agricultural support programmes in the community.
- Link clients with nutrition support programmes in the community.
- Link clients with animal husbandry, agricultural, and other income-generating activities in the community.

## **Helping Clients Avoid Alcohol and Drugs<sup>3,4</sup>**

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### **Substance use versus abuse**

Not everyone who uses drugs becomes addicted, but substance use and abuse can cause problems for individuals whether they are addicted or not. There are different levels of substance use:

1. Social or recreational use
2. More frequent use
3. Physical dependence or addiction to the substance

Healthcare workers can help adolescents avoid substance use in the first place, and can also help those clients using or abusing drugs and alcohol by providing counselling and support, including risk reduction counselling, and referrals to more intensive treatment if needed and available.



### **Drugs and alcohol: A part of everyday life for many adolescents**

- Many adolescents face a lot of challenges and temptations when it comes to drugs and alcohol.
- People sometimes drink or use drugs to take away their worries. However, using drugs or drinking alcohol to cope with sadness or stress will only make a person feel physically and emotionally worse in the long term, even if it makes them feel better initially.
- When people take drugs or alcohol, they may become addicted, which means that their body starts to need the substance and that they feel unwell if they do not get it.
- People who are addicted to drugs and alcohol often do not eat well because they spend most of their money on drugs and alcohol rather than on food. Also, drugs and alcohol can affect your appetite.
- Helping adolescents learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This can be done through individual counselling and health education sessions and through group health education sessions with adolescents (and caregivers).
- Screening adolescent clients for alcohol and drug use, and providing counselling, referrals, and treatment for adolescents who abuse substances are key components of adolescent HIV care and treatment. They are also important aspects of supporting ALHIV to live positively.

### **Predictors of abuse**

Some predictors of drug and alcohol abuse include:

- **Family factors:** Adolescents who observe their parents or close family members using or abusing drugs or alcohol, are more likely to use or abuse substances themselves. Other family risk factors include parental absence, inconsistent discipline, lack of communication within the family, conflict between parents and adolescents, death of parents due to HIV, and family breakup. Drug use is most prevalent among ALHIV who do not have strong support systems.
- **Peer factors:** Spending time with peers who use drugs is perhaps the strongest predictor of adolescent substance use.
- **Mental health problems:** There is a strong link between mental health problems and substance abuse.
- **Response to stress:** Substance and drug use in adolescents may be the result of feeling out of control, a sense of meaninglessness, or a lack of direction in life. Adolescents may use drugs to feel better about life events, which they see as being out of their control.

### **Consequences of adolescent substance abuse**

Adolescents face unique risks associated with substance abuse and are at risk for a number of problems, including the following:

- **Poor adherence to HIV care and treatment:** Substance abuse has a significant negative impact on an individual's adherence to HIV care and medications.
- **School-related problems:** Adolescent substance abuse is associated with declining grades, absenteeism from school, and dropping out of school.
- **Risky sexual practices:** Adolescents who use drugs and alcohol are more likely than non-using adolescents to have sex, initiate sex at a younger age, and have multiple sex partners. As substance abuse reduces their ability to practise safer sex, they are at greater risk for unplanned pregnancies, passing HIV, and passing or acquiring other sexually transmitted infections.
- **Delinquent behaviour and juvenile crime:** Drug use can lead to selling drugs, stealing, and violent behaviour.
- **Developmental problems:** Exposing the brain to alcohol during adolescence may interrupt key processes of brain development, possibly leading to mild cognitive impairment.
- **Physical and mental consequences:** Substance abuse has negative effects on the user's mind and body. The effects can be short-term, such as memory loss or high blood pressure, or long-term, such as certain cancers (for example, upper digestive tract cancers from alcohol abuse, lung cancer from smoking), heart or respiratory failure, stomach ailments, central nervous system damage, and sexual impotence. Alcohol use also interacts with conditions such as depression and stress to contribute to suicide. Some studies have shown that drinking alcohol may accelerate their HIV disease progression, as both HIV and alcohol suppress the body's immune system.

## Prevention of substance abuse

Prevention strategies should be linked to the overall goal of prevention or less harm/safer use. Some substance abuse prevention education strategies healthcare workers may use include:

- Ensuring ALHIV have positive peer support networks and are linked to support groups.
- Counselling clients to increase their awareness of the consequences of alcohol and drug use.
- Counselling clients on risk reduction to enhance healthy lifestyle decision-making ability.
- Ensuring clients receive psychosocial support to help them develop a range of positive coping skills (see Module 5).
- Ensuring clients with mental health problems or disorders receive support and treatment (see Module 6).

## Signs and Symptoms of Substance Abuse

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Healthcare workers should be alert to changes in an adolescent's behaviour and appearance that may signal substance abuse. The following behaviour changes, when extreme or lasting for more than a few days, may indicate alcohol- or drug-related problems and the need for further

screening by a qualified counsellor, social worker, or mental health professional.

- Sudden changes in personality without another known cause
- Loss of interest in favourite hobbies, sports, or other activities
- Sudden decline in performance or attendance at school or work
- Changes in friends and reluctance to talk about new friends
- Deterioration of personal grooming habits and personal hygiene
- Difficulty paying attention or forgetfulness
- Sudden aggressive behaviour, anger, nervousness or giddiness
- Increased secretiveness, heightened sensitivity to being asked questions
- Sudden changes or unexplained problems with adherence to medications or missed appointments

### **Alcohol use and abuse**

Healthcare workers should watch for signs of alcohol misuse and abuse among their patients and provide education on risk reduction and referrals for counselling and treatment. Where available, clients may find support groups specifically for alcoholics (such as Alcoholics Anonymous) very helpful. When medically necessary, detoxification is offered at, for example, Chainama Hospital.

Screen for alcohol misuse upon initial intake and whenever suspected based on medical history, report from family/partner, behaviour in the clinic, or findings from any of the psychosocial assessments (for example, the Assessment of Well Being Screening Tool, in Table 6.1, Module 6; or the HEADSS Interview Questions in Appendix 3B, Module 3). “Appendix 9E: Screening and Management of Alcohol Dependency” provides guidance on screening for and managing alcohol dependency.

### **Use and abuse of other drugs**

Healthcare workers should watch for signs that adolescent clients are abusing other drugs. In addition to alcohol, marijuana, glue (sniffing), and methamphetamines are commonly used in Zambia. There is also increasing evidence that some ARVs are being abused; for instance, efavirenz is sometimes crushed and smoked.

Screen for drug use and abuse upon initial intake and whenever suspected based on the medical history, report from family/partner, behaviour in the clinic, or findings from any of the psychosocial assessments (for example, the Assessment of Well Being Screening Tool, in Table 6.1, Module 6; or the HEADSS Interview Questions in Appendix 3B, Module 3). “Appendix 9F: Screening and Management of Drug Abuse” provides guidance on screening for and managing drug abuse. If drug abuse is suspected, provide supportive counselling and make referrals for ongoing counselling and detoxification.

## **Working with Clients who Show Signs of Substance Abuse**

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When working with clients who show signs of substance abuse, healthcare workers can:

- Be patient and accepting of the client's situation. Individuals with substance abuse problems can be very resistant to behaviour change, and recovery can be a gradual process.
  - Provide ongoing support and follow up. At every visit, ask ALHIV in recovery about the date of last use of substances.
  - Counsel the client about risks associated with use.
  - Teach the client to identify and resist peer group and family pressure (for example, role play communication skills).
  - Counsel the client on behaviour change, risk reduction, and safer sex practices.
  - Emphasize values and attitudes that support non-use or safe use (i.e., risk reduction, for example, using clean needles) where possible.
    - Refer the client to group counselling or a peer support group, if available. Support groups are an effective treatment model because they offer opportunities for these clients to learn that their concerns are not unique.
    - Refer client to any psychiatric and/or community-based support services for life skills training and substance abuse treatment.
- Healthcare workers should maintain open lines of communication with the referral facility to monitor client's progress and treatment plan.

### **Support and treatment for ALHIV with substance abuse problems**

- Healthcare workers should ensure that HIV-infected adolescents are enrolled in HIV care regardless of whether or not they are actively using drugs.
- Many adolescents can benefit from ongoing counselling, including risk education and risk reduction counselling, about alcohol, drug, and cigarette use — both individually and through group sessions such as support groups.
- Many people that have a drug addiction also have a mental health problem or a psychiatric illness, and this condition must be treated concurrently with the substance abuse (see Module 6).
- Although it is the role of healthcare workers to impart knowledge, skills, and to reinforce a sound values base in relation to health and drug use, healthcare workers should not accept sole responsibility for reducing a client's drug or alcohol use. Whenever possible, healthcare workers should involve parents and caregivers, community-based and youth-focused organisations, and the wider community, such as schools.
- Everyone responds in their own way to treatment and what may work for one person, may not work for another.

**Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To work through case studies that will help participants think about how to best handle challenging situations with adolescent clients</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>After reading each of the case studies below, the trainer will facilitate a large group discussion.</li> <li>Key discussion questions are as follows: <ul style="list-style-type: none"> <li><i>How will you assess the major issues?</i></li> <li><i>What questions would you ask the client and/or caregiver?</i></li> <li><i>What else would you want to know?</i></li> <li><i>Would you do any assessments to get more information?</i></li> <li><i>How would you counsel the client? What are some of the key “positive living” points that you should make for this client?</i></li> <li><i>What would the next steps be?</i></li> </ul> </li> </ol>

**Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion**
**Case Study 1:**

During a routine visit, Annie, a 16-year-old young woman, tells you that she has been feeling sad a lot lately and hardly ever feels hungry anymore. You also notice that she does not appear to have bathed in several days. She tells you that she has been living with HIV her whole life, and isn't sure what is causing her to feel so down. How would you proceed with Annie?

**Case Study 2:**

When you ask Katib, a 14-year-old boy, about his diet, he tells you that both of his parents are having trouble finding work and that there is rarely enough food to eat at home. Most days, they only have nshima, and sometimes there is money to buy chips or biscuits from the shop. How would you proceed with Katib?

**Case Study 3:**

When Louis, a 17-year-old young man, comes in for his appointment, he has come with his mother. She pulls you aside before the visit and tells you that she is very concerned that Louis is spending many evenings out drinking with his friends. She is worried that he is damaging his health and may not be adhering to his medications. How would you proceed with Louis and his mother?

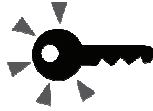
**Case Study 4:**

Estelle is a 16-year-old who recently found out that she has HIV. She comes to the clinic every month but is always quiet. One of the Peer

Educators mentioned that they saw her hanging out with some older men outside a store. She was smoking a cigarette and sharing some beer. How will you talk to her about positive living when she comes for her next clinic visit?

**Exercise 2: Planning a Presentation on Living Positively: Small group work and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"> <li>To provide participants with practice planning and carrying out group sessions on positive living topics</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>Participants will be asked to break into 4 small groups.</li> <li>Each of the small groups will be assigned one of the following topics: <ul style="list-style-type: none"> <li>Keeping the mind healthy</li> <li>Keeping the body healthy</li> <li>Nutrition and hygiene</li> <li>Alcohol and drugs</li> </ul> </li> <li>Small groups should plan a health education session on their assigned topic for adolescent clients and their caregivers. Groups should assume they have 30 minutes to run the group session, making an outline of the topics and sub-topics they would plan to cover and writing the outline on flip chart.</li> <li>Once groups have finished writing the outline, they should choose one part of their outline and practise/role play how they would facilitate it and what they would actually say to a group of ALHIV and their caregivers.</li> <li>Each group should prepare a 5-minute segment to present to the large group.</li> </ol>



## Module 9: Key Points

- Although adolescents have to ultimately reach within themselves to ensure their minds are healthy, healthcare workers can do much to assist adolescents to find emotional and psychosocial health. Healthcare workers should routinely address positive living with their adolescent clients. As ALHIV develop and age, so does their need for information about keeping healthy. Examples of healthy living include using condoms and another family planning method, attending routine healthcare, taking prescribed medicines exactly as recommended, staying active, making friends, getting rest, eating healthy and exercising regularly.
- The relationship between nutrition and HIV is cyclical. It starts with HIV increasing nutrient requirements and reducing nutrient intake and absorption. This, in turn, increases the risk of malnutrition. Then malnutrition increases the risk of opportunistic infections and speeds the progression of HIV to AIDS. Conversely, good nutrition can strengthen the immune system, delay or prevent OIs, increase quality and length of life.
- ALHIV should eat a well-balanced diet that includes a variety of fresh foods from all three of the food groups. ALHIV will notice that they will need to eat more (perhaps an additional snack or additional meal every day) just to keep from losing weight.
- Healthcare workers need to monitor nutritional and health status by weighing their adolescent clients at each visit, recording their weight in the patient chart, and looking for and asking about changes.
- Helping adolescents learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This can be done through individual counselling and health education sessions and through group health education sessions with adolescents (and caregivers).
- Healthcare workers should watch for signs of alcohol misuse and abuse in their clients and screen for abuse. Those who are identified as abusing substances need education, counselling and referrals. Those identified at risk of substance abuse should be provided with support and referrals to address underlying issues (for example, social issues, depression, anxiety).

## Appendix 9A: Web Resources for ALHIV

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**Avert.org:** An online resource with easy to understand information on HIV transmission prevention, treatment, care, epidemiology, pathology, politics, and more. (<http://www.avert.org>)

**The Body:** An online HIV and AIDS resource with the mission to 1) Use the Web to lower barriers between patients and clinicians; 2) Demystify HIV/AIDS and its treatment; 3) Improve patients' quality of life; and 4) Foster community through human connection. ([www.thebody.com](http://www.thebody.com))

**Body and Soul Charity:** A UK-based organisation supporting people living with HIV. Its Teen Spirit section (for people living with HIV aged 13 and up) provides comprehensive information and resources geared specifically toward young people living with HIV. (<http://www.bodyandsoulcharity.org>)

**"Does HIV Look Like Me?"** A campaign, conceived of by YPLHIV from Hopes Voice International. It is an effort using 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. ([www.doeshivlooklikeme.org](http://www.doeshivlooklikeme.org))

**Go Ask Alice!** Columbia University's web portal for young people's questions about sex, sexuality, and more. (<http://www.goaskalice.columbia.edu>)

**Global Network of People Living with HIV and AIDS (GNP+):** An organisation with several regional networks working to improve the quality of life for all people living with HIV and AIDS. (<http://www.gnpplus.net>)

**Global Youth Coalition on HIV/AIDS (GYCA):** A youth-led global network of 5,000 young people working to end the spread of HIV in over 150 countries worldwide. GYCA prioritises 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, mentors, donors, funders, scholarships, trainings and event opportunities related to HIV, AIDS and sexual reproductive health. ([www.youthaidscoalition.org](http://www.youthaidscoalition.org))

**Hopes Voice International:** A YPLHIV-led organisation committed to promoting the education and prevention of HIV and AIDS to young adults. Hope's Voice International aims to empower HIV positive youth to be leaders in educating their communities and be catalysts for change around



the globe. (<http://www.hopesvoice.org>)

**iAIDS.org:** A website for young people involved in the AIDS response with interactive tools and features. The results of the survey, respecting the privacy of anonymous responses, are available on the AIDS wiki website "iAIDS" designed by GYCA, TakingITGlobal, and UNICEF, as a resource for young people both infected and affected by HIV and AIDS as a collaborative space for information sharing and dialogue. ([http://wiki.iaids.org/en/Living\\_Positively](http://wiki.iaids.org/en/Living_Positively))

**International Community of Women Living with HIV (ICW):** A global community of women living with HIV. (<http://www.icw.org>)

**My Sex Life: Info for Poz Youth:** A youth-friendly, informative guide on safer sex and sexuality for YPLHIV, by the AIDS Committee of Toronto and Positive Youth Outreach, Canada. (<http://www.actoronto.ca/home.nsf/pages/mysexlife>)

**Youth R.I.S.E.:** An international youth network for reducing drug-related harm. (<http://youthrise.org/>).

Source: Global Youth Coalition on HIV/AIDS (GYCA). 2008. *Living Positively: Young People Living with HIV and the Health Sector Response* Available at: <http://www.youthaidscoalition.org/docs/livingpositively2008.pdf>

## Appendix 9B: Basic Food Groups

The basic food groups are as follows:

- **Energy giving (or “GO”) foods:** give us energy and make us **GO**. They include rice, maize, millet, sorghum, potatoes, sweet potatoes, bread, pasta, cassava and green bananas. These foods should make up the biggest part of each meal.
  - **Fats and sugars** can help give us energy, can help us gain weight, and can make foods taste better. However, they should be eaten with other healthy foods and in moderation. “Good fats” include things like avocados and groundnuts.
  - **Roughage, also known as fibre,** is important for the movement of the bowels and, therefore, helps to prevent constipation.
- **Body building (or “GROW”) foods** provide protein and help build our bodies and keep our muscles strong. They include meat, poultry, fish, offals, cheese, eggs, fresh and sour milk, beans, and groundnuts. Every meal should include at least 1 body building food. Note that ALHIV should try to eat legumes every day (for example, beans, lentils, peas, and nuts). They are usually cheaper than meat and provide a good source of protein.
- **Protective (or “GLOW”) foods** provide vitamins and minerals to help the immune system stay strong and fight off infections. They include all kinds of fruits and vegetables.

### Examples of energy giving, body building, and protective foods:

Energy giving foods (starches)	Body building foods (proteins and dairy)	Protective foods (fruits and vegetables)	
<ul style="list-style-type: none"> <li>• Nshima</li> <li>• Rice</li> <li>• Bread</li> <li>• Maize meal</li> <li>• Cassava</li> <li>• Yams</li> <li>• Millet</li> <li>• Sorghum</li> <li>• Potatoes</li> <li>• Crackers</li> </ul>	<ul style="list-style-type: none"> <li>• Beans</li> <li>• Lentils</li> <li>• Peas</li> <li>• Groundnuts</li> <li>• Sesame</li> <li>• Eggs</li> <li>• Fish</li> <li>• Beef</li> <li>• Lamb</li> <li>• Goat</li> <li>• Chicken</li> <li>• Pork</li> <li>• Milk</li> <li>• Yogurt</li> <li>• Cheese</li> <li>• Sour milk</li> <li>• Kapenta</li> </ul>	<ul style="list-style-type: none"> <li>• Bondwe</li> <li>• Carrots</li> <li>• Cabbage</li> <li>• Tomatoes</li> <li>• Okra</li> <li>• Spinach, leafy greens</li> <li>• Sweet potato and cassava leaves</li> <li>• Pumpkin leaves</li> <li>• Eggplant</li> <li>• Mushrooms</li> <li>• Cauliflower</li> <li>• Capsicum/peppers</li> </ul>	<ul style="list-style-type: none"> <li>• Avocadoes</li> <li>• Pineapple</li> <li>• Mango</li> <li>• Oranges</li> <li>• Lemons/limes</li> <li>• Pawpaw</li> <li>• Bananas</li> <li>• Pears</li> <li>• Peaches</li> <li>• Apples</li> <li>• Watermelon</li> <li>• Passion fruit</li> <li>• Guavas</li> <li>• Masuku</li> </ul>

## Appendix 9C: Key Components of a Nutritional Assessment

Measures	Interpreting results and next steps
<b>Anthropomorphic Assessment</b>	
<b>Weight and Height</b>	<ul style="list-style-type: none"> <li>In patients who have lost 10% of body weight or 6–7 kg in a month: Assess ART eligibility</li> <li>If loss &gt;5% of body weight over two to three months associated with OIs: Treat underlying conditions</li> <li>If loss of &gt;10% of body weight over two to three months associated wasting syndrome (WHO Stage 4): Start ART.</li> </ul>
<b>BMI = Weight (Kg) / Height (M<sup>2</sup>)</b> <ul style="list-style-type: none"> <li>BMI 18.5–24.9: Normal weight</li> <li>BMI 25–29.5: Overweight</li> <li>BMI 30 and above: Obese</li> </ul> (Does not apply to pregnant women)	<ul style="list-style-type: none"> <li>If BMI &lt;18.5: Provide counselling and supply therapeutic food supplements</li> <li>If BMI &gt;30: Recommend weight loss without compromising nutrition status</li> </ul>
<b>MUAC</b> (mid-upper arm circumference) Recommended for adolescents and adults who cannot stand up for weight and height measurements and for pregnant women	<b>Adults</b> <ul style="list-style-type: none"> <li>&lt;16 cm: Severe malnutrition</li> <li>16–18.5 cm: Moderate malnutrition</li> </ul> <b>Pregnant Women</b> <ul style="list-style-type: none"> <li>&lt; 17 cm: Severe malnutrition</li> <li>17–21.9 cm: Moderate malnutrition</li> </ul>
<b>Clinical assessment: what to look for</b>	
<ul style="list-style-type: none"> <li>GI problems (diarrhoea, nausea, vomiting)</li> <li>OIs that may interfere with food intake and absorption</li> <li>Concurrent medical conditions (diabetes, hypertension, lipid problems)</li> <li>Medication profile (medications taken, side effects that may affect food intake or absorption)</li> </ul>	
<b>Dietary assessment: what to ask about</b>	
<ul style="list-style-type: none"> <li>Eating patterns, food regularly consumed, and frequency of meals</li> <li>What foods are available and affordable</li> <li>Food intolerance, allergies, and aversions</li> <li>Dietary problems (for example, poor appetite, difficulty chewing and swallowing)</li> <li>Food preparation and handling practices</li> <li>Psychological factors that may contribute to inadequate food intake (for example, depression)</li> <li>Physical activity</li> <li>Use of mineral or vitamin supplements</li> <li>Living environment and functional status</li> </ul>	

Measures	Interpreting results and next steps
Biochemical assessment (where available)	
What to test for or evaluate	Next steps
• Serum albumin and/or proteins	• If low serum albumin: Advise a high protein diet
• Micronutrient deficiencies (for example, anaemia)	• If haemoglobin (Hb)<10: Advise diet high in iron and folic acid • If abnormal blood glucose: Profile for diabetes
• Glucose and lipid profile	• If abnormal lipid profile: Do further clinical evaluation

## Appendix 9D: Nutritional Management of Common Symptoms Related to Advanced HIV Infection

Sign/symptom	Nutritional recommendations and management
<b>Major weight loss</b> (sometimes called “wasting”)	<ul style="list-style-type: none"> <li>• Eat small meals often. Try to include “body building” (protein) foods with each meal.</li> <li>• Eat snacks during the day if possible (such as groundnuts, boiled eggs, and avocados).</li> <li>• Eat more “energy giving” foods (like rice, nshima, bread, and porridge).</li> <li>• Eat more beans, lentils, peas, and groundnuts.</li> <li>• Try to eat more meat, fish, and eggs.</li> <li>• Use more fats and oils in food, especially “good fats” like avocados and nuts.</li> <li>• Eat more dairy foods (like milk and yogurt).</li> <li>• Add dry milk powder or pounded groundnuts to foods (like porridge and cereals).</li> <li>• Add sugar, honey, syrup, or fruit jam to foods.</li> <li>• Try to eat more of your favourite foods.</li> <li>• Adhere to your care and treatment plan, including ART.</li> <li>• ALHIV may experience changes in their body shape. This is a long-term side effect that can be caused by ART. Some ALHIV may develop more fat on their stomach, breasts, or other areas and lose fat in their face, arms, and legs. These side effects may be confused with weight gain or weight loss.</li> </ul>
<b>Anaemia</b> (due to lack of iron in the diet; can also be caused by malaria and hookworm infections)	<ul style="list-style-type: none"> <li>• Try to eat more meat, legumes, fish, eggs, green leafy vegetables, dried fruits, and whole grains.</li> <li>• Do not drink coffee, tea, milk, or cocoa while eating — these reduce how the body processes iron.</li> <li>• Eat fruits and vegetables with lots of Vitamin C (such as oranges, lemons, and green leafy vegetables) to increase how the body processes iron.</li> <li>• Go to the health facility to treat malaria, hookworm, or other parasites.</li> <li>• Take a multivitamin with iron as well as iron tablets.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>
<b>Diarrhoea</b>	<ul style="list-style-type: none"> <li>• Eat soups and drink safe water, rice water, thin porridge, and weak tea to avoid dehydration.</li> <li>• Drink oral rehydration solution (ORS).</li> <li>• Eat small amounts of food many times a day.</li> <li>• Eat foods like millet, bananas, peas, and lentils to help retain fluids.</li> <li>• Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes, and crackers that are easy to digest.</li> </ul>

Sign/symptom	Nutritional recommendations and management
	<ul style="list-style-type: none"> <li>• Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-paws, mashed sweet potatoes, and mashed carrots.</li> <li>• Eat eggs, chicken, or fish for protein.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Strong citrus fruits (like oranges and lemons)</li> <li>• Dairy products, such as milk — try fermented products instead, like yogurt or sour milk</li> <li>• Caffeine (coffee and tea)</li> <li>• Alcohol</li> <li>• Fried foods</li> <li>• Very sugary foods</li> <li>• Extra oil, butter, or lard</li> <li>• Gas-forming foods (like cabbage, onions, and carbonated soft drinks)</li> </ul>
<b>Nausea and vomiting</b>	<ul style="list-style-type: none"> <li>• Drink fluids, especially clean water, to prevent dehydration.</li> <li>• Eat bland soups.</li> <li>• Eat fruit, such as bananas.</li> <li>• Eat lightly salty and dry foods, such as crackers or bread, to calm the stomach.</li> <li>• Drink herbal teas and lemon juice in hot water.</li> <li>• Eat small amounts of food many times a day.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Spicy or fatty foods</li> <li>• Caffeine (coffee and tea)</li> <li>• Alcohol</li> </ul>
<b>Mouth and throat sores or infection</b>	<ul style="list-style-type: none"> <li>• Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet potatoes, bananas, soup, paw-paws, and porridge.</li> <li>• Eat cold foods or foods at room temperature.</li> <li>• Drink liquids, such as beef broth, lentil, or pea soup.</li> <li>• Rinse the mouth with clean, warm salt water before and after eating.</li> <li>• Use cinnamon tea as a mouthwash.</li> <li>• Suck on clean ice, if available, to relieve pain.</li> <li>• For thrush, eat fermented foods, such as plain yogurt and sour milk. Sucking on a lemon and eating garlic can also help.</li> <li>• See the nurse or the doctor, and adhere to your care and treatment plan, including ART.</li> </ul> <p><b>Stay away from:</b></p> <ul style="list-style-type: none"> <li>• Spicy or salty foods that can irritate mouth sores</li> <li>• Strong citrus fruits and juices that can irritate mouth sores</li> </ul>

Sign/symptom	Nutritional recommendations and management
	<ul style="list-style-type: none"> <li>• Sugary foods and drinks</li> <li>• Rough foods like toast and raw vegetables</li> <li>• Alcohol</li> </ul>
<b>Loss of appetite</b>	<ul style="list-style-type: none"> <li>• Eat small, frequent meals throughout the day.</li> <li>• Eat nutritious snacks between meals.</li> <li>• Take walks before meals if possible — fresh air helps to stimulate appetite.</li> <li>• Avoid smoking — it reduces appetite.</li> <li>• Add seasonings, especially herbs, to food to give it more flavour.</li> <li>• Try rinsing out the mouth after meals.</li> <li>• Use lemon, raw tomatoes, or tonic water to stimulate the taste buds.</li> <li>• Chew food well and move it around the mouth to stimulate taste buds.</li> <li>• Avoid strong-smelling foods.</li> <li>• Eat with others as much as possible.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>
<b>Taste changes</b> (can sometimes be caused by ARVs and other medications)	<ul style="list-style-type: none"> <li>• Change sweetness, saltiness, or sourness of food by adding sugar, salt, jam, or lemon to increase the taste.</li> <li>• Try different herbs and spices.</li> <li>• Eat more fish or chicken, as meat can often have a metallic taste.</li> <li>• Eat lentils, beans, or split peas.</li> <li>• Brush teeth after eating to remove any aftertaste.</li> <li>• Adhere to your care and treatment plan, including ART.</li> </ul>

## Sources:

WHO/Food and Agriculture Organization (FAO). 2002. *Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS*. Geneva, Switzerland: WHO/FAO.

Colton, T., Dillow, A., Hainsworth, G., Israel, E., & Kane, M. 2006. *Community home-based care for people and communities affected by HIV/AIDS: A comprehensive training course for community health workers*. Watertown, MA: Pathfinder International.

## Appendix 9E: Screening and Management of Alcohol Dependency

✓	<b>Screening and management of alcohol dependency</b>
	<b>1. Use the CAGE questionnaire</b>
	<ul style="list-style-type: none"> <li>• Have you ever felt that you should <b>C</b>ut down on your drinking?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have people <b>A</b>nnoyed you by criticising your drinking?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever felt bad or <b>G</b>uilty about your drinking?</li> </ul>
	<ul style="list-style-type: none"> <li>• Have you ever had an <b>E</b>ye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?</li> </ul>
	<b>2. If the client responded “yes” to 2 OR MORE of the above questions, then he or she may have alcohol dependency.</b>
	<b>3. Give feedback about the results of the screening, provide support and referrals.</b>
	<ul style="list-style-type: none"> <li>• Provide information about the hazards of drinking (including poor adherence to HIV care and treatment).</li> <li>• Involve the adolescent’s caregiver(s), if appropriate and if the adolescent gives consent.</li> <li>• Emphasize the benefits of changing, and assess the client’s level of motivation to change.</li> <li>• If the client wants to change drinking behaviour, discuss goals and provide advice and encouragement.</li> <li>• Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and, if necessary, detoxification to treat delirium tremens (severe alcohol withdrawal).</li> </ul>

Adapted from: Ewing, J.A. 1984. *Detecting Alcoholism: The CAGE Questionnaire*. Journal of the American Medical Association 252: 1905-1907.



## Appendix 9F: Screening and Management of Drug Abuse

✓	<b>Screening and management of drug abuse</b>
	<b>1. Use the DAST questionnaire. In the last 12 months:</b>
	1. Have you used drugs other than those required for medical reasons?
	2. Have you abused prescription drugs?
	3. Do you abuse more than 1 drug at a time?
	4. Can you get through the week without using drugs?
	5. Are you always able to stop using drugs when you want to?
	6. Have you had “blackouts” or “flashbacks” as a result of drug use?
	7. Do you ever feel bad or guilty about your drug use?
	8. Do your parents (or spouse) ever complain about your involvement with drugs?
	9. Has drug abuse created problems between you and your parents (or spouse)?
	10. Have you lost friends because of your use of drugs?
	11. Have you neglected your family because of your use of drugs?
	12. Have you been in trouble at work/school because of your use of drugs?
	13. Have you lost a job because of drug abuse?
	14. Have you gotten into fights when under the influence of drugs?
	15. Have you engaged in illegal activities in order to obtain drugs?
	16. Have you been arrested for possession of illegal drugs?
	17. Have you experienced withdrawal symptoms (felt sick) when you stopped taking drugs?
	18. Have you had medical problems as a result of your drug use (for example, memory loss, hepatitis, convulsions, bleeding, etc.)?
	19. Have you gone to anyone for help for a drug problem?
	20. Have you been involved in a treatment programme especially related to drug use?
	<b>2. Score the questionnaire as follows</b>
	<ul style="list-style-type: none"> <li>Score 1 point for each “yes” response EXCEPT for the following two questions: <ul style="list-style-type: none"> <li><i>Can you get through the week without using drugs?</i></li> <li><i>Are you always able to stop using drugs when you want to?</i></li> </ul> For these two questions, score 1 point for “no” responses) </li> <li><b>If the client’s score is 6 OR MORE, then he or she may have a substance use problem.</b></li> <li><b>If the client’s score is 16 OR MORE, this may indicate very severe substance abuse.</b></li> </ul>

	<b>3. Give feedback about the results of the screening, provide support and referrals.</b>
	<ul style="list-style-type: none"> <li>• Supply information about the hazards of drug use (including poor adherence to HIV care and treatment).</li> <li>• Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent.</li> <li>• Emphasize the benefits of changing, and assess the client's level of motivation to change.</li> <li>• If the client wants to change his or her behaviour related to drug use, discuss goals and provide advice and encouragement.</li> <li>• Provide referrals to a support group and for further counselling. If needed, find a facility that may be able to help the patient overcome physical dependency and provide counselling and support.</li> </ul>

Adapted from: Gavin, D.R., Ross H.E., Skinner, H.A. 1989. *Diagnostic validity of the Drug Abuse Screening Test in the Assessment of DSM-III Drug Disorders*. British Journal of Addiction 84(3): 301-307.

## References and Resources

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<sup>1</sup> Republic of Zambia, Ministry of Health. 2008. Paediatric HIV Care Training Course, 2008

<sup>2</sup> Zambia Ministry of Health, National Food and Nutrition Commission. 2004. Nutrition Guidelines for Care and Support of People Living with HIV/AIDS. Available at: [http://www.fantaproject.org/publications/zambia\\_guide2005.shtml](http://www.fantaproject.org/publications/zambia_guide2005.shtml)

<sup>3</sup> Program for Appropriate Technology in Health (PATH). 2006. Tuko Pamoja Adolescent Reproductive Health and Life Skills Curriculum.

<sup>4</sup> United Nations Children's Funds. 2006. Life Skills – based Education for Drug Use Prevention Training Manual. UNICEF.



## Module 10

### Sexual and Reproductive Health Services for Adolescents

**Session 10.1: Values Clarification and Introduction**

**Session 10.2: Adolescent Sexuality**

**Session 10.3: Supporting Adolescent Clients to Practise Safer Sex**

**Session 10.4: Integrating Sexual Risk Screening, Risk Reduction Counselling, and STI Services into Adolescent HIV Services**

**Session 10.5: Providing Childbearing, Contraceptive, and PMTCT Counselling and Services to ALHIV**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Reflect on their own attitudes, values, and beliefs on adolescent sexuality and discuss how these may affect their work with adolescents.
- Define key terms related to sex, sexuality, sexual orientation, and sexual identity.
- Identify potential effects of HIV on sexuality among adolescents.
- Define safer sex and discuss how to empower adolescent clients to practise safer sex.
- Support adolescents to practise safer sex.
- Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients.



## PARTICIPANT MANUAL

- Explain the importance of and provide STI screening and treatment for adolescent clients.
- List ways to make SRH and other clinical examinations more adolescent-friendly.
- List the risks of adolescent pregnancy.
- Discuss childbearing choices and safe childbearing with adolescent clients.
- Understand adolescent-specific contraceptive issues and challenges.
- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT).

## Session 10.1 Values Clarification and Introduction

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### Session Objective

**After completing this session, participants will be able to:**

- Reflect on their own attitudes, values, and beliefs on adolescent sexuality and discuss how these may affect their work with adolescents.

### Introduction on Adolescent Sexuality

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Sexuality emerges during adolescence and for many people, so does sexual activity. Healthcare workers should never assume that their adolescent clients are not sexually active. Instead, they should recognise that their adolescent clients are already or will be sexually active. It is important that all members of the multidisciplinary team feel comfortable talking about sexuality and sexual and reproductive health (SRH) with adolescents, and are able to offer adolescent clients non-judgemental sexual education and SRH counselling and services.

#### Exercise 1: SRH Values Clarification: Large group exercise

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To help participants begin to think about their values, attitudes, and prejudices related to adolescent sexuality and SRH, and how these might affect their work with adolescent clients</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will notice that the trainer has posted on opposite sides of the training room flip chart papers that say "AGREE" and "DISAGREE".</li> <li>2. As the trainer reads statement out loud, participants should move to the "AGREE" or the "DISAGREE" sign, based on their opinions. If participants are not sure whether they agree or disagree with the statement, they can stand somewhere between the two signs.</li> <li>3. Participants will be invited to explain to the group why they agreed or disagreed with a particular statement.</li> </ol>

#### Statements for Values Clarification Exercise:

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1. Most parents are NOT comfortable talking with their adolescents about sex.
2. If a male client tells you he is sometimes attracted to other men, it is your job to discourage any homosexual behaviour.
3. Adolescents these days think about sex way too much.
4. HIV infection can have an affect on adolescents' sexuality.
5. We should encourage adolescents living with HIV to remain abstinent for as long as possible.
6. It is wrong for an adolescent living with HIV not to disclose his status to his partner.

7. There are safe ways for adolescents living with HIV to be sexually active.
8. It is important that an adolescent's parent or caregiver is present when a healthcare worker talks to him or her about sex.
9. It is best to refer adolescents to the STI clinic or the family planning clinic for these services instead of providing them in the care and treatment clinic.
10. Adolescents living with HIV who say they want to have children should be encouraged to wait.

## Session 10.2      Adolescent Sexuality and HIV

### Session Objectives

**After completing this session, participants will be able to:**

- Define key terms related to sex, sexuality, sexual orientation, and sexual identity.
- Identify potential effects of HIV on sexuality among adolescents.

### Exercise 2: Key Terms about Sex, Sexuality, and Sexual Orientation: Small group work and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To provide participants with definitions for words used to describe sexual expression and sexual orientation</li> </ul>
<b>Instruction</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>1. Participants will be asked to divide into small groups of about 3–4 people each. The trainer will distribute a set of cards to each group.</li> <li>2. Working in their small groups, participants should match the word card with its correct definition card.</li> <li>3. The trainer will distribute sheets of flip chart paper on which he or she has written 3 or 4 words. Participants should write the definitions of these words on that same sheet of flip chart paper.</li> </ol> <p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>4. Once the large group is reconvened, each small group will have an opportunity to give the definitions of the words listed on their sheet of flip chart.</li> </ol>

## Sex and Sexuality

### Sex (as a verb):

Sex can be a normal part of life for many older adolescents and adults. Sex means different things to different people, including:

- Vaginal sex (when the penis or fingers go into the vagina)
- Anal sex (when the penis or fingers go into the anus)
- Oral sex (when a person kisses or licks their partner's penis, vagina, or anus)
- Inserting fingers or objects into the vagina or anus
- Masturbation (alone or with a partner)
- Having sex with men, women, or both men and women.

Sex as a verb is also referred to as “intercourse” or “sexual intercourse”.



## Unsafe sex

- HIV is mainly spread to adolescents and adults through **unsafe sex**. **Unsafe sex** is any kind of sex that puts a person, or his or her sexual partners, at risk of getting a sexually transmitted infection, including HIV, or unwanted pregnancy.
- It is very important for healthcare workers to be comfortable talking about sex and reproduction with their adolescent clients. Frank, factual discussions about sex and sexuality can provide adolescents with the information they need to protect themselves and their partners from sexually transmitted infection and unplanned pregnancy.

## Sexuality:

- Is more than sex and sexual feelings.
- Includes all the feelings, thoughts, and behaviours of being a girl or boy, including being attractive, being in love, and being in relationships that include sexual intimacy and physical sexual activity.
- Exists throughout a person's life and is a component of the total expression of who we are as human beings, male or female.
- Is constantly evolving as we grow and develop.
- Is a part of us from birth to death.

## Sexuality: Key Terms

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The following are some aspects of sexuality. Each of these aspects is connected to each other and makes a person who he or she is.

- **Body image:** How we look and feel about ourselves, and how we appear to others
- **Gender roles:** The way we express being either male or female, and the expectations people have for us based on our sex
- **Relationships:** The ways we interact with others and express our feelings for others
- **Intimacy:** Sharing thoughts or feelings in a close relationship, with or without physical closeness
- **Love:** Feelings of affection and how we express those feelings for others
- **Sexual arousal:** The different things that excite us sexually.
- **Social roles:** How we contribute to and fit into society
- **Genitals:** The parts of our bodies that define our sex (male or female). They are part of sexual pleasure and reproduction
- **Ways we can express sexuality:** dancing, talking with other sex, wearing attractive clothes, sexual dreams, feeling sexual near others, masturbation, daydreams, and others

## Remember:

- In many places, “sex” is often thought to mean only penis-vagina sex between a man and a woman. But sexual behaviours include much more than penis-vagina sex.

- If healthcare workers do not talk about sex and sexual behaviours with clients, they may not get the information, skills, and supplies they need to protect themselves and their partners and reduce risks of HIV, STIs, sexual violence, discrimination, and unplanned pregnancy.
- While we all hold our own opinions about different sexual behaviours, as healthcare workers, we cannot project our own values on clients. Adolescent clients should always be made to feel comfortable talking about their sexual concerns, questions, and behaviours without risk of judgement.

## **Sexual Orientation and Identity**

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- Adolescence is a time of sexual experimentation and of defining one's sexual identity.
- Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL (regardless of the healthcare worker's personal views).
- Adolescence is a period of change, and an adolescent's sexual identity may not be his or her permanent identity.
- However, adolescence is a period when sexual identity starts to be defined. An adolescent who realises that he or she may be gay, bisexual, or transgendered may feel isolated and depressed. It is the healthcare worker's responsibility to help the adolescent cope with his or her sexual orientation and accept him- or herself.
- The healthcare worker does not have to be an expert on sexual orientation. The most important thing is that the healthcare worker be willing to listen to adolescent clients in a non-judgemental way, and to provide referrals if necessary.

### **Creating a gay-friendly atmosphere**

Although most adolescents are heterosexual, some will have a different sexual orientation such as homosexual or bisexual. Adolescents who are not heterosexual are particularly vulnerable. They may experience profound isolation and fear of discovery. They are more likely to experience harassment and violence and are at higher risk of dropping out of school, being kicked out of their homes, and experimenting with tobacco, alcohol, and illegal drugs at an earlier age. It is important that healthcare workers ensure that homosexual and bisexual youth know that they will not be judged and that they are welcome in the clinic. Healthcare workers are obligated to ensure that all youth — regardless of sexual orientation — feel comfortable and are provided with the care, treatment, and support that they need, including safer sex counselling. If clinic staff do not feel qualified to counsel gay youth about homosexuality, they should know where to refer for peer support.

## Sexual Orientation and Identity: Key Terms

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- **Sex (as a noun):** Refers to the physiological attributes that identify a person as male or female (genital organs, predominant hormones, ability to produce sperm or ova, ability to give birth, etc.).
- **Gender:** Refers to widely shared ideas and norms about women and men, including common beliefs about what characteristics and behaviour are “feminine” or “masculine.” Gender reflects and influences the different roles, the social status, as well as the economic and political power of women and men in society.
- **Heterosexuality:** The sexual orientation in which a person is physically attracted to people of the opposite sex.
- **Homosexuality:** The sexual orientation in which a person is physically attracted to people of the same sex.
- **Bisexuality:** The sexual orientation in which a person is physically attracted to members of both sexes.
- **Transvestism:** When a person dresses and acts like a person of the opposite gender.
- **Transsexual:** A person who desires to change, or has changed, his or her biological sex because his or her body does not correspond to his or her gender identity.
- **Transgendered:** A person who lives as the gender opposite to his or her anatomical sex (for example, a male living as a female but retaining his penis and sexual functioning).

## Effects of HIV on Sexuality Among ALHIV

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- ALHIV may have lower self-esteem than their peers.
- Approaching puberty, adolescents become preoccupied with their developing bodies and body image.
- Adolescents compare their bodies to those of their peers of the same sex. They have an intense need to “fit in.”
- Adolescents wonder and worry about their level of sexual attractiveness.
- The effects of HIV can result in adolescent clients having increased anxiety about sexuality, sexual relationships, and reproductive and sexual functions.
- ALHIV often have concerns about if/how they can have sexually intimate relationships and fears around disclosure to sexual partners and HIV transmission to sexual partners.
- ALHIV may have concerns and questions about being able to have safe sexual relationships and children in the future.
- Not ‘fitting in’ can be very traumatic for adolescents, especially when it involves ‘looking different.’
- ALHIV, especially those perinatally infected and those who went a long time without HIV treatment, may begin puberty later and grow and develop more slowly than their HIV-uninfected peers.
- ALHIV are subject to many illnesses, conditions, and drug side effects that may affect the way they look (for example, lipodystrophy, wasting,

skin conditions, stunting or short stature). These body characteristics and changes may affect an adolescent's body and self-image.

- Adolescents who acquired HIV through sexual abuse may harbour unresolved issues from the trauma related to the abuse (see next section).

## Sexual Abuse<sup>1</sup>

Sexual abuse is defined as forcing unwanted, improper or harmful sexual activity on another. Many victims of sexual abuse are adolescents.

Research in many countries has documented sexual abuse (ranging from harassment to rape and incest) among 7–34% of girls and 3–29% of boys.

Recognising sexual abuse can be a difficult task and one that is rarely straightforward. Identifying sexual abuse in young people requires careful investigation and assessment because very few signs and symptoms are conclusive of sexual abuse. Often, there is no physical evidence that an adolescent has been sexually abused; changes in behaviour are far more common.

The most reliable and most common indicator of sexual abuse is an adolescent's disclosure. When adolescents report that they are being or have been sexually abused, there is a high probability that they are telling the truth. Only in rare circumstances do adolescents have any interest in making false accusations. Sexual abuse — signs and symptoms of abuse, interviewing an adolescent who may have been abused, and follow up — is further discussed in “Appendix 10B: Adolescent Sexual Abuse” on page 42.

Zambia policy recommends the use of a multidisciplinary team approach in cases of sexual abuse among youth. The team should consist of at least 3 people and, when possible, include a representative from law enforcement, social welfare, and a healthcare worker. The purpose of the multidisciplinary team is to ensure that the physical, mental, and social support needs of the adolescent and family are met through a coordinated effort, thereby reducing the burden and distress faced by the adolescent.

### Exercise 3: OK For Me?: Large group exercise and discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To allow participants to examine their own values about sexual behaviours and discuss how these values and attitudes can affect the services provided to adolescents</li> </ul>
<b>Instruction</b>	<p><b>Individual Work</b></p> <ol style="list-style-type: none"> <li>1. Each participant will be given 9 or 10 “sexual behaviour” cards.</li> <li>2. Participants should take 3–4 minutes to read each sexual behaviour card to themselves and decide how they feel about each behaviour, circling one of the options on the card (this behaviour is “OK for me,” “Not OK for me, but OK for others,” or “Not OK”).</li> </ol>

	<p>3. Participant answers will be kept confidential: all cards will be collected and mixed up.</p> <p><b>Large Group Discussion</b></p> <p>4. Once all of the cards have been posted according to circled response: “OK FOR ME,” “NOT OK FOR ME, BUT OK FOR OTHERS,” and “NOT OK,” participants should gather around the flip chart pages and review the placement of the cards.</p> <p>5. Once participants have been seated, the trainer will then lead a discussion.</p>
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## Session 10.3      Supporting Adolescent Clients to Practise Safe Sex

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### Session Objectives

**After completing this session, participants will be able to:**

- Define safer sex and discuss how to empower adolescent clients to practise safer sex.
- Support adolescents to practise safer sex.

### Understanding Risk

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HIV is transmitted from one person to another through four body fluids: semen, vaginal secretions, blood, and breast milk. Any activity during which one or more of these body fluids is passed from one person to another could pose a theoretical risk of HIV transmission if:

- The body fluid is from a person infected with HIV.
- The body fluid enters the bloodstream of another person, typically through a cut or abrasion, less often through mucous membranes.

Given the mechanism by which HIV is transmitted from one person to another, sexual activities that present no risk of transmission are those during which no body fluids are exchanged. Sexual activities that present a risk involve semen, vaginal secretions, blood or breast milk.

#### **No risk:**

There are many ways to share sexual feelings that are not risky. These include:

- Hugging
- Kissing (Assuming there is no blood present in the mouth, even “French” kissing carries no risk of HIV transmission.)
- Holding hands
- Massaging
- Bathing or showering together
- Rubbing against each other with clothes on
- Sharing fantasies
- Self-masturbation
- Mutual masturbation

#### **Low risk:**

- Masturbating your partner or masturbating together, as long as males do not ejaculate near any opening or broken skin of their partner
- Using a male or female latex condom for **every** act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
- Using a barrier method for oral sex on a male or female, or for any mouth to genitals or mouth to anus contact

### **Medium risk:**

- Sharing sexual toys (rubber penis, vibrators) without cleaning them
- Oral sex without a latex barrier (some STIs, like gonorrhoea, are easily passed through oral sex while others, like Chlamydia, are not. The risk of HIV transmission through oral sex is generally low, but there is some risk, especially if the person has an STI or cuts/sores in the mouth or on the genitals)

### **High risk:**

- Unprotected (no male or female condom) anal or vaginal sex

## **What Do We Mean by “Safer Sex?”**

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**Safer sex** includes the range of ways that people can protect themselves and their partner(s) from HIV (or HIV “re-infection”), STIs, and unintended pregnancy.

- Safer sex involves choosing sexual practices and protection methods that prevent body fluids from passing from one person to another.
- Safer sex reduces these risks without reducing intimacy or pleasure.
- Safer sex includes the activities listed under “No risk:” (on page 11) and “Low risk:” (on page 11).

### **More on condoms:**

- Not having sex at all, known as abstinence, is one way to be completely safe. But for some adolescents this may not be practical. For people who are sexually active, using condoms is a reliable way to prevent STIs, HIV and unwanted pregnancy.
- There are a lot of myths about condoms, such as that they are only for sex workers or promiscuous people. Healthcare workers should promote condoms for young people as a way of protecting themselves and their partners from HIV and other STIs.
- Some people feel that condoms make sex less enjoyable. Healthcare workers should respect everyone’s personal experiences with condoms, but reframe condoms as part of pleasurable foreplay and sex with condoms as relieving the worry about an unplanned pregnancy or guilt related to risking HIV transmission.
- Some people think that if both partners are living with HIV, then they do not need to use condoms. It is important for healthcare workers to explain that even if both partners are living with HIV, they should still use condoms to reduce the risk of transmitting new strains of HIV. This is particularly risky if the strain of HIV transmitted is resistant to the ART regimens used in Zambia. Condoms can also prevent the spread of other STIs and prevent unintended pregnancy.
- Some healthcare workers may think that giving young people condoms is equated to encouraging sex — but this is not true! It is important that male and female condoms are available and offered to adolescent clients in multiple settings — in the clinic waiting area, in examination rooms, in the lab, in the pharmacy, by Peer Educators, etc. Healthcare

workers must remove as many barriers to condom use among adolescents as possible.

**Dual protection:**

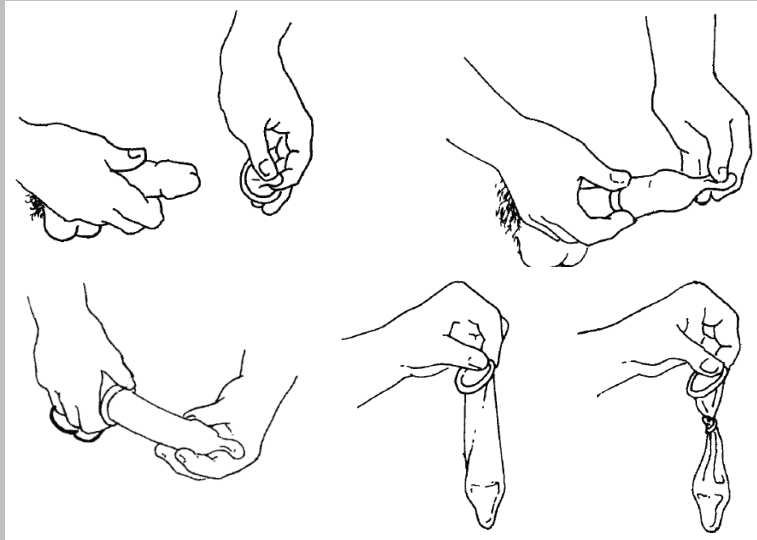
Dual protection means preventing STIs, HIV, and unwanted pregnancy at the same time. Various strategies offer dual protection, including abstinence and the “no risk” and “low risk” activities listed above. Other strategies include:

- Being in a monogamous relationship in which both partners are free of STIs and at least one partner is using effective contraception
- Using male or female condoms
- Using male or female condoms to protect against STIs and a second method to protect against unplanned pregnancy (often a hormonal method)



### How to use a male condom

These are the basic steps you should know for using and demonstrating how to use a male condom. If penis models are not available, you can use a bottle, banana, or corn. Only condoms made out of latex protect against HIV.



#### Steps to use a male condom:

- Look at the condom package and check the expiry date to make sure it is still good and that the package is not damaged.
- Open the packet on one side and take the condom out. Do not use your teeth to open the package.
- Pinch the tip of the condom to keep a little space at the tip. This will hold the semen and prevent the condom from breaking.
- Hold the condom so that the tip is facing up and it can be rolled down the penis. (Make sure it is not inside out!)
- Put it on the tip of an erect (hard) penis (only use condoms on an erect penis) and unroll it down to the bottom of the penis.
- After ejaculation (coming), the rim of the condom should be held while the man removes his penis without spilling the semen. The penis must be removed while it is still hard to make sure the condom does not fall off.
- Remove the condom and tie it in a knot to avoid spilling. Throw it away in a latrine or bury it. Do not put it in a flush toilet.

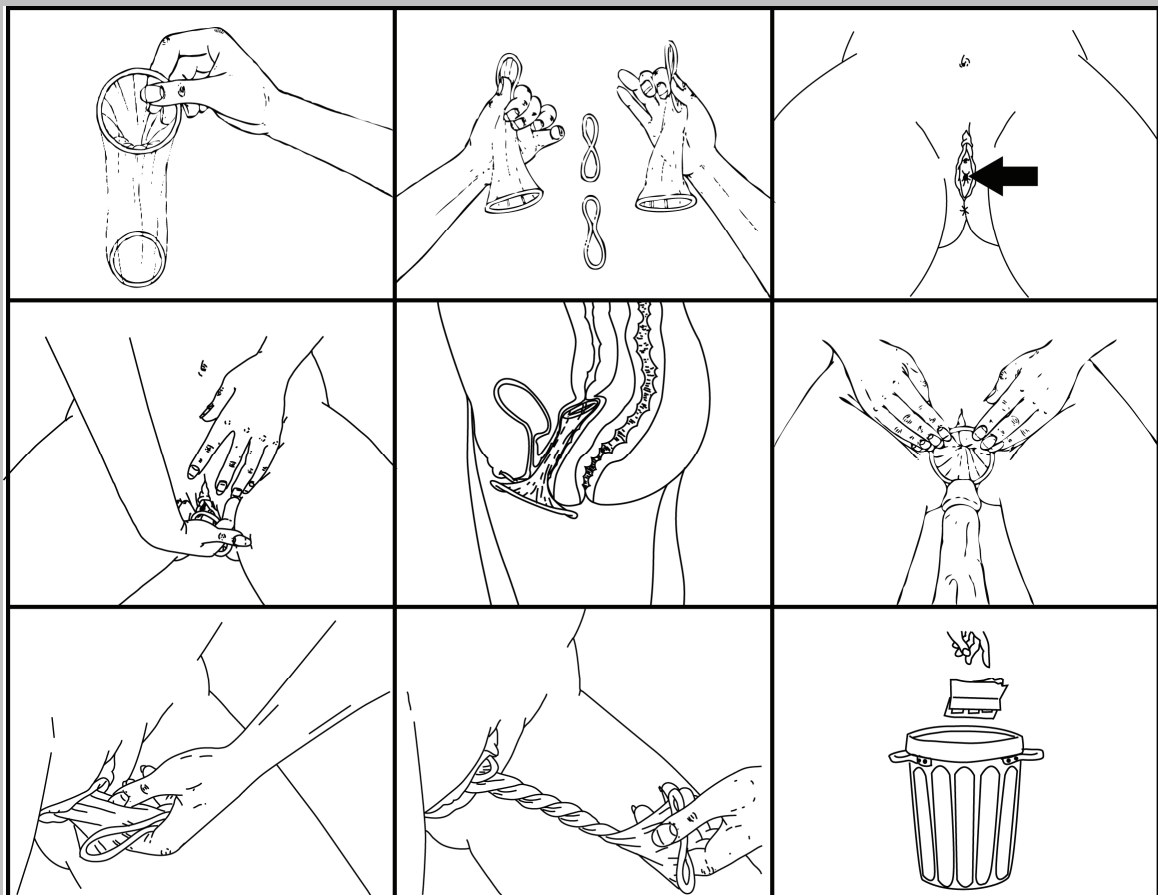
#### Also, it is important to:

- Use a condom every time you have sex — oral sex, anal sex, or vaginal. Use a new condom every time! Never reuse a condom!
- Use only lubricants made out of water, not oils.
- Store condoms in a cool, dry place, out of the sun. Do not keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange colour or damaged in any way. Throw them away.

Adapted from: Burns, A., Lovich, R., Maxwell, J., & Shapiro, K. 1997. *Where women have no doctor: A health guide for women*. Berkeley, CA: The Hesperian Foundation.

### How to use a female condom

Some women like the female condom because it gives them more control over their own bodies and over sex. Some men like it, too, because they do not have to use a male condom. The female condom is becoming more affordable and available. These are the main steps for using a female condom. If no vaginal model is available to demonstrate its use, you can use a box with a round hole cut in it or your hand.



#### Steps to use a female condom:

- Look at the condom package to make sure it is not damaged and check the expiry date to make sure it is still good.
- Open the packet. Do not use your teeth.
- Find the inner ring at the closed end of the condom. The inner ring is not attached to the condom.
- Squeeze the inner ring between the thumb and middle finger.
- Guide the inner ring all the way into the vagina with your fingers. The outer ring stays outside the vagina and covers the lips of the vagina.
- When you have sex, guide the penis through the outer ring so that the penis is inserted into the female condom.
- After the man ejaculates (comes), before the woman stands up, squeeze and twist the outer ring to keep the semen inside the pouch and pull the pouch out.
- Put the used condom in a latrine or bury it. Do not put it in a flush toilet.

Adapted from: Burns, A., Lovich, R., Maxwell, J., & Shapiro, K. 1997. *Where women have no doctor: A health guide for women*. Berkeley, CA: The Hesperian Foundation.

<b>Exercise 4: Condom Demonstration: Return demonstration and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To help participants feel comfortable demonstrating how to put on a male and female condom</li> </ul>
<b>Instruction</b>	<p><b>Large Group Demonstration — male condom</b></p> <ol style="list-style-type: none"> <li>The trainer or a participant volunteer will demonstrate to the group how to put on a male condom, using a penis model.</li> </ol> <p><b>Return Demonstration</b></p> <ol style="list-style-type: none"> <li>Working in pairs, participants will take turns demonstrating how to put on a male condom, as if they were doing such a demonstration with an adolescent in the clinic. Participants should explain each step correctly.</li> </ol> <p><b>Large Group Demonstration — female condom</b></p> <ol style="list-style-type: none"> <li>The trainer or a participant volunteer will demonstrate to the group how to insert a female condom using a vagina model.</li> </ol> <p><b>Return Demonstration</b></p> <ol style="list-style-type: none"> <li>Working in pairs, participants will take turns demonstrating how to insert a female condom, as if they were doing such a demonstration with an adolescent in the clinic. Participants should explain each step correctly.</li> </ol>

## Reasons Why Adolescents May Not Practise Safer Sex<sup>2</sup>

### Ignorance:

- They think they are not vulnerable to HIV, HIV re-infection, pregnancy, or STIs. *“It cannot happen to me”* or *“I do not have sex often enough to get pregnant.”*
- They do not have adequate or accurate information about safer sex:
  - Many adults are embarrassed to talk about sex with adolescents, or they may not have the facts themselves.
  - Some adults believe that adolescents should not be having sex.
  - School sex education is often inadequate or non-existent.
  - Parents and other adults are reluctant to provide practical information. Some believe that providing information encourages sexual activity, though this has been proven to be untrue.
  - The media portrays sexuality unrealistically and usually does not include any mention of protection.

- They have heard misinformation or myths about methods and their side effects.
- They do not know that methods are available or which methods can be used by ALHIV.
- They do not know where, how, or when to get condoms or other contraceptive methods.
- They do not know how to correctly use condoms.
- Myths about dangers of contraception are common and difficult to defuse.
- They are not aware of pleasurable alternatives to risky sex, such as mutual masturbation, etc.

### **Denial:**

- *“Sex just happened.”* (They did not expect to have sex).
- *“I only had sex once.”*
- *“Sex should be spontaneous.”*
- *“My friends are not using protection, so why should I?”*
- They don’t think they will get pregnant or an STI, or think that there is only a small chance of passing HIV during sex.

### **Lack of access:**

- Access to contraceptive services for adolescents is limited by law, custom, or clinic/institutional policy.
- Availability and cost may restrict access.
- Irregular supply of methods available.
- Sex happened spontaneously — method not available when needed.
- Healthcare worker attitudes towards contraception may prevent them from distributing protective methods to adolescents.

### **Coercion:**

- One of the partners wants to get pregnant.
- One of the partners will not let the other use protection.
- One of the partners forces the other to have sex.
- They have the attitude that condoms ruin sex or are unromantic.
- There is pressure from their family to conceive.

### **“What the heck” effect:**

- ALHIV may feel that because they are already HIV-infected, there is no need to protect themselves. This might be especially true if both sexual partners are HIV-infected.
- ALHIV may be depressed and have lost hope — thinking “What the heck, I already have HIV so why not take risks?”

### **Fear:**

- Fear of rejection by partner.
- Fear of people knowing HIV status if they use condoms/request partner to use condoms.

- Fear of the lack of confidentiality at the place methods can be obtained.
- Fear of using something new — fear of the unknown.
- Fear of side effects.
- Fear about the proper use of protective methods.
- Fear of where to keep protective methods so that no one sees them.
- Fear that something may go wrong if they start using certain contraceptive methods, like oral contraceptive pills, too early in life.
- Fear that their parents will find out they are having or planning to have sex.
- Fear that their peers or parents will know they are sexually active.
- Fear of being asked questions by a pharmacist or healthcare worker if they request condoms or contraceptive methods.
- Fear of being labelled as “cheap” or “loose”.

**Embarrassment:**

- Service providers and pharmacists are sometimes judgemental and/or moralistic about adolescent sexual activity. This is especially true for ALHIV — as many people think it is irresponsible for people living with HIV to have sex at all.
- They are embarrassed to buy condoms.
- Retail outlets often place contraceptive methods behind the counter so that customers have to ask for them.
- They are embarrassed to suggest using condoms in the “heat of the moment”.

**Other factors:**

- They lack the skill and expertise to negotiate condom use.
- They stopped using oral contraceptives because of the side effects.
- They are impulsive and sexual activity is often unplanned. Even when sex is anticipated, they often do not have protection available.
- They believe that the suggestion of protection implies mistrust of one’s partner and his or her faithfulness.
- They desire conception. For a girl, it may be a way to keep a relationship or a boyfriend; for a boy, conception may be a way to prove manhood; or they may be married.
- They lack the communication and negotiation skill to discuss protection.
- They think their partner “is taking care of protection.”
- They have not made a firm decision about whether or not they would like to get pregnant.
- They do not know how to dispose of condoms or do not have a place to dispose of them properly and privately.

## Session 10.4      Integrating Sexual Risk Screening, Risk Reduction Counselling, and STI Services into Adolescent HIV Services

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### Session Objectives

**After completing this session, participants will be able to:**

- Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients.
- Explain the importance of and provide STI screening and treatment for adolescent clients.
- List ways to make SRH and other clinical examinations more adolescent-friendly.

### Positive Prevention

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Although information alone cannot be expected to change the sexual behaviour of adolescents, healthcare workers can help adolescent clients understand the transmission risk of certain activities and provide guidance to help them reduce risky behaviour, have good sexual and reproductive health, and prevent new HIV infections. This is called **positive prevention**. See Module 9 (Session 9.2) for more information on positive prevention.

Adolescent clients need access to accurate information about HIV and STI transmission to address their concerns about sexuality, dating, future childbearing, disclosure, and transmission risk. In general, adolescents want their healthcare provider(s) to give accurate information and to sensitively ask them personal questions about HIV-related risk behaviour — without judgement and ensuring confidentiality.

In order for these discussions to be effective, adolescent clients must feel that their providers will comfortably and supportively engage in dialogue with them about any topic — no matter how uncomfortable it may be. Young people can sense when healthcare workers are out of their element or passing judgement discussing sensitive issues and this perception will likely prevent honest communication about risk behaviours.

### Sexual Risk Screening and Counselling

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#### The process:

- Start asking routine screening questions as early as possible with adolescent clients.
- Build trust with clients:
  - Start to address sexuality before the client becomes sexually active.

- Begin with safer topics, such as physical changes of puberty. Educate the client and caregivers about what to expect in terms of sexual, physical, emotional, and social development during puberty and adolescence.
- When meeting with caregivers, begin by exploring their expectations about their child's sexual activity and then use these expectations to begin providing guidance to both caregivers and the adolescent client.
- By the time they are 12 years old, see adolescent clients separately from their caregiver for at least part of each appointment.

### Overview of the discussion:

- Explain to adolescent clients and caregivers what information can and cannot be kept confidential, emphasizing that healthcare workers will protect their confidentiality, unless there is an emergency or there is a health risk requiring intervention.
- Use good communication and counselling skills (see Module 4).
- Avoid making assumptions about the client, including the client's knowledge, behaviour, sexual orientation, etc.
- Always ask about sexual behaviour rather than sexual identity.
- Avoid using any labels not first used by the client.
- If a discussion is awkward, respect a client's clues that further talk is unwanted.
- The elements of a sexual risk screening are in Table 10.1.
- The risk reduction counselling session, which would follow the sexual risk screening, is summarised in Table 10.2.

**Table 10.1: Sexual risk screening**

✓	Questions for client
	<b>1. Is client sexually active?</b>
	<ul style="list-style-type: none"> <li>• <i>Some adolescents have sex with their partners. Are you having sex?</i></li> </ul> If the response is "no" go to Table 10.2. If "yes" proceed to section 2 of this table.
	<b>2. If yes, with whom?</b>
	<ul style="list-style-type: none"> <li>• <i>Are you having sex with men, women, or both?</i></li> <li>• <i>How many partners do you have or have you had?</i></li> <li>• <i>What is the HIV status of your partner(s)?</i></li> <li>• <i>Which of your partners knows you have HIV?</i></li> </ul>
	<b>3. What?</b>
	<ul style="list-style-type: none"> <li>• <i>Do you have vaginal sex? Oral sex? Anal sex?</i></li> <li>• <i>What family planning method did you use the last time you had sex?</i></li> <li>• <i>When was the last time you used a condom?</i></li> <li>• <i>Has anyone caused you harm in the past; for example, hurt you physically or unwanted sexual encounters?</i></li> <li>• <i>How often in the last week have you used cigarettes, alcohol, or other drugs?</i></li> </ul>

**Table 10.2: Risk reduction counselling**

✓	Questions for client
	<b>1. Assess knowledge</b>
	<ul style="list-style-type: none"> <li>• <i>How is HIV transmitted?</i></li> <li>• <i>How is sexual transmission of HIV prevented?</i></li> <li>• <i>What is your plan for preventing sexual transmission of HIV?</i></li> <li>• <i>Did you know that even people with HIV should practise safer sex? Do you know why? (Response: to reduce risk of acquiring resistant virus.)</i></li> </ul>
	<b>2. Discuss options for sexual risk reduction</b>
	<ul style="list-style-type: none"> <li>• <i>There are a number of ways to reduce risk of HIV, other STIs and unwanted pregnancy, including:</i> <ul style="list-style-type: none"> <li>• <i>Abstinence</i></li> <li>• <i>Intimate touching without exchange of bodily fluids</i></li> <li>• <i>Reducing number of partners</i></li> <li>• <i>Disclosing status and negotiating sexual practices</i></li> <li>• <i>Correctly and consistently using condoms</i></li> <li>• <i>STI screening and treatment (HIV is transmitted more easily in the presence of other STIs).</i></li> <li>• <i>Maintaining maximal suppression of HIV through excellent adherence to ART, if eligible</i></li> <li>• <i>Avoiding alcohol, marijuana, party drugs, and other substances that impair good judgement and prevention</i></li> </ul> </li> </ul>
	<b>3. If an option, discuss abstinence</b>
	<ul style="list-style-type: none"> <li>• <i>Abstinence means not having sex, if you are abstinent you cannot get (re-infected with) HIV, STIs or have an unplanned pregnancy.</i></li> <li>• <i>Is abstinence an option for you?</i></li> <li>• <i>If you choose abstinence, you should have a back up plan as well, just in case you change your mind. What will be your back up plan?</i></li> </ul>
	<b>4. Discuss condoms</b>
	<ul style="list-style-type: none"> <li>• <i>Demonstrate steps for putting on a condom (male and female) and offer to supply the client with condoms.</i></li> <li>• <i>Help client improve condom negotiation skills by:</i> <ul style="list-style-type: none"> <li>• <i>Responding to the clients questions and concerns</i></li> <li>• <i>Reassuring the client that it can be difficult to bring up the topic of condoms with a partner</i></li> <li>• <i>Suggesting that he or she discuss condoms BEFORE they are needed (not in the heat of the moment)</i></li> </ul> </li> </ul>
	<b>5. Role play to encourage condom use</b>
	<ul style="list-style-type: none"> <li>• <i>If partner asks: "But you have never suggested we use condoms before."</i></li> <li>• <i>Client can say: "I went to the clinic today and my healthcare worker told me that I really need to use condoms for my health and so that</i></li> </ul>



	<p><i>we can prevent an unintended pregnancy.” (Or, the client may have another reason to explain a change of mind.)</i></p> <ul style="list-style-type: none"> <li>• If partner asks: <i>“You do not love me enough to have sex with out a condom?”</i></li> <li>• Client can say, <i>“It is because I love you and I love myself that I want to keep us both safe.”</i></li> <li>• If partner says, <i>“You want to use a condom because you have been messing around with other people.”</i></li> <li>• Client can say, <i>“Before we met, we both had other partners and I want to be sure that neither of us brings anything into the relationship.”</i></li> </ul>
	<b>6. Encourage disclosure</b>
	<ul style="list-style-type: none"> <li>• Encourage disclosure to partners, work with clients to facilitate the disclosure process, and offer the possibility of meeting with the client and partner together to help the client disclose (see Module 7).</li> </ul>

## What Makes Adolescents Vulnerable to STIs?3

Having an STI increases the risk of HIV transmission/acquisition. Many of the things that make adolescents vulnerable to HIV also make them vulnerable to STIs, such as the following.

### Biological factors

- The adolescent female genital tract, which is not yet fully mature, is more biologically susceptible to STIs than that of older women.
- ALHIV may have weakened immune systems, which make them more susceptible to STIs.
- Women often do not show signs or symptoms of chlamydia and gonorrhoea, the most common STIs, so infection may go untreated.

### Lack of knowledge

- Adolescents often lack basic knowledge about STI symptoms, transmission, and treatment.
- Adults are often uneasy talking with adolescents about STIs and sexual health, often thinking that they should not be having sex in the first place.

### Factors common in adolescence

- For adolescents, sex is often unplanned and spontaneous, making the use of condoms less consistent and increasing the risk for STIs. Adolescents may also have multiple, short-term sexual relationships.
- Young women are more at risk of sexual violence and exploitation, lack of formal education (including SRH education), inability to negotiate

safer sex with partners, and lack of access to SRH information and services.

- Adolescents may be subject to high-risk behaviours, such as anal sex to preserve virginity, dry sex, and scarification, which can increase the risk for STIs.
- Young men may have their first sexual experiences with commercial sex workers and young women with older men, which can increase the risk of STIs if condoms are not used consistently and correctly.
- Adolescents may be afraid to seek treatment for STIs for fear of stigma and discrimination. This is especially true for ALHIV because many adults feel they should not be having sex at all.

## **Making SRH and Other Clinical Procedures More Adolescent-Friendly<sup>4</sup>**

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There are many ways healthcare workers can make physical examinations less stressful for adolescent clients. Be sure to:

- Explain what is going to happen during each visit.
- Respect the adolescent client's privacy, for example, leave the room and close the door if they need to remove clothing or change into a gown. Try and expose only the parts of the body you are examining, leaving the rest covered. Do not leave any part of the body exposed when not being examined.
- Explain what you are going to do before you begin each step of the examination.
- Reassure the client about confidentiality.
- Give the client reassurance throughout the examination.
- Give feedback in a non-judgemental manner. For example, "I see you have a small sore here, does it hurt?"
- Offer to have the exam performed by a doctor or nurse of the same sex, if possible. Or, offer to have someone of the same sex in the room during the examination.
- Delay pelvic exams, unless the adolescent client is at risk of STIs or pregnancy or has multiple sexual partners.
- If a pelvic exam is necessary, address any concerns. For example, adolescent girls who are virgins may fear that the procedure will be uncomfortable or tear their hymen. Healthcare workers can reassure clients that the hymen only partially covers the vaginal opening and that the vagina will stretch if the client can relax. Let the client see and touch the speculum, try to use a small speculum (sometimes called a "virgin speculum"), always explain what is going to happen, and ask permission to touch the client with your hand or the speculum. Take great care to carry out all parts of the exam gently and smoothly to minimise the clients' discomfort and anxiety. Remind her to breathe deeply and try to relax during the exam.

## STI Screening and Treatment for ALHIV

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### Screening and physical examination

At every visit, ask adolescent clients who are sexually active (and **ALL** older adolescents clients — healthcare workers should assume they are sexually active or will be sexually active soon) about STI symptoms. If the answer to any question is ‘yes’, conduct a physical examination that includes the steps outlined in “Appendix 10C: Screening and Examining Adolescent Clients for STIs”. Ensure that there is privacy during all physical examinations and follow the tips to make examinations more adolescent-friendly (page 23).

Healthcare workers should also provide routine cervical screening on all sexually active women with HIV. Routine cervical screening is especially important as females living with HIV are at greater risk for cervical cancer than HIV-uninfected women.

See the “National STI Syndromic Case Management Guidelines for Zambia” for additional information.

### Diagnosis and treatment

A thorough physical examination is key to diagnosing STIs. Healthcare workers should use information from the physical examination in combination with the client’s history to make a **syndromic diagnosis** and manage according to the flow charts in the national STI guidelines.

Treat clients diagnosed with an STI syndrome for all of the possible STIs that could cause that syndrome. In addition:

- Counsel clients to avoid sex while being treated for STIs and to use condoms with every sexual encounter after sexual activity resumes.
- Counsel clients diagnosed with STIs to inform their sexual partner(s) to seek medical care so that they can be evaluated and treated for STIs as well.
- Conduct risk reduction counselling to help adolescent clients avoid STIs in the future, including counselling on safer sex and consistent condom use with every sexual encounter.

## Session 10.5      **Providing Childbearing and Contraceptive Counselling for ALHIV**

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### **Session Objectives**

**After completing this session, participants will be able to:**

- List the risks of adolescent pregnancy.
- Discuss childbearing choices and safe childbearing with adolescent clients.
- Understand adolescent-specific contraceptive issues and challenges.
- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT).

### **Risks of Adolescent Pregnancy<sup>5</sup>**

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#### **Health risks:**

- Pregnancy complications because they are not fully developed and their body may not be well prepared to handle child bearing. In these cases, there is a greater risk of obstructed delivery and prolonged labour, thereby increasing the risk of haemorrhage, infection, and fistula.
- Pre-eclampsia — or hypertension during pregnancy — which, if left untreated can progress to extreme hypertension, seizures, convulsions, and haemorrhage.
- Anaemia, which is more common in adolescent mothers than in older mothers.
- Complications associated with unsafe abortion.
- Premature births and low birth weight.
- Spontaneous abortion and stillbirths, especially among adolescents under the age of 15.
- Mother-to-child transmission if an ALHIV becomes pregnant. ART and ARVs can help reduce, but not eliminate, the risk (see below for more information on PMTCT).

#### **Psychological, social, and economic risks and consequences:**

- Pregnant adolescents, and especially those living with HIV, may face intense stigma from family, friends, community members, and healthcare workers — which can cause emotional distress and create an impediment to receiving needed HIV and PMTCT care and medicines.
- Pregnancy often means the end of formal education. If not expelled from school if pregnant, girls often have to drop out to care for the infant.

- Adolescent pregnancy can change a girl's choice of career, academic aspirations and future marriage possibilities. With limited career prospects, some mothers resort to low paying and risky jobs (such as prostitution) or marriage to support their children.
- Some men refuse to take responsibility for the pregnancy which can contribute to hardship for the mother and child.
- Young parents are often not prepared to raise a child, which could in extreme cases lead to child rearing problems like child abuse or neglect.
- Early marriage due to an unplanned pregnancy is frequently an unhappy, unstable one.

## **Counselling Adolescents on the Safest Times to Have Children in the Future**

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Many ALHIV have questions about whether or not they can safely have children in the future. Healthcare workers should provide education and counselling to adolescent clients on the safest times to become pregnant and have children.

- It is safest to wait until adulthood to become pregnant and have children. There are many health, psychological, social, and economic risks of having a baby during adolescence (see above).
- The safest time to get pregnant is when **both** partners:
  - Have CD4 cell counts over 350
  - Are healthy: they do not have any opportunistic infections (including TB) nor do they have advanced AIDS
  - Are taking and adhering to their ART regimens
- It is healthiest for a mother to wait until her child is at least 2 years before getting pregnant again.

It is important for ALHIV to know the facts about pregnancy and preventing mother-to-child transmission — BEFORE they become pregnant. These are good topics to discuss in ALHIV support groups and during individual counselling sessions. Adolescent clients should always be encouraged to talk with healthcare workers about pregnancy and PMTCT if they are thinking of having children. Healthcare workers should also encourage partners of adolescent clients to come to the clinic for education and counselling on these topics.

## **Common Contraceptive Issues for Adolescents**

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- Adolescents have special needs when choosing a contraceptive method. Social and behavioural issues are important considerations. For example, methods that do not require a daily regimen may be more appropriate because of adolescents' unpredictable sexual activity or the need to conceal intimacy and contraceptive use. In addition, sexually active adolescents who are unmarried have very different needs from those who are married and want to postpone, space, or limit pregnancy.

- However, whether married or unmarried, adolescents have been shown to be less tolerant of side effects and to have high family planning discontinuation rates. Expanding the number of methods to choose from can improve adolescents' satisfaction and increase contraceptive acceptance and use. Proper education and counselling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions.
- At a minimum, all adolescents should be counselled on correct condom use and clearly instructed that condoms or abstinence are the only ways to prevent HIV infection. Every effort should be made to prevent the cost of services or contraceptive methods from limiting options.

Always follow the national “Family Planning Counselling Kit” when providing family planning counselling and support and when prescribing a family planning method.

### **Contraceptive Side Effects:**

Some adolescents may experience side effects from contraceptive methods (i.e. weight gain, spotting, menstrual changes). These side effects can be uncomfortable, annoying, or worrisome to clients. Side effects are the major reason that adolescent clients stop using contraceptive methods. Therefore it is important that healthcare workers<sup>6</sup>:

- Treat all client complaints with patience and seriousness.
- Offer clients an opportunity to discuss their concerns.
- Reassure the client that side effects are manageable and reversible.
- Help the client differentiate between normal contraceptive side effects versus complications that require a return visit to the clinic.
- Offer clients information and advice on how to prevent/manage side effects.
- Always provide follow-up counselling.

A summary of common contraceptive options for ALHIV is in Table 10.3. A more detailed description of contraceptive options including special considerations for the adolescent client and advice on counselling the adolescent client about condoms can be found in “Appendix 10D: Survey of Family Planning Methods for Adolescents”.

**Table 10.3: Summary of contraceptive options for ALHIV**

Male and female condoms		
Advantages	Disadvantages	Summary
<ul style="list-style-type: none"> <li>• Provide protection from both pregnancy and STI (including HIV) transmission and acquisition</li> <li>• Highly effective when used consistently and correctly</li> </ul>	<ul style="list-style-type: none"> <li>• Correct and consistent condom use may be difficult to achieve, failure rates can be high.</li> <li>• Partner involvement is required, need to negotiate their use</li> <li>• Does not interfere with medications</li> </ul>	<ul style="list-style-type: none"> <li>• Good method for adolescents</li> <li>• Requires demonstration on proper use</li> </ul>

<b>Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills (POPs) — pills taken daily*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective when taken daily on schedule</li> <li>POPs may be a good choice for adolescents who cannot tolerate estrogen in COCs or who are breastfeeding</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Failure rates highest for adolescents due to confusion about how to take pill</li> <li>Side effects can include nausea, weight gain, breast tenderness, headaches, spotting</li> <li>Cannot be taken by clients on rifampicin</li> <li>ARVs may adversely affect the efficacy of low-dose COCs and/or increase their side effects</li> </ul>	<ul style="list-style-type: none"> <li>Women taking ARVs who want to use COCs should be counselled about the importance of taking COCs on time every day, and about consistent condom use</li> <li>POPs are safe for adolescents, but because they must be taken at exactly the same time everyday, they are not the best choice</li> </ul>
<b>Injectables — “shot” given every 2–3 months*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective when used correctly</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Side effects can include spotting at first, then amenorrhea and weight gain</li> </ul>	<ul style="list-style-type: none"> <li>Can be used by ALHIV without restrictions</li> <li>Remind adolescent when to return for next injection</li> </ul>
<b>Hormonal implants — small rods inserted under skin, lasts 3–7 years*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective</li> <li>Can be reversed</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Effectiveness of implant may be reduced by ARVs</li> <li>Side effects can include nausea, weight gain, and changes in monthly bleeding.</li> <li>Usually need to be inserted and removed at a family planning clinic</li> </ul>	<ul style="list-style-type: none"> <li>Can be used by ALHIV who do not take ART</li> <li>Can be used by ALHIV on ART, but should use condoms as a back-up method</li> <li>Provide counselling to prepare client for possibility of irregular bleeding</li> </ul>
<b>Emergency contraceptive pills (ECP) — 2 doses of pills taken within 120 hours after unprotected sex</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Reduces risk of pregnancy after unprotected sex by 75%</li> <li>Safe for all women, including those living with HIV and those taking ART</li> </ul>	<ul style="list-style-type: none"> <li>For emergency use only!</li> <li>Side effects can include nausea, vomiting, cramps, headache, breast tenderness, and changes in the menstrual cycle</li> </ul>	<ul style="list-style-type: none"> <li>Should be widely and easily available to ALHIV</li> <li>Provide counselling on adopting a regular contraceptive method, as well as on condom use for dual protection</li> </ul>
<b>Intra-uterine devices (IUDs) — device inserted into uterus, lasts up to 12 years*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Highly effective</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Should not be initiated in a woman with AIDS not taking ART</li> <li>Side effects can include heavy bleeding, discharge, cramping and pain during the first months</li> </ul>	<ul style="list-style-type: none"> <li>Appropriate for adolescents in stable, mutually monogamous relationships</li> <li>Not recommended for ALHIV with advanced HIV disease or AIDS,</li> </ul>

	<ul style="list-style-type: none"> <li>Usually needs to be inserted and removed at a family planning clinic</li> </ul>	especially if not on ART
<b>Male and female sterilisation — surgery*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Safe and effective</li> <li>Free of side effects</li> <li>Does not interfere with sex</li> </ul>	<ul style="list-style-type: none"> <li>Permanent and requires surgery</li> </ul>	<ul style="list-style-type: none"> <li>Permanent methods are not recommended for adolescents</li> </ul>
<b>Lactational amenorrhea method (LAM)*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>Temporary, natural contraceptive option for women who are less than 6 months postpartum, exclusively breastfeeding, and whose periods have not yet returned</li> </ul>	<ul style="list-style-type: none"> <li>Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV</li> </ul>	<ul style="list-style-type: none"> <li>Appropriate only for adolescents who have given birth within the past 6 months</li> </ul>
<b>Fertility awareness methods*</b>		
<b>Advantages</b>	<b>Disadvantages</b>	<b>Summary</b>
<ul style="list-style-type: none"> <li>No health risks or side effects</li> </ul>	<ul style="list-style-type: none"> <li>Requires a woman to identify her fertile days, which takes time and effort</li> <li>Requires considerable commitment, calculation and self-control, both by the woman and her partner</li> </ul>	<ul style="list-style-type: none"> <li>A difficult method for most adolescents to implement correctly and consistently</li> <li>Not reliable for pregnancy prevention</li> <li>Do not recommend</li> </ul>

\* Healthcare workers should recommend and provide condoms for dual protection.

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004.  
*Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7.* Watertown, MA: Pathfinder International.

## PMTCT Services for Adolescents

Healthcare workers should follow the Zambia “2010 National Protocol Guidelines — PMTCT” when providing services to pregnant ALHIV, their partners, and family members. Some of the key PMTCT concepts are summarised below.

**Table 10.4: Key PMTCT concepts**

<b>Key Concept 1 – Keep mothers healthy</b>
<ul style="list-style-type: none"> <li>The healthier the mother (the less HIV she has in her blood and the higher her CD4 cell count), the less likely it is that the baby will become HIV-infected. Conversely, the sicker the mother (a lot of virus in the blood and low CD4 cell count), the more likely it is that the baby will become HIV-infected.</li> <li>A healthy mother is able to take care of herself, her baby and her family. Without healthy mothers, we will not have healthy families or communities!</li> </ul>



**Key Concept 2 – Reduce risk at every stage**

The risk of passing HIV from a mother living with HIV to her baby depend on timing:

- During pregnancy, labour and delivery, about 20 out of 100 babies will get HIV if there are no ARVs or other services offered.
- During breastfeeding, about 12 out of every 100 babies in the absence of a PMTCT programme. This depends on how the baby is fed — mixed feeding in the first 6 months of life dramatically increases risk — and how long the baby is breastfed.

**It is important to reduce the risk of transmission at each of these stages.**

**Key Concept 3 – All mothers need ARVs**

- One of the best ways to lower the amount of HIV in the mother's body, increase her CD4 cell count and make her healthy and less likely to pass HIV to the baby is for her to get the care and treatment she needs to be as healthy as possible, including ART. All pregnant women with HIV need to take ARVs.
- If a mother has a CD4 cell count **at or below 350**, the baby is at high risk of getting HIV. According to the national PMTCT guidelines, women with a CD4 cell count of 350 or lower should start ART and stay on ART for their entire lives.
- If a mother has a CD4 cell count **above 350**, the baby has a lower risk of getting HIV than if the mother's CD4 cell count is low. According to new national recommendations, women with a CD4 cell count above 350 should also get ARVs during pregnancy to prevent the baby from acquiring HIV. Follow the Zambia "2010 National Protocol Guidelines — PMTCT".

**Key Concept 4 – All babies of HIV-infected mothers need ARVs and CTX**

- All babies need to take daily NVP at the time of birth and for the first six weeks of life, to help prevent them from becoming HIV-infected. If baby is breastfed and mother is not on ART, then the baby will continue taking daily NVP until one week after complete cessation of all breastfeeding. Babies of mothers on ART and those who are formula feeding, stop taking NVP at 6 weeks of age.
- Either the mother or the baby needs to be taking ARVs for the **entire time the baby is breastfeeding**. This helps protect the baby from getting HIV during breastfeeding.
- HIV-exposed babies need to take CTX starting at 6 weeks to prevent other infections that may make them very sick or lead to a rapid death. Babies should take CTX until it is certain that they are not HIV-infected.
- If the baby gets tested and is HIV-infected, the baby will also need lifelong ART (The Zambia MoH recommends that all HIV-infected babies under age 2 years begin ART).

## Challenges with PMTCT Services

Pregnant adolescents and new adolescent mothers, and their partners, face many of the same challenges adults face with PMTCT. However, healthcare workers should keep in mind challenges that could present barriers to adolescent clients in PMTCT programmes, including:

- Difficulty and challenges adhering to ART or ARVs
- Difficulty and challenges giving the baby medicines everyday
- Challenges with safe infant feeding, especially exclusive breastfeeding for the first 6 months of life
- Fears about having a baby that is HIV-infected; guilt about passing HIV to the baby
- Facing stigma for having HIV and becoming pregnant, and for being pregnant at a young age, especially if not married
- Difficulty foreseeing the future and lifelong HIV care, while also caring for a child
- Lack of emotional and financial support from family and/or from the child's father
- Financial instability and possibility of dropping out of school
- Inadvertent disclosure of HIV status to others
- Lack of access to youth-friendly PMTCT information and PMTCT services

### Exercise 5: Providing SRH Services to Adolescent Clients: Case studies, role play, and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• Participants have an opportunity to discuss and role play strategies to provide ALHIV with a range of sexual and reproductive health information, counselling, and services</li> </ul>
<b>Instruction</b>	<p><b>Case Studies and Role Play</b></p> <ol style="list-style-type: none"> <li>1. Participants will be asked to break into small groups of 3–4 people each. Each small group will be assigned 2 of the case studies below.</li> <li>2. Participants should review their case studies, recording key points on flip chart.</li> <li>3. Each small group should role play their 2 case studies, one at a time, taking turns playing the roles of “healthcare worker,” “adolescent client,” and “observer.” In some cases, there may be an additional role of the client’s family member.</li> </ol> <p><b>Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>4. Once the large group has been reconvened, some of the small groups will be invited to perform 1 of their role plays.</li> </ol>

### **Exercise 5: Providing SRH Services to Adolescent Clients: Case studies, role play, and large group discussion**

#### **Case Study 1:**

The mother of one of your adolescent clients, named Isaac, comes to the clinic to speak with you. She is very upset because she caught Isaac, who is 15, looking at pornographic magazines. She went through Isaac's things and was shocked to see photos of men having sex with other men. She tells you that she does not want Isaac coming to the adolescent support group anymore, because she thinks it is a bad influence and that the "city kids" might be "making him gay." What would you talk about with Isaac's mother? How would you proceed when you see Isaac during his clinical check up?

#### **Case Study 2:**

A noisy group of young boys are in the waiting room of the clinic laughing and talking loudly. They push one of the boys towards you and say: "He needs some condoms." The boy, named Themba, is about 16 years old, looks embarrassed and does not say anything. Themba comes in for his check up. How would you proceed with Themba? How would you make him feel comfortable since he's already embarrassed, what questions would you ask him, and what information and services would you provide?

#### **Case Study 3:**

Susan is a 15-year-old girl who has been brought to the clinic by her aunt. Her aunt tells you that she thinks Susan has an older boyfriend and that he is buying her new clothes and perfumes. Susan seems shy and unwilling to speak in front of her aunt at the clinic visit. How would you proceed with Susan? What kind of questions would you ask her and what kinds of information and counselling would you provide?

#### **Case Study 4:**

Peter is a 19-year-old young man who comes to the ART clinic regularly. You learned from one of the adolescent Peer Educators at your clinic that Peter was bragging that he has been with "about 10 women" but never uses condoms because they are "good girls" and they do not insist that he uses condoms, so why should he? When you offer him some condoms at the end of the appointment, he says that he does not need them. He says that he now has a steady girlfriend because he is feeling pressure from family to "get serious". How do you proceed with Peter?

#### **Case Study 5:**

George is a 16-year-old client who has been coming to the ART clinic since his childhood. You ask George if he is having any problems, and shyly, he tells you that he is having a lot of pain when he pees. You begin asking him some more questions about his symptoms and whether or not he is sexually active (he just nods his head "no" – that he is not sexually active) and he seems embarrassed, stops talking, and just looks down at the floor. How do you proceed with George?

**Case Study 6:**

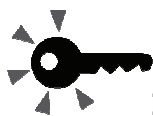
Ethel is a 16 year-old young woman who tested positive for HIV and recently started coming to the clinic. Ethel thinks she is sure that she contracted HIV from her ex-boyfriend. When Ethel tells you she is having some strange vaginal discharge, you suggest that you do a clinical exam because she might have an STI. Ethel starts crying and says she refuses to have anyone touch her “down there.” How would you proceed with Ethel?

**Case Study 7:**

Katherine is a 17-year-old young woman living with HIV. She is on ART and is feeling very well. She has a boyfriend and he knows about her HIV status and is accepting. She was taking oral contraceptives but stopped them because she said they made her feel nauseous and gain weight. Now, they usually use condoms, but they have had sex a few times without them. Katherine and her boyfriend do not want children right now, but they talk about getting married and having children in the future, once she finishes school. Katherine is getting a lot of pressure from her family to never have kids because of the risk that they would be HIV-infected. How would you proceed with Katherine?

**Case Study 8:**

Elizabeth is 19 years-old and was perinatally infected with HIV. She has been adherent to ARVs for many years. She has come to the clinic today for a check up because she is pregnant. She is happy to be pregnant, but is afraid that her baby will become HIV-infected. She is also worried about how her ARVs might be affecting her unborn child, and tells you that her boyfriend has told her to stop taking them so they do not hurt the baby. How would you proceed with Elizabeth?

**Module 10: Key Points**

- An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of clients. In order to do so, healthcare workers must be comfortable talking about sexuality and SRH with their clients and knowledgeable about the common SRH issues faced by adolescents.
- Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL (regardless of the healthcare worker's personal views). Healthcare workers do not have to be experts on sexual orientation. A willingness to listen, be understanding, and refer adolescent clients to resources is often enough.
- Safer sex describes the range of sexual activities that do not transmit STIs (including HIV) and that protect against unintended pregnancy but

are still pleasurable. Safer sex includes sexual practices during which body fluids are not passed between partners. Using condoms is a reliable way to practise safer sex and prevent STIs, HIV and unwanted pregnancy. For people who are living with HIV, condoms also prevent re-infection. ALHIV should have free and easy access to condoms in the clinic setting.

- Sexual risk screening starts before a client is sexually active and includes questions to help the healthcare worker assess if the client is sexually active, if so, with whom and what risks he or she is taking. Risk reduction counselling focuses on reducing risk of HIV, STIs and unwanted pregnancy by helping the client choose a strategy that is right for him or her.
- All adolescents who are sexually active should be screened for STI symptoms. If there is a suspicion of an STI, then conduct a physical examination. Follow the national STI guidelines for diagnosis and treatment.
- Given the risks of adolescent pregnancy, it is important that healthcare workers encourage their young clients to delay childbearing until they are adults, if possible, and to use contraceptive methods if they are sexually active. Healthcare workers can also provide counselling on the safest times to become pregnant, such as when the client has reached physical adulthood, when CD4 cell count is high, when the client is well, and when she is stable on and adhering to ART.
- Good education and counselling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions with which they are more likely to adhere in the long term. Counselling should always include discussion of side effects.
- The following family planning methods are good options for ALHIV: condoms, COCs/POPs, injectables, hormonal implants and IUDs.
- Counsel all clients on correct condom use, whether condoms are their primary contraceptive choice or will be used for dual protection.
- Ensure that all ALHIV clients know about emergency contraceptive pills, when they can be used and how to obtain them.
- Refer all pregnant clients to ANC for PMTCT services.

## Appendix 10A: Journal Article

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Adolescent health brief

### **Sexual Behavior and Desires Among Adolescents Perinatally Infected with Human Immunodeficiency Virus in Uganda: Implications for Programming**

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**See Editorial p. 101**

**Abstract** Counseling programs for adolescents living with human immunodeficiency virus (HIV) encourage abstinence from sex and relationships. This Uganda study, however, found that many of these adolescents are sexually active or desire to be in relationships but engage in poor preventive practices. Programs for HIV and acquired immunodeficiency syndrome (AIDS) programs therefore need to strengthen preventive services to this group. © 2009 Society for Adolescent Medicine. All rights reserved.

**Keywords:** Adolescents; HIV infection; Perinatal; Sexual behavior; Program implications; Uganda

The number of children living with human immunodeficiency virus (HIV) in Africa continues to escalate despite the advances made in prevention of mother-to-child transmission. Sub-Saharan Africa accounts for 90% of the estimated 3 million children living with HIV [1]. At the same time, the roll-out of anti-retroviral treatment (ART) programs has made it possible for perinatally HIV-infected infants to live through adolescence and adulthood thereby engaging in dating and sexual relationships. However the sexual and reproductive health needs of this unique and growing group of the population are largely unmet [2]. In Uganda, for example, treatment, care, and support programs for HIV and acquired immunodeficiency syndrome (AIDS) are organised around adult and pediatric care. This implies that adolescents who no longer fit under pediatric care and who feel uncomfortable with adult services lack programs to address their specific

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needs. Moreover the programs assume that HIV-infected young people remain sexually inactive and therefore hardly address their need for sexual and reproductive health information and services. Service providers and counselors, for instance, usually advise perinatally infected adolescents not to engage in sexual relationships [3,4]. In its efforts and continued commitment to care for people living with HIV, The AIDS Support Organization (TASO) in Uganda supported by the Population Council's Frontiers in Reproductive Health Program initiated a study in 2007 to understand the sexual and reproductive health needs of adolescents born with HIV. The study involved both survey and qualitative interviews with HIV-infected girls and boys aged 15–19 years. Its aim was to better understand the sexuality (desires, experiences, beliefs, and values) of this segment of the population, and to identify anxieties or fears they have around growing up, love and loving, dating, pregnancy, fatherhood, motherhood, relationships and intimacy. This brief describes some of the key findings from this study and discusses their programmatic implications.

### Methods

Study respondents were identified and recruited through existing HIV/AIDS treatment, care and support centers in four districts of Uganda, that is, Kampala, Wakiso, Masaka, and Jinja. Access to the client registers was granted by the management of the centers while the data officers working at the centers assisted with identifying clients falling within the desired age bracket. The counselors then helped with identifying those clients who were recorded as being perinatally infected with HIV or presumed to be so (that is, those who had been living with HIV since infancy) and to whom HIV sero-status had been disclosed.

**Table 1: Distribution of Study Respondents by Sociodemographic Characteristics**

Characteristic	Male (n = 263)	Female (n = 469)	Both genders (n = 732)
<b>Mean age (y)</b>	<b>17</b>	<b>16</b>	<b>17</b>
<b>Age, y (%)</b>			
15	35	33	34
16	14	17	16
17	8	10	9
18	25	23	24
19	18	17	17
<b>District (%)</b>			
Jinja	32	21	25
Kampala	24	29	27
Wakiso	18	35	29
Masaka	26	15	19

A total of 740 young girls and boys were identified for the survey and 732 were successfully interviewed. Female respondents comprised about two-

thirds (64%) of the study sample (Table 1). There was, however, no significant difference in the mean ages of male and female participants. Survey data were collected using a structured questionnaire in both English and either of the two other local languages, *Luganda* or *Lusoga*. A wide range of issues were covered including socio-demographic characteristics, access to sexual and reproductive health information, sexual behavior, preventive knowledge and practices, contraceptive knowledge and use, pregnancy and childbearing intentions and experiences, self-esteem, worries, and sexual and physical violence.

Another 48 young people were identified to participate in focus group discussions (FGDs) and 12 others were identified for in-depth interviews and ethnographic case stories. Seven FGDs were conducted, with each FGD having an average of six participants. In-depth interviews and case stories were conducted with all the 12 informants. Informed consent to participate in the study was sought at two levels: the parents/guardians first, followed by the individual adolescents. Parents/guardians of respondents aged 15–17 years were asked to provide written permission for their children to participate in the study. Subsequently, the respondents were asked to indicate their own willingness to participate by assenting to the study. Only individual written consent was obtained from respondents aged 18–19 years and those considered to be emancipated minors<sup>1</sup>.

## Results

Key findings are summarised in Table 2. Contrary to the emphasis by service providers on refraining from or postponing sexual initiation, the findings indicate that these adolescents are beginning or do desire to explore their sexuality. Of all interviewed respondents, 44% reported a desire to have sex, and 41% believed that there was no reason why someone who living with HIV should not have sexual intercourse. About 40% of all respondents had ever been in a relationship with a significantly higher proportion of male than female participants reporting having been in a relationship. In addition, 33% of the respondents reported having had sexual intercourse. Slightly more male than female respondents reported having had sex though the difference is not significant. It is also worth noting that of those who had had sex, close to three-quarters (73%) had consensual first sex, with significantly more male than female respondents reporting consensual first sex.

## Discussion

These patterns raise a number of questions that have implications for HIV transmission. First, what kinds of partners do young people living with HIV desire to have? Our findings show that over one-third (37%) of the respondents would prefer a partner who is HIV-negative with significantly more male than female respondents reporting such preference. Another

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<sup>1</sup> Adolescents not living under the control of parents or guardians, i.e., those who are married or are taking care of their siblings or their own children. In Uganda the National Council of Science and Technology allows emancipated minors to consent to participating in research as long as they are thoroughly informed about the risks involved.



29% indicated no preference, suggesting that the proportion of respondents who would prefer HIV-negative partners could even be higher. Indeed, of those who were currently in a relationship and knew the HIV status of the partner, 39% were in discordant relationships. The major reason given for preferring HIV-negative partners was to avoid HIV re-infection. Another interesting pattern is that significantly more female than male respondents reported no partner preference yet more female than male adolescents who knew the HIV status of the partner were in discordant relationships. This is further indication that the proportion of respondents preferring HIV-negative partners could be higher than what was reported.

The second question raised by the observed patterns is the extent to which young people living with HIV, who know their sero-status, and who are in relationships engage in safe sexual practices in order to avoid spreading the virus. The study findings show that among those who had ever had sex, only about one-third (37%) reported using a method to prevent HIV infection or re-infection at first sex with no significant difference between male and female respondents. Among current users of condoms, the proportions reporting usage to prevent infecting the partner with HIV and other sexually transmitted diseases (STDs) and to avoid self re-infection remained low. Much of current use of condoms was for pregnancy prevention. Moreover, less than half of those currently using condoms reported consistent use.

**Table 2: Percent distribution of respondents by their views about sex and sexual experiences**

	All respondents			
	Male (n=263)%	Female (n=469)%	Significance test <sup>e</sup>	Both genders (n=732)%
Ever had a boyfriend/girlfriend	46	37	*	41
Ever had sex	37	31	NS	33
Desires to have sex	55	38	**	44
HIV-positive person should have sex <sup>a</sup>	54	34	**	41
Partner preference				
• HIV-negative partner	42	34	*	37
• HIV-positive partner	35	34	NS	34
• No preference	23	32	**	29
Main reason for preferring HIV-negative partner <sup>b</sup>				
• Avoid re-infection	68	60	*	63
• Have HIV-negative children	14	13	NS	14
• Other	18	27	**	23
Worried about				
• Disclosing HIV status to friends	44	54	**	51
• Becoming pregnant/causing pregnancy	75	74	NS	74
• Infecting someone else with HIV	75	83	**	80
Sexually active respondents <sup>f</sup>				
• Had consensual first sex <sup>c</sup>	89 (n=98)	63 (n=144)	**	73 (n=242)
• Used a method to prevent HIV	35 (n=98)	39 (n=138)	NS	37 (n=236)

infection/re-infection at first sex				
• Currently using a condom to prevent <sup>d</sup>	(n= 49)	(n= 65)		(n= 114)
• Infecting partner with HIV/STDs	35	26	NS	30
• HIV re-infection	25	26	NS	25
• Pregnancy	61	54	NS	57
Frequency of current condom use	(n=49)	(n=65)		(n= 114)
• Always	45	43	NS	44
• Sometimes	33	31	NS	32
• Rarely	8	21	NS	16
• Missing	14	5	NS	9
Respondents currently in a relationship				
• Knows partner's HIV status	35 (n=63)	32 (n=96)	NS	33 (n=159)
• In discordant relationship	24 (n=21)	50 (n=30)	NS	39 (n=51)
• Disclosed HIV status to partner	42 (n=62)	35 (n=96)	NS	38 (n=158)

HIV = human immunodeficiency virus; NS = not significant; STDs = sexually transmitted diseases.

<sup>a</sup> Proportion of respondents who believed that there is no reason why a person living with HIV should not have sex.

<sup>b</sup> Participants who reported preference for HIV-negative partners. This was an open-ended question whose responses were re-coded after data entry.

<sup>c</sup> Both partners were willing or wanted to have sex.

<sup>d</sup> Multiple responses were allowed.

<sup>e</sup> Significance test of difference between male and female proportions: \*p <.05; \*\*p <.01.

<sup>f</sup> Participants who had ever had sex.

There is also evidence suggesting that risky sexual practices are affected by the disclosure of HIV status [5] though other studies have found otherwise [6]. The study findings show that disclosure of HIV status to the partner is low. Just over one-third (38%) of the respondents who were currently in a relationship disclosed their HIV status to their partners. In addition, disclosing one's sero-status was one of the greatest fears of the adolescents: 51% of all respondents feared disclosing their status to friends. Qualitative data further suggest that even in the event of disclosure, the partners do not mind engaging in the relationship even if they are discordant, as illustrated by the following examples:

*"I asked her to leave me and find someone else-negative. She told me that she was not going to leave because of my status." (Case Study No. 7)*

*"If you have a sign people may leave you alone. But if no sign, they come after you even if you tell them, they say you are lying . . ." (FGD No. 5)*

*"I have a boyfriend. He knows my HIV sero-status. I disclosed to him and he said that he did not mind." (FGD No. 3)*

These research findings have several implications. Of importance, the findings suggest that many of the HIV-positive adolescents are sexually active or desire to be in relationships. In addition, many prefer HIV-negative partners. However, preventive practices, including disclosing

one's HIV status to the partner, are poor. Some of these experiences apply to the general population as well [7,8]. Although not directly comparable, available Uganda data on young people aged 15–19 years who had ever had sex shows that the percentage that knew the HIV status of their partner was even lower (8% for males and 10% for females) with similar patterns being observed among adults (ages 15–49 years; 11% for males and 9% for females) [8]. Nonetheless, the case of those living with HIV is unique because they stand the greatest chance of transmitting the virus. HIV/AIDS programs therefore need to appreciate that perinatally infected adolescents have similar desires as of those of other children maturing into adolescence and adulthood. Thus, there is need to provide preventive sexual and reproductive health information and services to HIV-positive adolescents in order to prevent further HIV transmission and unwanted pregnancies. This should entail empowering these adolescents with skills to negotiate disclosure and consistent condom use.

### **Acknowledgments**

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## Appendix 10B: Adolescent Sexual Abuse

### The highest probability indicators of sexual abuse

As previously mentioned, in many cases of abuse, there are no physical symptoms. There are, however, some specific indications that abuse has occurred. These can include:

- Unexplained pregnancy
- Unexplained sexually transmitted infections; pain, swelling, bleeding or irritation of the mouth, genital or anal area; and urinary tract infections
- Hints, indirect comments, or statements about the abuse
- Problem sexual behaviours: Some adolescents who were sexually abused also may become sexually provocative and copy adult behaviour, displaying sexual knowledge, through language or behaviour, beyond what is normal for their age. Others merge sexual behaviour and aggression and may become the victimizers of others.

There is little dispute over the fact that some of these symptoms result from sexual activity, however, the age of the adolescent should be taken into consideration when pregnancy or sexually transmitted infections are found. In Zambia, the age of consent for sexual activity is 16 years. However, adolescents younger than 16 may have consensual sex, that is, sex in which they willingly engage. In some cases therefore, it may be necessary to make a judgement call about whether the sexual activity was forced. The younger the adolescent, the more likely it is that the activity was forced; adolescents under 12 are generally considered incapable of consenting to sexual contact. For adolescents between the ages of 12 and 16, or older, the determination of whether or not abuse occurred may require interview and clinical judgement.

### Recognising the signs and symptoms of sexual abuse in adolescents

The table below presents a checklist of physical and behavioural signs and symptoms that may be associated with sexual abuse in adolescents. This checklist is not a diagnostic tool; and these signs and symptoms may result from other causes. It is also important to remember that the absence of any signs or symptoms does not indicate that no sexual abuse has occurred. Each individual survivor reacts differently and a determination of sexual abuse cannot be based on signs or symptoms only. Behavioural signs of sexual abuse, while more common, can be indicators of other types of trauma. Therefore, even if these signs exist, it is necessary to gather more information to conclude whether or not sexual abuse has occurred.

#### Signs and symptoms associated with sexual abuse in adolescents

Physical signs	Yes	No
Difficulty walking or sitting		
Cuts and bruises		
Signs of physical abuse (for example, punch marks, restraint		

marks on the wrist, torn eardrums; all should be investigated as possible indication of physical and/or sexual abuse)		
Complaints of pain with urination or bowel movements		
Irritated or itching genitals or anus		
Bleeding from the genital area or anus		
Urinary tract infection, blood in urine, or difficulty with urination		
Vaginal or penile discharge		
Pregnancy (younger than 16)		
Sexually transmitted infection, warts, ulcers in genital area		
Unusual and offensive odours from genital area or anus		
Fresh or healed tears of the hymen or vaginal mucosa		
Developing frequent, unexplained health problems		
<b>Changes in behaviour</b>	<b>Yes</b>	<b>No</b>
<b>Nonsexual indicators</b>		
Avoidance of specific caregivers or caregiving situations		
Sleep disturbances, such as nightmares or bedwetting in younger adolescents		
Withdrawal from family, friends, or usual activities		
Unexplained fear of physical or gynecologic examination		
Significant increase or decrease in appetite (eating disorders)		
Excessive bathing or poor hygiene		
Reluctance to be with a certain person		
Mood changes, such as anger, outbursts, or depression		
Becoming worried when clothing is removed		
Academic problems		
Lowered self-esteem		
Symptoms of post-traumatic stress disorder, such as panic attacks		
Excessive crying		
<b>Sexual indicators</b>		
Age-inappropriate knowledge of sex		
Imitating sexual acts or copying adult sexual behaviour with younger children, toys, or pets		
Excessive masturbation		
Sexual experimentation with age-inappropriate partners		
<b>Note: This is not a diagnostic tool; these signs and symptoms may result from other causes.</b>		

Additional signs of sexual abuse that may be present in older adolescents include:

- Drug and alcohol use
- Delinquency
- Running away
- Depression
- Early sexual involvement/activity
- Promiscuity
- Criminal activity

- Self-destructive behaviour (for example, suicide attempts or self-mutilation)
- Eating disorders (anorexia/bulimia)

As adolescents mature, they become aware of societal responses to their sexual activity, and therefore overt sexual indicators of the type cited in the table above are less common. Moreover, some level of sexual activity is considered normal for adolescents. However, there are three sexual indicators that *may* signal sexual abuse:

- Sexual promiscuity among girls
- Being sexually victimized by peers or nonfamily members among girls, that is, repeated victimization when a adolescent is older may be evidence of earlier unrecognised sexual abuse
- Adolescent prostitution

Of these three indicators, the last is most compelling. One study found that 90 percent of female adolescents involved in sex work were sexually abused at some point in their lives<sup>2</sup>. Although there has not been comparable research on adolescent male sex work<sup>3</sup>, clinical observation suggests that they also become involved in the exchange of sexual services for goods or money as a result of sexual abuse.<sup>4</sup>

### **Interviewing an adolescent who may have been sexually abused**

Talking about sexual abuse is extremely difficult for most adolescents. They are afraid, may feel embarrassed or ashamed, and often do not know how to talk about what has happened to them. Sometimes they have been bribed, threatened, or made to feel responsible for their abuse. The ideal location to interview an adolescent about sexual abuse is in a quiet, comfortable, and private setting, either alone or with an adult of her or his choice. Sit at the adolescent's level and use the listening and learning skills described in Module 4.

Be very patient and take plenty of time. Keep in mind that if a young person is feeling defensive, they are not feeling safe. Do not push and prod. Stay as calm as possible. Adolescents often stop talking if they think that what they are saying makes you upset<sup>5</sup>. Adolescents are also more likely to give an answer that they think the questioner wants to hear. It is therefore important when asking questions not to appear to lead the adolescent to answer the question with a particular answer, but rather encourage the adolescent to be open and honest.

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<sup>2</sup>.Faller, K.C. 1990. *Understanding Child Sexual Maltreatment*. Newbury Park, CA: Sage.

<sup>3</sup> Please note that UNAIDS Editors' Notes for authors (August 2006) preferred the term juvenile prostitution for this group.

<sup>4</sup> Campagna, D. and Poffenberger, D. 1988. *Sexual Trafficking in Children*. Dover, MA: Auburn House.

<sup>5</sup> Adapted from: Prevent Child Abuse NY. Available at:  
<http://www.preventchildabuseny.org/resources/about-child-abuse/>

Be careful not to plant ideas in the adolescent's mind or to suggest what you expect to hear. Above all, reassure the adolescent that the abuse was not her or his fault. There is nothing that she or he did to deserve what happened. Help young people understand that it is all right to feel angry, and help them express their anger in ways that are healthy for themselves and others.

Healthcare workers will get further — and get a more accurate account — if they ask open-ended questions. (An open-ended question requires an explanation/description for an answer, rather than a simple yes/no one word answer.) For example, rather than asking, *“That man touched you on your private parts didn't he?”* it would be better to ask, *“Tell me about what happened when you were out with that man”* As a general rule, healthcare workers should not ask questions that start with “why”, as such questions may come across as accusatory. See Module 4 for more information on open-ended questions.

### **How to begin questioning related to suspected sexual abuse<sup>6</sup>:**

Always introduce the principle of shared confidentiality and explain your obligations as a healthcare worker, should disclosure of sexual abuse occur during the conversation.

Try to make the adolescent comfortable by explaining that you would like to ask her or him some questions. Explain that she or he should be honest and should not be afraid. Begin by first normalizing the topic. For example: *“Because I want to help my clients, I ask everyone about questions that may be sensitive. It is important that I know some things in order to help you.”*

Begin the interview with open-ended questions. Ask questions in a non-judgemental way. Avoid technical or medical language:

- *It looks like something might be bothering you. Can you tell me about it? I'd like to know more about this.*
- *Can you tell me about if someone ever touched you in a way you didn't like? How did they touch you?*
- *Has someone ever hurt you or made you feel bad? How so?*
- *Has someone ever touched your private areas? Where?*
- *What happened?*
- *Tell me more.*
- *When was last time this happened?*

For older adolescents:

- *How long have you been sexually active?*
- *Has anything ever happened sexually with a friend, a date, or someone you know that you didn't like? Were you ever pressured or forced you into*

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<sup>6</sup> Adapted from: United States Department of Health and Human Services, Administration of Children and Families. Available at: <http://www.childwelfare.gov/pubs/usermanuals/sexabuse/sexabusec.cfm>



*sexual activities when you did not want them? Touched you in a way that made you uncomfortable? Anyone at home? Anyone at school? Any other adult?*

- *Do you feel that you have control over your sexual relationships and will be listened to if you say “no” to having sex?*

Other possible questions for younger adolescents include:

- *Did you ever see an adult’s private parts? Whose did you see?*
- *Did anyone ever ask you to touch their private parts? Who?*
- *Did anything ever happen to your private parts that you didn’t like? What?*

Always validate the adolescent’s response:

- *Thank you for telling me about such a difficult experience.*
- *I’m sure that was hard for you to tell me. It is good that you told me.*
- *When someone hurts you, it is devastating in many ways. Let’s talk about some of the ways you need support.*

Evaluate and follow up

- Immediately evaluate present-day level of danger, other violence, drug and alcohol use, and health habits. Mention their disclosure again during another visit and continue to ask about his/her needs. Request a 1- to 2-week follow-up appointment with the adolescent.

### **Other clinical follow up after the interview**

If an adolescent discloses sexual abuse in the interview, a thorough physical and gynaecological examination (procedures described in Module 10) should be conducted by a healthcare worker, with the adolescent’s consent.

Respect for privacy during physical examinations is imperative for adolescents who have experienced sexual abuse. Healthcare workers have an excellent opportunity to demonstrate this respect and to help the adolescent regain a sense of control over his/her body by draping the adolescent and allowing them to stop the examination if they feel uncomfortable at any time. Healthcare workers should also model sensitive, respectful physical examination techniques to other members of the clinical team.

For all individuals without confirmed HIV infection, healthcare workers should follow national HIV testing guidelines in “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” and the PEP protocol in “Adult and Adolescent Antiretroviral Therapy Protocols”.

### **Follow up for psychosocial and mental health issues**

Adolescents need support to deal with what happened to them and to discharge and cope with their feelings. Healthcare workers can make referrals to peer support groups or local community-based services that have experience dealing with youth who have been sexually abused.

At a minimum, healthcare workers should conduct a psychosocial assessment to determine the impact of the abuse on the adolescent, level of family support to assist with coping, and the ability and willingness of the family to ensure the adolescent's continuing safety. The initial assessment should be accompanied by some mental health intervention to reduce the immediate impact of the trauma. There should also be a discussion with the adolescent, or with the caregiver if the adolescent is too young to understand and if the caregiver is not the perpetrator of sexual violence, of what to expect from the adolescent after the abuse. Helping the adolescent and caregiver understand what behaviours and emotions are likely to follow the abuse, and assisting them in understanding that these are a natural result of the abuse, will help them to cope more effectively with the impact of the abuse.

National policy recommends follow up for assessment and treatment of mental health issues at 7 days, 1, 2, 3 and 6 months after the abuse. Healthcare workers should be knowledgeable of the resources available within the facility and within the community to treat the adolescent. If the facility does not have the capability to provide mental health services, the adolescent should be referred to a facility that has mental health resources. For more information about assessment and treatment of mental health problems and disorder, refer to Module 6.

### **Legal follow up**

Healthcare workers must understand any relevant laws and report cases of sexual abuse, according to these laws.

The Victim Support Unit, part of the law enforcement division of police services, is required by law to be notified of suspected cases of abuse or neglect of adolescents under the age of 16 years. This department is responsible for working with representatives from social welfare and health services as part of a multidisciplinary team. Their duties include the investigation of the report, determination of whether abuse has occurred, to ensure the continued safety of the adolescent, and to prosecute the person who committed the abuse. Because sexual abuse is a criminal offense, healthcare workers may be responsible for reporting findings in a court of law. It becomes vital, therefore, for healthcare workers who have had contact with the adolescent or with evidence gathered from the adolescent to maintain the chain of evidence; that is, collecting, storing, and documenting all the gathered material for possible presentation in court proceedings.

## Appendix 10C: Screening and Examining Adolescent Clients for STIs

Screening questions	Physical examination steps
<b>For adolescent women:</b>	
<ul style="list-style-type: none"> <li>Do you have vaginal discharge that is not normal for you (colour, amount, smell)?</li> <li>Do you have any pain when you urinate (pee)?</li> <li>Do you have any sores or bumps in or around your genitals?</li> <li>Do you have any pain in your lower abdomen?</li> </ul>	<p>Ask the young woman to undress from the waist down and lie on an exam table, or if she is wearing a skirt, she can leave it on and take off her underpants. Be sure to cover her with a sheet and only expose the parts that you examine.</p> <p><b>External exam:</b></p> <ul style="list-style-type: none"> <li><b>Skin exam:</b> inspect the skin of the genitals, perineum, inguinal areas, thighs, lower abdomen, buttocks, chest, back, soles of feet and palms of hands. Look for vesicles, ulcers, warts, other growths, and rashes.</li> <li><b>External genital exam:</b> Inspect and palpate the external genitalia, then inspect the perineum and anus. Look for ulcers, vesicles, warts, and discharge.</li> <li><b>Inguinal exam:</b> Examine the inguinal area and palpate for lymph nodes.</li> <li><b>Abdominal exam:</b> Palpate the abdomen, checking for guarding, tenderness, rebound tenderness, and masses.</li> </ul> <p><b>Internal exam</b></p> <ul style="list-style-type: none"> <li><b>Internal genital exam:</b> Have the woman lie with her legs bent at the knees, keeping her feet and knees separated. Separate the labia and insert a bivalve speculum* lubricated with warm water. With a bright light shining on the area, inspect the vaginal walls and the cervix. Look for ulcers, warts, and cervical and vaginal discharge.</li> <li><b>Bimanual pelvic exam:</b> Remove the speculum and insert the lubricated index and middle fingers of your hand into the vagina. Place your other hand on the lower abdomen and examine the pelvis for swelling and tenderness. Move the cervix laterally and check for cervical motion tenderness. Check for tenderness and masses around the uterus and ovaries.</li> </ul> <p>* Some healthcare workers prefer to not use the speculum, or to use a smaller speculum, in women who are virgins.</p>
<b>For adolescent men:</b>	
<ul style="list-style-type: none"> <li>Do you have any discharge from your penis?</li> <li>Do you have any pain when you urinate?</li> <li>Do you have any sores or bumps around your genital area or your anus?</li> </ul>	<p>Ask the man to undress from the waist down and lie on an exam table. Be sure to cover him with a sheet and only expose the parts that you examine.</p> <ul style="list-style-type: none"> <li><b>Skin exam:</b> Inspect the skin of the genitals, perineum, anus, inguinal areas, thighs, lower abdomen, buttocks, chest, and back, soles of feet, and palms of hands. Look for vesicles, ulcers, warts, other growths, and rashes.</li> <li><b>External genital exam:</b> Inspect the penis, including the opening of the urethra, by retracting the foreskin. Look for ulcers, vesicles, and urethral discharge. If the patient complains of discharge and none is present, give the urethra</li> </ul>

	<p>a gentle squeeze and massage it forward to try and express any discharge. Inspect in and around the anus. Palpate the scrotal contents and note presence of ulcers or buboes.</p> <ul style="list-style-type: none"> <li>• <b>Inguinal examination:</b> Palpate the groin, feeling for enlarged lymph nodes and the presence of buboes.</li> </ul>
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Zambia Ministry of Health, *National STI Syndromic Case Management Guidelines for Zambia*.

## Appendix 10D: Survey of Family Planning Methods for Adolescents

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### Barrier Methods

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#### Male and female condoms

- Only condoms provide protection from both pregnancy and STI (including HIV) transmission and acquisition.
- Male and female condoms are highly effective when used consistently and correctly every time.
- In real-life situations, and especially among adolescents, correct and consistent condom use may be difficult to achieve. Partner involvement is required. Some people — more often men than women — report diminished sensation when using condoms during sex.
- Condom use does not interfere with medications, however, and except when an individual is allergic to latex, there are no common side effects for male and female condoms.
- **Special considerations for the adolescent client:** Male and female condoms are safe and appropriate for ALHIV. Because condoms are available without a prescription and are the only method offering dual protection, they are a good method for adolescents. It is important that condoms are always available to adolescents for free and without having to ask an adult for supplies. Adolescents require skill development and practice in learning how to use condoms and negotiate their use with sexual partner(s). Adolescent girls are frequently not assertive about the use of condoms if their partner rejects the idea; they require counselling and peer support to feel empowered and able to negotiate condom use and overcome cultural and other barriers. Consistent and correct condom use is effective in providing dual protection, but failure rates (i.e. unintended pregnancy) for condoms are high, especially among adolescents, who often do not use them consistently or correctly.
- **Counselling the adolescent client about condoms:** Always demonstrate, step-by-step, how condoms are used and correct disposal. Tell the client to return to the clinic if there is any problem, they need more condoms, if they are unhappy with the method, or if they think they or their partner may have been exposed to an STI. Always ask the adolescent client to repeat the instructions to ensure understanding.

## Spermicides and diaphragms with spermicides

- These methods are NOT recommended for adolescents or adults living with HIV, as they may increase the risk of HIV transmission.

## Hormonal Methods

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Hormonal contraceptives, including combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills (POPs), emergency contraceptive pills (ECP), injectables, and implants are appropriate and effective contraceptive methods for many ALHIV. They are generally easy to use, are suitable for short- and long-term use, are reversible, and provide noncontraceptive health benefits.

### COCs and POPs:

- These are pills that a woman takes once a day to prevent pregnancy.
- They contain the hormones oestrogen and progestin (in the case of COCs) and progestin alone (in the case of POPs).
- Both types are very effective at preventing pregnancy when taken on schedule.
- **Special considerations for the adolescent client:** Low-dose COCs are appropriate and safe for ALHIV. Many adolescents choose a COC because of the low failure rate, relief from painful periods, and the ease of using a method that is not directly related to sex. Failure rates for COCs are higher for adolescents than for all other age groups. Failure to take pills at the same time, every day, is often due to lack of knowledge or confusion about how to take pills. Healthcare workers should stress that COCs can prevent pregnancy but should always be used in combination with condoms to provide STI/HIV protection. Healthcare workers can assist adolescent clients to determine where they will keep their pills and how to remember to take them at the same time every day, similar to their ARVs. COCs are available in 21- or 28-day regimens. Most adolescents do better with the 28-day regimens because it is easier to remember to take a pill every day rather than stopping for 7 days.

COCs should not be taken by clients taking rifampicin for TB treatment.

ARVs may adversely affect the efficacy of low-dose COCs and/or increase their side effects. Women taking ARVs who want to use COCs can be given a formulation with at least 30mcg of oestrogen, counselled about the importance of taking COCs on time every day (without missing pills), and counselled about consistent condom use.

POPs are also safe for adolescents, but since they must be taken at exactly the same time everyday for them to be effective in preventing pregnancy, they may not be the best choice for adolescents. POPs may however be a good choice for adolescents who cannot tolerate estrogen in COCs or who are breastfeeding.

- Counselling the adolescent client about oral contraceptive pills:**  
 The most important counselling issue with adolescents is to make sure they understand the importance of taking pills correctly. Show the client the pill packet and explain in detail when to start taking pills and how to take the pills. Explain that if she forgets to take her pills, she may become pregnant. Instruct the client on what to do if she misses pills (for example, if she misses one, take it as soon as she remembers, if she misses 2, take 2 pills as soon as she remembers and use a back up method, etc.). Always review possible side effects, including that breakthrough bleeding may be common in the first cycles, but is not a reason to stop taking the pills. Like with ARVs, the client should be encouraged to talk with a healthcare worker about any side effects (nausea, weight gain, breast tenderness, headaches, spotting, etc.) and told that these will usually settle over time. Go over the times when she should return to the clinic, including if she thinks she may be pregnant, she has chest pain or shortness of breath, severe headaches with blurred vision, and swelling or severe leg pain. Make sure the client understands when to come back for re-supply and not to wait until she is out of pills (like with ARVs). Always have the client repeat information back to you so you can check understanding. And always promote dual protection with male or female condoms.

### **Injectables:**

- Progestin-only injectable contraceptives, such as Nur-Isterate and Depo-Provera (depot medroxyprogesterone acetate, aka DMPA and ‘the shot’), contain no estrogen.
- To prevent pregnancy, a shot is given to the woman in the arm or upper buttock every 2–3 months, depending on the type of injectable.
- Injectables are highly effective when used correctly.
- ALHIV can use progestin-only injectables without restrictions. Adolescents on ART can also use progestin-only injectables safely and effectively.
- It is important to counsel adolescents to come for their next injection on time and without delay.
- Side effects of injectables may include spotting at first, then amenorrhea and weight gain.
- Special considerations for the adolescent client: Injectables are safe and appropriate for adolescents. Many adolescents like this method because they don’t have to remember to take a contraceptive pill every day and no one needs to know they are using the method. It is important that adolescents are reminded when to return for their injections, ideally this can be combined with their routine HIV care appointments.
- Injectables do not offer protection from STIs/HIV, so should always be used with male or female condoms.

- **Counselling the adolescent client about injectables:** Healthcare workers should show their clients the vial of the injectable and explain how it is used. It is important to stress that the injections need to be given every 3 months and that injections can be given early if a client thinks she will not be able to return at the 3 month point. The injection will take effect immediately if she is between day 1–7 of her menstrual cycle. If the injection is given after day 7 of her cycle, she should use a back-up method for at least 24 hours. It is important for adolescents to understand possible side effects, which include irregular bleeding and prolonged light to moderate bleeding with the first few cycles of injectables. With time, this should stop and many women stop getting their menstrual cycle altogether while using injectables. Some women may also have weight gain or headaches. Healthcare workers should encourage clients to return to the clinic if they have any questions or problems or if they have very heavy bleeding, excessive weight gain, or severe headaches. Make sure the client repeats this information back to you to check understanding. As with all hormonal methods, healthcare workers should recommend and provide condoms for dual protection.

### **Hormonal implants:**

- Progestin-only implants (eg, Implanon, Norplant) consist of up to 6 hormone-filled, matchstick-like rods, which are inserted under the skin in a woman's upper arm.
- Hormonal implants can prevent pregnancy for between 3 and 7 years, depending on the type.
- Highly effective at preventing pregnancy, implants are a long-term contraceptive method that can be easily reversed.
- ALHIV who do not take ART can use progestin-only implants without restrictions. ALHIV on ART can also use progestin-only implants, but should use condoms as a back-up method in the event that the effectiveness of the implant is reduced by ARVs.
- Side effects of implants may include nausea, weight gain, and changes in monthly bleeding. As with all hormonal methods, women should also be encouraged to use condoms for dual protection.
- **Special considerations for the adolescent client:** Hormonal implants, such as Norplant, are safe for adolescents. The main reason adolescents discontinue using implants is irregular bleeding; counselling is important so they are prepared for this possibility. Programmes must ensure that adolescents have access to services to remove implants whenever they need or want them to be removed.
- **Counselling the adolescent client about implants:** Healthcare workers at the HIV clinic will likely have to refer adolescents to a family planning clinic for implant insertion and removal. It is important to explain how the implants work, what the insertion and removal procedures are, and how long the method will last. Adolescents should



also be counselled on care of the insertion area and possible bruising or swelling after insertion. Adolescents should know where to go if they have problems or questions, or if they want the implants removed. Healthcare workers should give information on common side effects, such as changes in bleeding, as well as serious problems requiring immediate care such as severe pain in the lower abdomen, very heavy bleeding, bad headaches, and yellowing of the skin or eyes.

### **Emergency contraceptive pills (ECP):**

- ECP is used to prevent pregnancy after unprotected sex.
- ECP can be used if no contraceptive method was used, or if the contraceptive method failed — for example, a condom broke during sex.
- ECP should be taken as soon as possible after unprotected sex (although it can be taken up to 120 hours after sex).
- Used correctly and in timely fashion, ECP can reduce the risk of pregnancy by 75%.
- ECP is usually a combination of oral contraceptives taken in 2 doses.
- ECP does not cause an abortion. It prevents an egg from implanting in the uterine wall.
- ECP is safe for all women, including those living with HIV and those taking ART.
- Side effects of ECP may include nausea, vomiting, and changes in the menstrual cycle.
- Adolescents receiving ECP should be counselled on adopting a regular contraceptive method, as well as on condom use for dual protection.
- **Special considerations for the adolescent client:** ECP should be widely and easily available to adolescents, including at the HIV clinic. Adolescents should be educated about the availability of ECP and the importance of coming to the clinic for ECP as soon as possible after unprotected sex. The earlier ECPs are taken after unprotected sex, the more effective they will be in preventing pregnancy. ECPs can be provided in advance to adolescents who are at high-risk of unprotected sex, but they should be counselled that ECPs are for emergency use only. ECPs do not provide dual protection and all adolescents using ECPs should be counselled on more effective contraceptive methods and condom use for dual protection.
- **Counselling the adolescent client on ECP:** Healthcare workers should explain how ECPs work and how the adolescent should take them (for example, the first dose should be taken as soon as possible after unprotected sex, up to 120 hours after unprotected sex, the second dose should be taken 12 hours after the first dose). If more than 120 hours have passed since unprotected sex, the client should not be given ECP. If the client vomits within 2 hours of taking a dose, the dose should be repeated. Taking the doses after eating or before bed will help reduce nausea. Healthcare workers should review what

adolescents can expect after taking ECPs — they may have nausea, vomiting, cramping, breast tenderness, or headaches, but these should not last more than 24 hours. The adolescent's period should come on time (or a few days late or early), and if she does not get her period within one week of when it is expected she should return to the clinic as she may be pregnant.

## Long-term and Permanent Methods

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### Intra-uterine devices (IUDs):

- This small device inserted into a woman's uterine cavity is highly effective at preventing pregnancy.
- The copper-containing CuT 380A — the most commonly used IUD — remains effective for up to 12 years.
- An IUD can be provided to a woman living with HIV if she has no symptoms of AIDS and no STIs. A woman who develops AIDS while using an IUD can continue to use the device. A woman with AIDS who is doing well clinically on ART can both initiate and continue IUD use but may require follow up.
- An IUD generally should not be initiated in a woman with AIDS who is not taking ART.
- Side effects of IUDs may include heavy bleeding and pain during the first months of use, as well as spotting.
- Encourage women choosing an IUD to use condoms for dual protection.
- **Special considerations for the adolescent client:** IUDs are appropriate for adolescents in stable, mutually monogamous relationships. Careful screening for STIs before insertion is critical and IUDs are not recommended for ALHIV with advanced HIV disease or AIDS, especially when the client is not on ART.
- **Counselling the adolescent client about IUDs:** It is important to explain that the IUD is a long-term method that lasts for 10–12 years and that it is most appropriate for adolescents who are in stable, monogamous relationships. Healthcare workers may have to refer adolescent clients for IUD insertion, but should provide counselling and follow up within the HIV clinic. It is important for adolescent clients to understand how the IUD works and how to check for the strings. Healthcare workers should explain side effects, including cramping and pain after insertion, heavier and longer menstrual flow for the first few months, vaginal discharge, and possible infection. Bleeding usually decreases during the first and second years of IUD use, and some women may not have regular periods. Adolescents should know the warning signs of potential complications with IUDs, including abnormal bleeding and discharge, pain, pain during sex, fever, and strings missing/shorter/longer. Make sure the client repeats this information to ensure understanding. It is very important to use condoms to prevent

STIs, which can cause infection and complications, especially when using an IUD.

### **Male and female sterilisation**

- These permanent methods are not usually recommended for adolescents, who may change their mind about wanting to have children in the future.
- However, some ALHIV may request sterilisation, in which case counselling should be provided and all options explored.

### **Traditional and Other Methods**

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**Natural methods** that do not require any materials (i.e. withdrawal, a woman learns to recognise when she is fertile and the couple avoids sex at this time.). In general, natural methods are not as effective in preventing pregnancy as the other “modern” methods. In some places, there are **traditional methods**. These are mostly traditional herbs that are given to prevent pregnancy. They are not reliable, because the dosage is not controlled and they are not scientifically proven.

### **Lactational amenorrhea method (LAM):**

- LAM is a temporary, natural contraceptive option for women who are less than 6 months postpartum, who are exclusively breastfeeding, and whose periods have not yet returned.
- Any clients practising LAM should be advised to use condoms for dual protection.
- Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV.

### **Fertility awareness methods:**

- These methods require a woman to identify the fertile days of her menstrual cycle and to abstain from sex during these times.
- To do so, she can observe fertility signs, such as the consistency of her vaginal mucus, or she can follow the calendar.
- This is a difficult method for many adolescents to implement correctly and consistently. It is also not very reliable for pregnancy prevention and does not protect against STIs and HIV.
- Encourage ALHIV to use condoms as dual protection, especially during fertile days, or to abstain.
- Also counsel on the availability of more reliable contraceptive methods, emphasizing the importance of using condoms for dual protection.

Adapted from: Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.

## References and Resources

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<sup>1</sup> de Bruyn, M., 1999. *Young Lives at Risk. Adolescents and Sexual Health*. Panos Briefing No. 35, London: Panos Institute London.

<sup>2</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 6*. Watertown, MA: Pathfinder International.

<sup>3</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 8*. Watertown, MA: Pathfinder International.

<sup>4</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 5*. Watertown, MA: Pathfinder International.

<sup>5</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.

<sup>6</sup> Senderowitz, J., Solter, C., & Hainsworth, G. 2002, revised 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum: Module 16: Reproductive Health Services for Adolescents, Unit 7*. Watertown, MA: Pathfinder International.



## **Module 11**

# **Community Linkages and Adolescent Involvement**

**Session 11.1: The Importance of Facility-Community Linkages**

**Session 11.2: Creating a Community Resource Directory**

**Session 11.3: Adolescent Participation and Peer Education Programmes**

### **Learning Objectives**

**After completing this module, participants will be able to:**

- Discuss common challenges and strategies to creating strong facility-community linkages in support of ALHIV and their caregivers.
- Describe community-based support services that ALHIV and their caregivers may need.
- Create a community resource directory for adolescent clients and caregivers.
- Describe the rationale for meaningful adolescent involvement and effective strategies to involve adolescents in service delivery.
- Understand the key components to implementing a successful adolescent Peer Educator programme.

## **Session 11.1      The Importance of Facility-Community Linkages**

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### **Session Objectives**

**After completing this session, participants will be able to:**

- Discuss common challenges and strategies to creating strong facility-community linkages in support of ALHIV and their caregivers
- Describe community-based support services that ALHIV and their caregivers may need

### **Improving Facility-Community Linkages**

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#### **Challenges to facility-community linkages**

Some key challenges to facility-community linkages include the following:

- Healthcare workers may not be aware of community-based services or there is no mechanism to exchange information or formalise 2-way referrals.
- Community organisations and leaders may not be aware of adolescent HIV services at the health facility or lack training in this area.
- Schools may not be familiar with ALHIV and the needs of youth who are most-at-risk, like orphans and other vulnerable children.
- Community organisations and leaders do not trust facility-based services or may prefer traditional medicine or healing.
- There may not be any community services specifically for ALHIV.
- Community members, including adolescents, may not understand the need for HIV-related services at the health facility.
- Adolescents may get treated poorly when they go to the health facility, and this information spreads through the community.
- Service delivery may be fragmented, uncoordinated, and/or not youth-friendly.
- It may cost a lot of money to get from the community to the health facility (transportation costs).

#### **Strategies to address barriers**

Below are strategies to improve facility-community linkages and to develop a more coordinated and collaborative approach to ALHIV service delivery.

- Learn what community organisations and services are available in the areas where adolescent clients live (and go to school or work). Make an appointment and go to these organisations. Invite them to visit the health facility for an informal meeting or a formal tour and “open house”. Meet with the staff to find out what services they offer, discuss the services offered at your facility, and set up formal or informal “2-way” referral systems. This means that the health facility can refer adolescents to the community organisation and the community organisation can refer adolescent clients to the health facility.

- Facilitate regular (for example, monthly or quarterly) meetings between health facility managers and staff and the staff of community-based youth groups, youth Peer Educators, school heads and teachers, PLHIV associations, community healthcare workers, and others to share insights and information about the special needs of ALHIV, the services available at health facilities and in the community, and how to facilitate interagency linkages and referrals.
- Meet with community leaders to talk with them about ALHIV and HIV care and treatment services and why they are important. Also try to clarify common myths about HIV, ALHIV, and ARVs.
- Participate in community meetings and community gatherings to discuss HIV, ALHIV, and care and treatment.
- Train/orient existing community-based Peer Educators and community healthcare workers to identify adolescents and refer them for HIV testing and care and treatment. They can also be trained to provide basic adherence and psychosocial support to ALHIV and their caregivers and to follow up with clients who have missed appointments.
- Start support groups for adolescents of different ages/stages at the health facility or in the community. Invite community healthcare workers to the support group meetings to provide guidance and information. See Module 5 for more information on setting up and leading support groups.
- Involve young community members openly living with HIV to strengthen facility-community linkages, such as by starting an adolescent peer education programme (see Session 11.3).

## Community Support Needs of ALHIV

Examples of common support needs of ALHIV, their caregivers, and families include:

- ALHIV support groups (including support groups for different ages/stages of adolescents) and associations
- Disclosure support (both for caregivers and for adolescents)
- Nutritional and food support
- Spiritual guidance and support
- Transportation to get to the clinic
- Education and counselling for caregivers and family members
- Social grants
- Grants to purchase supplies, such as soap, school supplies, school uniforms, condoms, etc.
- Support for child-headed households, orphans and vulnerable children
- Access to formal and non-formal education, including vocational training (for example, school/tuition fees) and life skills training
- Job preparation and placement
- Income-generating activities and savings and loan programmes

### Continuum of care

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### multi-agency

Remember, no single person or organisation can provide all of the services and support ALHIV and their families need. We must work together to provide a continuum of ongoing care and support in the health facility, in the community, and at home.

## PARTICIPANT MANUAL

- Home-based care
- Home-based adherence support
- Home-based infant feeding support
- Legal advice and support
- Others...



## Session 11.2      **Creating a Community Resource Directory**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Create a community resource directory for adolescent clients and caregivers.

### **Creating a Community Resource Directory**

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In order to provide effective referrals, healthcare workers need to be up-to-date on the community services available to young people and ALHIV.

- A good way of knowing where to refer clients is for each health facility to develop and regularly update a community resource directory (see “Appendix 11A: Community Resource Directory Template”). This makes it easier to refer clients to needed services.
- Each clinic should have an up-to-date community resource directory and formal two-way referral systems to and from these organisations and services. The resource directory should include day/times services are offered, fees, documentation required at initial visit, address, phone number, contact person, etc. The community resource directories should be posted in the clinic waiting room and available in all of the examination and counselling rooms for easy reference.
- Healthcare workers can also work together with youth (for example, Peer Educators) to map available resources for ALHIV and families in the community and post this map in the clinic and/or give photocopies of the map to clients.
- Resource directories need to be updated regularly to keep up with personnel changes and changes in addresses phone number or other changes. It is a good idea for one person to be responsible for keeping up to date with these changes as they occur.

#### **Exercise 1: Creating a Community Resource Directory: Small group work and large group discussion**

<b>Purpose</b>	<ul style="list-style-type: none"><li>• To provide an opportunity for participants to brainstorm and create their own resource directory</li></ul>
<b>Instruction</b>	<ol style="list-style-type: none"><li>1. Healthcare workers/participants from the same facilities should break into small groups to begin to develop a Community Resource Directory for adolescent clients and their family members.</li><li>2. Each small group should begin to fill in “Appendix 11A: Community Resource Directory Template”, thinking specifically about the availability of the following services to ALHIV and families affected by HIV in their facility’s catchment area:<ul style="list-style-type: none"><li>• ALHIV support groups</li></ul></li></ol>

	<ul style="list-style-type: none"> <li>• Nutritional and food support, such as community food banks</li> <li>• Home-based care and adherence support</li> <li>• Education and counselling for caregivers and family members</li> <li>• Social grants</li> <li>• Supplies, such as soap, school supplies, school uniforms, etc.</li> <li>• Support for child-headed households and orphans and vulnerable children</li> <li>• Education and life skills programmes</li> <li>• Job preparation and placement programmes</li> <li>• Spiritual guidance and support</li> <li>• Condom suppliers</li> <li>• Income-generating programmes</li> <li>• Legal advice and support</li> <li>• Others...</li> </ul> <p>For each service, participants should also discuss the following questions in their small groups:</p> <ul style="list-style-type: none"> <li>• <i>What is being done now to link clients with these groups and organisations?</i></li> <li>• <i>What could be done to improve referral linkages with the groups and organisations listed in the directory?</i></li> </ul> <p>3. Once the large group is reconvened, each small group will be invited to very briefly present the highlights of their discussion.</p>
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## Session 11.3      Adolescent Participation and Peer Education Programmes

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### Session Objectives

**After completing this session, participants will be able to:**

- Describe the rationale for meaningful adolescent involvement and effective strategies to involve adolescents in service delivery.
- Understand the key components to implementing a successful adolescent Peer Educator programme.

### Adolescent Involvement<sup>1</sup>

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The meaningful involvement of PLHIV and affected communities makes a powerful contribution to the HIV response by supporting people to draw on their own experiences to increase the effectiveness and appropriateness of services. PLHIV participation in all aspects of HIV programmes is critical to ensure that services are designed and implemented to meet client needs.

Effective and meaningful adolescent involvement in service delivery requires commitment from every member of the multidisciplinary care team.

Two important mechanisms to formally involve adolescent clients in service planning, implementation and evaluation is through the engagement of ALHIV as Peer Educators and the establishment of ALHIV consumer (or community or client) advisory boards (CAB). Both are discussed below.

### Adolescent Peer Educators

Adolescent Peer Educators can complement the work of healthcare providers and play an important role in improving adherence and service quality. Peer education offers many benefits to HIV care and treatment programmes, among them:

#### **A safe environment:**

- People trust others in similar situations, so ALHIV feel safer discussing their personal circumstances with someone who shares and relates to their situation and is also an adolescent.

#### **Improved adherence:**

- Peer Educators can support clients' adherence because they may have a deeper understanding of the challenges faced by other adolescents and the range of potential solutions to those challenges.
- Youth involvement and youth providers make HIV care and treatment services more attractive to adolescents, and likely improve their adherence to and retention in care.

**Improved linkages:**

- Peer Educators can draw on their own knowledge and experiences to help other ALHIV navigate health facilities and strengthen linkages between the clinic and community services.

**Positive living:**

- Building on their own experiences, Peer Educators can serve as role models to encourage positive living and positive prevention.
- Programmes can empower and create positive changes in the lives of the Peer Educators themselves, help to decrease stigma and discrimination against ALHIV in the community, and encourage other adolescents in the community to access HIV services.

**Improved service quality:**

- ALHIV Peer Educators can help programmes become more youth friendly. They can also help identify and address programme barriers in reaching young people.
- Adolescent Peer Educators are in a unique position to contribute to quality assurance activities, based on their own experiences as clients in the programme and by soliciting feedback from their peers.
- Peer Educators can make services more accessible to youth, by helping to plan and facilitate peer support groups and activities, using art, drama, music, sports, and other youth-friendly activities.

**Community participation and advocacy:**

- Peer Educators can play a role in community mobilisation, decreasing stigma, serving as positive role models, and increasing support for ALHIV.

**Job opportunities:**

- The training and work experience that comes with the Peer Educators job will prepare these adolescents for future job opportunities in the formal economic sector.

**Increased access to services:**

- When young people, such as adolescent Peer Educators, also conduct outreach and advocacy work in their communities, more adolescents are reached with information about clinical services.
- Adolescent Peer Educators can also play a role in identifying and reaching most at-risk adolescents in their communities.

**Clients served have a closer connection to young providers:**

- Young people are a vital source of information about youth needs.
- Programmes that utilise youth staff tend to address young clients' needs and concerns more sensitively and accurately.
- Peers may hear of client challenges or successes that don't come to the attention of other team members.

- Also, young people often speak the “same language” and Peer Educators can help explain things in terms and language that their peers will understand (instead of, for example, formal or clinical adult language and ways of explaining things).

## **CABs**

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Some healthcare programmes may be interested in establishing a formal mechanism to facilitate feedback from clients through the establishment of a CAB. CABs are autonomous bodies that advise the clinic on quality of services, gaps in care and make recommendations to improve service provision. CABs:

- Include 5–20 members, 7–9 is typical, most or all of whom are clients or caregivers. Members should be able to represent a wide range of the clients served by the clinic.
- Typically meet every other week at first, and then once established, monthly.
- Have a direct line of communication with clinic management. Typically a clinical manager would attend every meeting.
- Are guided by a set of by-laws developed by members and approved by the clinic they advise.

## **Avoid Tokenism**

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Adolescents should be recognised, integrated and supported as the vital human resource that they are. Tokenism is NOT partnership or meaningful involvement and participation. Examples of tokenism include:

- Having youth present but with no clear role, training, support, or supervision. Both CAB members and adolescent Peer Educators need training before they can fully contribute in their new roles. They also need ongoing support and supervision to continue to develop skill and capacity.
- Asking youth their opinions, but not taking them seriously or incorporating them into programme decisions or planning
- Assigning to youth tasks that adults do not want to do, such as filing or cleaning

## **Ensure Expectations are Appropriate**

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Remember: Health facilities should always use a developmental perspective when involving adolescents in programme delivery:

- Keep expectations and assigned responsibilities and tasks realistic; expectations should always match an adolescent’s developmental capacity and responsibilities should always be appropriate for their age and ability. So, for example, an adolescent Peer Educator should not be expected to provide professional level counselling or mental health screening and management to other clients.
- Provide follow-up training and ongoing mentoring and supervision. If Peer Educators are not well trained it will compromise the quality and

effectiveness of their work. Peer Educators also need ongoing support, mentoring and supervision. They need an experienced supervisor to:

- Observe their work, frequently at first and then regularly thereafter (for example, weekly progressing to monthly) and provide constructive feedback afterwards. The supervisor should observe both one-to-one interactions and interactions within the support group setting.
- Lend a listening ear. As an ALHIV, it can be difficult to separate yourself and your issues from those of your clients. The death of a client can be a particularly difficult time, during which Peer Educators may require much support.
- Answer questions.
- Not “look over their shoulders”, as this can undermine self-confidence and client confidence in their work.
- It is important to make the boundaries with adolescent Peer Educators and CAB members very clear and to enforce them in a transparent way. Make sure that the programme has stated policies and rules for addressing what is appropriate and inappropriate behaviour and make sure that Peer Educators are appropriately supervised and supported to adhere to these policies.

## **Key Steps to Implementing a Facility-based Adolescent Peer Education Programme**

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Before implementing a peer education programme, it is important to consider how Peer Educators will function within the exiting programme framework — that is, how Peer Educators will assist other adolescent clients and how they will become part of the multidisciplinary team as a whole. Neglecting to do so can result in unclear job descriptions, mismatched expectations, poor peer performance, and ultimately, compromised client service.

### **Key steps to implement a programme<sup>2</sup>**

There are 10 key steps for implementing effective Peer Educator programmes are as follows:

1. Conduct a participatory situational analysis and needs assessment: Ask colleagues, adolescent clients, and caregivers how youth are involved at the moment, how they can be involved, and how they are involved in planning, implementing and evaluating services at other organisations.
2. Engage stakeholders in participatory programme design: Ask adolescents and their caregivers how they would like the peer involvement project structured. What should the Peer Educators do? How should they be trained and managed?
3. Define programme indicators, set targets, and develop tools: Indicators and targets might be, for example: “To train 12 Peer Educators by April 1, 2012.” “To engage 6 Peer Educators by May 1, 2012. Tools might include supervisory tools, job descriptions, personal criteria, etc.

4. Develop a detailed budget and workplan: This is the budget and workplan that cover the cost and activities involved in recruiting, training and engaging Peer Educators.
5. Recruit Peer Educators, based on selection criteria
6. Adapt or develop a Peer Educator training curriculum
7. Train Peer Educators
8. Engage health facility teams to rollout peer education activities
9. Provide ongoing support, supervision, and mentoring to Peer Educators
10. Continuously monitor, evaluate, and adjust the programme

A sample job description for Adolescent Peer Educators is included as “Appendix 11B: Template for Adolescent Peer Educator Job Description”.

## **Qualifications of Peer Educators**

Some suggested qualifications for Peer Educators are as follows:

- Older adolescent
- Living positively with HIV
- Adherent to care and medications
- Open-minded and non-judgemental attitude (for example, respectful and tolerant of different perspectives, cultural backgrounds, and lifestyles)
- Basic literacy and numeracy skills
- Good interpersonal and oral communication skills
- Commitment to working with other ALHIV
- Demonstrates self-confidence
- Ability to be self-disciplined and work independently, as well as within a team
- Availability to work at clinic (which does not conflict with school or work attendance)
- Represent age, ethnicity, socio-economic status, gender, language preference/abilities, and other characteristics of adolescent clients at the clinic
- Other qualifications identified by the health facility and as suggested by young people

For additional information on setting up and managing peer education programmes and on training adolescent peer educators see “Appendix 11C: Resources for Peer Educator Programmes and CABs”.



## **Module 11: Key Points**

- Linkages to community resources and support are important to help ALHIV and their caregivers get the services and support they need, across the continuum of HIV care.
- There are many ways to strengthen facility-community linkages, such as informal and formal meetings with community and youth group leaders; orienting community organisations and staff/volunteers working with youth on the needs of ALHIV; and developing a strong two-way referral system between the health facility and community organisations working with PLHIV, ALHIV, and youth in general.
- Healthcare workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and maintain a directory of these services to facilitate making referrals. Such directories should be shared with community organisations so that they, too, have current lists of the community- and health facility-based services for adolescents.
- PLHIV participation in all aspects of HIV programmes is critical to ensure that programmes are designed and implemented to meet client needs. Young people can play important roles in direct service delivery with their peers, as well as planning, monitoring, evaluation and quality assurance activities at the facility. Two important ways to include adolescents are through CABs and Peer Educator programmes.
- As ALHIV and service recipients themselves, Adolescent Peer Educators can give meaningful feedback to healthcare programmes, offering insights into the best ways retain young people in care and support their adherence to ART.
- Peer education can be a powerful approach to improving the youth-friendliness and quality of ALHIV care and treatment services. But peer education programmes require careful planning, clear objectives, regular supervision, and good communication.



## Appendix 11A: Community Resource Directory Template

DISTRICT NAME: \_\_\_\_\_ FACILITY NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

NAME OF ORGANISATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEORGAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
1.					
2.					
3.					
4.					
5.					
6.					
7.					

# PARTICIPANT MANUAL

NAME OF ORGANISATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEORGAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
8.					
9.					
10.					
11.					
12.					
13.					
* "Other" might include, for example, hours of opening, fees, documentation needed at initial visit, information about how to get there (transportation, bus line, directions if difficult to find), etc.					

## Appendix 11B: Template for Adolescent Peer Educator Job Description

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### Job description:

#### Adolescent Peer Educators are expected to:

- Participate as an active member of the multidisciplinary care team in the clinic, including attending meetings and trainings, if required
- Openly disclose their HIV-status to clients
- Help conduct/co-facilitate support groups and other psychosocial support activities for youth living with HIV (YLHIV)
- Conduct peer education sessions with YLHIV and provide support on the following topics:
  - Basic information about HIV and HIV care and treatment
  - Adherence to HIV care and treatment
  - Disclosure
  - Basic emotional and psychosocial support
  - Positive living and positive prevention
  - Safer sex
  - Others, as decided by the programme
- Help YLHIV with referrals within the health facility
- Help link YLHIV with needed community support services
- Be positive living and adherence role models to other YLHIV
- Act as a link between adolescent clients and the multidisciplinary care team
- Keep basic records and compile monthly reports

#### Expectations and time requirements for Adolescent Peer Educators (fill in/adapt as needed):

- Once selected, Adolescent Peer Educators will be expected to serve at least 1 year in their position.
- Adolescent Peer Educators are expected to attend and participate in the initial 10 day basic adolescent peer education training
- Adolescent Peer Educators will be expected to be present and work at the clinic at least 2–3 days per week.
- Adolescent Peer Educators may be expected to attend meetings or refresher trainings on weekends or during holidays, as needed. Estimated to be (fill in) days per month/year.

#### Supervision and reporting lines:

Adolescent Peer Educators will report to, and be supervised by, (fill in).

#### Incentives:

Adolescent Peer Educators are volunteers, but will receive the following incentives, supplies, and stipends (fill in).

## Appendix 11C: Resources for Peer Educator Programmes and CABs

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### **FHI Youth Peer Education Toolkit:**

**<http://www.fhi.org/en/Youth/YouthNet/Publications/peeredtoolkit/index.htm>**

The Youth Peer Education Toolkit is a group of resources designed to help programme managers and master trainers of Peer Educators. Collectively, these tools should help develop and maintain more effective peer education programmes. The 5 parts of the toolkit are based on research and evidence from the field as well as local examples and experiences. They are designed to be adapted locally as needed. The toolkit resulted from a collaboration between the United Nations Population Fund (UNFPA) and Family Health International. It was produced for the Youth Peer Education Network (Y-PEER), a project coordinated by UNFPA.

The 5 parts of the toolkit are as follows:

1. Training of Trainers Manual
2. Standards for Peer Education Programmes
3. Theatre-Based Techniques for Youth Peer Education
4. Performance Improvement
5. Assessing the Quality of Youth Peer Education Programmes

### **ICAP, Comprehensive Peer Educator Training Curriculum,**

**<http://cumc.columbia.edu/dept/icap/resources/peresources/PE.html>**

To share lessons learned, experiences and materials more widely, ICAP developed, and has recently updated per the new WHO guidelines, generic Peer Educator materials, which can be adapted by organisations and implementing partners wishing to start or scale-up peer education programmes.

Training content areas were selected to prepare Peer Educators for integration into the multidisciplinary HIV care team and provide added support in key areas of PMTCT and HIV care and treatment service delivery. The curriculum contains 15 basic and 4 advanced Modules. Both Manuals can easily be adapted to specific country and programme contexts.

The training curriculum consists of 3 components:

1. Trainer Manual, which is highly participatory, easy to follow and contains step-by-step instructions for facilitators.
2. Participant Manual, which includes key information, as well as illustrations to engage participants and improve learning. The Participant Manual can also be used as a reference for Peer Educators after the training.
3. Implementation Manual, which will be helpful to Ministries of Health, PLHIV Associations or NGOs initiating or expanding facility-based Peer Educator programmes. It provides practical advice on planning, managing and monitoring Peer Educator programmes. The Appendices of the Manual include a number of generic tools that can be adapted.

**ICAP, Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators (coming soon in May 2011)**

**<http://www.columbia-icap.org/resources/peresources/index.html>**

A generic curriculum to train adolescent Peer Educators, developed by ICAP, which will be available on the ICAP website in mid-2011. This easy-to-use, youth-friendly curriculum (Trainer Manual and illustrated Participant Manual) can be adapted to a range of country, program, and organizational settings wishing to start, scale-up or improve the involvement of ALHIV as Peer Educators.

**IMPAACT Community Advisory Board (ICAB) Training Curriculum: Trainer Manual**

**<https://impaactgroup.org/icab-trainer-manual>**

Although the ICAB training curriculum is designed to provide training and support to CAB members responsible for advising research and clinical trials, the first module of the curriculum includes content on how to develop a CAB mission statement, identify goals, determine CAB structure, and develop standard operating procedures.

## References and Resources

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<sup>1</sup> Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Planning, Managing and Monitoring Peer Educator Programs: An Implementation Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs (ICAP).

<sup>2</sup> Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. 2009. *Planning, Managing and Monitoring Peer Educator Programs: An Implementation Manual, Version 1.0.*, International Center for AIDS Care and Treatment Programs (ICAP).



## Module 12

### Supporting the Transition to Adult Care

**Session 12.1: Key Considerations for Healthcare Transition**

**Session 12.2: Preparing and Empowering Adolescent Transition into Adult Care**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Understand the key considerations when transitioning from paediatric to adolescent to adult care.
- Prepare adolescents for, and support them in, the transition to adult care.

## Session 12.1      Key Considerations for Healthcare Transition

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### Session Objective

**After completing this session, participants will be able to:**

- Understand the key considerations when transitioning from paediatric to adolescent to adult care.

### Key Considerations for Transition to Adult Care

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There are parallels between the maturation of adolescents into adults and the transition from paediatric to adult HIV programmes. ALHIV may face challenges to transitioning to adult care or learning to independently manage their own care. These challenges affect healthcare workers in paediatric and adult clinics, as well as adolescents and their caregivers. The role of the healthcare worker is to provide ALHIV and their caregivers with adequate support and to help them to increase their capacity to manage their own care and advocate for themselves in the clinical setting.

#### Goal of transition

The goal of transition is to ensure the provision of health care that is uninterrupted, coordinated, developmentally and age appropriate, and comprehensive before, during and after the transition.

Some key challenges for ALHIV during the transition process may include:

- **Balancing complicated care:** Adolescents must manage multiple medications and appointments, and must deal with a variety and a range of providers.
- **Leaving a familiar care network:** Adolescent clients may feel a reluctance to leave a familiar care setting and may be fearful and uncertain about how to manage a new clinic setting, new providers, and losing contact with support networks and friends in the clinic.
- **Psychosocial and developmental challenges:** Adolescents are simultaneously coping with the typical changes, feelings and worries of adolescence (which may include relationships, employment, education) and may be struggling with disclosure of their diagnosis to peers and family. Given the number of life changes happening at once, adherence to ART can lose priority. Healthcare workers need to work closely with ALHIV who are about to transition to adult care to ensure that they continue to adhere to their ART regimen and to their care.
- **System challenges:** Adult clinics typically lack specific services for adolescents and a lack of understanding and appreciation of adolescent's needs and issues.



Transition is applicable to every ALHIV as they mature into adulthood. All adolescents require support — within and outside of the clinic setting — to take greater ownership over their health care, behaviour, lives, and adherence to care and treatment.

- Transition to adult care generally occurs in parallel with an adolescent's emotional and physical maturation into adulthood. Effective transition must also allow for the fact that adolescents are undergoing changes that impact much more than their clinical care. Adolescents' psychological maturation may be influenced by how and when they assume responsibility for their care, and vice versa.
- Healthcare workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognising the young person's increasing maturation, capacity to make choices, and independence.
- Encouragement to develop as much independence as possible, both from their families and healthcare workers, will help bridge the gap to adult services and help adolescents make informed decisions about their own care.
- The overall goal of helping adolescents achieve independent management of their care is a gradual process and should involve the caregivers and family, whenever possible.
- Some caregivers will need assistance to understand their changing roles as the focus moves toward a confidential relationship between the adolescent and the healthcare worker, as opposed to always having a caregiver present at appointments.

## **Session 12.2      Preparing and Empowering Adolescent Transition into Adult Care**

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### **Session Objective**

**After completing this session, participants will be able to:**

- Prepare adolescents for, and support them in, the transition to adult care.

### **Helping ALHIV Prepare for Transition**

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Successful transition involves a client-centred process and a developmental approach; it is not a one-time event. The following principles can help to ensure a smooth transition from paediatric/adolescent to adult care programmes:

- The healthcare worker should begin the process early, working as a team with the adolescent client, caregivers, and other members of the multidisciplinary team.
- The transition process should enhance youth autonomy, cultivate a sense of personal responsibility, facilitate self-reliance and self-efficacy, and boost the adolescent's capacity for self-care and self-advocacy.
- The transfer of care should be individualised and should consider an adolescent's developmental stage.

**Healthcare workers and Peer Educators can support ALHIV and help them prepare for the transition process by:**

- Reviewing the client's medical history together with the client and encouraging him or her to ask questions about his or her care and medicines and discuss possible changes in the future.
- Ensuring that the adolescent understands his or her diagnosis, needed medications, the importance of adherence to care and medicines, and health precautions including ways to prevent new HIV infections and live positively (see Module 9 for more information about living positively with HIV).
- Promoting linkages to adolescent/peer support groups and to support groups in the adult clinic (for example, programmes can consider having Peer Educators make visits in both adolescent and adult clinics and organise support groups in the paediatric/adolescent clinic for transitioning adolescents).
- Transitioning adolescents to adult care in cohorts or groups, if possible, so adolescents can support one another.
- Organising health talks for transitioning adolescent clients, consider having the talk led by an older adolescent that has successfully transitioned to adult care.

- Encouraging older adolescents to take responsibility in making and keeping appointments and adhering to medicines (for example, ensure the adolescent maintains a calendar of clinic appointments and a medication calendar).
- Identifying and orienting adult providers on the necessity of youth-friendly services — including specific information on the medical and psychosocial needs of ALHIV — through meetings, orientations, and trainings.
- Accompanying the adolescent to the adult clinic for an orientation, to meet the clinic’s healthcare workers — including the adult Peer Educators or other lay counsellors — and to discuss specific concerns and questions.
- Transferring medical records to the new clinic and holding case conferences to discuss key issues in the adolescent’s care.
- Involving Peer Educators, social workers, and counsellors when planning for transition to adult care, especially for most-at-risk ALHIV or those with complex needs.
- Using a variety of youth-friendly activities (such as journaling or creating a Transition Workbook in which the adolescent might record information about his or her health, future goals, and sources of support).
- Connecting ALHIV to other community-based services, such as vocational training, social grants, food relief, etc.

**Healthcare workers can help older ALHIV be more involved in their own HIV care and treatment and help prepare them for transition to adult care. They can encourage adolescent clients to:**

- Think ahead about requirements for their care, such as appointments, meetings, adherence requirements (for example, medication refills).
- Ask questions and ask for help, if they need it.
- Learn more about their care and treatment plan.
- Understand which medicines they are taking.
- Get the results of every test and understand the results.
- Join an ALHIV association and a support group.
- Ensure they can follow up on all referrals, if not, ask the right questions to ensure they get the information they need so that they can follow up on referrals.

Healthcare workers can also use “Appendix 12A: Transition Checklist for Healthcare Workers” and Table 12.1, as tools to support ALHIV in the transition process. There are a number of resources available on transition to adult care for healthcare workers and for adolescent clients. Some of these resources are listed in “Appendix 12B: Transition Resources for Healthcare Workers and ALHIV (for Adaptation)” and these can be adapted to any clinical or programme setting.

**Table 12.1: A self-care and transition timeline for ALHIV**

10–12 years old	13–16 years old	16–19 years old
<ul style="list-style-type: none"> <li>• Encourage caregivers to fully disclose to the child</li> <li>• Solicit direct conversation with the adolescent</li> <li>• Increase private meetings and counselling sessions with the adolescent</li> <li>• Begin to explain medications and adherence</li> <li>• Deal with early adherence issues and challenges</li> <li>• Link to support groups</li> </ul>	<ul style="list-style-type: none"> <li>• Assist adolescent with a calendar for appointments and medicines</li> <li>• Ensure adolescent understands diagnosis, needed medications, adherence, health precautions, positive living, and positive prevention</li> </ul>	<ul style="list-style-type: none"> <li>• Enforce responsibility in making and keeping appointments</li> <li>• Provide ALHIV with copies of medical records and any other forms or documents required by the adult clinic</li> <li>• Review medical history with the client</li> <li>• Encourage questions about care plan and treatment regimen and possible changes</li> <li>• Transfer medical records to new provider, highlight key issues</li> <li>• Visit the adult clinic together with the adolescent client</li> </ul>

Adapted from: AETC National Resource Center. 2003. *Practitioner Transition Timeline and Checklist*.

### Exercise 1: Supporting ALHIV in their Transition to Adult Care: Case studies and large group discussion

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To discuss particular issues related to transition of care for ALHIV and how healthcare workers can assist to make the transition process smoother</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. A volunteer will be invited to read the first case study (below) out loud.</li> <li>2. The trainer will facilitate a discussion about each case study using the following questions:             <ul style="list-style-type: none"> <li>• <i>What fears or concerns do you think this client has about transitioning to adult care?</i></li> <li>• <i>What could healthcare workers do to prepare this client for transition to adult care?</i></li> <li>• <i>What types of activities could healthcare workers do with, or suggest to the client, to assist with his or her transition to adult care?</i></li> <li>• <i>What follow up could healthcare workers provide once the adolescent is enrolled in the adult clinic?</i></li> </ul> </li> <li>3. Participants should refer to “Appendix 12A: Transition Checklist for Healthcare Workers” when considering their answers to the above questions.</li> </ol>

**Exercise 1: Supporting ALHIV in their Transition to Adult Care: Case studies and large group discussion**
**Case Study 1:**

Peter is an ALHIV who is 16 years-old. In a few months, he is moving to a new district, where he will need to start getting care and treatment at the adult clinic because there is no paediatric clinic. He is nervous about this change — not knowing the staff and knowing that he will have to deal with a large, crowded clinic. How can you support Peter with this transition?

**Case Study 2:**

Mary is an ALHIV who is 19 years-old. She has been receiving services from the adult clinic for the past year. Recently, Mary has returned to the adolescent clinic to see you. When you ask her about her care and treatment, she tells you that she has stopped taking her ARVs for the last 3 weeks. When you try and discuss this situation with her more in detail, she cries and tells you that she does not like the people at the adult clinic. How would you proceed and support Mary in the transition process?

**Case Study 3:**

Betty is 20 years-old and is a client at the paediatric clinic where you work. Betty has been diagnosed with some learning problems and developmental delays. Although she should transition to the adult clinic soon because of her age, you have some concerns about her development and ability to independently manage her own care. You are afraid she will get “lost” at the adult clinic. How do you proceed with Betty?



## **Module 12: Key Points**

- In some places, adolescents will have attended paediatric clinics, where they may have been getting services since birth or for many years. After a certain age, they usually have to transition to the adult ART clinic. This care transition can be difficult for the adolescent — not only is it a matter of adjusting to a new, less nurturing environment and to new healthcare workers, but adult clinics expect that their clients take on responsibility for their own care. Taking on a greater role in self-care and self-advocacy may be challenging for the adolescent, depending on their level of development and maturation.
- Healthcare workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognising the young person's increasing maturation, capacity to make choices, and independence.
- Not all ALHIV will be ready to make the transfer to adult care at the same age. Healthcare workers must take into account their cognitive and physical development, their emotional maturity, their support at home and in the community, and their health status.
- It is possible for adolescents to have a smooth transition to adult care and receive adolescent-friendly services in the adult clinic. Key factors that support successful transition include: an agreed transition plan that gives the ALHIV time to prepare for the transition and to take on more responsibility for self-care, an adult clinic that is willing to meet the special needs of adolescents and is staffed with healthcare workers who understand the special needs of ALHIV.

## Appendix 12A: Transition Checklist for Healthcare Workers

This checklist contains the key points related to preparing older adolescents to transition to adult care. This checklist is meant to assist healthcare workers or other members of the multidisciplinary care team by outlining the basic steps involved in supporting adolescents with the transition process. The checklist provides suggested subjects for discussion, although additional areas may be identified to meet individual adolescent's needs. In the 'Action' section, the healthcare worker should record major actions undertaken, referrals made or information — such as medical records — given to the adolescent or caregiver during the discussion.

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	<b>1. Introduce the transition</b>	
	Introduce and discuss transition during adolescent support group meetings and group health education sessions	
	Discuss transition during clinical check ups and individual counselling sessions with adolescent clients	
	Discuss transition with caregivers, during group or individual sessions	
	<b>2. Encourage the adolescent to assume increasing responsibility for his or her own health care management</b>	
	Assure the adolescent understands his or her own health condition, care plan, and medications	
	Talk about transition and transfer to the adult clinic, discuss expectations, and answer any questions	
	Talk to adolescents about general coping, positive living, and building supportive relationships	
	Give caregivers an opportunity to discuss their feelings about transition and any concerns about having a less active role in the adolescent's care	
	<b>3. Assess client's ability to make independent health care decisions, assess readiness for the transition, and determine additional support needs</b>	
	Assess <i>client's</i> understanding of own care and transition process (for example, using an assessment method such as quiz, questionnaire, discussion, etc.)	
	Assess <i>caregiver's</i> understanding of own care and transition process	
	If usually accompanied by family members, encourage the adolescent to make their next appointment (on their own) and to refill their medications also on their own	
	Initiate any needed referrals, including to support groups	

	<b>4. Provide anticipatory guidance</b>	
	Review plans for continued adherence to care	
	Review adherence to medicines and ensure the client has, and knows how to use, a medicine calendar or other system of keeping track of doses	
	Ensure client knows where to access help/assistance, if he or she has questions about the new clinic	
	<b>5. Implement the transfer to an adult clinic</b>	
	Send copies of reports, letters, and tests to the adolescent and caregivers so they have their own records	
	Transfer medical records	
	Discuss the adolescent's care with healthcare workers at the adult clinic	
	Provide orientation to the adolescent, ideally with the healthcare workers or member of the multidisciplinary team in the adult clinic	
	Follow up after the transfer (for example, schedule a follow-up visit with the adolescent, encourage Peer Educators to visit the adult clinic and talk with newly transitioned adolescents, etc.)	
	<b>6. Other activities that may help healthcare workers and ALHIV plan for the transition process</b>	
	Meet with an adolescent client who has transitioned to adult care	
	Schedule a visit to the adult clinic, so adolescents can learn more about the services and the healthcare providers before the transfer takes place	
	Attend a support group session with other transitioning adolescents	
	Suggest trying journaling activities, to address transition and issues such as future goals	
	Use a comprehension assessment tool (for example, quiz, questionnaire, etc.) about HIV and adherence to care and medications to assess readiness	



## Appendix 12B: Transition Resources for Healthcare Workers and ALHIV (for Adaptation)

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### Resources for Providers:

<http://hivcareforyouth.org/pdf/TransitioningYouth.pdf>

This is a comprehensive guide for healthcare providers. It includes many tools and resources and is designed for perinatally infected youth, but broadly applicable.

<http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272>

This curriculum slide set is designed to provide an introduction to issues adolescents who have perinatally acquired HIV infection face. It uses a developmental approach to explore issues from the perspective of the adolescent, the family, and the healthcare provider.

### Resources for ALHIV (teaching self advocacy/encouraging independent health behaviour):

<http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-269>

Youth-friendly workbook for adolescent patients to assist with the transition from a paediatric care setting.

### Reference Articles:

Blum, R. 1995. *Transition to adult health care: Setting the stage*. Journal of Adolescent Health, 17, 3-5.

Kelly, A. 1995. The primary care provider's role in caring for young people with chronic illness. *Journal of Adolescent Health*, 17, 32-36.

Scal, P., Evans, T., Blozis, S., Okinow, N. & Blum, R. 1999. *Trends in transition from pediatric to adult health care services for young adults with chronic conditions*. Journal of Adolescent Health, 24, 259-264.



## **Module 13**

# **Monitoring, Evaluation, Quality Improvement, and Supportive Supervision**

**Session 13.1: Monitoring, Evaluation, and Data Collection**

**Session 13.2: Quality Improvement and Supportive Supervision**

### **Learning Objectives**

**After completing this module, participants will be able to:**

- Discuss the importance of routinely monitoring adolescent HIV care and treatment activities.
- Discuss how information from monitoring and evaluation can be used to support programme improvement.
- Describe the purpose of Quality Improvement (QI).
- Define and describe supportive supervision.

## Session 13.1      Monitoring, Evaluation, and Data Collection

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### Session Objectives

**After completing this session, participants will be able to:**

- Discuss the importance of routinely monitoring adolescent HIV care and treatment activities.
- Discuss how information from monitoring and evaluation can be used to support programme improvement.

### Monitoring

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Monitoring is the routine collection and tracking of key programme data over time. Monitoring is a process that helps to identify problems early so that they can be corrected quickly. This requires that data be collected, compiled, and analysed on a routine basis.

Healthcare workers play a vital role in the monitoring process by regularly collecting (by recording), compiling and reporting data to determine, for example, the number of adolescents enrolled in HIV care and receiving ART, the number of adolescents retained in care over time, and the types of clinical and support services offered to adolescents.

### Monitoring and evaluation of adolescent HIV care and treatment programmes can help to:

- Assess whether the programme is meeting its targets, and
- Identify and improve problem areas in the implementation of adolescent HIV care and treatment services.

Routine monitoring and evaluation are necessary to gather information on:

- **Individual outcomes**, such as: Is she responding to treatment? Is she being retained in care? Is he adhering to his medicines? Is he receiving the comprehensive care and support services he needs?
- Care and treatment **programme outcomes**, such as: Is the programme retaining adolescent clients in care? Are all eligible adolescents receiving ART? Are routine lab tests and clinical follow-up visits being conducted on schedule?). Programme outcomes are usually the cumulative tally of individual outcomes and can give insight into strengths and areas needing improvement within the individual facility or in a district.

## Targets

**Targets** are specific goals established before a new programme or service is implemented and on a regular basis thereafter. For example, a target may be “To ensure that 95% of eligible adolescent clients initiate ART.”

## Indicators

- Indicators are summary measures used to help indicate the status of your programme’s activities.
- Indicators measure things such as the number of adolescent clients tested and informed of their HIV status, the number enrolled in HIV care, and of those, the number initiating ART. See Table 13.1 for more examples of indicators.
- Paediatric and adult HIV care and treatment indicators are established on a national level according to the needs, resources, and standards of the programme. Indicators are often defined in the national strategic plan for HIV.
- National level indicators generally cover service delivery to PLHIV, quality of care, and management-related information.
- Though indicators are identified at the national level, they can be calculated for facility, district, or national levels depending on need and how the data will be used.
- Some facilities will have their own indicators in addition to the national indicators. Facility-level indicators can help to identify progress, problems, challenges, and solutions in the delivery of adolescent HIV care and treatment services at a specific site. For example, facility level indicators could show how many adolescents are missing appointments and of these, how many are followed up and returned to care.
- Indicators may need to be revised periodically (for example, in response to changes in national guidelines for the programme or services being monitored).
- Indicators reflect a certain timeframe — for example the month, the quarter, or the year.
- It is important to measure changes in indicators over time. So, for example if the number of HIV-infected adolescent enrolled in care as 20 in 2000, 40 in 2002, and 30 in 2004, then we can see that performance in 2004 was very poor (in comparison to 2002).

**Table 13.1: Examples of adolescent HIV care and treatment indicators**

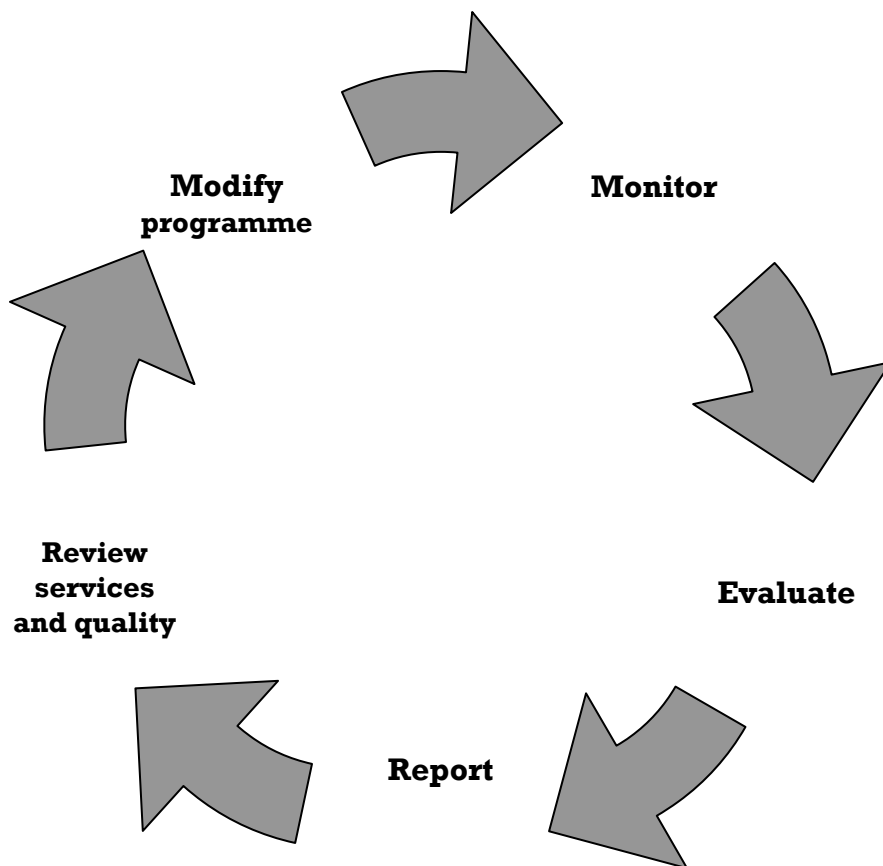
- Number HIV-infected adolescents (age 10–19) enrolled in care
- Number of adolescents who initiated ART
- Number of adolescents currently receiving ART
- Number of adolescents who had a change of therapy
- Number of adolescents for whom ART was discontinued
- Number of adolescents lost to follow-up
- Number of adolescents transferred to other facilities
- Number of adolescents who have died
- Number of adolescents who have become pregnant

## Evaluation

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While monitoring helps look at progress in indicators and helps us know if we are reaching our targets, evaluation examines the process in greater depth and helps us understand what the indicators are really telling us.

- Evaluations are typically conducted at specific time periods (for example, at the end of the year), whereas monitoring happens on a daily, monthly, and quarterly basis.
- An evaluation of the adolescent HIV care and treatment programme will demonstrate how well the programme has met the expected goals and targets. So, for example, an evaluation might help to answer the following questions:
  - Are adolescents enrolled in the programme living longer than those not enrolled in care?
  - Are adolescents enrolled in the programme experiencing a better quality of life?
  - Has the programme reduced the number of adolescents hospitalised for HIV-related illnesses?
  - How might the programme be improved to reach its targets and goals more quickly?
  - What are the barriers to reaching our goal?
- Evaluations should be conducted regularly to look at changes that occur as the adolescent HIV programme is implemented and maintained. For example, has the ALHIV hospitalisation rate changed from 2008 to 2010? If so, can this change be attributed to our programme? This will enable programme staff to identify areas of programme strength and weakness (“review services and quality” in Figure 13.1) and to respond to weaknesses by investigating and correcting problems (“modify programme” in Figure 13.1).
- The monitoring and evaluation process is a continuous one, as shown in Figure 13.1, below.

**Figure 13.1: Monitoring and evaluation as a continuous process**

Source: Republic of Zambia, MoH. 2010. *National Training Package on Provider-Initiated Paediatric HIV Testing & Counselling in Zambia*.

## Reporting

Individual client data is recorded in **registers**. Data in the registers is tallied and the totals recorded on the **monthly summary forms**. The figures on the monthly summary forms summarise a facility's progress on key indicators (such as those listed in Table 13.1). The monthly summary forms are then submitted to the district level. The districts collate (that is, put together the monthly summary forms from all of the district clinics) the monthly summary forms and submit the collated data to the national level.

The monthly summary form should be compiled into a **monthly report** for local staff to review how the programme is doing. The monthly report for the facility might include data in addition to that which was reported to the district (such as that collected on retention from appointment books or wait times).

All staff must be aware of the importance of accurately completing registers. The monthly summary forms and reports are accurate only if the registers are completed correctly and consistently. This is discussed further in the next session.

## Programme Modification

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At every level of the system (facility, district, and national) monthly summary forms should prompt discussion on how the programme can be modified, or improved, to better meet targets. (This activity is referred to as “review services and quality” in Figure 13.1.) So, for example if the most recent annual report indicated that 45% of ALHIV clients were lost to follow-up last year and the target was to reduce loss to follow-up to no more than 10%, we would know that the programme needs to be modified, or improved in order to reach the target. Such programme improvements will require discussion of:

- **What is the problem:** Why is loss to follow-up so high? How can we find out? Can we interview our clients? Shall we interview clients that have dropped out of care? Shall we interview our staff to find out more? What will we ask them? Shall we ask them not only why the problem exists but also what they think are the potential solutions?
- **How will we address the problem:** Once the key problems have been identified, how will these problems be addressed?
- **Decide on a plan:** Once the key solutions and specific actions have been identified, *who* will address the issue, by *when* and using what *funding* (if funding is needed).
- **How will we decide if the plan is working:** How will we know if the new initiative is working? Will we look at this year’s firstly quarterly summary form? Is so, what improvement do we expect to see? Will we consider the program modifications successful if our loss to follow up drops to 40%? (Probably not.) How about 15%? (Probably, but with recognition that further improvement is needed.)

## Adolescent HIV Care and Treatment Data Collection

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Standard data collection and accurate recording of activities and outcomes are essential. **Data collection for adolescent HIV care and treatment is part of the existing national system and uses existing national HIV care and treatment forms and registers; it is not a separate system with adolescent-specific forms.**

In most cases, adolescent data will be captured in the national forms for paediatric HIV, meaning that the same system and tools can be used to describe, monitor, and evaluate both the paediatric HIV programme and the adolescent programme. However, if an adolescent client is provided with care in an adult HIV clinic (either because he or she has been transitioned to the adult HIV clinic or because paediatric services are unavailable), then facilities should use the national forms for adult HIV care and treatment to report activities related to the ALHIV.

**Systems for documenting care and treatment activities must also maintain client confidentiality. All records, including registers, must be kept in a secure location and no identifying data should leave the site.**

It is the responsibility of all staff members that complete registers or summary forms to ensure that data is accurate and complete and that data collection protocols are followed. Attention to accuracy will help to ensure that monthly, quarterly and annual reports accurately reflect services and activities conducted in the clinic.

**The following is a list of some of the key registers and forms facilities use to monitor activities in their adolescent programmes** (note that this list assumes adolescents are being captured on paediatric registers and forms, adapt as needed if adolescents will only be seen in adult clinics):

- Ward or clinic registers
- General HIV counselling and testing register
- Patient care card
- HIV care summary sheet
- Paediatric clinical follow-up form
- Paediatric ARV eligibility form
- Paediatric adherence form
- Pharmacy logbook/register
- Patient status form
- TB diagnostic worksheet and TB screening tool
- Paediatric patient locator form

### Characteristics of effective M&E systems

Effective monitoring and evaluation systems require record keeping that is:

- **Accurate** — that is, correct and true. So if the client's CD4 is 401, ensure that "401" is entered correctly in the appropriate cell against his or her identifying code or name
- **Reliable** — completed the same way every time
- **Standardised** — recorded using the same tools (for example the same register, using the same abbreviations, formulas, and definitions) in every clinic across the district or country
- **Recorded** following established guidelines

## Tracking Missed Appointments

Health facilities also use an **appointment book** to keep track of upcoming appointments and if appointments were missed. A follow-up system should be developed to contact adolescent clients and their caregivers when appointments are missed and try to bring the adolescent back into care.

### A follow-up system requires:

- A working appointment system whereby healthcare workers can readily track missed appointments and contact clients (and caregivers) who miss appointments to bring them back to the clinic.
- In urban areas, contact may involve the use of cell phones (calling, SMS) while in rural areas, community workers, NGOs, Peer Educators, family members, or friend networks may serve this purpose.
- Contacting clients and families when appointments are missed, either by telephone or by home visit, requires the consent of the adolescent client and/or the caregiver; therefore, a system should be in place to



both obtain contact information and to routinely request consent to follow-up missed appointments.

<b>Exercise 1: Using Data for Decision-making: Small group work and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To review adolescent HIV care and treatment data and analyse the data for use in programme decision-making</li> </ul>
<b>Instruction</b>	<p><b>Small Group Work</b></p> <ol style="list-style-type: none"> <li>Participants will be asked to break into small groups to discuss the sample quarterly report below.</li> <li><b>Part 1 of small group work:</b> Small groups will have about 20 minutes to review the data in "Table 13.2: Sample data for Exercise 1" (below) and answer the following questions:             <ul style="list-style-type: none"> <li>For which indicators is Clinic Make Believe doing well and meeting their targets? How do you know?</li> <li>For which indicators is Clinic Make Believe NOT meeting its targets? How do you know?</li> <li>If the number of adolescents enrolled in care in Q4 (the 4<sup>th</sup> quarter) of 2009 was 450 and the number of adolescents receiving ART was 290, would you say that in 2010 they are doing better or worse enrolling clients in ART?</li> <li>Which areas should Clinic Make Believe staff focus on improving?</li> </ul> </li> <li><b>Part 2 of small group work:</b> Small groups will have another 10 minutes to identify one of the areas that need improvement at Clinic Make Believe and then discuss:             <ul style="list-style-type: none"> <li>What is the problem?</li> <li>How should we (assuming we are the managers at Clinic Make Believe) address the problem?</li> </ul> </li> </ol> <p><b>Small Group Presentations and Large Group Discussion</b></p> <ol style="list-style-type: none"> <li>Once the large group is reconvened, one of the small groups will be invited to present their findings for part 1. Other groups will be invited to comment.</li> <li>Another group(s) will be invited to report on part 2 of the small group work.</li> </ol>

**Table 13.2: Sample data for Exercise 1**

<b>Quarterly adolescent HIV care and treatment summary report for Clinic Make Believe</b>		
<b>Number of adolescents enrolled in care</b>	<b>2010, Q4</b>	<b>Target*</b>
• Age 10–14, female	100	
• Age 10–14, male	95	
• Age 15–19, female	150	
• Age 15–19, male	165	
• Total	510	550
<b>Number of adolescents receiving ART</b>	<b>2010, Q4</b>	<b>Target*</b>
• Age 10–14, female	75	
• Age 10–14, male	70	
• Age 15–19, female	102	
• Age 15–19, male	120	
• Total	367	350
<b>Number of new adolescent clients in the quarter</b>	<b>2010, Q4</b>	<b>Target*</b>
• Age 10–14, female	1	
• Age 10–14, male	2	
• Age 15–19, female	22	
• Age 15–19, male	12	
• Total	37	40
<b>Number of adolescent clients who missed appointments in the quarter</b>	<b>2010, Q4</b>	<b>Target*</b>
• Age 10–14, female (75 had appointments this quarter)	20	
• Age 10–14, male (70 had appointments this quarter)	23	
• Age 15–19, female (95 had appointments this quarter)	37	
• Age 15–19, male (105 had appointments this quarter)	42	
• Total (345 had appointments this quarter)	122	10% of those in care, max
<b>Number of adolescent clients attending support group meetings</b>	<b>2010, Q4</b>	<b>Target*</b>
• Age 10–14, female	55	
• Age 10–14, male	45	
• Age 15–19, female	120	
• Age 15–19, male	130	
• Total	350	50% of those in care
<b>Number of support group meetings held at the clinic</b>	<b>2010, Q4</b>	<b>Target*</b>
• For 10–14 year olds	6	
• For 15–19 year olds	10	
• For caregivers	3	
• Total	19	9
<b>Number of active adolescent Peer Educators at the clinic</b>	<b>2010, Q4</b>	<b>Target*</b>
Number of active adolescent Peer Educators at the clinic	15	6

\*Target is based on 2009 figures as well as national and funder goals. If a cell is blank it means that sub-targets have not been stated.

## Session 13.2      **Quality Improvement and Supportive Supervision**

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### **Session Objectives**

**After completing this session, participants will be able to:**

- Describe the purpose of Quality Improvement (QI).
- Define and describe supportive supervision.

### **Quality Improvement**

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Quality Improvement is the means by which activities are routinely evaluated to check that the services offered by the multidisciplinary team are following the established guidelines and standard operating procedures. QI is also referred to as quality assurance (QA). The purpose of QI is to identify problems so that they can be corrected, thereby improving services for adolescent clients and their caregivers.

QI should be a routine part of the normal functioning of health facilities. QI incorporates procedures in which all staff, at all levels, not solely supervisors, should be involved.

### **Methods to Assess Quality**

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It is often necessary to use a variety of methods to assess programme quality. Standard monitoring tools such as patient forms and registers capture only a fraction of services provided to adolescents, and provide no information on the quality of those services. For example: If only forms, client records, and registers were used to assess quality, there would be no information on the quality and youth-friendliness of clinical services, or of psychosocial support, adherence, and other counselling sessions, or of referrals made to community-based support services.

### **QI activities might, for example, examine and evaluate:**

- Quality and youth-friendliness (see Module 2) of services
- Compliance with national guidelines, standard operating procedures and protocols for HIV care and treatment
- Adequacy of space and attention to privacy and confidentiality
- Linkages to ongoing support and community-based services

QI activities may vary somewhat from one facility to the next based on the type of facility and the facility's experience with adolescent HIV care and treatment services.

**QI activities may include, for example:**

- Periodic reviews of records, with staff feedback — the reviewer should check for accuracy, completeness, and consistency of entries in the various forms, registers, and patient files.
- Direct observation of clinical procedures and counselling sessions.
- Periodic assessments of youth-friendliness of services, including youth participation (the checklist presented in Module 2 could be used to periodically assess youth-friendliness).
- Interviews with staff indirectly or directly involved in the adolescent care and treatment programme to obtain feedback on specific indicators. A case conference format may be used as a forum to highlight current challenges, systems that are working, and those that need improvement and provide a forum for proposing solutions.
- Individual interviews or focus groups with adolescent clients who receive care and treatment services at the clinic. For example, do adolescent clients feel that adequate information and support was provided in the counselling sessions? Did they feel welcomed at the clinic? Were they treated non-judgementally by healthcare workers? Were they clear about what was expected of them, for example, how and when to follow-up? Were their other health and psychosocial needs assessed and addressed (for example, sexual and reproductive health services)? Was their privacy and confidentiality respected?
- Individual interviews or focus groups with caregivers of adolescent clients who attend the clinic. For example, do caregivers feel that they were provided with adequate information on supporting the adolescent at home?
- Client exit interviews or anonymous surveys by clients.
- Evaluation of physical space, client flow, and time concerns through observation and staff and client interviews.
- Meeting with representatives of services where adolescent clients and caregivers are referred. Ask them about client needs, gaps in services, and feedback on services.

**How often should QI be conducted?**

During initial implementation, daily or weekly QI activities allow for immediate follow-up to correct identified problems. As the services become established, reviews should become a formal part of overall adolescent HIV care and treatment programme monitoring activities at designated intervals (monthly progressing to quarterly reviews). Although supervisors have the ultimate responsibility for QI, the activities related to QI should be shared with other members of the team.

It is important to set aside time for multidisciplinary team members and managers to discuss QI findings and issues and jointly come up with solutions and ideas for quality improvement. This can be accomplished, for example, as a part of routine monthly multidisciplinary team meetings or through dedicated quarterly meetings on QI review.

## Supportive Supervision

Quality Improvement activities are not complete without assessing the results of the QI review and planning a response. Often weaknesses discovered through QI activities require supervisors to work with staff (including adolescent Peer Educators) to address the problems. An important component of responding effectively to QI findings is to provide **supportive supervision**. Supportive supervision requires the supervisor to work with staff to establish goals, monitor performance, identify and correct problems, and proactively improve the quality of adolescent HIV care and treatment services through training, one-to-one support, mentoring, and coaching.

### Focus of QI

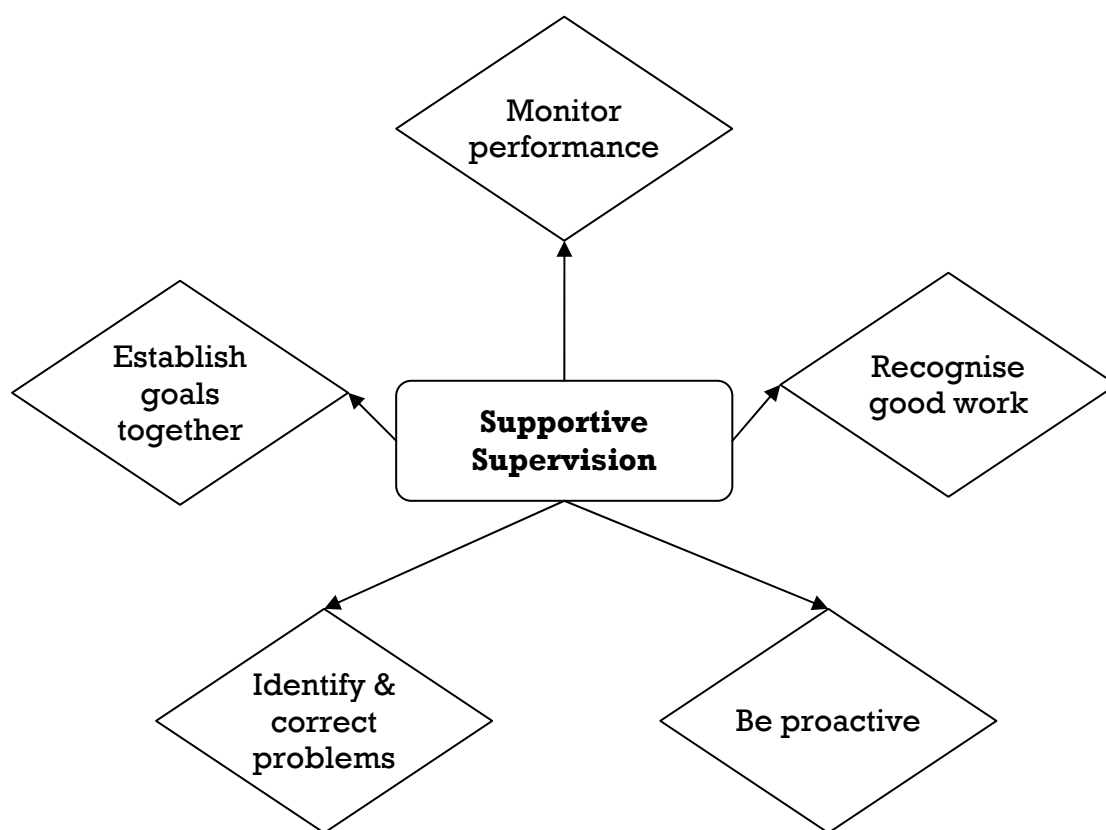
QI is most effective when the focus is on providing guidance and mentorship, as well as group problem solving techniques, to assist healthcare workers to correct problems and overcome barriers to a high quality programme.

It is important that supervisors explain to their staff that QI activities are not simply the responsibility of supervisors, but rather that all activities conducted by any staff member that aims to improve services are a part of the continuous QI process.

### Supportive supervision aims to:

- Obtain valuable information on programme functioning and quality.
- Improve healthcare worker performance by providing one-to-one support to address an identified deficiency.
- Acknowledge good practices by providing positive feedback and noting contributions to the success of the programme.
- Involve supervisors, healthcare workers, and adolescents themselves (such as adolescent Peer Educators) to improve service provision (it is not the sole responsibility of the supervisor). Healthcare workers and Peer Educators can support each other by mentoring their peers.
- Facilitate on-site, participatory problem-solving. Healthcare workers should be encouraged to become comfortable actively participating with their supervisors to address weaknesses.
- Assure the programme is successful in meeting the needs of ALHIV and their caregivers and families.
- Motivate staff.

Once a deficiency in service provision is identified, supportive supervision must be established as quickly as possible to prevent poor practices from becoming routine. “Figure 13.2: Supportive supervision” illustrates the concept of supportive supervision.

**Figure 13.2: Supportive supervision**



### Module 13: Key Points

- Monitoring and evaluation is the standardised process by which data related to the delivery of services is collected and evaluated. This data can be used to monitor progress in the implementation of adolescent care and treatment services from the facility perspective.
- Indicators provide information about key service interventions. Indicators can be calculated for facility, district, or national levels depending on need and how the data will be used. Indicators are calculated using routinely collected data that are recorded in registers and summarised on monthly summary forms.
- A review of the monthly forms that summarise monitoring data can help to identify service strengths and weaknesses. Programme successes and weaknesses need to be communicated back to staff to initiate discussion on how weaknesses can be addressed.
- Quality Improvement is the means by which activities are routinely evaluated to check that the services offered by the multidisciplinary team are following the established guidelines and standard operating procedures. Services not following established procedure, once identified, can be corrected. Information that supports QI activities includes that from monitoring and evaluation processes.
- A variety of methods may be used to conduct QI, including:
  - Periodic reviews of records
  - Direct observation of healthcare workers' (and Peer Educators') activities
  - Assessments of youth-friendliness of services
  - Individual interviews or focus groups with adolescent clients and caregivers
- An important component of responding effectively to QI findings is to provide supportive supervision. Supportive supervision requires collaboration between the supervisor and staff to:
  - Establish goals.
  - Monitor performance.
  - Identify and correct problems.



## Module 14

### Supervised Clinical Practicum

**Session 14.1: Practicum Planning and Preparation**

**Session 14.2: Supervised Clinical Practicum and Debrief**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Be familiar with the core competencies needed to provide adolescent HIV care and treatment services.
- Feel prepared for the clinic-based practical sessions.
- Be able to demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
- Discuss and debrief on the practicum sessions.
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services, and plan for ongoing practice and mentorship.



## **Session 14.1      Practicum Planning and Preparation**

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### **Session Objectives**

**After completing this session, participants will:**

- Be familiar with the core competencies needed to provide adolescent HIV care and treatment services.
- Feel prepared for the clinic-based practical sessions.

### **Core Competencies**

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Participants will be asked to practise and demonstrate a number of skills learned during the training. Refer to “Appendix 14B: Practicum Checklist” for more information on the core competencies for healthcare workers.

Preceptors will be available to help and mentor participants as they master the skills learned in training.

### **Conduct during the Practicum Session**

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- Remember that we are guests at the health facility and must respect the wishes of the healthcare workers and managers who work in the facility.
- Keep all discussions and observations during the practicum confidential. Only share with other participants, trainers, or preceptors, and *only* for learning purposes. When discussing cases after the practicum, change any identifying information about specific individuals so that no one will be able to guess who is being described.
- *Always* inform the preceptor if you need to take a break or leave the facility for any reason during the practicum.
- *Always* introduce yourself to other healthcare workers and clients. Tell them that you are currently on a course about care and treatment services for adolescents, and that the training includes observation and practice in the health facility.
- *Always* ask adolescent clients and their caregivers for their verbal consent to observe or practise. Keep in mind that clients have the right to refuse to give consent or to withdraw their consent at any time. Participants and preceptors are obligated to concede to the client’s request.
- *Always* ask the preceptor if you have a question or a concern.

Preceptors will be using “Appendix 14B: Practicum Checklist” to assess participant performance during the practicum. Become familiar with the content of this form, including how the preceptors will make a final evaluation.

## Session 14.2      Supervised Clinical Practicum and Debrief

### Session Objectives

**After completing this session, participants will:**

- Be able to demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
- Discuss and debrief on the practicum sessions.
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services, and plan for ongoing practice and mentorship.

### Exercise 1: Supervised Clinical Practicum and Daily Practicum Debrief

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To practise core competencies needed to provide adolescent HIV care and treatment services in a clinical setting</li> </ul>
<b>Instruction</b>	<p><b>Practicum</b></p> <ol style="list-style-type: none"> <li>1. Participants should refer to the core competencies listed in “Appendix 14B: Practicum Checklist” as these are the skills that they will be expected to practise during the practicum session.</li> <li>2. Participants will be observed and mentored by preceptors. Preceptors will note which skills each participant was able to practise during the day on the Practicum Checklist.</li> <li>3. Participants may want to complete the Practicum Checklist for themselves, noting which core competencies were conducted and any comments.</li> </ol> <p><b>Daily Debriefing</b></p> <p>Participants should reconvene as a large or small group at the end of each practicum day to discuss the following questions:</p> <ul style="list-style-type: none"> <li>• <i>What core competencies did you practise during the day?</i></li> <li>• <i>Which competencies were the most comfortable for you to conduct? Which were the most challenging?</i></li> <li>• <i>Are there areas in which you feel you need more practice? Which ones?</i></li> <li>• <i>Were there any unexpected or new things that you observed today during the practicum session?</i></li> <li>• <i>Do you have suggestions to improve tomorrow’s practicum session?</i></li> </ul>

<b>Exercise 2: Final Practicum Debrief : Small and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To share experiences and lessons learned during the multi-day practicum.</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will be asked to break into small groups.</li> <li>2. In their small groups, they should take about 30 minutes to discuss and note responses to the following questions:             <ul style="list-style-type: none"> <li>• <i>What was your overall experience during the practicum?</i></li> <li>• <i>What skills were the most difficult to perform?</i></li> <li>• <i>What skills were less difficult?</i></li> <li>• <i>In which areas would you like more mentoring in the future?</i></li> <li>• <i>What did you learn that you had not anticipated learning?</i></li> <li>• <i>What was your most memorable experience from the practicum?</i></li> <li>• <i>How can participants and preceptors continue to support one another in building their skills once the training is over?</i></li> </ul> </li> <li>3. Once the large group is reconvened, the small groups will be invited to briefly present key points from their discussions.</li> </ol>

## Appendix 14A: Tips on Mentoring and Coaching with Preceptors

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### What are the qualities of a good preceptor?

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- Strong knowledge, skills, and experience related to adolescent HIV care and treatment
- Professional
- Understands the importance of skill sharing and capacity building and is therefore willing to teach and to mentor
- Respects others
- Conscientious and trustworthy
- Accountable for her or his work; responsive to feedback
- Upholds confidentiality at all times
- Ethically sound decision making
- Leadership

### Preceptor Do's and Don'ts

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#### Do:

- Make participants feel welcome and valued.
- Set shared achievable goals.
- Put yourself in the participant's shoes.
- Ask questions that show interest in developing participants' skills.
- Monitor progress and give feedback frequently.
- Provide guidance, encouragement and support.

#### Don't:

- Appear unprepared.
- Be vague about your expectations.
- Confine the participant to passive roles.
- Leave feedback to the final assessment.
- Embarrass or humiliate participants.
- Accept behaviour that is unethical or unsafe.
- Judge if a participant does not know something.

#### Five-step method for teaching clinical skills

1. Provide an overview of the skill and how it is used in patient care.
2. Demonstrate exactly how the skill is conducted without commentary.
3. Repeat the procedure, but describe each step.
4. Have participant "talk through the skill" by detailing each step.
5. Observe and provide feedback to the participant as he or she performs the skill.

Adapted from: George, J.H., & Doto, F.X. 2001. A simple five-step method for teaching clinical skills. Family Medicine, 33, 577-8.

## Appendix 14B: Practicum Checklist

This checklist includes many of the core competencies taught during the training. The checklist can be used during the practical sessions of the training and, **after the training it can also be a useful tool for supervisors and healthcare workers in the adolescent clinic.** It is unlikely that participants will be able to practise and demonstrate all of the competencies in this checklist during the 2 day practicum, but the checklist can be used when participants return to their sites after training, as part of supportive supervision and mentoring activities.

**Preceptor instructions:** Use one checklist per participant in your group. As you observe a skill, tick your rating as GOOD, FAIR or POOR. Record any comments or recommendations in the right-hand column; be prepared to share comments with the participant. Use this checklist to complete the final evaluation for each participant. **Participant instructions:** Complete this checklist during the practicum with your assessment of your own performance. In the “Comment” column, record areas for improvement or further study.

**Name of Participant:** \_\_\_\_\_ **Dates of Practicum:** \_\_\_\_\_

**Name of Preceptor(s):** \_\_\_\_\_ **Name of Health Facility:** \_\_\_\_\_

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Clinical care of ALHIV skills				
Observes at least 1 baseline clinical assessment				
Observes at least 1 follow-up clinical assessment				
Conducts at least 1 baseline medical and social history				
Conducts at least 1 interval medical and social history				
Demonstrates familiarity with national HIV guidelines — identifies criteria for ART initiation, failure, and prophylaxis in adolescents				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Assesses growth and nutrition (weight, height) for at least 1 client				
Assesses WHO clinical stage of at least 1 client				
Performs at least 1 general physical examination on each of the following: 1. Pre-pubertal female 2. Pre-pubertal male 3. Post-pubertal female 4. Post-pubertal male				
Performs at least 1 SRH examination on each of the following: 1. Post-pubertal female 2. Post-pubertal male				
Prescribes CTX correctly to at least 1 eligible client				
Conducts at least 1 screening for tuberculosis				
Prescribes isoniazid preventive therapy (IPT) correctly to at least 1 eligible client				
Demonstrates knowledge of which laboratory tests to request and the timing of those requests				
<b>Communication and counselling skills</b>				
Effectively presents health education session/health talk to a group of clients or caregivers				
Ensures privacy and explains confidentiality to adolescent clients				
Uses active listening skills when speaking with adolescent clients				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Uses gestures and responses to show interest when talking with adolescent clients				
Uses open-ended questions when communicating with and counselling adolescent clients				
Empathizes with the adolescent client and shows understanding				
Avoids words that sound judging when communicating with adolescent clients				
Uses reflection skills during counselling sessions				
Summarises main points of a counselling session and help the adolescent client set goals				
Tailors counselling according to age and developmental stage of the adolescent				
<b>Psychosocial support for ALHIV</b>				
Conducts at least 1 psychosocial assessment and completes a Psychosocial Assessment form				
Suggests positive and practical ways to cope when a client expresses psychosocial concerns				
Offers practical suggestions to clients to cope with and fight stigma and discrimination				
<b>Mental health and ALHIV</b>				
Screens for mental health well being during routine check-up				
Identifies serious mental health problems and provides support or refers appropriately, using suggested guidance or algorithms				
Gives practical support to ALHIV who are experiencing mild mental health problems, such as mild anxiety or				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
sadness				
<b>Disclosure support</b>				
Assesses caregiver's readiness for disclosure to child and counsels caregiver on the importance of disclosure				
Conducts at least 1 disclosure support session with caregiver on disclosing to the child/adolescent				
Conducts at least 1 disclosure support session with ALHIV on disclosing his or her status to others				
Offers follow-up disclosure support to adolescent clients and caregivers through the disclosure process				
<b>Adherence support</b>				
Explains the importance of adherence to adolescent clients in understandable terms				
Conducts at least 1 ART readiness assessment with adolescent who is starting ART and caregiver				
Conducts all 3 of the standard adherence preparation visits (1 time each) with adolescent and/or caregiver				
Provides individualised counselling to make an adherence plan with client and caregiver				
Provides follow-up adherence support and counselling to at least 1 client on ART and to at least 1 caregiver whose child is on ART.				
<b>Positive living</b>				
Provides accurate, age-appropriate, and comprehensive positive living counselling to ALHIV				
Provides accurate information and counselling on positive prevention				



CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Provides nutrition counselling and support to at least 1 client				
Provides accurate information and counselling on personal and home hygiene to clients and caregivers				
Asks clients about alcohol and drug use and provides accurate risk reduction counselling				
<b>Sexual and reproductive health</b>				
Provides non-judgemental counselling about adolescent sexuality and SRH issues				
Conducts an SRH risk assessment and provides non-judgemental, accurate sexual risk reduction counselling				
Provides accurate, non-judgemental counselling and information on ways to practise safer sex				
Provides condoms to clients and accurately demonstrates male and female condom use				
Provides adolescent-friendly STI counselling, screening, and treatment for male and female clients				
Provides accurate, non-judgemental counselling on safe childbearing				
Provides accurate, non-judgemental contraceptive counselling and supplies (and/or referrals)				
Provides accurate, non-judgmental PMTCT counselling and services				
Provides PMTCT counselling and information; refers pregnant ALHIV for PMTCT services				
<b>Community linkages</b>				
Understands how to establish linkages with other agencies, including community-based organisations				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Provides appropriate referrals to clients and follows-up on those referrals				
<b>Transition to adult care</b>				
Provides counselling and support to ALHIV to prepare them for taking on a greater role in their self-care in preparation for transitioning to adult care				
<b>Monitoring and evaluation</b>				
Correctly completes essential registers and forms				
Understands how monitoring data can be used to identify strengths and weaknesses of services				

**FINAL EVALUATION BY PRECEPTORS:**

**Name of participant:** \_\_\_\_\_

**Tick one:**

\_\_\_\_ Demonstrated a majority of core competencies effectively and is ready to start providing adolescent HIV care and treatment services in a clinical setting

\_\_\_\_ Demonstrated some core competencies effectively, but still needs more practice before providing adolescent HIV care and treatment services in a clinical setting

\_\_\_\_ Unable to demonstrate most skills and should participate in the training course again before providing adolescent HIV care and treatment services in a clinical setting

**Additional comments:**

**Preceptor(s) signature(s):** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Date:** \_\_\_\_\_



## Module 15

### Action Planning, Course Evaluation, and Closure

**Session 15.1: Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning**

**Session 15.2: Reflection on Training Objectives and Concerns, Expectations, and Strengths**

**Session 15.3: Post-test, Training Evaluation, and Closing**

#### Learning Objectives

**After completing this module, participants will be able to:**

- Have reviewed the key steps and considerations to initiate or scale-up of adolescent HIV care and treatment services.
- Have started development of a site-specific action plan to initiate or improve adolescent HIV care and treatment services.
- Have identified the potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to those challenges.
- Have discussed whether or not the training objectives have been achieved.
- Have reflected on the concerns, expectations, and strengths discussed on the first training day.
- Have listed next steps, including training follow up and supportive supervision.
- Have completed the training post-test.
- Have evaluated the training and given suggestions for improvement.

## **Session 15.1      Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning**

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### **Session Objectives**

**After completing this session, participants will:**

- Have reviewed the key steps and considerations to initiate or scale-up of adolescent HIV care and treatment services.
- Have started development of a site-specific action plan to initiate or improve adolescent HIV care and treatment services.
- Have identified the potential challenges to implementing adolescent HIV care and treatment services at their site and potential solutions to those challenges.

### **Key Steps to Initiate or Scale-up Adolescent HIV Care and Treatment Services**

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As you have learned during this training, there are many different aspects involved in the successful provision of HIV care, treatment, and support services for adolescent clients. As you begin to think about how to initiate, integrate, or scale-up adolescent services at your facilities, it is important to keep all of these factors in mind.

As you know from Module 2, there are many things healthcare workers, health facility managers, and youth can do to improve the youth-friendliness of comprehensive HIV care and treatment services. Sometimes, even the smallest adjustments or changes can help — without creating additional workload, or incurring additional costs. Here are some suggestions:

- Conduct a needs assessment of adolescent services currently provided at the health facility. These may be located within a paediatric HIV clinic or in the adult clinic. Do not forget to involve young people in this assessment to ensure their views and opinions are reflected. See Module 2 for more information. The needs assessment should identify existing gaps or problems, based on what you know about the characteristics of a youth-friendly clinic.
- Develop a measurable action plan to prioritise activities that will fill gaps and solve problems. Each action item should have a timeline and the people responsible should be clearly documented. The action plan should also document any other resource needed. Remember, making services youth-friendly does not have to cost a lot of money. Work with what you have!
- Present the action plan to managers, healthcare workers, and youth that will be involved in the programme and regularly revisit the action plan

to see what progress has been made and where adjustments are needed.

It is important to remember that setting up youth-friendly HIV care and treatment services is the start – but quality, evidence-based HIV care must be provided within the context of YFS in order to meet the needs of ALHIV.

## Characteristics of Youth-Friendly Services

Recall from Module 2 the discussion of youth-friendly services. The point was made at that time that in order to serve ALHIV with HIV prevention, care, treatment, support and related health services, clinics and programmes must be able to attract, meet the needs of, and retain clients. The clinics that are most likely to attract and retain adolescent clients are those that are youth-friendly. The key characteristics of youth-friendly services, whether they are for HIV, reproductive health, or other types of care are summarised in Table 15.1, below.

**Table 15.1: Characteristics of youth-friendly services**

Healthcare worker characteristics	Health facility characteristics	Programme design characteristics
<ul style="list-style-type: none"> <li>• Specially trained/oriented staff*</li> <li>• All staff display respect for youth</li> <li>• Privacy and confidentiality</li> <li>• Enough time for healthcare worker-client interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Separate space for young people</li> <li>• Special times when young people can receive services</li> <li>• Convenient hours</li> <li>• Convenient location</li> <li>• Adequate space and privacy</li> <li>• Comfortable, youth-friendly surroundings</li> <li>• Availability of Peer Educators</li> </ul>	<ul style="list-style-type: none"> <li>• Youth involvement in programme design and monitoring</li> <li>• Drop-in clients welcomed</li> <li>• Short waiting times</li> <li>• Set up to provide chronic disease management, including multiple appointments and medications</li> <li>• Appointment systems in place and tracking systems for clients who miss appointments</li> <li>• Affordable or no fees for services</li> <li>• Publicity, marketing or recruitment materials that inform and reassure youth</li> <li>• Friendly to both male and female clients</li> <li>• Wide range of services available — “one-stop shopping”</li> <li>• Referrals available to clinical and community-based services</li> <li>• Youth-friendly educational materials available to take away</li> <li>• Youth support groups</li> <li>• Peer educators available</li> </ul>
<p>* Including training in the following areas:</p> <ul style="list-style-type: none"> <li>• Clinical HIV care for adolescents</li> <li>• How to build trust with and counsel adolescents</li> <li>• Providing psychosocial support to adolescents</li> <li>• Mental health assessment, counselling, and referrals</li> <li>• Disclosure counselling</li> <li>• Adherence counselling</li> <li>• Positive living counselling</li> <li>• Sexual and reproductive health counselling and services</li> <li>• Preparing adolescents for the transition to adult care</li> </ul>		

Source: Senderowitz, J., Solter, C., & Hainsworth, G. 2004. *Comprehensive Reproductive Health and Family Planning Training Curriculum. 16: Reproductive Health Services for Adolescents*. Watertown, MA: Pathfinder International.

<b>Exercise 1: Action Planning: Small group work and large group discussion</b>	
<b>Purpose</b>	<ul style="list-style-type: none"> <li>To create an action plan to initiate or improve adolescent HIV care, treatment, and support services at their individual facilities</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>Participants will be asked to break into small groups so that healthcare workers from the same facilities are grouped together.</li> <li>Participants should refer to the “Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services” from Exercise 2 in Module 2 (Appendix 2B). Participants may want to use this as a starting point for the exercise. Participants should also refer to “Table 2.2: Making services more youth-friendly” for a fuller explanation of the categories listed in the column on the far left.</li> <li>Ask each group to spend about 60 minutes discussing and filling in “Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template”, thinking about what they want to achieve in the next 6 months.</li> <li>Note that participants should also talk about likely challenges to implementing the action items, and potential solutions to each. There is space to record these potential challenges on the action planning matrix.</li> <li>Each group should draw a star next to the top 5 priority actions. When presenting to the large group, each of the small groups should focus on the priority items from their action plan.</li> </ol>

## **Session 15.2      Reflection on Training Objectives and Concerns, Expectations, and Strengths**

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### **Session Objectives**

**After completing this session, participants will:**

- Have discussed whether or not the training objectives have been achieved.
- Have reflected on the concerns, expectations, and strengths discussed on the first training day.
- Have listed next steps, including training follow up and supportive supervision.

### **Adolescent HIV Care and Treatment Training Objectives**

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By the end of this training, participants will be able to:

1. Understand how adolescence differs from childhood and adulthood, and how to ensure HIV-related services are tailored to the special needs of adolescents (youth-friendly).
2. Define the package of HIV-related care and treatment for adolescents.
3. Discuss how to establish trust and rapport with adolescent clients using effective counselling skills.
4. Conduct a psychosocial assessment and provide psychosocial support services to adolescent clients.
5. Screen for major symptoms related to persistent mental illness in adolescents.
6. Provide developmentally appropriate disclosure counselling and support to adolescents and, where appropriate, their caregivers or partners.
7. Identify common barriers to adherence and provide age-appropriate support to prepare adolescent clients and caregivers for adherence and to support adherence to care and medicines over time.
8. Support adolescents to live positively and attain key life skills.
9. Conduct sexual risk screening and sexual risk reduction counselling with adolescent clients as a component of sexual health services.
10. List the contraceptive choices available to ALHIV.
11. Provide an overview of PMTCT services for adolescents living with HIV.
12. Actively link adolescents with facility and community-based support services.
13. Prepare and support adolescents through the transition to adult care.
14. Discuss how information from monitoring and evaluation can be used to support programme improvement.
15. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting.
16. Develop a site-specific action plan for implementing adolescent HIV care and treatment services.



## Session 15.3 Post-test, Training Evaluation, and Closing

### Session Objectives

**After completing this session, participants will:**

- Have completed the training post-test.
- Have evaluated the training and given suggestions for improvement.

### Training post-test

- Participants will have about 20 minutes to complete the post-test, which can be found in “Appendix 15B: Post-test”. The post-test contains the same questions as the pre-test, which participants took in Module 1.
- Participants should record the same number at the top of the post-test as was written at the top of their pre-tests.
- Tests will be scored and then compared to the pre-test results. Changes in scores from the beginning to the end of the training will reflect the group’s (not an individual’s) knowledge gain from the beginning to the end of the course. The results will provide some indication of whether the material and teaching methods have been successful.
- The test answers will be reviewed after the post-tests are collected.

### Exercise 2: Training Evaluation: Individual work

<b>Purpose</b>	<ul style="list-style-type: none"> <li>• To get participants’ feedback on the training.</li> </ul>
<b>Instruction</b>	<ol style="list-style-type: none"> <li>1. Participants will have 10–15 minutes to complete the training evaluation form, which they can find in “Appendix 15C: Training Evaluation Form”. Participants need not write their name or position on the form if they do not want to, but that it is helpful to provide the name of their facility if they feel comfortable doing so.</li> <li>2. When completing the 2nd section “How helpful were each of the training modules to you and your work? If you have specific comments, please write them on the next page”, participants should feel free to refer to their Participant Manuals as a way of refreshing their memory on the content of each of the modules.</li> </ol>

## Appendix 15A: Adolescent HIV Care and Treatment Action Planning and Implementation Template

Category	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
<b>Conduct a needs assessment of adolescent HIV services currently provided</b>	1.				
	2.				
	3.				
<b>Provide training/ orientation to staff and volunteers</b>	1.				
	2.				
	3.				
<b>Make the health</b>	1.				

<b>facility more friendly to adolescent clients</b>					
	2.				
	3.				
<b>Involve youth in programme design and service delivery</b>	1.				
	2.				
	3.				
<b>Improve the quality of adolescent clinical care and treatment services</b>	1.				
	2.				
	3.				
<b>Provide “one-</b>	1.				

<b>stop shopping” to adolescent clients</b>					
	2.				
	3.				
<b>Develop and/or improve appointment and tracking systems</b>	1.				
	2.				
	3.				
<b>Develop peer support programmes and support groups for ALHIV</b>	1.				
	2.				
	3.				

<b>Develop strong referral systems and establish linkages</b>	1.				
	2.				
	3.				
<b>Develop and implement data collection, reporting, monitoring, and evaluation systems</b>	1.				
	2.				
	3.				

**Anticipated challenges to implementing the adolescent HIV care and treatment action plan and possible solutions**

Anticipated Challenge	Possible Solution(s)
1.	
2.	
3.	
4.	
5.	



## Appendix 15B: Post-test

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Participant identification number: \_\_\_\_\_ Score: \_\_\_\_/25

- 1) Which of the following statements are factors in the scale up of adolescent HIV care and treatment services in Zambia? *(select all that apply)*
  - a) Young people are no more vulnerable to HIV than adults.
  - b) Youth living with HIV face unique health, adherence, and psychosocial issues and challenges.
  - c) Healthcare workers need specific knowledge and skills to meet the needs of adolescent clients.
  - d) Programmes and clinical services need to be youth-friendly to attract and retain adolescent clients
  
- 2) Which of the following are characteristics of “youth-friendly” services? *(select all that apply)*
  - a) Special times that allow young people to receive services
  - b) Services are provided anonymously.
  - c) Healthcare workers are friendly to both male and female clients
  - d) Clinic services are affordable or available for no fees
  - e) Healthcare workers create services without the input of adolescents
  
- 3) To be effective, the adolescent package of care must ensure: *(select all that apply)*
  - a) Integration of services
  - b) That services are age and developmentally appropriate
  - c) That the needs of both perinatally infected adolescents, as well as those infected later in childhood or adolescence
  - d) That services are empowering, in other words, they encourage adolescents to take responsibility for their own health
  - e) That the adolescent client receives care in the paediatric clinic for life
  
- 4) The key clinical components of care for ALHIV differ greatly from care of adults.
  - a) True
  - b) False
  
- 5) Adolescent clients should be started on ART when their CD4 cell count is:
  - a) Less than 200
  - b) Less than 250
  - c) Less than 300
  - d) Less than 350
  - e) None of the above



- 6) CD4 cell count should be monitored how frequently?
- a) Every 12 months; but 6 monthly as CD4 count approaches threshold (to initiate ART)
  - b) Every 9 months; but 4 monthly as CD4 count approaches threshold
  - c) Every 6 months; but 3 monthly as CD4 count approaches threshold
  - d) Every 4 months; but 2 monthly as CD4 count approaches threshold
  - e) Every 2 months; but monthly as CD4 count approaches threshold
- 7) Healthcare workers can use the 5 “A’s” when providing clinical and psychosocial care and support to clients. What are the 5 “A’s”?
- a) Assess, admire, agree, ask, arrange
  - b) Analyze, advise, agree, ask, arrange
  - c) Assess, advise, agree, assist, arrange
  - d) Assess, advise, assert, ask, arrange
  - e) Awake, advise, agree, ask, arrange
- 8) Counselling includes which of the following? *(select all that apply)*
- a) Solving another person’s problems
  - b) Helping people to make informed decisions
  - c) Telling another person what to do
  - d) Respecting everyone’s needs, values, culture, religion, and lifestyle
  - e) Keeping good records
- 9) Family-centred care means that healthcare workers can talk openly with caregivers about any information shared between the adolescent and healthcare workers.
- a) True
  - b) False
- 10) Which of the following are coping strategies that healthcare workers should suggest to clients and caregivers to help them reduce stress and promote psychosocial well-being? *(select all that apply)*
- a) Talk with a Peer Educator
  - b) Join a support group
  - c) Exercise
  - d) Disclose HIV status to all people in the community
  - e) Change your environment and take a walk
- 11) Adolescence is a unique stage of life that is characterised by:
- a) Challenging caregivers or elders
  - b) Focus on body image
  - c) Sense of immortality
  - d) Significant physical, emotional, and mental changes
  - e) All of the above
- 12) Which of the following are signs or symptoms of depression? *(select all that apply)*
- a) Hopelessness
  - b) Shaking and sweating

- c) Really tired with no energy
  - d) Heart pounding fast
  - e) Do not enjoy the things you used to (loss of interest or pleasure)
  - f) Sleep too much or not enough
  - g) Cannot eat or eat too much
  - h) Cannot breathe or shortness of breath
- 13) Disclosure is a one-time event, rather than an ongoing process.
- a) True
  - b) False
- 14) The process of disclosing HIV status to an adolescent with HIV should include discussion of the following:
- a) The diagnosis, the infection and disease process, and health changes that could occur.
  - b) Strategies to prolong a healthy life (in particular adherence to ART) and responsibilities now and in the future.
  - c) How to cope with the possible negative reactions of others.
  - d) A and C
  - e) All of the above
- 15) The Zambia “Adult and Adolescent Antiretroviral Therapy Protocols, 2010” recommends a minimum of 3 adherence preparation visits, as part of a structured treatment preparation plan prior to initiating ART.
- a) True
  - b) False
- 16) The only reliable way to assess client adherence is with pill counts.
- a) True
  - b) False
- 17) What is positive prevention? *(select all that apply)*
- a) Partner disclosure and testing
  - b) Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
  - c) Sexual risk reduction and sexual health
  - d) Prevention and treatment of STIs
  - e) Bathing regularly
  - f) PMTCT
  - g) Prevention of blood-borne HIV transmission, including transmission through injecting drug use, sharing sharp instruments to cut or pierce the skin.

- 18) What questions would you ask to screen for alcohol dependency?  
(select all that apply)
- a) Have you ever felt that you should cut down on your drinking?
  - b) Have people annoyed you by criticising your drinking?
  - c) Have you ever found it difficult to wake up for school or work?
  - d) Have you ever felt bad or guilty about your drinking?
  - e) Have you ever experienced rapid heartbeat after drinking?
  - f) Have you ever had an eye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?
- 19) Which of the following statements is correct?
- a) Healthcare workers need to stress that only heterosexual behaviour is NORMAL
  - b) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is NORMAL
  - c) Healthcare workers need to stress that homosexual, bisexual, and transsexual/transgendered behaviour is ABNORMAL
  - d) Healthcare workers need to stress that transsexual/transgendered should not be tolerated
- 20) The following sexual activities are considered **high** risk for transmitting HIV: (select all that apply)
- a) Unprotected (no male or female condom) anal or vaginal intercourse
  - b) Sharing sexual toys (rubber penis, vibrators) without cleaning them
  - c) Using a male or female latex condom for every act of sexual intercourse (penis in vagina, penis in anus, penis in mouth, etc.)
  - d) Mutual masturbation
  - e) Oral sex without a latex barrier
- 21) The adolescent female genital tract is more biologically susceptible to STIs than that of older women.
- a) True
  - b) False
- 22) What advice would you give an ALHIV who wanted to get pregnant?  
(select all that apply)
- a) It is safest to wait until adulthood to become pregnant
  - b) Do not eat eggs while pregnant
  - c) Talk to your provider and ask for his/her advice
  - d) Make sure you do not have any opportunistic infections
  - e) Make sure you are adhering to your ART regimen

- 23) Which of the following are good family planning options for ALHIV? *(select all that apply)*
- a) Condoms
  - b) Combined oral contraceptive pills (COCs), progestin-only oral contraceptive pills
  - c) Spermicides and diaphragms with spermicides
  - d) Male and female sterilisation
  - e) Hormonal implants
- 24) In reference to transitioning to adult care, which of the following statements is true? *(select all that apply)*
- a) Clients should be transitioned to adult care by 18 years of age
  - b) In preparing to transition, the healthcare worker should support the adolescent to develop self-care and self-advocacy skills
  - c) In preparation to transition, adolescents should visit and tour the adult clinic
  - d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure they adherence to their ART regimen
- 25) Which of the following are examples of indicators? *(select all that apply)*
- a) Number of adolescents who initiated ART
  - b) Number of adolescents currently receiving ART
  - c) To ensure that 95% of eligible adolescent clients initiate ART.
  - d) To ensure that at least 120 new clients initiate ART in the next 3 months
  - e) To ensure loss to follow up is no more than 5%





## Appendix 15C: Training Evaluation Form

Name (optional): \_\_\_\_\_



Your position (optional): \_\_\_\_\_

Health facility where you work (optional): \_\_\_\_\_

**INSTRUCTIONS:** Please rate the following statements on a scale of 1 to 5.

	 Strongly Disagree	Disagree	Neither agree nor disagree	Agree	 Strongly Agree
1. The training objectives were clear.	1	2	3	4	5
2. This training met my expectations.	1	2	3	4	5
3. The technical level of this training was appropriate.	1	2	3	4	5
4. The pace of this training was appropriate.	1	2	3	4	5
5. The facilitators were engaging and informative.	1	2	3	4	5
6. The information I learned in this training will be useful to my work.	1	2	3	4	5
7. I am confident that after this training, my facility will be able to provide HIV-related care, treatment, and support services to adolescents.	1	2	3	4	5

How helpful were each of the training modules to you and your work? If you have specific comments, please write them on the next page.

	 Not helpful				 Very helpful
Module 1: Introduction and Course Overview	1	2	3	4	5
Module 2: The Nature of Adolescence and Provision of Youth-Friendly Services	1	2	3	4	5
Module 3: Clinical Care for Adolescents Living with HIV	1	2	3	4	5
Module 4: Communicating with and Counselling Adolescents	1	2	3	4	5
Module 5: Providing Psychosocial Support Services for Adolescents	1	2	3	4	5
Module 6: Adolescents, HIV, and Mental Health	1	2	3	4	5
Module 7: Providing Disclosure Counselling and Support	1	2	3	4	5
Module 8: Supporting Adolescent's Retention in, and Adherence to, HIV Care and Treatment	1	2	3	4	5
Module 9: Positive Living for Adolescents	1	2	3	4	5
Module 10: Sexual and Reproductive Health Services for Adolescents	1	2	3	4	5

## PARTICIPANT MANUAL

Module 11: Community Linkages and Adolescent Involvement	1	2	3	4	5
Module 12: Supporting the Transition to Adult Care	1	2	3	4	5
Module 13: Monitoring, Evaluation, Quality Assurance, and Supportive Supervision	1	2	3	4	5
Module 14: Supervised Clinical Practicum	1	2	3	4	5
Module 15: Action Planning, Course Evaluation, and Closure	1	2	3	4	5

**What was the best part of this training?**

**How can we improve this training?**

**Other comments:**

**Thank you for your participation, and for your commitment to adolescents and families in Zambia!**

