ADOLESCENT HIV CARE AND TREATMENT

A Training Curriculum for Health Workers

Participant Manual

2012

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Foreword

"Give young people a greater voice. They are the future and they are much wiser than we give them credit for."
- Archbishop Desmond Tutu

Thinking back to the turn of the century, it was unimaginable that the global pediatric HIV epidemic would be so dramatically transformed over the course of a single decade. Images of severely ill, malnourished infants filling hospital wards remain vivid depictions of the most dramatic manifestations of this infection in pediatric populations. However, with the success of the global scale-up of HIV prevention and treatment services, a new paradigm for pediatric HIV is emerging, representing a slow shift from a fatal infection threatening the lives of infants and young children to a manageable, chronic disease affecting adolescents and young adults.

Multiple factors have contributed to this remarkable transformation. Effective antiretroviral treatment (ART) has enabled increasingly large numbers of children with perinatal HIV infection to survive the vulnerable periods of infancy and early childhood. In addition, the scale up of prevention of mother-to-child transmission (PMTCT) services has resulted in more women being reached with ever-more potent antiretroviral regimens and a reduced number of babies being born with HIV infection. Finally, improved access to testing has facilitated the identification of older children and adolescents with perinatal infection, as well as those with behaviorally acquired disease. By 2009, there were an estimated 4.3 to 5.9 million youth aged 15-24 years living with HIV and, currently, an estimated 2,500 new infections occur among youth each day. These figures reflect not only the successful treatment of those with perinatal infection, but also the existing (and growing) HIV burden among youth.

As the number of adolescents (defined as those aged 10-19 years) with HIV increases, doctors, nurses, program managers, parents, caregivers, and communities are beginning to recognize the distinct health, psychological, and social needs of this population. Adolescents living with HIV face considerable challenges and have unique needs and vulnerabilities, as compared with both young children and adults. As a result, questions are rapidly emerging as to how best to address these needs while also ensuring successful treatment, long-term retention, and optimal outcomes during the complex and often difficult transition from childhood to adulthood. Programs are responding by incorporating attributes of youth-friendly services into HIV care, including reproductive and sexual health care, peer-based activities, mental health and psychosocial support services, and other features appealing to young people, such as flexible clinic hours, specific clinic times for adolescents, and the availability of drop-in services. At the same time, health workers — who often play critical roles in the lives of young people — are anxious to enhance their skills to ensure that they are well-equipped to provide optimal health care services to the growing population of adolescents living with HIV.

This training package was developed with health workers in mind and aims to support them in meeting the evolving needs of adolescents with HIV infection. The materials cover a broad range of subjects, including youth-friendly services, HIV clinical care, counseling, psychosocial support, mental health, adherence and disclosure support, sexual and reproductive health, the transition to adult care, and monitoring and evaluation. The curriculum was built with the understanding that services for adolescents must be youth-friendly, comprehensive (including biomedical and psychosocial care and support), multidisciplinary, and integrated to include as many different services and providers under one roof as possible. Adolescent HIV care services should aim to become the medical home for adolescents living with HIV, and health workers should be able to attend to the broad set of needs that are likely to emerge when providing services to this population. Central to the philosophy of this curriculum is the premise that health workers need to interact with adolescents, both as individuals with unique needs, wants, and hopes for the future, and as parts of families, peer groups, and communities.

In developing this training package, the authors relied on lessons learned by centers of excellence, public health programs, and individuals in the United States and Africa, specifically the Family Care Center in Harlem, New York and the University Teaching Hospital's Department of Paediatrics HIV Centre of Excellence (PCOE), and Dr. Chipepo Kankasa in Lusaka, Zambia. We pilot tested portions of the curriculum at the Centre Hospitalier Universitaire de Kigali (CHUK) Pediatric Center of Excellence in Kigali, Rwanda and are forever indebted to the staff of ICAP-Rwanda, RBC/TRAC-Plus, and the Centre Hospitalier Universitaire de Butare (CHUB) for both their attendance during the pilot sessions and their feedback on our training methods and course content. Additionally, this training package borrowed from other areas of public health that have successfully engaged young people, in particular sexual and reproductive health and HIV prevention programs.

Providing comprehensive adolescent HIV services depends on a commitment to scaling up medical and psychosocial services that meet the unique needs of adolescents, as well as continuously improving the knowledge and skills of health workers so they are equipped to address the specific needs of clients. *Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers* represents a key step in ensuring the rollout of HIV-related services that truly serve the needs of adolescents living with HIV.

I am hopeful that this training package will help individuals, multidisciplinary health care teams, agencies, governments, and organizations in their efforts to provide high-quality health services to adolescents living with HIV, and that these materials will help all of us engage, listen to, learn from, and support adolescents as they travel down the path from childhood to adulthood.

"Guard your light and protect it. Move it forward into the world and be fully confident that if we connect light to light to light, and join the lights together of the one billion young people in our world today, we will be enough to set our whole planet aglow." -Hafsat Abiola

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Between 2010 and early 2011, ICAP at Columbia University's Mailman School of Public Health developed *Adolescent HIV Care and Treatment: A Training Curriculum for Multidisciplinary Healthcare Teams* with the Ministry of Health in Zambia. Subsequently, in mid-2011, Dr. Elaine Abrams responded to increasing interest and focus on adolescents in ICAP country programs and initiated a process to revise the Zambia training package into this generic curriculum. The principle aim was to facilitate easy adaptation of the curriculum by any country or program wishing to establish or improve adolescent HIV services.

ICAP would like to acknowledge a number of contributors to this generic adolescent HIV care and treatment training package, including independent consultant Tayla Colton and ICAP team members Anne Schoeneborn, Dr. Beatriz Thome, Dr. Ruby Fayorsey, Dr. Francine Cournos, Dr. Rosalind Carter, Leah Westra, and Tesmerelna Atsbeha. ICAP would also like to thank the François-Xavier Bagnoud (FXB) Center, School of Nursing, University of Medicine and Dentistry of New Jersey for their contributions to the original and generic training packages, including Virginia Allread, Beth Hurley, Aliya Jiwani, Karen Forgash, Deborah Hunte, Anne Reilly, and Mary Jo Hoyt. Thanks also go to Petra Röhr-Rouendaal for the illustrations used throughout these materials.

Several modules of this generic curriculum were piloted in Kigali, Rwanda in December 2011 at the Centre Hospitalier Universitaire de Kigali (CHUK). ICAP would like to thank the following people for their assistance with this pilot activity, their inputs into the materials, and their active participation in and co-facilitation of this first adolescent HIV care and treatment training held in Rwanda — from ICAP-Rwanda: Dr. Veronicah Mugisha, Dr. Tene Gilbert, Odette Mukansoro, and Didine Munezero; from ICAP-Rwanda/CHUK: Dr. Jean Leonard Hakizimana, Beata Sangwayire, Angeline Ingabire, and Verdiane Umutesi; from Rwanda Biomedical Center (RBC)/TRAC *Plus* Clinic: Sister Marie Josee Maliboli, Malanie Muhizi, and Chantal Umurungi; from Centre Hospitalier Universitaire de Butare (CHUB): Pascasie Mukeshimana and Elisabeth Mukankaka; and special thanks to our three adolescent co-trainers for their active participation in the training and invaluable inputs: Elyse Igihozo, Diane Uwimana, and Romeo Manzi.

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Acronyms

3TC	Lamivudine
ABC	Abacavir
ADHD	Attention deficit hyperactivity disorder
AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescent(s) living with HIV
ALT	Alaninaminotransferase, a liver enzyme
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
ATV/r	Atazanavir/ritonavir
AZT	Zidovudine
BMI	Body mass index
CAB	Client/consumer/community advisory board
CD4	T-lymphocyte CD4 cell count
CHUB	Centre Hospitalier Universitaire de Butare
CHUK	Centre Hospitalier Universitaire de Kigali
COCs	Combined oral contraceptives
CTX	Cotrimoxazole
d4T	Stavudine
ddI	Didanosine
DOT	Directly observed therapy
ECP	Emergency contraceptive pills
EFV	Efavirenz
ETV	Etravirine
FTC	Emtricitabine
HBsAg	Hepatitis B surface antigen
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
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	Lopinavir/ritonavir
M&E	Monitoring and evaluation
MDR TB	Multi-drug resistant tuberculosis
MTCT	Mother-to-child transmission (of HIV)
NGO	Non-governmental organization
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OI	Opportunistic infection
PEP	Post-exposure prophylaxis
PI	Protease inhibitor
PITC	Provider-initiated HIV testing and counseling
PLHIV	Person (or people) living with HIV
PMTCT	Prevention of mother-to-child transmission (of HIV)
POPs	Progestin-only oral contraceptive pills
QA	Quality assurance
QI	Quality improvement
sdNVP	Single-dose nevirapine

SGBV	Sexual and gender-based violence
SMS	Short message service
SOCs	Standards of care
SOP	Standard operating procedure
SQV/r	Saquinavir/ritonavir
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
TB	Tuberculosis
TDF	Tenofovir
TST	Tuberculin skin test
TWG	Technical Working Group
VCT	Voluntary counseling and testing
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization
XDR TB	Extremely drug-resistant tuberculosis

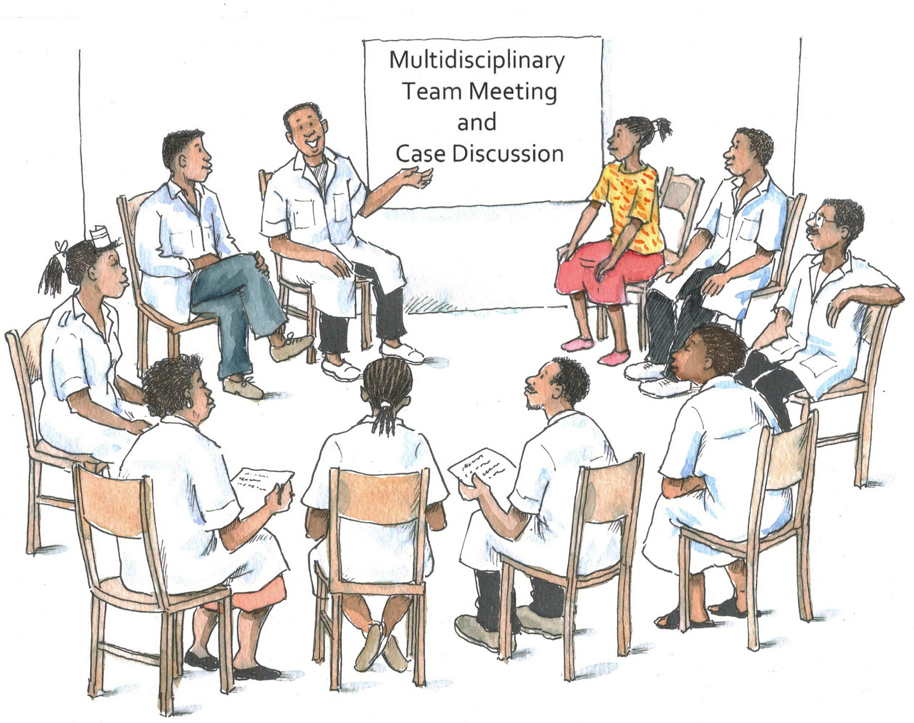
Module 1 Introduction and Course Overview

Session 1.1:	**Welcome and Introductory Activity**
Session 1.2:	**Training Objectives and Ground Rules**
Session 1.3:	**Training Pre-Test**
Session 1.4:	**Values Clarification**

Learning Objectives

After completing this module, participants will:

- Know more about the trainers and other training participants, and will have discussed expectations for the training
- Be able to explain the importance of a training specific to adolescent HIV care and treatment
- Understand the training objectives
- 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

Session Objective

After completing this session, participants will:

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

Exercise 1: Getting to Know Each Other: Large group discussion and individual reflection	
Purpose	• To provide an opportunity to get to know one another a bit better • To create a comfortable learning environment • To introduce and understand the role of the adolescent co-trainer/co-trainers (optional) • To discuss participants' personal and professional strengths, their concerns about adolescent HIV care and treatment, and their expectations for the training
This exercise consists of 3 parts: • Part 1: Introductions • Part 2: Individual Reflection • Part 3: Large Group Discussion	

Session 1.2 Training Objectives and Ground Rules

Session Objectives

After completing this session, participants will:

- Be able to explain the importance of a training specific to adolescent HIV care and treatment
- Understand the training objectives
- Have set training "ground rules"

Key Facts about Adolescents and HIV[1, 2]

Global epidemiology

- In 2009, 41% of all new HIV infections (in people aged 15 and over) were among youth 15–24 years of age.
- 2 million adolescents aged 10–19 years are living with HIV (1.5 million of whom reside in sub-Saharan Africa).
- Slightly more than half of all people living with HIV are women or girls. In sub-Saharan Africa, young women aged 15–24 years are 8 times more likely than men to be HIV positive.
- Globally, deaths among children under 15 years of age are declining. An estimated 260,000 children died from AIDS-related illnesses in 2009 — this is approximately 19% fewer deaths than occurred in 2004. This trend reflects the steady expansion of PMTCT services and an increase in access to antiretroviral treatment for children.

Global knowledge and behavior

According to UNAIDS (2010):

- Among young people in 15 of the most severely affected countries, HIV prevalence has recently fallen by more than 25%. This decline is due to:
  - Increased adoption of safer sexual practices, including increased condom use
  - Delayed sexual debut
  - Reductions in multiple partnerships.
- Less than half of young people living in 15 of the 25 countries with the highest HIV prevalence can correctly answer 5 basic questions about HIV and its transmission.*
- Young people aged 15–24 years who live in the 25 countries with the highest HIV prevalence have shown gradually improving knowledge about HIV, but they still fall short of global targets and what is necessary to keep them safe.

* These countries include: Botswana, Burundi, Cameroon, Central African Republic, Chad, Congo, Côte d'Ivoire, Guinea-Bissau, Kenya, Malawi, Nigeria, South Africa, Togo, Tanzania, and Zambia.

Why a Training on Adolescent HIV Care and Treatment?

- Young people are at the center of the HIV epidemic. They are particularly vulnerable to HIV infection due to social, political, cultural, biological, and economic reasons.[3]
- With increased access to pediatric 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. In addition, more adolescents who are pregnant are being tested for HIV through PMTCT programs.
- ALHIV face unique health, adherence, and psychosocial issues and challenges.
- Programs and clinical services need to be youth-friendly to attract and retain adolescent clients.
- There are successful models of adolescent HIV care and treatment services in many cities across high-, medium-, and low-prevalence countries. These models can be adapted and scaled-up nationally.
- Health 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

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

1. Describe the stages and characteristics of adolescence and the unique needs and challenges of adolescent clients
2. Implement strategies to make HIV-related services youth-friendly
3. Define and implement the package of HIV-related care and treatment services for adolescents
4. Implement effective communication and counseling skills with adolescent clients
5. Conduct a psychosocial assessment and provide ongoing psychosocial support services to adolescent clients
6. Describe the importance of mental health services for adolescent clients, recognize when a mental health problem may exist, and provide appropriate referrals and support
7. Recognize the signs of and be able to screen for alcohol and substance use disorders among adolescents, and provide support and referrals
8. Provide developmentally-appropriate disclosure counseling and support to adolescents and, where appropriate, their caregivers
9. Provide developmentally-appropriate adherence preparation and ongoing adherence support to adolescent clients and caregivers
10. Support adolescents to live positively with HIV
11. Conduct sexual risk screening and provide non-judgmental, comprehensive counseling on sexual and reproductive health to adolescent clients
12. Provide basic, non-judgmental contraceptive counseling and services to adolescent clients
13. Describe the key components of PMTCT services for adolescents and provide referrals and support along the continuum of PMTCT care
14. Describe ways of linking adolescents with needed facility and community-based support services
15. Describe and implement activities to meaningfully involve adolescent clients in clinical services, such as through adolescent peer education programs
16. Prepare and support adolescent clients throughout the transition to adult care

17. Describe how monitoring and evaluation can be used to support adolescent HIV program improvements
18. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting
19. Develop a site-specific action plan for implementing adolescent HIV care and treatment services

Adolescent HIV Care and Treatment Core Competencies

The "core competencies" are the skills that participants are expected to have mastered by the end of the training (they are listed in *Appendix 15B: Practicum Checklist)*. They differ from the objectives (listed in the previous section) in that core competencies focus on specific skills, whereas objectives are sweeping statements that provide a summary of what is to be taught. There are 19 objectives for this course and approximately 60 competencies.

Training Syllabus and Agenda

The training includes 16 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 the Provision of Youth-Friendly Services
- Module 3: Clinical Care for Adolescents Living with HIV
- Module 4: Communicating with and Counseling Adolescents
- Module 5: Providing Psychosocial Support Services for Adolescents
- Module 6: Adolescents, HIV, and Mental Illness
- Module 7: Providing Disclosure Counseling 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: Family Planning and PMTCT Services for Adolescents
- Module 12: Community Linkages and Adolescent Involvement
- Module 13: Supporting the Transition to Adult Care
- Module 14: Monitoring, Evaluation, and Quality Improvement
- Module 15: Supervised Clinical Practicum
- Module 16: Action Planning, Course Evaluation, and Closure

Exercise 2: Setting Ground Rules and Introducing Daily Activities: Large group discussion	
Purpose	• To develop and agree on a set of ground rules that will create an environment that facilitates learning • To introduce the *“Anonymous Question Bowl”* as a safe space for asking questions • To introduce the “*Morning Rounds”* as a way to start each day of the training off on the right foot • To introduce the *“How Did it Go”* daily evaluation activity as a way of giving feedback to the trainers so they can make adjustments DURING the training course
This exercise consists of 3 parts: • Part 1: Develop and Agree on Ground Rules • Part 2: Introduction of the “*Anonymous Question Bowl”* • Part 3: Introduction of the *“Morning Rounds”* • Part 4: Introduction of the Daily Evaluation — *“How Did it Go?”*	

Session 1.3 Training Pre-Test

Session Objective

After completing this session, participants will:

- Have completed the training pre-test

See *Appendix 1B: Pre-Test.*

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	
Purpose	To help participants begin to think about their own values, attitudes, and prejudices, as well as how these might either positively or negatively impact their work with adolescents
The trainer will read a series of statements out loud. After each statement is read, move to the “agree” or “disagree” sign, based on your opinion. If you are not sure whether you agree or disagree with a statement, you can stand somewhere in-between the 2 signs.	

Appendix 1A: Sample Training Agenda

As this curriculum is modular, the training agenda is flexible. Although the curriculum can be completed in 10 consecutive days, it is recommended that the content be taught over a longer period of time. This is preferable because it allows participants to apply what they have learned and to bring those lessons back to the classroom. Teaching the content over a longer period of time also minimizes disruptions to clinical services.

For example:

- Training could be conducted on 2 or 3 Fridays per month for 4 months, or on 2-3 consecutive days each month for 4-5 months (see sample agenda that follows).
- Alternatively, the training could be conducted 1 module at a time over a period of 15 half-days; for example, every other Friday morning for 30 weeks.

If training modules/days are split up over a period of time, it is recommended that the practical sessions in the clinic also be integrated into each phase of training so participants have opportunities to practice what they have learned shortly after the classroom sessions.

Month A

Day 1	
Morning Session	• Official Opening • Module 1: Introduction and Course Overview (2.5 hours)
LUNCH	
Afternoon Session	• Module 2: The Nature of Adolescence and the Provision of Youth-Friendly Services (3 hours, 20 minutes) • "*How Did it Go?*"
Day 2	
Morning Session	• Recap and "*Morning Rounds*" • Module 3: Clinical Care for Adolescents Living with HIV (4 hours, 30 minutes)
LUNCH	
Afternoon Session	• Module 3 (continued) • Prepare for clinical practicum • "*How Did it Go?*"
Practicum Session: 1-3 days (practical sessions should be planned based on the availability of participants and preceptors, and the days and times when adolescents receive services)	
Morning Session	• Recap and "*Morning Rounds*" • Clinical practicum, covering knowledge and skills in Modules 1-3
LUNCH	
Afternoon Session	• Debrief on clinical practicum • "*How Did it Go?*"

Month B

Day 1	
Morning Session	- Introductions (if there are any new participants), recap, and "*Morning Rounds"* - Discussion of lessons learned since we last met - Module 4: Communicating with and Counseling Adolescents (4 hours, 15 minutes)
LUNCH	
Afternoon Session	- Module 4 (continued) - Module 5: Providing Psychosocial Support Services for Adolescents (3 hours, 35 minutes) - "*How Did it Go?*"
Day 2	
Morning Session	- Recap and *"Morning Rounds"* - Module 6: Adolescents, HIV, and Mental Illness (3 hours, 30 minutes)
LUNCH	
Afternoon Session	- Module 7: Providing Disclosure Counseling and Support (3 hours, 50 minutes) - Prepare for clinical practicum - "*How Did it Go?*"
Practicum Session: 1-3 days (practical sessions should be planned based on the availability of participants and preceptors, and the days and times when adolescents receive services)	
Morning Session	- Recap and "*Morning Rounds"* - Clinical practicum, covering knowledge and skills in Modules 4-7
LUNCH	
Afternoon Session	- Debrief on clinical practicum - "*How Did it Go?*"

Month C

Day 1	
Morning Session	- Introductions (if there are any new participants), recap, and "*Morning Rounds"* - Discussion of lessons learned since we last met - Module 8: Supporting Adolescents' Retention in and Adherence to HIV Care and Treatment (4 hours, 10 minutes)
LUNCH	
Afternoon Session	- Module 8 (continued) - Module 9: Positive Living for Adolescents (3 hours, 15 minutes) - *"How Did it Go?*"

Day 2	
Morning Session	• Recap and "*Morning Rounds*" • Module 10: Sexual and Reproductive Health Services for Adolescents (4 hours, 30 minutes)
LUNCH	
Afternoon Session	• Module 10 (continued) • Module 11: Family Planning and PMTCT Services for Adolescents (2 hours 35 minutes) • Prepare for clinical practicum • *"How Did it Go?"*
Practicum Session: 1-3 days (practical sessions should be planned based on the availability of participants and preceptors, and the days and times when adolescents receive services)	
Morning Session	• Recap and "*Morning Rounds*" • Clinical practicum, covering knowledge and skills in Modules 8-11
LUNCH	
Afternoon Session	• Debrief on clinical practicum • *"How Did it Go?"*

Month D

Day 1	
Morning Session	• Introduction (if there are any new participants) and recap • Discussion of lessons learned since we last met • Module 12: Community Linkages and Adolescent Involvement (2 hours, 45 minutes)
LUNCH	
Afternoon Session	• Module 13: Supporting the Transition to Adult Care (1 hours, 40 minutes) • *"How Did it Go?"*
Day 2	
Morning Session	• Module 14: Monitoring, Evaluation, and Quality Improvement (2 hours, 15 minutes)
LUNCH	
Afternoon Session	• Module 15: Supervised Clinical Practicum (2–2.5 days) • *"How Did it Go?"*
Practicum Session: 1-3 days (practical sessions should be planned based on the availability of participants and preceptors, and the days and times when adolescents receive services)	
Morning Session	• Recap and "*Morning Rounds*" • Clinical practicum, covering knowledge and skills in Modules 12-14 (or all modules if practical sessions have not been incorporated throughout the training so far)
LUNCH	
Afternoon Session	• Debrief on clinical practicum • Module 16: Action Planning, Course Evaluation, and Closure (3 hours, 10 minutes)

Appendix 1B: Pre-Test

Participant identification number: ____________________ **Score:** ____/25

1) Which of the following statements are factors to be considered in the scale up of adolescent HIV care and treatment services? (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) Health workers need specific knowledge and skills to meet the needs of adolescent clients.
   d) Programs and clinical services need to be youth-friendly to attract and retain adolescent clients.

2) Adolescence is a unique stage of life that is characterized by:
   a) Challenging caregivers or elders
   b) A focus on body image
   c) A sense of immortality
   d) Significant physical, emotional, and mental changes
   e) All of the above

3) Which of the following are characteristics of "youth-friendly" services? (select all that apply)
   a) There are special days/times set aside for young people to receive services.
   b) Young clients can only come to the clinic when they have a scheduled appointment.
   c) Young people are involved in designing and monitoring programs.
   d) Multiple services are available in one clinic, known as "one-stop shopping."
   e) Health workers mainly use group counseling sessions in order to save time.

4) To be effective, the adolescent package of care must ensure: (select all that apply)
   a) The integration of services
   b) That services are age- and developmentally-appropriate
   c) That the needs of both perinatally infected adolescents and those infected later in childhood or adolescence are met
   d) That services encourage adolescents to take responsibility for their own health
   e) That adolescent clients receive care in the pediatric clinic for life

5) The adolescent package of HIV care closely resembles the package of HIV care for adults; however, the way services are delivered can impact their success among adolescents.
   a) True
   b) False

6) Adolescent clients should be started on ART when their CD4 cell count is:
   a) 200 or less
   b) 250 or less
   c) 300 or less
   d) 350 or less
   e) None of the above

7) How frequently should CD4 cell count be monitored in adolescent clients?
   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

8) Counseling includes which of the following? (select all that apply)
   a) Solving another person's problems
   b) Helping another person make informed decisions
   c) Telling another person what to do
   d) Respecting everyone's needs, values, culture, religion, and lifestyle
   e) Recording key points of the counseling session in the client's clinic file

9) Family-focused care means that health workers can talk openly with caregivers about any information shared by the adolescent client.
   a) True
   b) False

10) Which of the following are coping strategies that health workers should suggest to adolescent clients to help them reduce stress and promote their psychosocial well being? (select all that apply)
   a) Talking with a Peer Educator
   b) Joining a support group
   c) Exercising
   d) Disclosing their HIV-status to all of their friends
   e) Participating in recreational activities, like sports or youth clubs

11) Which of the following statements about mental illness are correct? (select all that apply)
   a) Mental health problems are very rare among adolescents living with HIV.
   b) Mental illness and substance abuse are closely related.
   c) Only trained psychologists and psychiatrists can recognize the signs of possible mental illness in adolescents.
   d) Adolescents are susceptible to depression, anxiety disorders, behavioral disorders, and alcohol/substance use disorders.
   e) All clinics should have standard procedures on how to manage adolescent clients with possible or confirmed mental illness.

12) Disclosure to a child or adolescent is a one-time event for which the caregiver must be well-prepared.
   a) True
   b) False

13) Which of the following statements about disclosure are true? (select all that apply)
   a) Health workers can work with caregivers to develop and implement a disclosure plan; they can also play a supportive role throughout the disclosure process.
   b) Research shows that disclosing a child/young adolescent's HIV-status often results in psychological problems, emotional harm, and difficulties with adherence.
   c) There are times when health workers may need to facilitate disclosure discussions with children/young adolescents.
   d) It is recommended that children/young adolescents be fully disclosed to when they are developmentally ready — typically by the time they are 10–12 years old.
   e) Health workers should encourage older adolescents not to disclose to their friends because they may face stigma and discrimination.

14) Adherence preparation and ART initiation can usually be completed in 1 visit.
   a) True
   b) False

15) The only reliable way to assess client adherence is with pill counts.
   a) True
   b) False

16) Positive prevention includes which of the following? (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
   d) Prevention and treatment of STIs
   e) Washing hands and bathing regularly
   f) Preventing mother-to-child transmission (PMTCT)

17) Which of the following statements is correct?
   a) Health workers need to stress that ONLY heterosexual behavior is normal.
   b) Health workers should understand different sexual behaviors and sexual orientations and talk openly and non-judgmentally about them with clients.
   c) Health workers need to stress that homosexual and bisexual behavior is abnormal.
   d) Health workers need to stress that transsexual/transgendered behavior should not be tolerated.

18) 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) Using a latex condom during every act of vaginal or anal intercourse
   c) French/deep kissing
   d) Mutual masturbation
   e) Oral sex without a latex barrier

19) The adolescent female genital tract is less susceptible to STIs than that of adult women.
   a) True
   b) False

20) What advice would you give an adolescent client living with HIV who wants to get pregnant? (select all that apply)
   a) It is safest to wait until adulthood to become pregnant.
   b) There are many health, psychological, social, and economical risks of adolescent pregnancy.
   c) Stop having sex because it is dangerous for you and your partner.
   d) It is important to continue to talk with health workers to know the facts and risks about getting pregnant and to understand the facts about PMTCT services.
   e) Switch to or start taking efavirenz before trying to become pregnant.
   f) Make sure you (and your partner, if HIV-infected) are adhering to your ART regimen and have a CD4 count over 500 before trying to get pregnant.

21) Which of the following are usually good contraceptive options for adolescents living with HIV? (select all that apply)
   a) Male and female condoms
   b) Oral contraceptive pills
   c) Spermicides and diaphragms with spermicides
   d) Male and female sterilization
   e) Injectable contraceptives
   f) Hormonal implants

22) Which of the following statements are true? (select all that apply)
   a) Dual protection and dual method use mean the same thing.
   b) Condoms provide dual protection.
   c) Dual protection refers to the practice of taking ART and cotrimoxazole.
   d) Dual method use should be recommended for sexually active adolescents. This means they use condoms and another method of contraception (such as oral or injectable contraceptives).

23) In reference to transitioning to adult care, which of the following statements is true? (select all that apply)
   a) All adolescent clients should be ready to transition to adult care by age 16.
   b) In helping prepare an adolescent to transition, the health worker should support him or her to develop self-care and self-advocacy skills.
   c) In preparation for transition, adolescents should visit and tour the adult HIV clinic.
   d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure that they adhere to their ART regimen.

24) Which of the following statements about adolescent involvement are true? (select all that apply)
   a) Adolescent peer education programs and community advisory boards are useful mechanisms to involve adolescents in services.
   b) Adolescent peer educators can take on the same responsibilities as adult peer educators.
   c) Adolescent peer educators can help create a safe clinic environment, improve adherence and positive living among clients, and improve service quality.
   d) Asking adolescents to help with clinic filing and cleaning are examples of meaningful involvement.
   e) It is important to have a clear training and supervision plan in adolescent peer educator programs.

25) Which of the following are examples of indicators? (select all that apply)
   a) Number of adolescents who initiated ART in the quarter
   b) Percentage of adolescent clients lost to follow-up in the year
   c) To ensure that 95% of eligible adolescent clients initiate ART this year
   d) All adolescent clients should be screened for TB at enrollment
   e) % of adolescent clients screened for TB at enrollment in the quarter

References

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[1] Joint United Nations Programme on HIV/AIDS (UNAIDS) (2010). *UNAIDS report on the global AIDS epidemic, 2010.*

[2] UNICEF. (2011). *Opportunity in crisis: Preventing HIV from early adolescence to young adulthood.* Available at: www.unicef.org/media/files/OiC_FactSheet.pdf

[3] United Nations Population Fund. *Young people: The greatest hope for turning the tide.* Available at: http://www.unfpa.org/hiv/people.htm

Module 2 The Nature of Adolescence and the Provision of Youth-Friendly Services

Session 2.1:	**Stages and Changes of Adolescence**
Session 2.2:	**Adolescent Vulnerabilities, Risk-Taking Behaviors, 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 ALHIV 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 as well as 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

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 ALHIV are different from children and adults living with HIV
- Discuss the ways in which adolescents are a heterogeneous group

Who Are We Talking About?

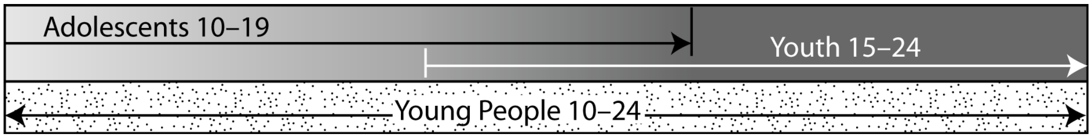
Who are we referring to when we talk about "adolescents?" In general, the term "adolescent" refers to people in their second decade of life, meaning those between the ages of 10 and 19 years. Other commonly used terms are "youth" and "young people." These terms have slightly different definitions (see 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

Focus of this training

Figure 2.1: Young people (age 10–24 years) includes the overlapping categories of "Youth" and "Adolescents"



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

There are a number of <u>physical and sexual changes</u> that occur during adolescence.

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

In both females and males:
- Accelerated growth
- Increased perspiration
- The presence of acne
- Face has characteristics of young adult
- Change in tone of voice
- Sexual desire activated
- Initiation of sexual activities

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

The system used most frequently to categorize these physical and sexual changes in girls and boys is referred to as the "Tanner staging system" (see *Appendix 2A: Tanner Staging System)*. The first stage represents the pre-pubertal child and the final stage represents the "mature" or adult stage. The Tanner staging system can be used to determine maturity when deciding whether an adolescent should receive an adult or pediatric ARV dosing, as discussed in the next module.

There are also a number of <u>psychological and emotional changes</u> that occur during adolescence:[1]
- Mood swings
- Insecurities, fears, and doubts
- Behavioral expressions of emotion, which may include withdrawal, hostility, impulsiveness, and 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
- A need to feel autonomous and independent

The Stages of Adolescent Development

Adolescence can be categorized 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 may not yet be capable of abstract thinking (a characteristic of early adolescence). Another adolescent may appear small and stunted, but may demonstrate advanced intellectual or psychological 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)
GROWTH OF BODY	• Secondary sexual characteristics appear • Rapid growth reaches a peak	• Has advanced secondary sexual characteristics • Growth slows down; reaches approximately 95% of adult size	• Physically mature
COGNITION (ability to get knowledge through different ways of thinking)	• Thinks in concrete terms (i.e. the "here and now") • Does not understand how actions affect future	• Thinking can be more abstract (theoretical) but goes back to concrete thinking when under stress • Better understands long-term results of own actions	• Abstract thinking now established • Plans for the future • Understands how current choices and decisions have an effect on the future
PSYCHO-LOGICAL AND SOCIAL	• Worries about rapid physical growth and body image • Has frequent mood changes	• Has established body image • Thinks about fantasies or impossible dreams • Feels very powerful • May experiment with sex, drugs, friends, risks	• Plans and follows long-term goals • Has established sense of identity (who he or she is)
FAMILY	• Still defining comfort with independence/ dependence	• Has conflicts with authority figures	• Is moving from a child-parent/ guardian relationship to more adult-adult relationships
PEERS	• Peers very important for development • Has intense friendships with same sex • Has contact with opposite sex in groups	• Has strong peer friendships that help affirm self-image • Peer groups define right and wrong	• Decisions/values less influenced by peers and more influenced by individual friendships • Selection of partner based on individual choice rather than on what others think
SEXUALITY	• Focus is on self-exploration and evaluation	• Has preoccupation with romantic fantasy • Tests how he or she can attract others • Sexual drives emerging	• Forms stable relationships • Has mutual and balanced sexual relations • Is more able to manage close and long-term sexual relationships • Plans for the future

Sources:
WHO. (2003). *Orientation programme on adolescent health for health-care providers.* Geneva, Switzerland: WHO Press.
WHO. (2010). *IMAI one-day orientation on adolescents living with HIV.* Geneva, Switzerland: WHO Press.

Effects of HIV Infection on the Changes of Adolescence[2]

Growth:
HIV affects growth in adolescents who are perinatally infected with HIV. The following section is not meant to pertain to ALHIV who were infected as adolescents, as they have typically already reached their adult height by the time they are diagnosed with HIV. Even in perinatally infected children, the physical effects of HIV may be minimized through the use of effective ART.

- If HIV disease is fairly advanced, an adolescent may experience delays in physical development, including delays in 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 yet 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 self-image and may also affect how other people view the adolescent (e.g. as sick and younger than his or her actual age).
- ALHIV may experience drug-related side effects, including those that change physical appearance, like lipodystrophy (changes in fat distribution on the body).

Cognition:

- Adolescents perinatally infected with HIV may experience neurological consequences of longstanding HIV infection. The result may be developmental delays and learning problems.

Psychological and social effects:

- ALHIV are very likely to experience emotional difficulties. These difficulties may not necessarily be due to health status, but rather to the pressures of life and a history of loss (including the loss of parents and home).
- Illness may prevent ALHIV from going to school regularly, from making friends, and from learning sports and hobbies. Due to illness, ALHIV may miss out on activities that help define adolescents' identities.[3]
- HIV can bring with it concerns about prognosis; body image; stigma and isolation; fear of disclosure; and having to take multiple medications. These concerns may affect ALHIV's mental health and their sense of fitting in with peers.
- Many ALHIV live with either one or neither birth parent. Although they may be living with extended family, in some cases these adolescents may not feel "attached" or like they are a part of their adopted home. This can lead to a sense of isolation or a sense that "nobody loves them."

Peers:

- ALHIV may experience peer problems, which can be exacerbated by the stigma associated with HIV.
- ALHIV may have to regularly miss school to attend clinic appointments. This may impact their educational attainment and their sense of fitting in with peers.
- In some places, few ALHIV attend school. This suggests that the school environment is not supportive of ALHIV's needs, which further alienates them from their school-attending peers.[4]
- If adolescents feel different from their peers, they have a harder time bonding with them. This can have an adverse effect on the attachments of ALHIV, making it difficult for them to separate from their parents or caregivers.

No Longer Children, Not Yet Adults[5]

There are a number of characteristics that distinguish adolescents from both children and adults. As these are generalizations or even stereotypes, however, they are not applicable to every adolescent client. Distinguishing characteristics of adolescents may include:

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

HIV prevention, care, treatment, and support services need to be tailored to meet the needs and characteristics of adolescent clients. Services that are tailored in this way are referred to as "youth-friendly services" and are discussed further in Session 2.3.

Exercise 1: Adolescents: Not Big Children or Little Adults: Small group work and large group discussion	
Purpose	• To understand some of the important things health workers should consider about the special needs of adolescent clients • To understand how and why adolescents are a heterogeneous (diverse) group and what implications this has for their care
While working in small groups, participants will be asked to discuss 1 of the following questions: • *What are some of the special characteristics of adolescents that health workers need to consider when providing them with HIV care and treatment?* • *How and why do the needs of adolescent clients differ from those of pediatric and adult clients?* • *Adolescents are a heterogeneous/diverse group. What are some of the differences health workers may see among different adolescent clients? What are the implications of these differences for their HIV care?*	

Special Considerations for Adolescent Clients[2]

Adherence to medicines:

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

(Adherence to medications is discussed further in Module 8.)

Adherence to care:

- Adolescent clients often have less disciplined or structured lives than adults. They may also have less stable relationships outside of the family. These factors make adherence to care and treatment more difficult.
- Adolescent clients are more likely than adults to lack the skills to negotiate health services and to understand side effects, treatment options, and regimen requirements.
- Outreach is more difficult with 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 become lost in the system when in transition from pediatric to adult HIV services. (Transition is discussed further in Module 13.)

(Adherence to care is discussed further in Module 8.)

Stigma and discrimination:

- Blame is often placed on adolescents living with HIV (especially those who acquire HIV behaviorally) because of an assumption that they were infected after voluntarily engaging in "risky behavior." This blame — often misplaced and always oversimplified — results in stigma and discrimination.
- The stigma and discrimination associated with HIV prevents many adolescents from disclosing their HIV-status. This may be a particular issue when adolescents decide to become involved in a sexual relationship.

(Stigma and discrimination is discussed further in Module 5.)

Counseling adolescents:

- Adolescents' cognitive abilities and skills are different from adults. They require both different counseling approaches and, in many cases, more extensive and intensive counseling 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 can therefore not always make independent decisions.
- Adolescent clients have a range of future decisions to make, like whether to have children, whether to get married, etc.
- Adolescents face strong peer pressure and tend to be dependent on peers for lifestyle guidance.

(Counseling is discussed further in Module 4.)

Safer sex:

- Adolescents may not understand risk-taking behavior or the importance of risk reduction. This makes them vulnerable to unintended pregnancy and sexually transmitted infections (STIs).
- There is a widespread belief that adolescents living with HIV are "not supposed" to be having sex. As a result, they often hide their sexuality.
- Adolescents may have limited access to condoms and other contraceptives. Even when they do have access to contraceptives, they may lack the skills to use them correctly and/or negotiate their use.
  - For young women living with HIV, gender inequality may further reduce their ability to negotiate condom use.

(Safer sex is discussed further in Module 10.)

How Adolescents Differ from One Another

Adolescents are a heterogeneous group. By definition, they range in age from 10 to 19 years. The personality and expectations of a person who is 10 years old is very different from that of a 19-year-old, even though both are adolescents.

Adolescents differ according to their stage of development; gender; sexual orientation; home and family situation; and educational level. Some come from well-off families, others come from poor families; some are from urban areas while others are from rural areas. Some adolescents are in a relationship, some are married, and others have yet to have a romantic relationship. Some adolescents know their HIV-status while others do not; some have never experienced stigma or discrimination while others may face it every day.

Health workers need to assess each adolescent client's care, treatment, and support needs. They must also ensure that the adolescent's care and treatment plan is tailored to meet these unique needs. In particular, counseling and education need to "meet the adolescent where he or she is."

(Sexual orientation is discussed further in Module 10.)

Session 2.2 Adolescent Vulnerabilities, Risk-Taking Behaviors, and Their Consequences

Session Objectives

After completing this session, participants will be able to:

- Discuss risk-taking as a normal part of adolescence as well as the consequences of negative risk-taking
- Discuss some of the vulnerabilities faced by adolescents

Risk-Taking As a Normal Part of Growing up

Risk-taking is simply part of an adolescent's struggle to test out an identity that provides self-definition and separation from others, including the adolescent's caregivers. Adolescents must attain social autonomy during their second decade of life and this often involves moving away from dependence on their family. As the influence of their family decreases, new social relationships — especially with peers — begin to gain greater importance. Adolescents' peers often influence their risk-taking.

Risk-taking can be healthy or unhealthy. Healthy-risk taking provides important opportunities for growth, whereas unhealthy risk-taking involves activities that are dangerous.

- Healthy risk-taking includes participating in sports, developing artistic and creative abilities, traveling, making new friends, and contributing constructively to one's family or community.
- Curiosity, sexual maturity, a natural inclination toward experimentation, and peer pressure can lead to unhealthy or negative risk-taking (risk-taking that can be dangerous). This includes drinking, smoking, using drugs, driving recklessly, unsafe sexual activity, self-mutilation, running away, and stealing.
- A sense of powerfulness, feelings of invulnerability, and impulsiveness can lead to a lack of future planning and can compromise protective behavior.
- Sometimes, unhealthy risk-taking is caused by a lack of knowledge about life's risks. For example, adolescents may know little about STIs, may find it difficult to use condoms consistently and correctly, or may lack communication and negotiation skills. As a result, they may not use condoms during sex.
- In some cultures, young men are encouraged to take risks as a way of proving their masculinity.

Health workers should:

- Encourage and help adolescents to find healthy risks, which may prevent unhealthy risk-taking.
- Help adolescents evaluate risks, anticipate the consequences of their choices, and develop strategies for diverting their energy into healthier activities when necessary.
- Share lessons learned from their own histories of risk-taking and experimenting.
- Advise adolescents to seek additional help if they are:
  - Experiencing psychological problems (such as persistent depression or anxiety that goes beyond more typical adolescent "moodiness")
  - Having problems at school
  - Engaging in illegal activities

(Psychosocial support and mental health issues are discussed further in Modules 5 and 6.)

Types and Consequences of Unhealthy Risk-Taking Behavior[1,2,6]

Unhealthy risk-taking can result in:

- Poor adherence to ART or HIV care and treatment, resulting in a drop in CD4 count, disease progression, opportunistic infections (OIs), a greater chance of passing HIV to sexual partners, and drug-resistance
- Unprotected sex, resulting in putting partners at risk of HIV infection and resulting in a risk of unwanted pregnancy, unsafe abortion, and contracting STIs (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 judgment and adherence; poor medication adherence will cause a decline in immune-system function.
  - Alcohol use can suppress the immune system, can lead to increased susceptibility to opportunistic infections, and can compromise the body's response to AZT.[2]
  - Many illicit drugs, including nicotine, can reduce the functioning of the immune system, which may strengthen the virus.[2]
  - For adolescents on ART, substance use and abuse can adversely interact with HIV medications, causing illness.[2]
  - Like many ARVs, illegal substances are often processed through the liver. Combining illegal substances with ARVs can lengthen the time that illegal substances stay in the bloodstream, thus increasing toxicity and the chance of overdose.[2]
  - Alcohol reduces inhibitions and affects decision-making. Alcohol can also cloud people's judgment and give them the "courage" to do things they 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 who drink heavily were more likely to have unprotected sex, to have multiple partners, and to pay for sex with money or other resources. [6] Intergenerational sex was also strongly associated with heavy drinking.

  (Substance abuse is discussed further in Module 9).

Physical Vulnerabilities[1,7]

- Young people are more vulnerable to STIs than adults for many reasons (see next section).
    - Young women are particularly susceptible to STIs because the cells that line the inside of the normal adolescent cervical canal are more vulnerable to infections than the cells that line the mature cervical canal of an adult.
    - The prevention and early treatment of STIs in people living with HIV is important to reduce the risk of both STI and HIV transmission to sexual partners (and babies), as well as to prevent the long-term health consequences of STIs.
- 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 and caloric deficiencies, due to the increased energy demands that HIV imposes on the body.
- HIV can contribute to compromised physical and psychological development, including stunting and slower than normal growth.

Social, Psychological, and Emotional Vulnerabilities[1]

- Psychological factors that put many adolescents at increased risk of physical harm (e.g. of having an automobile accident or getting an STI) include a general sense of invulnerability, the desire to try new things (including drugs and alcohol), and a willingness to take risks (e.g. having unsafe sex, changing sexual partners often, or having a partner who has multiple partners).
- Adolescents may be living in family situations where there is little social and material/ financial support.
- Mental health problems can increase during adolescence, due to the hormonal and other physical changes of puberty and changes in adolescents' social environment. (Mental health issues of ALHIV are discussed further in Module 6.)
- Adolescents often lack assertiveness and good communication skills, which can make 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.
- Often, there are unequal power dynamics between adolescents and adults (adults may still view adolescents as children).
    - Adolescents are more vulnerable than adults to sexual, physical, and verbal abuse because they are less able to prevent these shows of power.
- Adolescents may lack the maturity to make good, rational decisions.

Socioeconomic Vulnerabilities[1]

- 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 hardship can increase health risks, particularly if accompanied by poor sanitation, lack of clean water, or an inability to afford/access health care and medications.
- Adolescents are more likely to experiment with drugs and alcohol, and disadvantaged adolescents are at greater risk of substance abuse.
- Young women often 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 recognized when she marries and has a child. Some young women marry very young to escape poverty and, as a result, may find themselves in yet another challenging situation.
- Many young people are at risk due to other socioeconomic and political reasons. These especially vulnerable youth include street children, sex workers, child laborers, refugees, young criminals, those orphaned because of AIDS or 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

Health worker characteristics	Health facility characteristics	Program design characteristics
• Specially trained/oriented staff* • All staff display respect for youth • All staff maintain privacy and confidentiality • Enough time for health worker-client interaction	• Separate space for young people • Special times when young people can receive services • Convenient hours • Convenient location • Adequate space and privacy • Comfortable, youth-friendly surroundings • Peer Educators available	• Youth involvement in program design and monitoring • Drop-in clients welcomed • Short waiting times • Set up to provide chronic disease management, including multiple appointments and medications • Appointment systems in place as well as tracking systems for clients who miss appointments • Affordable rates or no fees for services • Publicity, marketing, or recruitment materials that inform and reassure youth • Friendly to both male and female clients • Wide range of services available —“1-stop shopping” • Referrals available to clinical and community-based services • Youth-friendly educational materials available to take away • Youth support groups • Peer Educators available
* Including training in the following areas: • Clinical HIV care for adolescents • How to build trust with and counsel adolescents • Providing psychosocial support to adolescents • Mental health assessment, counseling, and referrals • Disclosure counseling • Adherence counseling • Positive living counseling • Sexual and reproductive health counseling and services • Preparing adolescents for the transition to adult care		

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.

Organizing Youth-Friendly Services

There are many things health 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 necessarily creating additional workload or incurring any additional costs. A step-by-step guide for making services more youth-friendly is provided in Table 2.4. In addition, a sample of a client satisfaction survey for youth is provided in *Appendix 2C*. Please note that the topics of program modification and quality improvement will be discussed further in Module 14.

Table 2.4: Making services more youth-friendly

Step	How
Assess clinic needs: figure out what needs to be done to make services more youth-friendly.	• Conduct an assessment using a tool such as the one included in *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services*. • **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 come back and what could be done to make the clinic more youth-friendly. • **Ask parents** what could make services more welcoming for their children. • **Ask colleagues** what needs to change in order to ensure that services are accessible and meet the needs of young people. • Review national or local reports on the topic or review manuals from other clinics or programs to find out what others have done to attract and retain young people. • Visit a neighboring clinic that has been very successful in welcoming youth.
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 for that activity.	• Based on interviews and research done 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 is rude, one of the areas for improvement might be: "Ensure that receptionist makes clients feel welcome." Then suggest ways to address this need; for example, by providing one-to-one training and support for the current receptionist, by relieving the receptionist of other duties so that he or she can focus solely on welcoming clients, by recruiting a new receptionist, etc. Be sure to include the date by which this activity should be completed and the person who is going to make it happen. (See Module 16 for a template.)
Identify the needed human and material resources.	• If an activity requires funds, identify the budget where these funds could come from. **Remember that making services youth-friendly does not need to be expensive.**

Step	How
Present the action plan to stakeholders.	• To gain general agreement and support for the action plan, first present it to the manager/supervisor. • Work with others in management to ensure that the needed support exists to implement the recommended changes. • The action plan may need to be revised several times to incorporate the suggestions of those in management and ensure their support. • Once management has approved the plan, present it to the health workers and youth that will be involved in the program.
Implement, monitor, and evaluate the planned activities.	• Start implementing the activities 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. • Six months to a year after implementation, evaluate: find out if the action plan has had an effect on the number of clients retained in care by comparing the present year's figures with those of the previous year.

Remember that setting up youth-friendly HIV care and treatment services is a start, but in order to really meet the needs of adolescent clients, **quality, evidence-based HIV care** must be provided within the context of youth-friendly services.

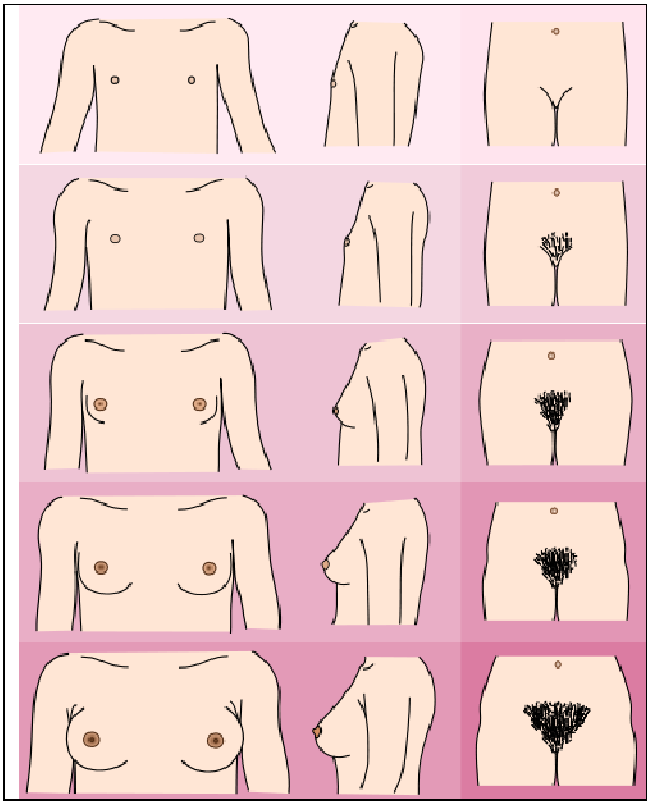
Exercise 2: Making Services Youth-Friendly: Small group work and large group discussion	
Purpose	• To learn more about the characteristics of youth-friendly HIV care and treatment services • To begin to assess gaps and challenges, and to start planning next steps for providing youth-friendly HIV care and treatment services at participants' health facilities
Refer to *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services* when working in small groups.	

Module 2: Key Points

- Adolescence, the years between the ages of 10 and 19, is characterized by rapid growth and development as well as significant psychological and emotional changes.
- During adolescence, social relationships move from being family-centered to being more peer- and community-centered. It is also a time when new skills and knowledge are acquired and new attitudes are formed.
- ALHIV may experience adolescence differently. Most notably, long-standing HIV infection and/or advanced HIV disease may affect ALHIV's expected physical and emotional development. Social development may be atypical as well, particularly if the adolescent has been ill for significant periods of time or if he or she has felt alienated from peers because of HIV-related discrimination or because he or she feels different from peers.
- As part of growing up, adolescents take risks. Risk-taking is the tool adolescents use to define and develop their identities. Healthy risk-taking is a valuable experience.
- Unhealthy risk-taking, however, can sometimes have lifelong consequences. For ALHIV, such consequences can include poor adherence to medications or the discontinuation of care. ALHIV may also take sexual risks, which can lead to the further spread of HIV.
- Health workers should remember the reasons that clients may be vulnerable as well as the ways these vulnerabilities relate to risk-taking behavior and their participation in and adherence to HIV care and treatment. An understanding of their adolescent clients' lives can help health workers work with ALHIV to transition safely into adulthood.
- In order to serve adolescent clients with HIV-related health services, clinics and programs must be able to attract, meet the needs of, and retain these clients.

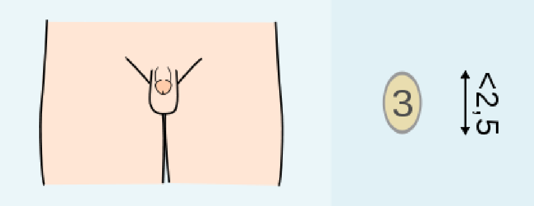
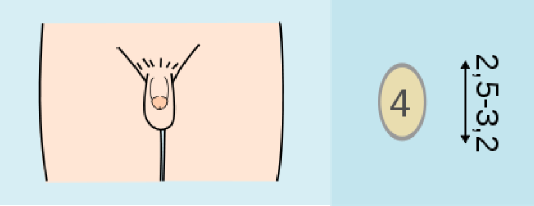
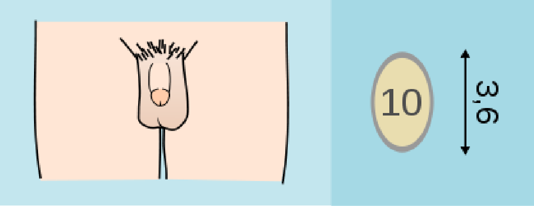
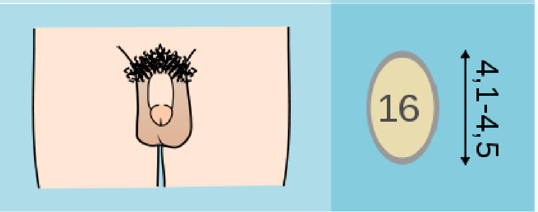
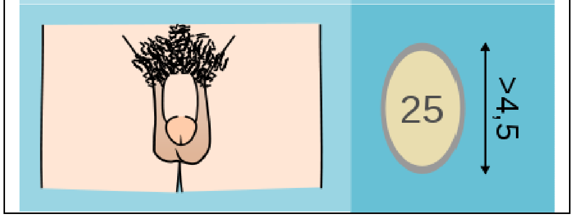
Appendix 2A: Tanner Staging System

Girls — breast and pubic hair development

Stage	Breast development	Pubic hair development	Description
1			Breasts: pre-pubertal, no breast tissue with flat areola. No pubic hair.
2			Breast budding with widening of the areola. Small amount of long hair at base of female labia majora.
3			Larger and more elevated breast extending beyond the areola. Pubic hair: moderate amount of curly and courser hair extending outwards.
4			Larger and more elevated breast; areola and nipple projecting from the breast contours. Pubic hair resembles adult hair but does not extend to inner surface of thigh.
5			Mature stage: breast is adult size with nipple projecting above areola. Pubic hair: adult type and quantity extending to the thigh surface.

Female Tanner staging image by Michał Komorniczak, medical illustrations. Poland.

Boys — development of external genitalia and pubic hair

Stage	Development of external genitalia and pubic hair*	Testicular volume in ml, length in cm	Description
1			Genitals: pre-pubertal, testes small in size with childlike penis. No hair.
2			Testes reddened, thinner, and larger (1.6–6cc) with childlike penis. Small amount of long hair at base of male scrotum.
3			Testes larger (6cc–12cc) and scrotum enlarging; increase in penile length. Moderate amount of curly and courser hair extending outwards.
4			Testes larger (12cc–20cc) with greater enlargement and darkening of the scrotum; increase in length and circumference of penis. Pubic hair resembles adult hair but does not extend to inner surface of thigh.
5			Testes over 20cc with adult scrotum and penis. Pubic hair: adult type and quantity extending to the thigh surface.
* Note that a circumcised penis is depicted here — an uncircumcised penis would look slightly different.			

Male Tanner staging image by Michal Komorniczak, medical illustrations. Poland.

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

Facility name: ________________________________ **Type of facility/clinic:** ________________________________

Questions to Assess Youth-Friendliness	Answer	Comments/Recommendations
Location		
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?		
Facility hours		
During what hours 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?		
Facility environment		
Does the facility provide a comfortable setting for young clients?		
Does the facility have a separate space to provide services to adolescent clients?		
Does the facility have a separate waiting area for adolescent clients?		
Is there a counseling 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 women welcomed and served at the clinic?		

Questions to Assess Youth-Friendliness	Answer	Comments/Recommendations
Staffing		
Are all health workers trained in pediatric HIV care and treatment?		
Are all health workers trained in adolescent HIV care and treatment?		
Have all staff members (including data clerks, pharmacists, receptionists, etc.) received orientation about adolescent services?		
Do health workers show respect for adolescent clients during counseling sessions and group sessions?		
Are there job aides available to help health workers in their daily work with adolescents?		
Services provided		
Is 1-stop shopping provided to adolescent clients? Describe.		
Are the following services provided to adolescent clients directly (note if through referral):		
• HIV testing and counseling		
• Comprehensive care, including the prevention and treatment of OIs		
• Malaria prophylaxis and treatment		
• ARVs/ART		
• Adherence preparation		
• Ongoing adherence assessment & counseling (at each visit)		
• Pregnancy testing, antenatal care, and PMTCT		
• Sexual and reproductive health counseling		
• Condoms and water-based lubricant		
• Contraception (which methods?)		
• STI screening and treatment		
• Positive prevention counseling		
• Psychosocial counseling and support		

Questions to Assess Youth-Friendliness	**Answer**	**Comments/Recommendations**
• Nutrition counseling		
• Laboratory tests (CD4, other HIV tests)		
• PEP, as per national guidelines		
Are there outreach services, especially targeting 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 counseling 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?		
Peer education and counseling		
Is a peer education program available?		
How many Peer Educators are working at the facility?		
How many hours/days per week do Peer Educators work 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?		
Educational activities		
Are educational/information materials available? 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 the materials?		

Questions to Assess Youth-Friendliness	Answer	Comments/Recommendations
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 (with younger adolescents)? Describe.		
Are adolescent support groups held (with older adolescents)? Describe.		
Are there ways for adolescent clients to access information or counseling off-site (via a hotline, etc.)?		
Youth involvement		
Are adolescents involved in decision-making about how programs and services are delivered?		
What ways are there for adolescents to give feedback to clinic staff?		
How could adolescents be more involved in decision-making at the facility?		
What other roles could adolescents play in clinic planning, operations, and evaluation?		
Supportive policies		
Do clear, written guidelines or standard operating procedures (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?		

Questions to Assess Youth-Friendliness	Answer	Comments/Recommendations
Are there policies or procedures that pose barriers to youth-friendly services?		
Administrative procedures		
Is the registration process private so that others cannot see or hear?		
Can adolescent clients be seen without an appointment?		
How long do adolescent clients normally have to wait?		
What is the average time allotted for client/health worker interaction?		
Publicity/recruitment		
Does the clinic publicize the services available to adolescents, stressing confidentiality?		
Are there staff or volunteers who do outreach activities? Describe.		
Fees		
Are adolescents charged for any services? If so, which ones and how much?		
If there are fees, are they affordable to adolescent clients?		
OTHER?		

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: Sample Client Satisfaction Survey for Youth

Clinic/Facility: ________________________
Lead physician or nurse *(if applicable):* __________________
Your name *(optional):* ______________________ Date: __________________

Please help us improve our services by answering some questions about the services you received.

We are interested in your honest opinion — whether positive or negative. Your answers will be kept confidential.

1. The staff at the clinic communicated clear information to me.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

2. People at the clinic included my opinions when making decisions.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

3. The staff at the clinic listened to me.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

4. The staff at the clinic involved my family/caregivers in my care.

1	2	3	4
More than I wanted	About the right amount	Less than I wanted	No involvement, which is what I wanted

5. I am satisfied with the progress I have made toward my treatment goals (taking medication/adherence, participating in psychosocial support activities, etc.)

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

6. The staff at the clinic worked well together.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

7. The staff at the clinic spent enough time with me.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

8. The staff at the clinic treated me with respect.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

9. The staff at the clinic gave me support.

1	2	3	4	5
Strongly Disagree	Disagree	Somewhat Agree	Agree	Strongly Agree

10. I would recommend this clinic/program to a friend who needed similar help.

1	2	3	4	5
Strongly Disagree	Disagree	Don’t Know	Agree	Strongly Agree

11. On a scale from 1-10, how would you rate the care you received?

1	2	3	4	5	6	7	8	9	10
WORST									BEST

12. Is there a staff member who worked especially well with you? If yes, can you explain why?

____

____

____

____

13. Comments? *(Please use the back of this page if necessary)*

____

____

____

____

Thank you for helping us improve the quality of our services. Your opinion is important to us!

Adapted from: Foster Family-based Treatment Association. *Sample TFC youth satisfaction survey* (2008) and *Customer satisfaction survey, Child version* (2007).

References

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[1] 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.

[2] Baylor International Pediatric AIDS Initiative. (2010). *HIV curriculum for the health professional.* Houston, TX: Baylor College of Medicine.

[3] Usitalo, A. *Psychiatric issues in adolescents with HIV/AIDS.* PowerPoint presentation for the Florida/Caribbean AIDS Education and training Center, May 13-14, 2011 in Orlando, Florida.

[4] Obare, F., van der Kwaak, A., et al. (2010). *HIV-positive adolescents in Kenya: access to sexual and reproductive health services.* KIT Development Policy and Practice, Bulletin 393. Amsterdam: KIT Publishers.

[5] WHO. (2010). *IMAI one-day orientation on adolescents living with HIV.*

[6] Weiser SD., Leiter K., Heisler M., McFarland W., Percy-de Korte F., et al. (2006). *A population-based study on alcohol and high-risk sexual behaviors in Botswana.* PLoS Med, 3(10): e392. Available at: http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0030392

[7] Hsu, JW., et al. (2005). *Macronutrients and HIV/AIDS: a review of current evidence: consultation on nutrition and HIV/AIDS in Africa: evidence, lessons and recommendations for action.* Durban, South Africa: WHO, Department of Nutrition for Health and Development.

Module 3 Clinical Care for Adolescents Living with HIV

Session 3.1:	**HIV Acquisition — Modes and Implications for Care and Treatment**
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 who acquired HIV during childhood or adolescence
- Discuss the importance of comprehensive care for ALHIV
- Define the package of HIV-related care and treatment for adolescents

Session 3.1 HIV Acquisition — Modes and Implications for Care and Treatment

Session Objective

After completing this session, participants will be able to:

- Discuss the needs of adolescents who acquired HIV perinatally versus those who acquired HIV during childhood or adolescence

HIV Transmission in Adolescents

It is important for health 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, labor, delivery, or breastfeeding.
- As pediatric HIV treatment programs have become more available and accessed, there are more and more perinatally infected children who survive into adolescence and adulthood.
- 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 through a testing campaign.
- Adolescents in this group may have initiated ART in infancy and taken various ART regimens by the time they reach adolescence. Others may still be taking the initial regimen they started during early childhood.
- Several recent studies suggest that there are significant numbers of perinatally infected adolescents who, despite being symptomatic, have been "missed" by the health care system.
- 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 1 caregiver of a perinatally infected adolescent knows about the adolescent's HIV-status.

Challenges faced by adolescents with perinatally-acquired HIV and their families often include disclosure of HIV-status to the child and the mother's acceptance of her HIV-status (including her commitment to, enrollment in, and adherence to lifelong care and treatment). Other challenges may include:

- For the family/caregivers: the demands of caring for a child with chronic HIV infection — balancing multiple appointments, tests, and medications
- Developmental delays and physical disabilities in the child/adolescent
- The complexity of living in a home affected by HIV, particularly if the adolescent's caregivers are unemployed, unwell, or have died, or if the child/adolescent was adopted and this has not been disclosed to him or her yet

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, through sharing cutting/piercing instruments, or through injecting drug use.
- It is important to recognize that some adolescents in this group will have acquired HIV through sexual abuse, including rape (sexual abuse will be discussed further in Module 10).
- Adolescents in this group may have learned their HIV-status only recently and generally have not had extended contact with the health care system. They are often identified via HIV testing programs (voluntary counseling and testing (VCT), routine provider-initiated testing and counseling (PITC), etc.).
- Some adolescent girls are identified as HIV-infected when they seek antenatal care and receive routine testing as part of PMTCT services.

Many adolescents who acquire HIV during adolescence fall into WHO clinical stage 1 or 2, feel well, and do not yet need ART. However, it is important that adolescents not eligible for ART still receive ongoing care, support, and monitoring for ART eligibility.

The challenges faced by adolescents who acquired HIV during childhood or adolescence often relate to:

- Acceptance of HIV-status
- Disclosure to family, partner, and peers
- If raped or abused, dealing with the emotional and physical repercussions of that experience

Both adolescents with perinatally-acquired HIV and those who acquired HIV during childhood or adolescence may have issues related to retention in care (especially if they are not eligible for ART), adherence to ART, positive living, and positive prevention. Both groups of ALHIV are also likely to face stigma and discrimination, to worry about their futures, and to be concerned about finding a partner and, in most cases, starting a family.

See Table 3.1 for additional information. Keep in mind that these are generalizations and therefore may not apply to all adolescents. Each person is unique!

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

DIFFERENCES (AND SIMILARITIES) RELATED TO:	**PERIOD WHEN HIV WAS ACQUIRED**	
	PERINATAL (dependant on current age and stage of development)	**ADOLESCENCE**
AGE AT PRESENTATION IN ADOLESCENT CARE	• May present at an earlier age, but tend to be younger: 10–19 years	• Tend to be older: 15–19 years
PHYSICAL DEVELOPMENT	• May be delayed: short stature and late puberty	• Normal physical development and puberty
SEXUAL & REPRODUCTIVE HEALTH	• Not yet sexually active (or, if older, may be thinking about sex or have already had sexual debut)	• Probably sexually active • May have been sexually abused
	Similarities: • May need SRH services, including safer sex education and support • May want children	
RELATIONSHIPS/ MARRIAGE	• May or may not be in a relationship (depending on age and development) • May want intimate relationship • May want marriage	• Probably in a sexual relationship • May want marriage
DISCLOSURE	• Primary caregiver knows adolescent's HIV-status • Caregiver needs to disclose to adolescent if he or she does not already know status	• Coping with new diagnosis • Coping with disclosure to primary caregiver • Coping with disclosing to partner
	Similarities: • Coping with process of disclosing to family and peers	
FAMILY SUPPORT	• Living with parents or caregivers, who typically know adolescent's HIV-status so can offer support	• Support system for HIV depends on disclosure
ECONOMIC SUPPORT	• May be unstable if adolescent has been orphaned	• May have few resources (money, information, experience) if adolescent has left home
ART	• Often on ART for many years	• May not need ART yet
	Similarities: • Adherence challenges in childhood and adolescence	
STIGMA/"BLAME"	• Less likely to be blamed • Considered "innocent"	• More likely to be blamed because of "irresponsible" behavior
	Similarities: • Face stigma	

Adapted from: WHO. (2010). *IMAI one-day orientation on adolescents living with HIV. Facilitator guide.* Geneva: WHO.

Session 3.2 The Package of Adolescent HIV Care and Treatment Services

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

Approaches to Service Provision[1]

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
- Prevent further spread of HIV

Adolescents with perinatally-acquired HIV:

- Have typically been in care since they were young (although this is not always the case)
- Likely began their experience in HIV care and treatment when they were children, under the care of health workers with expertise in pediatrics (who followed pediatric guidelines)
- Have typically been on ART for many years and may even be on a 2nd or 3rd line regimen
- Often look young for their age and, due to delays in development and overprotection by caregivers, are often young socially as well

Young people who acquired HIV during adolescence, on the other hand:

- May be socially experienced, possibly more so than many of their peers
- May be relatively inexperienced in terms of navigating the health care system and dealing with health workers
- Are typically treated as adults, with their treatment directed by adult guidelines

Remember: Regardless of how long they have been infected or how they acquired HIV, the package of care for all ALHIV is very similar. The approach for all adolescents should be family-centered and developmentally appropriate. While the components of the adolescent package of HIV care closely resemble those of the adult package, **the way** these components are delivered has an important impact on their uptake and success among adolescents.

To be effective, adolescent services must:

- Be integrated
- Be age and developmentally appropriate
- Be responsive to the needs of both perinatally infected adolescents and those infected later in childhood or adolescence
- Be empowering; in other words, they must encourage adolescents to take responsibility (as they are developmentally able) for their own health by taking responsibility for their care, for their treatment, and for living positively
- Emphasize both care **and** treatment; and emphasize retention in care, whether or not a particular adolescent is eligible for ART

The importance of 1-stop shopping for adolescents

We can increase adolescent clients' ability to access and benefit fully from services by:

- Ensuring services are integrated, or at least co-located **("1-stop shopping")**
- Ensuring services are youth-friendly (see Module 2)

The Importance of Family-focused Care

- 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, health workers should make it a routine practice to ask him or her about caregivers and other family members. They should also encourage the client to bring family members to the clinic for services, if needed. Health workers can provide family members with ongoing education and information on HIV care and treatment, adherence counseling and support, and general support on caring for ALHIV.
- With older adolescents, health 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, and HIV testing and treatment.

Remember: Adolescents' 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!

Using the 5 "A's" in Consultations with Adolescent Clients

The 5 "A's" are part of the WHO Integrated Management of Adolescent and Adult Illness (IMAI) guidelines on working with clients (including adolescents) who have chronic conditions (including HIV). Some of the most surprising examples of poor patient care have stemmed from health workers communicating clinical information to clients in a manner that is abrupt, insensitive, and completely dismissive of their potential reaction. The 5 "A's" offer a framework for communicating both psychosocial and clinical information to clients. The 5 "A's" support the provision of information and support in a manner that is sensitive and client-centered.

Table 3.2: Using the 5 "A's" during clinical visits with adolescents

The 5 "A's"	More Information	What the Health Worker Might Say
ASSESS	• Assess the client's goals for the visit • Asses the client's clinical status, classify/identify relevant treatments, and/or advise and counsel • Assess risk factors • Assess the client's (caregiver's) knowledge, beliefs, concerns, and behaviors • Assess the client's understanding of the care and treatment plan • Assess adherence to care and treatment (see Module 8) • Acknowledge and praise the client's efforts	• *What would you like to address today?* • *What can you tell me about ______?* • *Tell me about a typical day and how you deal with ______?* • *Have you ever tried to _____? What was that like for you?* • *To make sure we have the same understanding, can you tell me about your care and treatment plan in your own words?* • *Many people have challenges taking their medicines regularly. How has this been for you?*
ADVISE	• Use neutral and non-judgmental language • Correct any inaccurate knowledge and gaps in the client's understanding • Counsel on risk reduction • Repeat any key information that is needed • Reinforce what the client needs to know to manage his or her care and treatment (for example, recognizing 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.)	• *I have some information about ____ that I'd like to share with you.* • *Let's talk about your risk related to ____. What do you think about reducing this risk by ______.* • *What can I explain better?* • *What questions do you have about ________?*
AGREE	• Negotiate WITH the client about the care and treatment plan, including any changes • Plan when the client will return	• *We have talked about a lot today, but I think we've agreed that ______. Is this correct?* • *Let's talk about when you will return to the clinic for ____.*
ASSIST	• Provide take-away information on the plan, including any changes • Provide psychosocial support, as needed • Provide referrals, as needed (to support groups, peer education, etc.) • Address obstacles • Help the client come up with solutions and strategies that work for him or her	• *Can you tell me more about any obstacles you've faced with ______ (for example, taking your medicines regularly, seeking support, practicing safer sex)?* • *How do you think you can overcome this obstacle?* • *What questions can I answer about _____?* • *I want to make sure I explained things well — can you tell me in your own words about _____?*
ARRANGE	• Arrange a follow-up appointment • Arrange for the client to participate in a support group or group education sessions, etc. • Record what happened during the visit	• *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.* • *What day/time would work for you?*

Sources:
WHO. (2004). *General principles of good chronic care: IMAI. Guidelines for first-level facility health workers.* Geneva: WHO.
WHO. (2010). *IMAI one-day orientation on adolescents living with HIV.* Geneva: WHO.

The 5 "A's" are referred to throughout this training and developed further in Module 5. Participants will have an opportunity to practice the 5 "A's" towards the end of this session.

Comprehensive Care for ALHIV

The care of the child with HIV is directed by pediatric HIV guidelines. However, as the child ages and develops, his or her care transitions to follow adult HIV guidelines. The care of adolescents is often guided by pediatric guidelines, adult guidelines, or both. Although pediatric and adult guidelines have many similarities (for example, criteria for ART initiation for children over 5 years of age is the same as for adults), their differences give health workers the flexibility to tailor the package of care to meet each adolescent client's needs.

Comprehensive care for ALHIV includes the provision of the services listed in the clinical assessment checklists in Tables 3.3, 3.4 and 3.5 below.

- **Table 3.3** lists the steps to be conducted at the initial, or enrollment, visit. As many adolescents with perinatally-acquired HIV have been in care for years, they will have undergone an enrollment assessment as infants or children. As such, the checklist in Table 3.3 is for use at **entry into the adolescent program**. Note that it may take several visits to complete all the steps included in this assessment
- **Table 3.4** lists the steps to be conducted at follow-up visits for clients ***not*** on ART.
- **Table 3.5** lists the steps to be conducted at follow-up visits for clients on ART.

Table 3.3: Key steps — enrollment visit

✓	Steps
	1. Take history
	• Take a complete medical and social history, including prenatal, birth, and family history
	• Confirm HIV infection status
	• Identify concomitant medical conditions (e.g., TB disease, hepatitis B or C infection, other co-infections or OIs, pregnancy in adolescent girls)
	• Enquire about disclosure to the adolescent (if perinatally infected, take time alone with caregiver to discuss) or disclosure to others
	• Enquire about HIV and treatment status of family and household members
	• Enquire about concomitant medication (e.g., CTX, oral contraceptives, traditional therapies)
	• Review immunization status
	• If clinically indicated, undertake a nutritional status assessment
	• Ask about sexual activity and condom and other contraceptive use (alone with adolescent)
	• Conduct psychosocial assessment and provide counseling, referrals, and support (see Module 5 and *Appendix 3B: HEADSS Interview Questions*)
	• Assess any other practical needs, such as legal support, housing, school/career, and financial
	2. Conduct physical exam
	• Assess growth and nutrition (weight, height, and BMI), as appropriate for age
	• Assess development and neurodevelopment, as appropriate for age
	• Conduct physical examination, including Tanner staging
	• Conduct skin exam (tattoos, bruises, acne) and scoliosis evaluation
	• Screen for STIs in adolescents who are sexually active
	• Screen for pregnancy in sexually active adolescent females
	• Screen for TB; screen for other OIs and other concomitant conditions, diarrhea, malaria
	• Discuss findings from physical examination with ALHIV and his or her caregivers
	3. Make laboratory assessment plan
	• Conduct baseline tests according to local resources and guidelines: • CD4: recommended; HBsAg: desirable; other tests, if clinically indicated
	4. Make assessments
	• Review findings from history, physical assessment, and laboratory work and make diagnosis
	• Assess WHO clinical stage. If on ART, determine if there are any new stage 3 or 4 events
	• If not on ART, determine if ALHIV meets the criteria for ART initiation
	• Decide if CTX or IPT are indicated
	5. Make decisions
	• Discuss prevention of illnesses (OIs, including TB, STIs, diarrhea, malaria, and other illnesses) and initiation or continuation of CTX, IPT, and any other medications
	• If applicable, discuss prevention of STIs, positive prevention, and prevention of unintended pregnancy; provide condoms and contraceptive counseling and methods
	• For those eligible for ART, initiate adherence preparation
	• Discuss treatment of current illnesses identified in physical examination
	• If eligible, initiate CTX or IPT; discuss adherence and side effects
	• If applicable, provide nutrition counseling and support
	• Provide counseling, support, and referrals based on psychosocial assessment and needs

✓	Steps
	6. Agree on an action plan
	• Agree on key action steps from history and physical examination
	• Discuss when to seek medical care; for example, with unexpected illness or side effects
	• Reiterate agreed upon plan to support adherence to medications
	• Discuss steps to live positively and prevent further HIV infections
	• Agree on key action steps based on psychosocial assessment (e.g., reduce alcohol intake, discuss HIV-status with friend, join support group)
	• Provide referrals, including name of person/agency, address, and contact information of referral point. If possible, contact referral and make appointment on behalf of ALHIV
	• Schedule next visit as per national guidelines: • **If pre-ART:** every 3–6 months, with more frequent visits if CD4 is approaching treatment criteria • **If on ART:** every 3 months, with more frequent visits if clinically unwell or CD4 is declining • Schedule earlier appointment if required for follow-up of problems identified during the visit or if adolescent is ill • Encourage ALHIV to drop in (without an appointment) if a problem arises and to participate in other clinic activities, such as support groups

Table 3.4: Key steps — follow-up visit, clients NOT on ART

✓	Steps
	1. Take history
	• Review interim medical history
	• Review concomitant medication (e.g., CTX, oral contraceptives, traditional therapies)
	• Conduct psychosocial assessment and provide counseling, referrals, and support
	• Re-assess other practical needs, such as legal support, housing, school/career, and financial
	2. Conduct physical exam
	• Assess growth and nutrition (weight, height, and BMI), as appropriate for age
	• Assess development and neurodevelopment, as appropriate for age
	• Conduct physical examination, including Tanner staging
	• Conduct skin exam (tattoos, bruises, acne) and scoliosis evaluation
	• Screen for STIs in adolescents who are sexually active
	• Screen for pregnancy in sexually active adolescent females
	• Screen for TB; screen for other OIs and other concomitant conditions, diarrhea, malaria
	• Discuss findings from physical examination with ALHIV and his or her caregivers
	3. Make laboratory assessment plan
	• Conduct laboratory tests according to local resources and guidelines
	4. Make assessments
	• Review clinical findings at this visit and laboratory findings (including CD4 cell count) from recent visits; consider eligibility for ART
	• Assess WHO clinical stage; consider eligibility for ART
	• If on CTX, provide refill; monitor and discuss adherence. If not on CTX, re-assess eligibility
	• If on IPT, provide refill; monitor and discuss adherence. If not on IPT, re-assess eligibility
	5. Make decisions
	• If applicable, discuss prevention of STIs, positive prevention, and prevention of unintended pregnancy; provide condoms and contraceptive counseling and methods
	• For those eligible for ART, initiate adherence preparation
	• Discuss treatment of current illnesses identified in physical examination
	• If applicable, provide nutrition counseling and support
	• Discuss disclosure to the adolescent (if perinatally infected) or disclosure to others
	• Discuss positive living and positive prevention
	• Provide counseling, support, and referrals based on psychosocial assessment and needs
	• Provide education, care, and support for family members and/or partner
	• Provide support for clients who are switching providers or transitioning into adult care
	6. Agree on an action plan
	• Agree on key action steps from history and physical examination
	• Discuss when to seek medical care, for example, with unexpected illness or side effects
	• Reiterate agreed upon plan to support adherence to medications
	• Agree on key action steps based on psychosocial assessment
	• Provide referrals and, if possible, contact referral to make appointment on client's behalf
	• Schedule next visit as per national guidelines: ◦ **If pre ART:** every 3–6 months ◦ **If initiating ART at this visit:** schedule appointment for weeks 2, 4, 8, 12, and then every 3 months once the adolescent has stabilized on ART ◦ Schedule earlier appointment if required for follow-up of problems identified during the visit or if adolescent is ill ◦ Encourage ALHIV to drop in (without an appointment) if a problem arises and to participate in other clinic activities, such as support groups

Table 3.5: Key steps — follow-up visit, clients on ART

✓	Steps
	1. Take history
	• Review interim medical history
	• Review concomitant medication (e.g., CTX, oral contraceptives, traditional therapies)
	• Conduct psychosocial assessment and provide counseling, referrals, and support
	• Re-assess other practical needs, such as legal support, housing, school/career, and financial
	2. Conduct physical exam
	• Assess growth and nutrition (weight, height, and BMI), as appropriate for age
	• Assess development and neurodevelopment, as appropriate for age
	• Conduct physical examination, including Tanner staging
	• Conduct skin exam (tattoos, bruises, acne) and scoliosis evaluation
	• Screen for STIs in adolescents who are sexually active
	• Screen for pregnancy in sexually active adolescent females
	• Screen for TB; screen for other OIs and other concomitant conditions, diarrhea, malaria
	• Discuss findings from physical examination with ALHIV and his or her caregivers
	3. Make laboratory assessment plan
	• Conduct laboratory tests according to local resources and guidelines
	4. Make assessments
	• Review clinical findings at this visit and laboratory findings (including CD4 cell count) from recent visits
	• Assess WHO clinical stage; determine if there are any new stage 3 or 4 events; assess CD4 cell count to check response to treatment; determine if treatment failure has occurred.
	• Provide ART refills; monitor and discuss adherence and side effects
	• If on CTX, provide refill; monitor and discuss adherence. Consider discontinuation
	• If on IPT, provide refill; monitor and discuss adherence. If not on IPT, re-assess eligibility
	5. Make decisions
	• If applicable, discuss prevention of STIs, positive prevention, and prevention of unintended pregnancy; provide condoms and contraceptive counseling and methods
	• Discuss treatment of current illnesses identified in physical examination
	• If applicable, provide nutrition counseling and support
	• Discuss disclosure to the adolescent (if perinatally infected) or disclosure to others
	• Discuss positive living and positive prevention
	• Provide counseling, support, and referrals based on psychosocial assessment and needs
	• Provide education, care, and support for family members and/or partner
	• Provide support for clients who are switching providers or transitioning into adult care
	6. Agree on an action plan
	• Agree on key action steps from history and physical examination
	• Discuss when to seek medical care, for example, with unexpected illness or side effects
	• Reiterate agreed upon plan to support adherence to medications
	• Agree on key action steps based on psychosocial assessment
	• Provide referrals and, if possible, contact referral to make appointment on client's behalf
	• Schedule next visit as per national guidelines: • **If ART was recently initiated:** schedule appointment for weeks 2, 4, 8, 12 • **If stable on ART:** schedule appointment every 3 months (and refills more frequently) • Schedule earlier appointment if required for follow-up of problems identified during the visit or if adolescent is ill • Encourage ALHIV to drop in (without an appointment) if a problem arises and to participate in other clinic activities, such as support groups

Remember: Always follow your most recent national guidelines.

Further guidance can also be found in WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* and *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access, Recommendations for a public health approach, 2010 revision.*

Laboratory Monitoring

Every patient consultation starts with a history (or interim history) and then a physical examination. If available, laboratory results can support the findings from the history and examination. Laboratory assessments should be conducted at enrollment (that is, entry into HIV care) and as indicated in *Appendix 3A: Laboratory Monitoring Before, During, and After Initiating ART.*

Guiding principles[2]

1. Laboratory monitoring is not a prerequisite for the initiation of ART.
2. **CD4:** although not required for initiating and monitoring ART, CD4 cell count is strongly recommended. Use of clinical criteria alone tends to under-diagnose eligibility for ART — a 2007 study from Uganda found that clinical criteria missed half the patients who would have been eligible for ART had CD4 cell measurements been used.[3]
3. **Hemoglobin:** desirable test at initiation of ART if AZT-containing regimen will be used
4. **Viral load testing** can be used to monitor ART and to diagnose treatment failure. If resources permit, measure viral load every 6 months with the objective of detecting failure earlier. If resources are not available, use immunological and/or clinical criteria alone to define failure or prioritize the use of viral load testing to confirm suspected treatment failure. Always follow national guidelines.
5. Symptom-directed laboratory monitoring for safety and toxicity is recommended for those on ART.

The unavailability of laboratory monitoring, including CD4 and chemistries, should NOT prevent adolescents from receiving ART.

CD4 should be measured at the time of diagnosis AND:

- **For adolescents not yet eligible for ART**: monitor every 6 months and, as CD4 cell count approaches threshold for starting ART, every 3 months
- **For adolescents on ART**: measure just prior to starting ART (if previous CD4 was measured more than 3 months ago) and at least every 6 months thereafter
- **For all adolescents**: measure CD4 if a new clinical staging event develops, including growth faltering and neurodevelopmental delays

Cotrimoxazole (CTX)[2,4]

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 ALHIV who are symptomatic.

WHO criteria for initiating CTX

Indications for CTX:

- **Clinical criteria:** Start CTX when adolescent is symptomatic (WHO clinical stage 2, 3, or 4)
- **Immunologic criteria:** When CD4 testing is available, start CTX when CD4 count is <350cells/mm^3, regardless of clinical stage, or according to national guidelines

Discontinuing CTX

- CTX can be discontinued in an adolescent on ART if he or she shows evidence of sustained immune recovery of CD4 >350cells/mm^3 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 1 year of therapy), good adherence, and secure access to ART.
- If CTX is discontinued, it should be restarted if the client's CD4 count falls below 350 cells/mm^3 or if he or she has a new or recurrent WHO clinical stage 2, 3, or 4 condition.
- Always follow national guidelines when initiating and discontinuing CTX.

Discontinuation of CTX due to adverse events

CTX is very well tolerated by the vast majority of clients and adverse reactions are rare (<2% per person-year). CTX should be discontinued if the adolescent experiences drug-related adverse events, such as extensive exfoliative rash, Stevens-Johnson syndrome, severe anemia, or pancytopaenia. Remember that such drug-related adverse events are unusual.

Contraindications to CTX

Contraindications of CTX include:

- Adolescents with a history of severe and life-threatening adverse reactions — grade 3 or 4 to CTX or other sulfa drugs — should not be prescribed CTX. Dapsone 100 mg/day should be given as an alternative.
- See WHO's *Guidelines on Co-trimoxazole Prophylaxis for HIV-related Infections among Children, Adolescents and Adults, Recommendations for a Public Health Approach* for additional information, including guidance on de-sensitizing those with a history of grade 1, 2, or 3 reaction to CTX.
- Severe liver insufficiency
- Severe renal insufficiency

Table 3.6: Dosing for CTX

Recommended once daily dose by age	Suspension	Child tablet (100mg/20mg)	Single strength adult tablet (400mg/80mg)	Double strength adult tablet (800mg/160mg)
10–14 years (or 15–30 kg) 400 mg sulfamethoxazole/ 80 mg trimethoprim	10 ml	4 tablets	1 tablet	½ tablet
>14 years (or >30 kg) 800 mg sulfamethoxazole/ 160 mg trimethoprim	N/A	N/A	2 tablets	1 tablet
Frequency — once a day				
CTX can be safely continued or initiated during pregnancy (regardless of stage of pregnancy) and breastfeeding.				

Source: WHO. (2006). *Guidelines on co-trimoxazole prophylaxis for HIV-related infections among children, adolescents and adults, Recommendations for a public health approach*, p. 15 and 21. Geneva: WHO.

HPV

Genital human papillomavirus (HPV) is the most common STI. Most people who are infected with HPV do not know they have it. In most cases (9 out of 10), the body's immune system clears HPV naturally within 2 years. However, some of the more than 40 different types of HPV can cause genital warts and others can cause normal cells in the body to turn abnormal, which can lead to cervical and other cancers over time.

Reducing HPV risk through vaccination[5]

HPV is prevented in the same ways that HIV is prevented: through abstinence, being faithful, and consistent and correct condom use. Unlike HIV, however, HPV can also be prevented through vaccination.

HPV vaccination

There is now a vaccine that can lower a person's risk of getting HPV. In countries where it is available, HPV vaccination can be initiated between the ages of 9–26 years, but is typically recommended at the age of 11 or 12. Vaccination requires a total of 3 shots over 6 months. The best way a person can get the most benefit from HPV vaccination is to complete all 3 doses before beginning sexual activity.

When to Start ALHIV on ART

ART helps preserve and enhance the immune systems of people living with HIV. ART reduces the risk of OIs, restores growth, improves mental functioning, and improves the client's overall quality of life. By adolescence, most clients with perinatally-acquired HIV will already be on CTX and many will be on ART. The decision to start ART in an adolescent who is newly infected or perinatally infected and recently diagnosed or eligible relies on clinical and immunological criteria as well as an assessment of other issues.

Immunological and clinical criteria to start ART

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

- **CD4 ≤350 or**
- **WHO stage 3 or 4** (regardless of CD4 count) **or**
- **Active TB disease or**
- **HIV/HBV-coinfection,** if HBV infection (chronic active hepatitis) requires treatment, irrespective of CD4 cell count or WHO clinical stage **or**
- For asymptomatic or mildly symptomatic adolescents (i.e. those in stages 1 and 2), **when immunological values fall near the threshold values**. A drop below threshold values should be avoided.
    - Consider treatment in serodiscordant couples in stable, long-term relationships if index partner has **CD4 >350**.[6]

Other issues to consider before initiating ART

Before initiating ART, health workers should help ALHIV understand that they are starting lifelong therapy and prepare them (and caregivers) to adhere to their HIV care plan and ART regimen.

Adherence preparation should help the adolescent (and caregivers) to:

- Understand what HIV is
- Understand what ART is and that it is a lifelong commitment
- Understand how the ART is to be taken
- Understand the challenges of adherence
- Develop an individual adherence plan
- Seek family and peer support for adherence

Adherence preparation can take 1, 2, 3, or more visits, depending on the individual adolescent, his or her health status, the health worker(s) involved, and the time available. At times, there may be more urgency to initiate ART quickly, especially with very sick children/adolescents. In these cases, health workers can minimize adherence preparation and increase post-ART initiation adherence support. There is more information on adherence preparation and support in Module 8.

Prior to initiating ART, it is recommended that, in addition to providing adherence preparation counseling and support:

- Minimum enrollment laboratories have been completed (see *Appendix 3A: Laboratory Monitoring Before, During, and After Initiating ART*):
  - Recommended: CD4
  - Desirable: Hb if using AZT; ALT if using NVP; creatinine clearance if using TDF; pregnancy test for sexually adolescent females initiating EFV
- Other necessary laboratory tests have been conducted, based on history and physical exam
- CTX has been initiated
- The adolescent has been screened for TB
- The adolescent has been tested for Hepatitis B
- Adolescents with perinatally-acquired HIV know their HIV-status (i.e, have been disclosed to). Keep in mind that this is a recommendation and not a requirement to initiate ART. There may be times when the disclosure process cannot occur entirely before initiation.
- Adolescents who know their status have disclosed to someone they trust. Again, this is a recommendation and should not be a requirement to initiate ART.

For more information, see *Appendix 3A: Laboratory Monitoring Before, During, and After Initiating ART*; *Appendix 3C: WHO Clinical Staging of HIV Disease in Children with Established HIV Infection;* and *Appendix 3D: WHO Clinical Staging of HIV Disease in Adults and Adolescents.*

Recommended 1st Line ART Regimens for ALHIV

Introduction to ART regimens

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

WHO recommends basing the choice of ART regimen and dosage for adolescents on their sexual maturity rating (see *Appendix 2A: Tanner Staging System*):

- Adolescents who are at **Tanner stages I, II, and III** should be started on the pediatric schedule and monitored with particular care. This is because they are undergoing pubertal changes associated with rapid growth.
- Adolescents who are at **Tanner stages IV and V** are considered to be adults. The same recommendations and special considerations that apply to adults apply to these adolescents.

Younger adolescents

For younger adolescents (Tanner stage I, II, or III), 1st line ART regimens contain NVP or EFV, plus a "backbone" consisting of 2 NRTIs. See Table 3.7 for WHO preferred and alternative 1st line regimens. Note: specific regimens are indicated in national guidelines. Always check national guidelines before prescribing an ART regimen.

Table 3.7: Regimens for children and younger adolescents (Tanner stages I, II, or III)

	Regimen	
	NRTI backbone	**NNRTI component**
Preferred 1st line	AZT + 3TC	NVP[1] or EFV[2, 3, 4]
Alternative 1st line[5]	ABC + 3TC	NVP[1] or EFV[2, 3, 4]
2nd Alternative 1st line	d4T + 3TC	NVP[1] or EFV[2, 3]

1 Symptomatic NVP-associated hepatotoxicity or serious rash, while uncommon, is more frequent in females than in males, and is more likely to be seen in ARV-naive females with higher absolute CD4 cell counts (>250 cells/mm^3). If used in adolescent girls with absolute CD4 counts between 250 and 350 cells/mm^3, careful monitoring, preferably including liver enzymes, is needed during the first 12 weeks of therapy.

2 The preferred regimen for adolescents with tuberculosis is EFV + the 2 NRTI backbone.

3 The use of EFV should be avoided in adolescent girls who are at risk of becoming pregnant (i.e., are sexually active and not using adequate contraception) or those in the 1st trimester of pregnancy. If possible, adolescent girls taking EFV should be switched to a NVP-based or other regimen, or counseled on and provided with a contraceptive method.

4 In situations where both EFV and NVP are contraindicated in 1st line regimens for adolescent girls, the use of a triple NRTI regimen may be indicated.

5 Use the alternative 1st line regimen only if there are contraindications to AZT (for example, severe anemia, <8g/dl; or neutropenia, <500 cells/mm^3) or AZT availability cannot be assured.

Additional notes and references:

- Preferred 2nd line ART options are listed in *Appendix 3E*: *Preferred 2nd line ART Options.*
- Specific regimens are indicated in national guidelines — always check your national guidelines before prescribing an ART regimen.
- See also *Appendix 3F: ARV Dosages*.
- For additional information, see WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* or consult an HIV specialist for guidance on transitioning to the 2010 recommendations.
- Note that the 2010 WHO guidelines call for the **phasing out of d4T-containing regimens** for adults and adolescents, unless AZT or ABC are contraindicated or not assured. Refer to WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* and your national guidelines for advice on drug substitution for adolescents currently on d4T.

Dosing in younger 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 Annex E in WHO's *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access, Recommendations for a public health approach, 2010 revision.*

Older adolescents and adults

WHO preferred ART regimens for ART-naïve older adolescents (Tanner stage IV and V) and adults are listed in Table 3.8. The regimens were selected based on safety profile, suitability for use in most patient groups, cost, treatment durability, and the benefits of using fixed-dose combinations.

Table 3.8: Regimens for older adolescents (Tanner stage IV and V) and adults

	Regimen	
	NRTI backbone	**NNRTI component**
Preferred 1st line	AZT[4] or TDF[3] + 3TC or FTC	NVP[1] or EFV[2]
Pregnant women	AZT[4] + 3TC	NVP[1] or EFV[2]
HIV/TB co-infection	AZT[4] or TDF[3] + 3TC or FTC	EFV[2]
HIV/HBV co-infection	TDF[3] + 3TC or FTC	NVP[1] or EFV[2]

1 Avoid use of NNRTI component in women who have had exposure to sdNVP without NRTI tail for 7 days within the last 12 months (for PMTCT); instead substitute LPV/r. If unsure whether tail coverage for sdNVP was provided, then use LPV/r. If NVP is initiated in women with a CD4 cell count of 250–350 cells/mm^3, monitor hepatic enzymes at weeks 2, 4, and 12 after initiation (if possible).

2 Women who are planning to become pregnant or who may become pregnant should use a regimen that does not include EFV in order to avoid the highest risk period of exposure in utero (conception to day 28 of gestation). If a woman is diagnosed as pregnant before 28 days of gestation, EFV should be stopped and substituted with NVP or a PI. If a woman is diagnosed as pregnant after 28 days of gestation, EFV should be continued.

3 TDF: Because of its association with renal toxicity, monitor patients for creatinine clearance before initiation and every 6 months. The inability to perform creatinine clearance is not a barrier to TDF use. Creatinine clearance monitoring is recommended in those with underlying renal disease, of older age groups, and with low body weight or other renal risk factors, such as diabetes or hypertension. Avoid TDF or adjust dose if CrCl <50 ml/min.

4 Measure hemoglobin (Hb) before the initiation of AZT and then as indicated by signs/symptoms. Patients receiving AZT-containing regimens who have low body weight and/or low CD4 cell counts are at greater risk of anemia. These patients should have routine Hb monitoring 1 month after initiating AZT and then at least every 3 months. AZT should not be given if Hb is <7 g/dl.

Additional notes and references:

- Preferred 2nd line ART options are listed in *Appendix 3E*: *Preferred 2nd line ART Options.*
- Specific regimens are indicated in national guidelines. Always check national guidelines before prescribing an ART regimen.
- See also *Appendix 3F: ARV Dosages for Older Adolescents and Adults.*
- For additional information, see WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* or consult an HIV specialist for guidance on transitioning to the 2010 recommendations.

Possible events during the first 6 months on ART

The first 6 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 during the second year. Some adolescents, however, fail to respond as expected or may even exhibit clinical deterioration.

- Complications during the first few weeks following ART initiation are seen most commonly in those with severe immunodeficiency.
- Apparent failure to improve in an adolescent with advanced HIV disease does not necessarily reflect a poor response to ART — it takes time for HIV viral replication to be controlled by ART and for the client's immune system to recover. It may, however, reflect inadequate adherence.
- 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 ART initiation, 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 its success—and the resulting immune reconstitution. When IRIS is suspected, consult a clinician experienced in managing ALHIV.
- Allow sufficient time (at least 6 months on therapy) before judging the effectiveness of a regimen. Switching the ART regimen during the first 6 months on therapy is usually inappropriate and supporting adherence during this period is critical.
- Persistent failure to see a CD4 response should alert the health worker to potential adherence problems or non-response to ART. In such cases, viral load determination can be useful as well as consultation with a clinician experienced in managing ALHIV.

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

- Improvement in growth or weight gain in adolescents who have been failing to grow
- Decreased frequency of infections (bacterial infections, oral thrush, and/or other OIs)

Supporting Adherence to Care and Treatment among ALHIV

Adherence to both care and medicines is the cornerstone of effective and successful HIV care. Adolescents often face unique challenges with adherence—challenges that are different from those of pediatric or adult clients. Adherence preparation, assessment, counseling, 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 (and national guidelines). After starting ART, ***follow-up visits should occur at a minimum at weeks 2, 4, 8, 12, and then every 3 months*** (once the adolescent has stabilized on ART).
- **Adolescents not yet eligible for ART**: As a general rule, follow-up visits should occur every 3 months if the client's CD4 cell count is between 350–500 and every 3–6 months if the client's CD4 cell count is greater than 500. However, schedule the next visit sooner if required for follow-up of problems identified during the visit.

Toxicities

Toxicity can be monitored clinically, based on adolescent/caregiver reporting and physical examination. It can also be assessed by a limited number of laboratory tests. Drug toxicities generally fall into 1 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 they do not require discontinuation of all ART.
- **Severe life-threatening toxicities** require discontinuation of all ARVs and the initiation of appropriate supportive therapy until the patient is stabilized and the toxicity is resolved.
    - NNRTIs have a longer half-life than NRTIs and stopping all 1st line drugs simultaneously may result in exposure to sub-therapeutic levels of the NNRTI and, subsequently, to the development of NNRTI resistance.
    - Nonetheless, if an adolescent has a life-threatening toxicity, all ARVs should be stopped simultaneously until the patient is stabilized.

For additional information about dealing with toxicities, refer to national guidelines, WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* and *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access, Recommendations for a Public Health Approach, 2010 revision*, or 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 potential side effects.
- During the early stages of treatment, offer support during minor and moderate adverse reactions.

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

Treatment Failure

Treatment failure is when ART stops controlling an individual's virus and he or she starts getting sicker. Treatment failure needs to be confirmed in a timely manner. If diagnosed prematurely, clients are often switched to expensive 2nd line ART regimens unnecessarily. If diagnosed late, the result could be disease progression or even death.

When treatment failure is suspected, verify these 5 things:

- The adolescent has been on ART for at least 24 weeks.
- The adolescent has been adherent (in other words, he or she has taken all medicines exactly as prescribed). If adherence has not been optimal, the first course of action is to keep the adolescent on the same regimen and to provide adherence counseling and support.
- Any inter-current infection or major clinical event has been treated and resolved.
- IRIS has been excluded.
- The adolescent is receiving adequate nutrition (if considering a change in treatment because of growth failure).

Criteria for treatment failure

There are 3 criteria for treatment failure (see Table 3.9):

- Clinical
- Immunologic
- Virologic

Although virological failure is the most accurate method of diagnosing and confirming treatment failure, if viral load is not available, use immunological criteria to confirm clinical failure (i.e. CD4 cell count).

Table 3.9: WHO definition and criteria for switching ART in adults and adolescents

Failure	Definition	Comments
Clinical failure	• New or recurrent WHO stage 4 condition	• Condition must be differentiated from immune reconstitution inflammatory syndrome (IRIS) • Certain WHO clinical stage 3 conditions (e.g. pulmonary TB, severe bacterial infections) may be an indication of treatment failure
Immunological failure[1]	• Fall of CD4 count to baseline (or below) **OR** • 50% fall from on-treatment peak value **OR** • Persistent CD4 levels below 100 cells/mm^3	• Without concomitant infection to cause transient CD4 cell decrease
Virological failure[2]	• Plasma viral load above 5000 copies/ml	• The optimal viral load threshold for defining virological failure has not been determined. Values of >5,000 copies/ml are associated with clinical progression and a decline in CD4 cell count. See *Appendix 3F.*

1 **Note**: Immunological failure is not a good predictor of virological failure — 8–40% of individuals who present with evidence of immunological failure actually have virological suppression.

2 Viral load measurement is considered a better indicator of treatment failure than clinical or immunological indicators. Depending on availability, viral load may be used:

- Targeted strategy: To confirm clinical/immunological failure or, occasionally, to assess adherence within 4–6 months of ART initiation in at-risk clients
- Routine strategy: To detect viral replication every 6 months

For additional information on treatment failure, see WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 revision* and *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access, Recommendations for a Public Health Approach, 2010 revision.*

Once treatment failure has been detected, select a new regimen using national guidelines or after consulting an HIV specialist. See *Appendix 3E: Preferred 2nd line ART Options* for WHO-recommended 2nd line ART regimens. The patient should be switched to a new regimen within 1 month of confirming treatment failure.

Whenever an ALHIV is switched to a new regimen:

- Counsel him or her on reasons for the change in regimen, differences in drug types, dosages, and timing of administration.
- Review with the adolescent and his or her caregiver possible side effects of the new regimen.
- Re-assess for social issues that could negatively influence adherence and review the importance of adhering to the clinic visit schedule as well as to the regimen.
- Provide ongoing adherence counseling and support (see Module 8).

Tuberculosis Screening

People living with HIV, including adolescents, are at risk of developing TB — regardless of CD4 count. HIV is the strongest risk factor for TB. Co-infection with HIV/TB is a major public health threat for PLHIV and TB is responsible for more than one-quarter of all deaths among PLHIV. TB threatens the significant health benefits achieved with the scale-up of HIV care and treatment.

Therefore, all ALHIV should be screened for active TB at each visit.

- If found to be co-infected, they should be started on anti-TB medications immediately. If they are not already on ART, they should be started on ART soon thereafter.
- All ALHIV who do not have any signs of active TB should be offered isoniazid preventive therapy (IPT) as part of the comprehensive package of care — for at least 6 months.
- ALHIV who have had a significant TB contact should be screened for TB and, if no active TB is found, should be offered IPT for 6 months.
- Recent studies show that PLHIV who have been treated for TB can benefit from IPT and should be offered secondary prophylaxis after completing TB treatment.

Screening for TB[7]

All ALHIV should be evaluated at every visit to a health facility for contact with a TB source case and for current TB symptoms, regardless of immunologic status, HIV treatment status (whether currently on ART), or whether currently receiving Isoniazid (INH). See Figure 3.1.

Screen for contact with a TB source by asking if the client:

- Has had close contact with someone (someone in the same household or with whom the client has frequent contact) who has been diagnosed with TB
- Has had close contact with someone who has a chronic cough, fever, or who has lost a lot of weight

If client has had contact with a TB source, exclude active TB disease per national guidelines and, if there is no evidence of active TB, offer IPT.

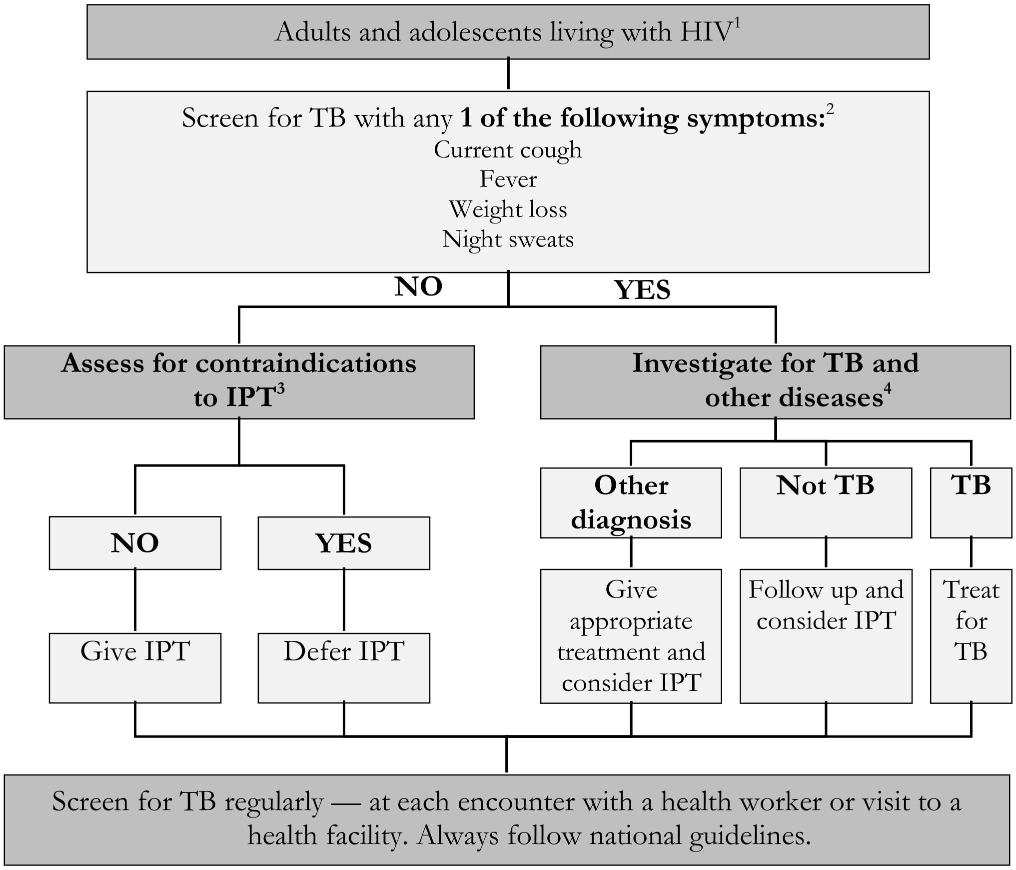
Screen for symptoms of TB – always follow national guidelines

For younger adolescents, ask about:	For older adolescents, ask about:
• Current cough	• Current cough
• Fever	• Fever
• Weight loss or poor weight gain	• Night sweats
	• Weight loss

If the client has **none of the above symptoms**, active TB disease is unlikely and they should be offered IPT (see below).

If the client has **1 or more of the above symptoms**, evaluate for active TB disease per national guidelines. Sample TB screening tools are included as *Appendix 3G: TB Screening Tool for Children and Younger Adolescents* and *Appendix 3H: TB Screening Tool for Older Adolescents and Adults*.

Figure 3.1: Algorithm for TB screening in adults and adolescents living with HIV in HIV-prevalent and resource-constrained settings



Footnotes:

1 Every adult and adolescent should be evaluated for eligibility to receive ART. Infection control measures should be prioritized to reduce *M. tuberculosis* transmission in all settings that provide care.

2 Chest radiography can be done if available, but is not required to classify patients into TB and non-TB groups. In high HIV-prevalence settings with a high TB prevalence among people living with HIV (e.g. greater than 10%), strong consideration must be given to adding other sensitive investigations.

3 Contraindications include: active hepatitis (acute or chronic), regular and heavy alcohol consumption, and symptoms of peripheral neuropathy. Past history of TB and current pregnancy should not be contraindications for starting IPT. Although not a requirement for initiating IPT, TST may be done as a part of eligibility screening in some settings.

4 Investigations for TB should be done in accordance with existing national guidelines.

Source: WHO, Department of HIV/AIDS and Stop TB Department. (2011). *Guidelines for intensified tuberculosis case-finding and isoniazid preventive therapy for people living with HIV in resource-constrained settings.*

Prevention of TB with IPT[5,8]

Provision of IPT is part of the **WHO's "3 I's" strategy** to improve TB case finding and prevent TB. The 3 I's are: Isoniazid preventive treatment, intensified case finding for active TB, and TB infection control.

The following should receive IPT:

- All HIV-infected adolescents with no evidence of active TB disease and no contraindications to IPT should begin IPT as part of a comprehensive package of HIV care. IPT should be given to ALHIV irrespective of the degree of immunosuppression and should also be given to those on ART, those who have been previously treated for TB, and those who are pregnant.
- ALHIV who do not have any of the symptoms listed in the symptom screen should be offered IPT for at least 6 months.

- ALHIV who have been successfully treated for TB disease should be offered IPT for 6 months. Note that there is no evidence for IPT after treatment of multi-drug-resistant (MDR) or extremely drug-resistant (XDR) TB, so secondary prophylaxis should not be provided.
- ALHIV who have had contact with a TB case and do not have active disease should be offered IPT for 6 months

The **recommended dose of isoniazid (INH) for preventive therapy in HIV co-infection among most adolescents is 1 adult tablet (300mg) daily or 3 100mg tablets** (if pill size or formulation is limited). For adolescents weighing less than 25kg, follow the dosing schedule in Table 3.10 below. Also give vitamin B6 with INH at a dose of 25 mg daily.

Table 3.10: Simplified dosing schedule for INH

Weight range (kg)	Number of 100 mg tablets of INH to be administered per dose (total dose 10 mg/kg/day)	Dose given (mg)
10–13.9	1 ½ 100mg tablets	150
14–19.9	2 100mg tablets	200
20–24.9	2 ½ 100mg tablets	250
> 25 (most adolescents)	**3 100mg tablets or 1 adult 300mg tablet**	**300**
Give vitamin B6 with INH at a dose of 25 mg daily.		

Source: WHO, Department of HIV/AIDS and Stop TB Department. (2011). *Guidelines for intensified tuberculosis case-finding and isoniazid preventive therapy for people living with HIV in resource-constrained settings.*

Treatment considerations in adolescents with TB and HIV:

- Prompt treatment is especially important for co-infected adolescents.
- Any ALHIV with active TB disease should begin TB treatment immediately and should start ART, regardless of CD4 cell count, as soon as possible — within 2-8 weeks.[2]
- The co-management of TB and HIV is complicated by drug interactions, particularly between rifampicin and the PI classes of ARVs. These drugs have similar routes of metabolism and co-administration may result in sub-therapeutic drug levels. EFV is the preferred NNRTI in patients starting ART while on TB treatment.
- Ensure all household contacts and anyone else with whom the client has had regular contact is referred to the clinic for screening and, if needed, treatment.

For information on the treatment of TB and HIV, see your national TB/HIV guidelines and WHO's *Guidance for National Tuberculosis and HIV Programmes on the Management of Tuberculosis in HIV-infected Children: Recommendations for a Public Health Approach,* 2010 (for younger adolescents) and *Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a Public Health Approach,* 2010 (for older adolescents).

Recommended ART regimens for adolescents with TB/HIV co-infection are included in Tables 3.7 and 3.8.

Adherence support:

- Provide ALHIV and caregivers with adherence counseling and monitoring at every clinic visit.
- Adherence support for IPT or anti-TB therapy can be included in the ART adherence discussion.

ART switching for ALHIV who develop TB while on 1st line ART:

- ART should continue in ALHIV already on a 1st line ART regimen who are subsequently diagnosed with TB. However, the ART 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 1st line regimen who develop TB, make adjustments to their ART regimen as follows:
  - If on a regimen of 2 NRTI + NVP, switch NVP with EFV.
  - If the ALHIV is on a PI regimen, consult an expert for guidance.
- **Note:** Where TB is being considered as a sign of treatment failure of the 1st line regimen, consider switching to a 2nd line regimen 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 2nd line regimen.

Neurocognitive and Developmental Disorders

HIV in children, particularly those infected perinatally, is associated with developmental delays and cognitive impairments. Cognitive impairments can include language, motor, and behavioral impairments. Some children living with HIV 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.

Assessment of neurocognitive and developmental status should be routinely incorporated into the care of all children and adolescents with HIV infection.

Signs and symptoms of neurocognitive and developmental disorders:

- Slowed psychomotor speed (taking longer than normal to understand what someone else is saying and then respond)
- Delayed expressive language skills (problems expressing oneself with language)
- Memory deficits (experiencing a loss of memory)
- Poor attention (difficulty concentrating or paying attention)
- Developmental impairment (failure to achieve developmental milestones); developmental impairment is most common among children who experienced severe immunodeficiency during the first few years of life. However, even children and youth with less advanced HIV disease can have mild to moderate developmental impairments related to HIV infection.
- Difficulty learning social behaviors and/or self-care

Management and treatment for neurocognitive and developmental disorders:

- Provide client and family with tailored supportive counseling that meets the unique strengths, disabilities, and needs of the adolescent
- Encourage caregivers to follow this general principle: reward effort, not results
- Ensure that the adolescent is on an adequate ART regimen to prevent or slow further progression of neurocognitive impairment
- Refer the client for neuropsychological testing
- Link client and family to specialized care and community-based resources for children and adolescents with intellectual and developmental disabilities, if available
- Provide the caregivers of older, stronger adolescents who are severely impaired with assistance and support, including through linkages to community resources

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

Purpose	To review clinical care and treatment of ALHIV according to national guidelines

Refer to Table 3.2: “Using the 5 ‘A’s’” to guide your case study discussions.

Case Study 1:
K___ recently tested HIV-positive at the district hospital. Today is her 1st visit to your clinic. Although she is 14 years old, you think that she acquired HIV through MTCT because she has never had sex and has no history of abuse. The fact that K___’s mother died of a disease described as TB when she was 16 months old has further supported your suspicion. Although she is relatively healthy, you notice that she takes longer than most 14-year-olds to understand what you are saying, she becomes impatient quickly with the clinic processes, and her auntie (her primary caregiver) complains that she doesn’t do well in school and has difficulty concentrating. You can’t help but notice that she looks more like a 10-year-old than a 14-year-old. *How do you proceed with K___?*

Case Study 2:
S___ is 17 years old and was diagnosed with HIV at the STI clinic about 2 months ago. This is her 2nd visit to the HIV clinic. After being screened for TB at her enrollment visit 1 month ago, she was started on both IPT and CTX. You just received her lab work and her CD4 cell count is 325 (even though she is clinical stage 2) and her Hb is 12 g/dl. *How do you proceed with S___?*

Case Study 3:
T___ is 17 years old and was diagnosed with HIV 1 year ago. T___ is quite healthy; at her last visit, her CD4 cell count was 500 and she was a clinical stage 1. The only reason she was tested last year was because she had heard through a friend that her old boyfriend was rumored to have HIV. Today, however, T___ looks thin and tired — much different from the way she looked the last time you saw her just 6 months ago. When she comes into the exam room, you realize that she has also been coughing. *How do you proceed with T___?*

Case Study 4:
A___ is 13 years old and acquired HIV perinatally. He is at the clinic today for his routine appointment. A___ has been on AZT + 3TC + EFV since he was 5 years old. He remains on this same regimen and was just discharged from the inpatient unit with bacterial pneumonia. When you examine A___ today, you realize that he has lost 4 kg since his last visit. His CD4 cell count is currently 350, when previously it was over 500. *How do you proceed with A___?*

Module 3: Key Points

- Some ALHIV will have acquired HIV perinatally, while others will have acquired HIV later in childhood or adolescence. Although their histories, experiences, and needs may differ significantly, there are also many similarities between these 2 groups of ALHIV.
- HIV programs for adolescents should include a broad package of services and support, including much more than just the provision of ART.
- Adolescent services should be age- and developmentally-appropriate and should be responsive to the needs of both perinatally and behaviorally infected clients.
- Providing "1-stop shopping," youth-friendly services, and family-focused care will better help meet the needs of adolescent clients.
- Health workers can use the 5 "A's" when providing clinical and psychosocial care and support to adolescent clients (and caregivers).
- Always refer to national guidelines and training packages for specific details and guidance on adolescent HIV care and treatment.
- The clinical assessment for a client with HIV needs to be thorough and should focus on clinical, laboratory, psychosocial, nutrition, and social parameters. It is also important to routinely assess clients' developmental and neurocognitive status.
- Where available, CD4 cell count should be measured at time of diagnosis and at least every 6 months thereafter, regardless of whether the ALHIV is on ART or not.
- The unavailability of laboratory monitoring, including CD4 and chemistries, should NOT prevent adolescents from receiving ART.
- Initiate CTX when CD4 count is <350cells/mm^3, regardless of clinical stage, or, if CD4 count is unavailable, start when adolescent is in clinical stage 2, 3, or 4.
- The decision to initiate ART is based on immunological and clinical criteria (CD4 ≤350 or WHO stage 3 or 4) and is also informed by other considerations, such as laboratory results, opportunistic infection screening, and adherence readiness. Always follow national guidelines.
- Health workers should be aware of and look out for possible events after ART initiation. It is important to allow at least 6 months before judging a regimen's effectiveness.
- After starting ART, clinical monitoring visits should occur at minimum at weeks 2, 4, 8, and 12, and then every 3 months. ALHIV not eligible for ART should visit the clinic every 3-6 months.
- Treatment failure is when ART stops controlling an individual's virus and he or she starts getting sicker. There are 3 criteria for treatment failure: clinical, immunologic, and virologic.
- All ALHIV should be screened for active TB, contact with a TB source case, and current TB symptoms at every visit to a health facility.
- All ALHIV with no evidence of active TB disease and no contraindications to IPT should begin IPT. ALHIV with active TB disease should begin TB treatment immediately and should also start ART as soon as possible. Always follow national TB guidelines.

Appendix 3A: Laboratory Monitoring Before, During, and After Initiating ART

Phase of HIV management	Recommended test	Desirable test
At HIV diagnosis	CD4	HBsAg
Pre-ART	CD4	
At start of ART	CD4	Hb for AZT[1] Creatinine clearance for TDF[2] ALT for NVP[3] Pregnancy test for sexually active adolescent females prior to initiating EFV
On ART	CD4	Hb for AZT[1] Creatinine clearance for TDF[2] ALT for NVP[3]
At clinical failure	CD4	Viral load
At immunological failure	Viral load	
Women exposed to PMCT interventions with sd-NVP with a tail within 12 months and without a tail within 6 months of initiating ART	Viral load 6 months after initiation of ART	

1 Recommended test in patients with high risk of adverse events associated with AZT (low CD4 or low BMI). For children and young adolescents, measure hemoglobin at week 8 after initiation of AZT-containing regimens, or more frequently if symptoms indicate.

2 Recommended test in patients with high risk of adverse events associated with TDF (underlying renal disease, older age group, low BMI, diabetes, hypertension, and concomitant use of a boosted PI or nephrotoxic drugs).

3 Recommended test in patients with high risk of adverse events associated with NVP (ART-naive HIV+ women with CD4 of >250 cells/mm^3, HCV coinfection).

Patients who are not yet eligible for ART should have CD4 count measurement every 6 months and more frequently as they approach the threshold to initiate ART. If feasible, HBsAg should be performed to identify people with HIV/HBV coinfection and who, therefore, should initiate TDF-containing ART.

Source: WHO. (2010). *Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach, 2010 revision*. Geneva: WHO.

Appendix 3B: HEADSS Interview Questions

✓	Topic and key points
	1. Home and environment
	• Where do you live and who lives there with you?
	• How many brothers and sisters do you have and what are their ages? Are your brothers and sisters healthy?
	• Are there any new people living in your home?
	• What are the rules like in your home?
	• 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 when there is a disagreement?
	• Is there anything you would like to change about your family?
	2. Education and employment
	• Are you in school? What are you good at in school? What is hard for you? What grades do you get?
	• Which school do you go to? Any recent changes in schools?
	• What do you like best and least about school? Favorite subjects? Worst subjects?
	• What were your most recent grades? Are these the same or different from past grades?
	• How many hours of homework do you do every day?
	• How much school did you miss last/this year?
	• What do you want to do when you finish school? Any future plans/goals?
	• Do you work now? How much? Have you worked in the past?
	• How do you get along with teachers? Employers?
	3. Activities
	• What do you do for fun? What things do you do with friends? What do you do with your free time?
	• Are most of your friends from school or somewhere else? Are they the same age as you?
	• Do you hang out with mainly people of your same sex or with a mixed crowd?
	• Do you have 1 best friend or a few friends? Do you have a lot of friends?
	• Do you spend time with your family? What do you do with your family?
	• Do you see your friends at school and on weekends? Are there a lot of parties?
	• Do you do any regular sport or exercise? What are your hobbies or interests?
	• Do you have a religious affiliation, belong to a church/temple/mosque/synagogue, or practice some kind of spiritual belief?
	• Do you read for fun? What do you read?
	• What is your favorite music?

✓	Topic and key points
	4. Drugs
	• Many young people experiment with drugs, alcohol, or cigarettes. Have you or your friends ever tried them? What have you tried?
	• When you go out with your friends or to a party, do most of the people you hang out with drink or smoke? Do you? How much and how often?
	• Does anyone in your family drink, smoke, or use other drugs? If so, how do you feel about this — is it a problem for you?
	• Have you or your friends ever tried any other drugs? Which drugs specifically? Have you ever used a needle?
	• Do you regularly use other drugs? How much and how often?
	• Have you ever been in a car accident or in trouble with the law? Were any of these related to drinking or using drugs?
	• How do you pay for your cigarettes, alcohol, or drugs?
	5. Sexuality
	• Are you involved in a relationship? Have you been involved in a relationship in the past? How was that experience for you?
	• How would you describe your feelings towards boys or girls?
	• How do you see yourself in terms of sexual preference, i.e. gay, straight, or bisexual?
	• Have you had sex? Was it a good experience? Are you comfortable with sexual activity? How many partners have you had?
	• Are you using contraception? What type and how often (10%, 50%, or 70% of the time)?
	• Have you ever been pregnant or had an abortion? For males, Ask: has a partner of yours ever been pregnant?
	• Have you ever had a discharge or sore that you are concerned about? What do you know about STDs and prevention?
	• Have you ever had a pap smear?
	• 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?
	• If someone abused you, who would you talk to about this? How do you think you would react to this?
	• For females: Ask about menarche, last menstrual period (LMP), and menstrual cycles. Also inquire about breast self examination (BSE) practices.
	• For males: Ask about testicular self-examination (TSE) practices.
	6. Depression/suicide
	See *Appendix 6B: Sample Screening Tools for Depression and Suicide.*

Adapted from: *H.E.A.D.S.S. — A Pyschosocial Interview For Adolescents*. Available at: http://search.phsa.ca/cgi-bin/MsmGo.exe?grab_id=0&page_id=8144&query=HEADSS

Appendix 3C: WHO Clinical Staging of HIV Disease in Children with Established HIV Infection

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

Clinical Stages	
Clinical Stage 1	
• Asymptomatic	• Persistent generalized lymphadenopathy
Clinical Stage 2	
• Unexplained persistent hepatosplenomegaly • Papular pruritic eruptions • Extensive wart virus infection • Extensive molluscum contagiosum • Unexplained persistent parotid enlargement	• Recurrent oral ulcerations • Lineal gingival erythema • Herpes zoster • Recurrent or chronic upper respiratory tract infection (otitis media, otorrhea, sinusitis, tonsillitis) • Fungal nail infections
Clinical Stage 3	
• Unexplained moderate malnutrition not adequately responding to standard therapy • Unexplained persistent diarrhea (14 days or more) • Unexplained persistent fever (above 37.5°C, intermittent or constant, for longer than 1 month) • Persistent oral Candidiasis (after first 6 weeks of life) • Oral hairy leukoplakia • Acute necrotizing ulcerative gingivitis/periodontitis	• Lymph node TB • Pulmonary TB • Severe recurrent bacterial pneumonia • Symptomatic lymphoid interstitial pneumonitis • Chronic HIV-associated lung disease including bronchiectasis • Unexplained anemia (<8.0 g/dl), neutropenia (<0.5x10^9/L^3) or chronic thrombocytopenia (<50 x 10^9/L^3)
Clinical Stage 4	
• Unexplained severe wasting, stunting, or severe malnutrition not responding to standard therapy • Pneumocystis pneumonia • Recurrent severe bacterial infections (e.g. empyema, pyomyositis, bone or joint infection, meningitis, but excluding pneumonia) • Chronic herpes simplex infection (orolabial or cutaneous of more than 1 month's duration, or visceral at any site) • Extrapulmonary TB • Kaposi sarcoma • Oesophageal candidiasis (or candiadisis of trachea, bronchi, or lungs) • Central nervous system toxoplasmosis (after the neonatal period)	• HIV encephalopathy • Cytomegalovirus (CMV) infection; retinitis or CMV infection affecting another organ, with onset at age more than 1 month • Extrapulmonary cryptococcosis, including meningitis • Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidioidomycosis, penicilliosis) • Chronic cryptosporidiosis (with diarrhea) • Chronic isosporiasis • Disseminated non-tuberculous mycobacterial infection • Cerebral or B cell non-Hodgkin lymphoma • Progressive multifocal leukoencephalopathy • HIV-associated cardiomyopathy or nephropathy
Some additional specific conditions can be included in regional classifications (e.g. penicilliosis in Asia, HIV-associated rectovaginal fistula in Southern Africa, reactivation of typanosomiasis in Latin America), see national guidelines.	

Source: WHO. (2010). *Antiretroviral therapy for HIV infection in infants and children: Towards universal access, recommendations for a public health approach, 2010 revision.* Geneva: WHO.

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

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

Clinical Stages	
Clinical Stage 1	
• Asymptomatic	• Persistent generalized lymphadenopathy
Clinical Stage 2	
• Moderate unexplained weight loss (under 10% of presumed or measured body weight) • Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis) • Herpes zoster	• Angular cheilitis • Recurrent oral ulceration • Papular pruritic eruptions • Seborrhoeic dermatitis • Fungal nail infections
Clinical Stage 3	
• Unexplained severe weight loss (over 10% of presumed or measured body weight) • Unexplained chronic diarrhea for longer than 1 month • Unexplained persistent fever (intermittent or constant for longer than 1 month) • Persistent oral candidiasis • Oral hairy leukoplakia • Pulmonary tuberculosis	• Severe bacterial infections (e.g. pneumonia, empyema, meningitis, pyomyositis, bone, or joint infection, bacteraemia, severe pelvic inflammatory disease) • Acute necrotizing ulcerative stomatitis, gingivitis, or periodontitis • Unexplained anemia (below 8 g/dl), neutropenia (below 0.5 x 10^9/l), and/or chronic thrombocytopenia (below 50 x 10^9/l)
Clinical Stage 4	
• HIV wasting syndrome • *Pneumocystis jiroveci* pneumonia • Recurrent severe bacterial pneumonia • Chronic herpes simplex infection (orolabial, genital, or anorectal of more than 1 month's duration or visceral at any site) • Oesophageal candidiasis (or candidiasis of trachea, bronchi, or lungs) • Extrapulmonary tuberculosis • Kaposi sarcoma • Cytomegalovirus disease (retinitis or infection of other organs, excluding liver, spleen, and • lymph nodes) • Central nervous system toxoplasmosis • HIV encephalopathy	• Extrapulmonary cryptococcosis, including meningitis • Disseminated nontuberculous mycobacteria infection • Progressive multifocal leukoencephalopathy • Chronic cryptosporidiosis • Chronic isosporiasis • Disseminated mycosis (histoplasmosis, coccidiomycosis) • Recurrent septicaemia (including nontyphoidal Salmonella) • Lymphoma (cerebral or B cell non-Hodgkin) • Invasive cervical carcinoma • Atypical disseminated leishmaniasis • Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy

Source: WHO. (2006). *Revised WHO clinical staging and immunological classification of HIV and case definition of HIV for surveillance*. Geneva: WHO.

Appendix 3E: Preferred 2nd line ART Options

Recommended 2nd line regimens for adolescents younger than 15 years of age in the event of treatment failure of 1st line regimens

Recommended 2nd Line: Boosted PI component + 2 NRTI components					
	Preferred 2nd line regimen				
1st line regimen at failure	**RTI components (NRTI/NNRTI)[a]**		**PI component**	**Strength of recommendation**	**Quality of evidence**
2 NRTIs + 1 NNRTI: AZT- or d4T-containing	ABC + 3TC OR ABC + ddI	PLUS	LPV/r[d]	Strong	Moderate
OR ABC-containing	AZT + 3TC OR AZT + ddI		LPV/r[d]	Strong	High
Triple NRTI	ddI[b] + EFV[c] OR NVP		LPV/r[d]	Strong	High

[a] Continuation of 3TC in 2nd line regimens may be considered.

[b] ddI may not need to be taken on an empty stomach in children.

[c] EFV is currently not recommended for children <3 years of age, and should be avoided in post-pubertal adolescent girls who are either in the 1st trimester of pregnancy or are sexually active and not using adequate contraception.

[d] LPV/r is available as solid and liquid co-formulations.

Source: WHO. (2010). *Antiretroviral therapy for HIV infection in infants and children: Towards universal access.* Geneva: WHO.

Recommended 2nd line ARV therapy for adolescents and adults 15 years of age or older in the event of treatment failure of 1st line regimens

Target population		Preferred options	Comments
Adults and adolescents (including pregnant women)	If d4T or AZT used in 1st line therapy	TDF + 3TC or FTC + ATV/r or LPV/r	NRTI sequencing based on availability of FDCs and potential for retained antiviral activity, considering early and late switch scenarios ATV/r and LPVr are comparable and available as heat-stable FDCs or co-package formulations
	If TDF used in 1st line therapy	AZT + 3TC + ATV/r or LPVr	
TB/HIV coinfection	If rifabutin available	Same regimens as recommended above for adults and adolescents	No difference in efficacy between rifabutin and rifampicin Rifabutin has significantly less drug interaction with bPIs, permitting standard bPI dosing
	If rifabutin not available	Same NRTI backbones as recommended for adults and adolescents plus LPVr or SQV/r with superboosted dosing of RTV (LPV/r 400 mg/400 mg twice daily or LPV/r 800 mg/200 mg twice daily or SQV/r 400 mg/400 mg twice daily)	Rifampicin significantly reduces the levels of bPIs, limiting the effective options. Use of extra doses of ritonavir with selected bPIs (LPV and SQV) can overcome this effect but with increased rates of toxicity
Hepatitis B coinfection		AZT + TDF + 3TC or FTC + ATV/r or LPVr	In case of ART failure, TDF + 3TC or FTC should be maintained for anti-HBV activity and the 2nd line regimen should include other drugs with anti-HIV activity

Source: WHO. (2010). *Antiretroviral therapy for HIV infection in adults and adolescents: recommendations for a public health approach, 2010 revision.* Geneva: WHO.

Appendix 3F: ARV Dosages for Older Adolescents and Adults

Generic Name	Dose
Nucleoside reverse transcriptase inhibitors (NRTIs)	
Abacavir (ABC)	300 mg twice daily or 600 mg once daily
Didanosine (ddI)	400 mg once daily (>60 kg) 250 mg once daily (≤60 kg)
Emtricitabine (FTC)	200 mg once daily
Lamivudine (3TC)	150 mg twice daily or 300 mg twice daily
Stavudine (d4T)	30 mg twice daily
Zidovudine (AZT)	250-300 mg twice daily
Nucleotide reverse transcriptase inhibitors (NtRTIs)	
Tenofovir (TDF)	300 mg once daily[1]
Non-nucleoside reverse transcriptase inhibitors (NNRTIs)	
Efavirenz (EFV)	600 mg once daily
Etravirine (ETV)	200 mg twice daily
Nevirapine (NVP)	200 mg once daily for 14 days, followed by 200 mg twice daily[2]
Proteases inhibitors (PIs)	
Atazanavir + ritonavir (ATV/r)	300 mg + 100 mg once daily
Darunavir + ritonavir (DRV/r)	600 mg + 100 mg twice daily
Fos-amprenavir + ritonavir (FPV/r)	700 mg + 100 mg twice daily
Indinavir + ritonavir (IDV/r)	800 mg + 100 mg twice daily
Lopinavir/ritonavir (LPV/r)	Fixed Dose Combination tablets (LPV 200 mg/RTV 50 mg) Two tablets (400 mg/100 mg) twice daily[3]
	Considerations for individuals on TB therapy: • In the presence of rifabutin, no dose adjustment required • In the presence of rifampicin, use ritonavir superboosting (LPV 400 mg + RTV 400 mg twice daily) or LPV 800 mg + RTV 200 MG twice daily, with close clinical and hepatic enzyme monitoring
Saquinavir + ritonavir (SQV/r)	1000 mg + 100 mg twice daily
	Considerations for individual on TB therapy: • In the presence of rifabutin, no dose adjustment required • In the presence of rifampicin, use ritonavir superboosting (SQ 400 mg + RTV 400 mg twice daily) with close clinical and hepatic enzyme monitoring
Integrase strand transfer inhibitors (INSTIs)	
Raltegravir (RAL)	400 mg twice daily

[1] TDF dosage adjustment for individual with altered creatinine clearance can be reconsidered (using Cockcroft-Gault formula).
Creatinine clearance ≥50ml/min. 300 mg once daily.
Creatinine clearance 30-49 ml/min. 300 mg every 48 hours.
Creatinine clearance 10-29 ml/min (or dialysis). 300 mg once every 72-96 hours.
Cockcroft-Gault formula: *GFR = (140-age) x (Wt in kg) X (0.85 if female) / (72 x Cr)*

[2] In the presence of rifampicin, or when patients switch from EFC to NVP, no need for lead-in dose of NVP.

[3] LPV/r can be administered as 4 tablets once daily (i.e. LPV 800 mg + RTV 200 mg once daily) in patients with less than three LPV resistance-associated mutations on genotypic testing. Once-daily dosing is not recommended in pregnant women or patients with more than three LPV resistance-associated mutations.

Source: WHO. (2010). *Antiretroviral therapy for HIV infection in adults and adolescents. Recommendations for a public health approach, 2010 revision.* Geneva: WHO.

For information on serious, acute, and chronic toxicities, see: WHO's *Antiretroviral Therapy for HIV Infection in Adults and Adolescents. Recommendations for a Public Health Approach, 2010 Revision*. Available at: http://www.who.int/hiv/pub/arv/adult2010/en/index.html

For more information on pediatric ARV dosing, including simplified dosing charts, refer to your national pediatric ART guidelines and WHO (2010) *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access*. Geneva: WHO. Look for *ANNEX E: Prescribing Information and Weight-based Dosing of Available ARV Formulations for Infants and Children*, which starts on page 101. Available at: http://www.who.int/hiv/pub/paediatric/infants2010/en/index.html

Appendix 3G: TB Screening Tool for Children and Younger Adolescents

Name: ___________________________________ **ART#:** ______________________ **Gender: M F Date of Birth:** ___/___/___

Date of Screening:	/ /	/ /	/ /	/ /	/ /	/ /
Age:						
1. **Is child currently receiving anti-TB medications?** (Yes or No) If Yes, STOP Screen. Rescreen after completion of TB Treatment. If No, answer questions below.	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
2. **Is child currently receiving Isoniazid Prophylactic Therapy (IPT)?** (Yes or No)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
3. **TB Exposure History:** Close contact with a person diagnosed with pulmonary TB in the **past 12 months**? (Yes or No)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
4. **TB Symptom Screen:** Does the child **currently have** any of the following TB symptoms? (Yes or No)						
A. Does child currently have cough?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
B. Does child have documented weight loss or failure to thrive during the past 3 months, not responding to nutritional rehabilitation?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
C. Does child have fever?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Screening Results: (A through C above) **Positive =** presence of **one or more of symptoms** **Negative=** absence of all symptoms	☐ Positive ☐ Negative	☐ Positive ☐ Negative	☐ Positive ☐ Negative	☐ Positive ☐ Negative	☐ Positive ☐ Negative	☐ Positive ☐ Negative
5. **Follow up:**						
A. Child Has <u>No Exposure to TB</u> and <u>TB Symptom Screen is Negative</u>: Re-screen in 6 months. Write date for next screen.	/ /	/ /	/ /	/ /	/ /	/ /
B. Child Has <u>Exposure to TB</u> and /or <u>Positive Symptom Screen</u>: Child is a **TB Suspect** and needs to be evaluated for TB disease. This includes physical exam, CXR, sputum for AFB, gastric aspirate, or Induced sputum	☐ CXR ☐ AFB Smear	☐ CXR ☐ AFB Smear	☐ CXR ☐ AFB Smear	☐ CXR ☐ AFB Smear	☐ CXR ☐ AFB Smear	☐ CXR ☐ AFB Smear
6. **Nurse Initial/Signature:**						

Instructions

→ **For new forms:** Record the **Patient's Name**, **ART Number, Gender,** and **Date of Birth** at the top of the form.
→ **For previously used forms:** Review the notes about the previous visit screen before starting.
→ **Screening date:** Record the day (**DD**), month (**MM**), and year (**YY**) screening was performed.
→ **Age**: Record the child's age.

1) Is child currently receiving anti-TB medications? Ask the caregiver if child is currently on anti-TB treatment? **(Yes)** If yes, stop screen. Rescreen after completion of anti-TB treatment. **(No)** Continue TB screen by asking questions below.

2) Is child currently on Isoniazid Prophylactic therapy (IPT)? Yes (Y) or No (N). Children on IPT should be screened carefully for signs and symptoms of TB.

3) TB Exposure History: Ask the parent or caregiver if the child has been in close contact (living in the same household or in frequent contact) with any person who was diagnosed with pulmonary TB in the past 12 months. Write **(Yes)** if the child has a close contact with pulmonary TB and **(No)** if there is no history of TB contact.

4) TB Symptom Screen: Complete TB screening by asking the caregiver if the child currently has any of the TB symptoms. Write (Yes) or (No) in the appropriate column.

A. Does child currently have a cough?
B. Documented weight loss or failure to thrive, clear deviation from previous growth trajectory, and/or documented crossing of percentile lines during the past 3 months, not responding to nutritional rehabilitation. For growth assessment, please look at the growth chart to ascertain if there has been growth failure.
C. Does child have fever?

TB Screening Outcome:
Presence of any symptom = **Positive**
Absence of all symptoms = **Negative**
Tick the appropriate box

5) Follow-up:

A. Child Has <u>No Exposure to TB</u> and <u>TB Symptom Screen is</u> <u>Negative</u>: Rescreen the child in 6 months. Record the date of the next screen in the space provided.
B. Child Has <u>Exposure to TB</u> and/or <u>Positive Symptom Screen</u>: Child is a TB suspect. Child needs full diagnostic work-up for TB. This includes physical exam, CXR, sputum for AFB smear, gastric lavage, etc.

6) Nurse Initial/Signature

Appendix 3H: TB Screening Tool for Older Adolescents and Adults

Patient's Name:____

Follow-up Visits

Adult & adolescents TB screening questions		**Date: __/___/____ Screening result: Yes/No**	**Date:___/___/____ Screening result: Yes/No**	**Date:___/___/____ Screening result: Yes/No**	**Date:___/___/____ Screening result: Yes/No**	**Date:___/___/____ Screening result: Yes/No**
1. Current cough		☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
2. Fever		☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
3. Weight loss		☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
4. Night sweats		☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Evaluate for TB if "yes" to anyone of the above (positive TB screening)						
Bacteriology: Sputum for AFB(+/_induced)	Done = ☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	Result (AFB +, -ve, unknown)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Radiology: CxR, etc.	Done = ☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	Result (Suggestive, inconclusive, other dx, unknown etc.)	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
FNA, Culture, Ultrasound, etc.	Done = ☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
	If done result	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
TB diagnosed	☐ Yes (write type of TB) ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Is patient eligible for IPT	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Contraindications for IPT: Active hepatitis (acute or chronic), regular and heavy alcohol consumption or symptoms of peripheral neuropathy						
IPT start date:						
Date INH collected	**TB Symptoms [cough, fever, weight loss] (Yes/No)**	**Hepatotoxicity [abd pain, nausea, jaundice,vomiting, abnormal LFT] (Yes/No)**	**Neurologic Sx [numbness, tingling, paresthesia] (Yes/No)**	**Rash (Yes/No)**	**Adherence (≥90% =good; 80-90%= Fair <80%=Poor)**	**Remarks**
/ /						
/ /						
/ /						
/ /						
/ /						

Outcome of IPT(Date):
Completed:___/___/____ Defaulted:___/___/____ Died:___/___/____ Pt stopped:___/___/____ Provider stopped:___/___/____Transferred out:___/___/___

Drafted by ICAP-Ethiopia.

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Module 4 Communicating with and Counseling Adolescents

Session 4.1: Establishing Trust and Rapport with Adolescent Clients

Session 4.2: Effective Techniques for Counseling Adolescents

Learning Objectives

After completing this module, participants will be able to:

- Discuss ways of establishing trust and rapport with adolescent clients
- Demonstrate effective counseling skills

Session 4.1 Establishing Trust and Rapport with Adolescent Clients

Session Objective

After completing this session, participants will be able to:

- Discuss ways of establishing trust and rapport with adolescent clients

Strategies for Establishing Trust and Rapport with Adolescent Clients[1]

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

- Adolescence is a unique phase of life and adolescents are going through dramatic biological and emotional changes. Seeking health care may seem challenging to young people because the normal changes of adolescence affect their self-confidence, relationships, social skills, and general thinking.
- Adolescents may feel fearful, embarrassed, or uncomfortable around health workers. They may be reluctant to disclose personal information because they fear 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 health workers. **Health workers should always reassure adolescents during one-to-one counseling sessions that what is discussed in the counseling session will remain confidential.**
  - Clarify what this means: although the health worker may have to share information with other health 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. Discussions had with clients are not even shared with caregivers or partners, unless the client gives explicit permission.

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

- *Shy* about being in a clinic and 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, etc.)
- *Worried* that someone will see them and tell their parents or other people
- *Inadequate* at describing their concerns and ill-informed about health matters in general
- *Anxious* that they have a serious condition that will have 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 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 related to living with HIV
- *Loyal* to a health worker with whom they have a long-established relationship
- *Hopeful* that clinic staff can provide them with care that will make them more comfortable and able to live a normal life

The following are tips for building rapport with adolescents:

- Treat everyone equally and with respect.
- Be genuinely open to adolescents' questions or need for information.
- Do not use judgmental words or body language. Do not talk down to adolescents by scolding, shouting, blaming, or getting angry.
- Use words and language that adolescents can understand and that 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 adolescents' appearance, concerns, or behavior.
- If sensitive issues are being discussed, make sure that conversations are not seen or overheard by others.
- Reassure adolescents 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 clients, including what they say or that they are living with HIV.
- Do not threaten to break adolescents' confidentiality "for their own good."
- Adolescents may be reluctant to disclose personal information if their parents or caregivers are present. Health workers should stress that information entrusted with them will not be shared — even with caregivers — unless the client gives his or her permission.
- Allow enough time for adolescents 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 to put yourself "in the adolescent's shoes."
- Understand that adolescents 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	
Purpose	To practice establishing rapport and building trust with adolescent clients

Case Study 1

M___ is 18 years old and recently found out that she is HIV infected. She disclosed her HIV-status to her boyfriend who, much to her surprise, broke up with her immediately. Now M___ is not only heart-broken but also worried that her ex-boyfriend will, out of spite, disclose her HIV-status to others. *How do you proceed with M___?*

Case Study 2

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

Session 4.2 Effective Techniques for Counseling Adolescents

Session Objective

After completing this session, participants will be able to:

- Demonstrate effective counseling skills

Overview of Counseling and Communication

Why do we counsel people?

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

Counseling includes:

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

Remember: Counseling requires that health workers recognize their own values (this often requires values clarification — see Exercise 3 in Module 1) and that they ensure that their values are not imposed on others.

Counseling 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

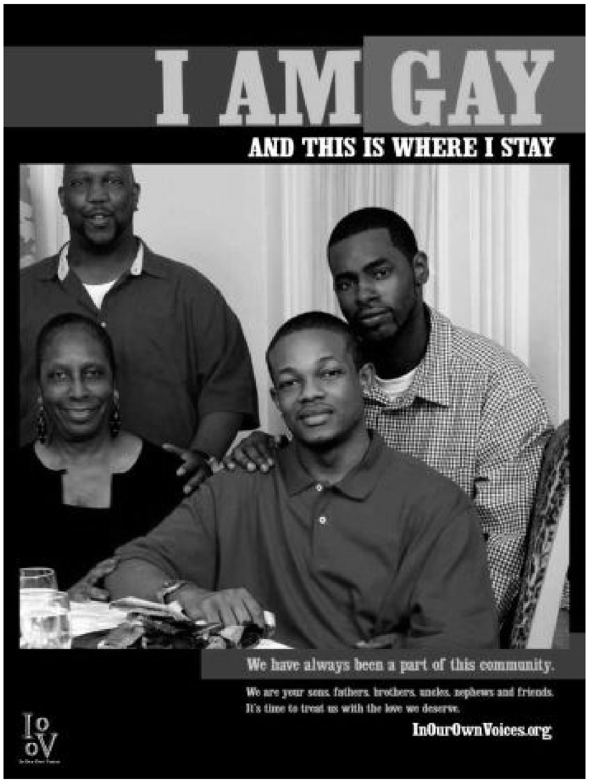
Communicating with Adolescents

General tips for communicating with adolescents[1]:

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

- **Ask indirect questions:** Initially, ask about the behavior of peers and friends rather than asking direct questions about the adolescent's own behavior: *"Do any of your friends smoke pot/dagga?"; "Have you ever joined them?"*

Figure 4.1: "I am gay" poster



- **Reduce stigma around an issue by normalizing the issue:** An adolescent who is living with HIV may feel embarrassed seeking help to deal with different issues, but you can reduce stigma and feelings 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 they 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 hang posters in common areas that communicate important messages in an eye-catching, youth-friendly manner. See Figure 4.1 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." This type of poster would communicate to a young homosexual man that the clinic is gay-friendly, making him more likely to open up about his sexuality.

- **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 thus telling the client how he or she should feel, you could respond by asking, "*So it doesn't bother you that your family is giving you a hard time? How does this make you feel?*" When put into a question, many adolescents begin to re-think the statements 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 recognize that they are not alone in dealing with the types of problems they have. ALHIV may not respond to adults who tell them to take their medication every day; but they might listen to a peer who tells them the same thing. Using other adolescents who have struggled with the same problems related to care and treatment, like adherence challenges or disclosure, can be an extremely effective motivator for adolescent clients. 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.
- They need some time to observe you! Do not expect them to instantly begin talking. Allow plenty of time and be patient.
- They may feel scared and they may fear being judged.
- They may feel anxious or embarrassed when asking for help.
- Explain things in simple terms.
- Younger adolescents understand concrete things that they can touch and see. Drawing, demonstrations, or visual aids can be used to make information more concrete.
- Just because an adolescent is not asking questions does not mean that he or she is not thinking about what is being said.
- Do not force adolescents to share. Positively reinforce their efforts to express themselves.
- If a youth is rude or aggressive, remember that this behavior may not be directed at you. He or she may be feeling angry with adults in general for treating him or her badly or for letting him or her down. Be patient and don't take it personally.

Considerations when communicating with older adolescents:

Like younger adolescents, older adolescents also need to feel safe and may feel embarrassed asking for help. However, to earn the trust of older adolescents, health worker will need to try somewhat different strategies than those used with younger adolescents.

- Ask older adolescents about the things that are important to them: hobbies, friends, sports, fashion, cars/motorbikes, music, family, boy/girlfriends, etc. Get to know older adolescents as a way of establishing trust.
- Try to understand the perspective of adolescent clients. Keep in mind that their life experiences are still relatively limited. When providing advice to adolescents, do so from the perspective that they have not yet had the opportunity to appreciate or know what you are explaining to them, rather than scolding them for their lack of knowledge. Never criticize them or say something they may interpret as criticism.
- Never assume that they are not yet sexually active. Also never assume that they ***are*** sexually active. The best way to know for sure is to build trust and rapport with adolescent clients so they feel comfortable sharing this type of information with you.
- Do not assume that any one adolescent has the same interests or issues as other adolescents you have met recently. Adolescent clients may pride themselves on having the confidence to be different.
- In summary, never make assumptions, use open-ended questions (discussed in the next section), and always remain non-judgmental.

Table 4.1: Activities to do with adolescents to promote expression

Appropriate for…		Activity
Younger adolescents?	**Older adolescents?**	
Yes	**Probably not**	**Storytelling or reading together**: The health worker could read or tell a story during a group or individual counseling session. After finishing the story, the health worker should ask key questions to encourage thought and discussion.
Yes	**Yes**	**Journaling**: Encourage adolescent clients to keep a journal or diary. The journal is a place adolescents can write about what is happening in their lives and how they feel about it (for example, they could answer the question, *How would I describe myself?* or fill in the sentence, *Last week I felt…..because….).* Younger adolescents may prefer to draw in their journals.
Yes	**Probably not**	**Drawing**: Encourage clients to draw a picture of their families or their homes. The health worker should then ask questions about the drawing to show interest and encourage expression: • *"Tell me about your drawing."* • *"What happened here?"* • *"How did you feel then?"*
Yes	**Yes**	**Letter writing**: Encourage adolescent clients to write letters to friends or family members about what is happening or how they are feeling.
Yes	**Yes**	**Doing something fun**: Do 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[2,3,4]

Good counselors use verbal and non-verbal listening and learning skills to help clients through their process of exploration, understanding, and action. Specifically, when communicating with and counseling clients, health workers should use the following 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 summarize each counseling session

For additional information, refer participants to *Appendix 4B: General Tips on How to Talk with Adolescents, Appendix 4C: Basic Counseling 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 conversation that convey information without the use of words. This includes messages conveyed through gestures, gaze, posture, and facial expressions. Non-verbal communication reflects people's attitudes. Helpful non-verbal communication encourages the client to feel that the health worker is listening and cares about what is being said.

The acronym "ROLES," as shown in Table 4.2, can be used to help remind health workers of behaviors that convey caring.

Table 4.2: ROLES

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

Note: These physical behaviors convey respect and genuine caring; however, these are only guidelines and should be adapted based on cultural and social expectations.

Skill 2: Actively Listen and Show Interest in the Client

Another way of showing that you are interested and want to encourage a client to talk is by using gestures like nodding and smiling, responses like *"Mmm"* or *"Aha,"* and skills like clarifying and summarizing. These behaviors, also referred to as attending skills, demonstrate that the health worker is actively listening to the client. They also invite the client to relax and talk about him- or herself.

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

Summarizing: Summarizing means pulling together the themes that have come up during a counseling discussion so the client can see the whole picture. Summarizing helps ensure that the client and the health worker understand each other.

- Health workers should review the important points of the discussion and highlight any decisions made.
- Health workers can summarize key points at any time during the counseling session, not just at the end.
- Summarizing can offer support and encouragement to clients and help them carry out the decisions they have made related to their own health and well being.

Table 4.3: Example of actively listening and showing interest

What to do
HW: *Hey, you seem sad today. What's going on?*
Male adolescent client: *It's school, I don't want to go anymore.*
HW: *umhumm** (nods understandingly)
Adolescent: *Well, it's not really school, it's the other pupils at school…I don't have any friends.*
HW: *So, you don't like going to school because you feel like you don't fit in?***
Adolescent: *Yeah, the other children make fun of me. They call me mean names.*
HW: *umhumm**
Adolescent: Y*esterday one of the bigger boys even pushed me to the ground and tried to take my pocket money.*
HW: *That's terrible. It seems to me that the other boys are harassing you. What one thing would you like to change to make this situation better?****
* A gesture that shows interest ** Clarifying *** Summarizing

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 words like "*how," "what," "when," "where,"* or *"why."* An example of an open-ended question is: *"When was the last time you used a condom?"* This type of question encourages the client to talk openly and in a way that leads to further discussion. They help clients explain their feelings and concerns, and they also help counselors get the information they need to help clients make decisions.

Closed-ended questions, on the other hand, usually start with words like *"are you?," "did he?," "has she?,"* or *"do you?,"* and usually only require a *"Yes"* or *"No"* answer. An example of a closed-ended question is: *"Do you use condoms?"* Closed-ended questions are good for gathering basic information at the start of a counseling or group education session. However, they are less helpful in getting at how the client is really feeling.

In general, health workers should try to avoid asking questions that have a *"Yes"* or *"No"* answer. Therefore, instead of asking, *"Are you concerned about talking to your family about your diagnosis?,"* you could 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 could ask, *"How many times have you taken your ARVs in the last 3 days*?" *"What problems have you had taking your ARVs lately?" "Which doses did you miss?" "What can you do to make it easier to remember the doses that you tend to miss?"*

Please note that very sensitive questions, particularly when working with adolescents, are easier to ask as close-ended rather than open-ended questions. For example, when asking if a client is sexually active, it may be offensive to the inexperienced client if you ask, *"When was the last time you had sex?"* Instead, it may be more appropriate to say, *"Many adolescents have sex with their partners. Are you having sex*?," even though this is a closed ended question.

Skill 4: Reflect Back What the Client is Saying

"Reflecting back," also referred to as paraphrasing, means repeating back what a client has said in order to encourage him or her to say more. Try saying what the client has said, but in a slightly different way. For example, if a client says, *"I can't tell my boyfriend about my HIV-status,"* the health worker could reflect back by saying, *"It sounds like talking to your partner is not something that you feel comfortable doing right now."* After the client confirms that this is accurate, the health worker could then say, *"Let's talk about that some more."*

Health workers 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 didn't know what to do."*

Reflecting back shows that the health worker is actively listening, it encourages dialogue, and it helps the health worker understand the client's feelings in greater detail.

Exercise 2: Reflecting Back: Pair work	
Purpose	To practice reflecting back what the client is saying

Scenario and scripts:

- You are the mother of a 15-year-old male ALHIV. You initiate the counseling session with the health worker by saying:
    - *“Two days ago, I found my son, I___, looking at pornographic magazines. I’m not sure how I feel about this.”*
- You are a 16-year-old ALHIV. When the *health* worker asks you how you are doing today, you say:
    - *“I’m not doing very well. I’m actually glad to be here today because it means I don’t have to be at school. I really don’t like going to school.”*
- You are the aunt of a 15-year-old female ALHIV whom you have accompanied to the clinic today. You step into the health worker’s office without your niece and explain the following:
    - *“I think my niece, who is here today for her appointment, has an older boyfriend who is buying her new clothes and perfumes.”*
- You are a 16-year-old female client who has been coming to the ART clinic since you were a child. Today at your appointment, you tell the health worker:
    - *“I know that you wanted me to tell my boyfriend that I have HIV, but the time just hasn’t been right to tell him yet.”*
- You are a 17-year-old female. When the health worker asks you how you are doing today, you say:
    - *“I’m finishing school next month. I have to admit, although I’m looking forward to school being over, I’m also a bit worried about what I’m going to do next. I haven’t yet been accepted to a university and I don’t have a job.”*

Skill 5: Empathize — Show That You Understand How the Client Feels

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

Showing empathy helps encourage clients to discuss issues further. For example, if a client says, *"I just can't tell my partner that I have HIV!,"* the health worker could respond by saying, *"It sounds like you might be afraid of your partner's reaction."* Or 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 health worker could respond by saying: *"That must be really upsetting. It sounds like you feel very frustrated with him."* If, on the other hand, the health worker responds with a factual question like, *"How often do you have these kinds of fights about condoms?,"* the client may feel that the health worker does not understand because his or her response was not in reference to the client's underlying feelings.

Empathy is used to respond to emotional statements. When empathizing, the health worker identifies and articulates the emotions behind a client's statement. This is different from "Skill 4: Reflect back what the client is saying," which is used to summarize a conversation that is primarily factual.

Skill 6: Avoid Judging Words

Judging words are words like: *right, wrong, well, badly, good, enough,* and *properly*. If a health worker uses judging words when asking questions, adolescent clients may feel that they are in the wrong or that they need to respond in a certain way to avoid disappointing the health worker. Health workers should also avoid phrasing questions in a way that is judging, which means asking questions that lead the client to respond in a certain way because they are scared to disappoint the health worker. Examples of what **NOT** to do:

Examples of using judging words

HW:	*Did you listen to me and use a condom?*
Client:	*Um…yes.*
HW:	*Did you take your medicine correctly (or properly)?*
Client	*I think so.*
HW:	*Didn't you understand what I told you about taking your medicine?*
Client:	*I don't know, I think so.*
HW:	*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?)*
Client:	*Well, yes, I tried to talk to her….*

Notice in these examples that the client has not fully responded to the health worker's questions. Instead, the health worker is making the client uncomfortable. In such situations, it is quite likely that the client will give the health worker a misleading response because he or she fears being judged.

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

More examples using open-ended questions and avoiding judging words:

Examples of using non-judging words	
HW:	*What form of family planning, if any, did you use the last time you had sex?*
HW:	*How many times in the last 3 days have you taken your ARVs?*
HW:	*When do you usually take your medicines? How do you take them (with water? with food?, etc.)? What has been your experience with taking ART? What problems, if any, have you had taking your ARVs?*
HW:	*Can we go back to our discussion about disclosure? Who have you told about your HIV test result since your last visit?*

Note: Sometimes a health worker needs to use "good" judging words to build a client's confidence and to recognize and praise him or her for doing the right thing.

Example of using judging words to build confidence	
HW:	*You are doing a great job remembering to come to your appointments.*
HW:	*You are doing the right thing for yourself and your baby by taking your ARVs.*

Skill 7: Help the Client Set Goals and Summarize Each Counseling Session

Toward the end of a session, the health worker should work with the adolescent client to come up with "next steps" and to summarize the session:

- **Develop "next steps"**: The health worker could initiate this part of the discussion by saying, *"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 health 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?*
- **Summarize the client's plan and review next steps**: The health 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 he or she has an appointment.
- **Record key points of the session and next steps in the client's clinical notes.**

Next steps and goals should:

- Be developed by the health 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)

Note: "Motivational interviewing" is a technique that aims to help clients identify and change behaviors that may be placing them at risk of developing health problems or may be preventing optimal management of a chronic condition. All of the listening and learning skills just covered are used in motivational interviewing. Additional information about motivational interviewing can be found in *Appendix 4E: Motivational Interviewing.*

Tips for Counseling Adolescents

- Involve adolescents in their care! (Of course, their involvement should be appropriate given their interest level and developmental stage.)
- Assess each adolescent's emotional and developmental level (including level of understanding, capacity to express him- or herself, and capacity for self-care). This will help ensure that expectations of the adolescent are appropriate.
- Keep in mind the changing capacities of each adolescent.
  - With very young adolescents, the focus of the counseling session is generally on the caregiver.
  - As adolescents get older, their understanding and ability to express themselves continually improve and the focus shifts away from the caregiver.
  - However, because of differences between adolescents, it is important that counseling is always adapted to the needs of each particular adolescent.
- Find out what the adolescent knows and be guided by the questions he or she asks.
- Listen to ALHIV, reflect back their feelings, offer empathy, and show that you care about what they are going through. ALHIV may be angry, depressed, or afraid — especially after learning about their diagnosis.
- Encourage them to ask questions to check their understanding.
- Be aware of each adolescent's attention span. (Younger adolescents will usually lose interest more quickly than older adolescents.)
- Watch the adolescent's body language to determine if he or she is taking in the information (for example, fidgeting, slumping, changing the subject, or falling asleep are indications he or she is not). If the adolescent is inattentive, stop and try again at a later time.
- Schedule adolescents to see the health worker with whom they best get along/relate. Sometimes an adolescent will feel more comfortable with one particular health worker than with another. Use the skills, strengths, and approaches of different health workers on the multidisciplinary team to meet clients' needs.

Advice on dealing with difficult counseling scenarios can be found in *Appendix 4F: Common Counseling Scenarios*.

Exercise 3: Practicing Listening and Learning Skills: Case studies in small groups and large group discussion

Purpose	To provide participants with an opportunity to gain experience using listening and learning skills with adolescent clients

This exercise consists of 3 parts:

- (Optional) Part 1: Trainer Demonstration
- Part 2: Small Group Work
- Part 3: Large Group Discussion

Refer to *Appendix 4D: Listening and Learning Skills Checklist* during Parts 1 and 2. The case studies for Part 2 appear below.

Part 1: Trainer Demonstration

G___, who has had HIV since she was a baby, has been coming to your clinic ever since you can remember. G___ is now 19 years old and, while at clinic today, she asked for a pregnancy test. Although she has had the same boyfriend since she was 14, she looks upset when you tell her that the test result is positive.

Part 2: Small Group Work

Case Study 1:
M___ is an 18-year-old client you see regularly at the ART clinic. He tells you that he has a male partner he sees on the weekends. He also tells you that he is very worried that his family and friends at school will find out that he is HIV infected. *How do you counsel M___?*

Case Study 2:
P___ is a 12-year-old girl who acquired HIV perinatally. Her mother died when she was 5 and she has been living with her grandmother ever since. Her grandmother does not like to talk about P___'s HIV-status and none of P___'s friends know she has HIV. When you speak to P___, she doesn't say anything and keeps looking at the floor with her arms crossed. *How do you counsel P___?*

Case Study 3:
G___ is a 16-year-old young man 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, that he isn't doing well in school, and that he feels really angry most of the time. His girlfriend is threatening to break up with him because of his moodiness. When you ask him questions, he gives you short responses in an angry voice. *How do you counsel G___?*

Module 4: Key Points

- Establishing a comfortable and open relationship is the foundation for communication and education, and it increases the chances that the client will return to the clinic and stay engaged in care.
- When asked by health workers about sensitive issues like sexual activity, adolescents may be reluctant or embarrassed to disclose information because they fear being scolded or mocked.
- When communicating with adolescent clients, it is important to be respectful, to ensure privacy, to maintain confidentiality, to be honest, to use language they understand, and to be open to their ideas and choices — even if they are not the ones you would have wanted them to make.
- Some communication and counseling tips for adolescents are: start the conversation by building rapport and by discussing non-threatening issues, ask indirect questions, and try to reduce stigma around a sensitive issue by normalizing it.
- Younger adolescents sometimes require a more activity-based approach to counseling — using storytelling, games, reading, art, etc.
- Good communication is the key component to effective counseling. The 7 key listening and learning skills health workers should always use are:
  - 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 summarize each counseling session.

Appendix 4A: Common Counseling Mistakes[3]

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

- Not allowing enough time for counseling, which can make it hard for the client to take in all the information and react to it.
- Conducting counseling in a non-private space, like in a corridor or waiting area, or allowing interruptions during the counseling session.
- Controlling the discussion instead of allowing the client to control it and giving him or her time to ask questions and express his or her feelings and needs.
- Judging the client — making statements that show the client does not meet the health worker's standards.
- Preaching to the client — telling him or her how to behave or how to lead his or her life, for example, saying: *"you never should have trusted that guy, now you have created a big problem for yourself."*
- Labeling the client instead of finding out his or her individual motivations, fears, or anxieties.
- Reassuring the client without even knowing his or her health status — for example, telling the client, *"you have nothing to worry about."*
- Not accepting the client's feelings — for example, saying *"you shouldn't be upset about that."*
- Advising the client before he or she has enough information or before he or she has had enough time to arrive at his or her own solution.
- Interrogating — asking accusatory questions. Questions that start with *"why…?"* can sound accusatory, although the tone makes a difference ("why" questions can also be a way of asking an open-ended question).
- Encouraging dependence — increasing the client's need for the health worker's guidance.
- Persuading or coaxing — trying to get the client to accept new behavior by flattery or fakery. *"I know you are a good girl and will take your ARVs like I have told you."*

Appendix 4B: General Tips on How to Talk with Adolescents[2]

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

The age and developmental stage of the adolescent is critical to the way the health worker should communicate with him or her. Some basic principles about working with adolescents include:

- Make the adolescent feel comfortable from the beginning. Create a comfortable environment by encouraging the adolescent to talk about general things that interest him or her before moving onto specific issues in the client's life. (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 it yourself?)*
- Engage and take an interest in the adolescent as a person, and not just in his or her physical condition.
- Meet the adolescent at his or her level. This might mean using creative methods to help adolescents (especially younger ones) feel comfortable and express their feelings, and to make the information being presented more concrete.
- Maintain eye contact.
- Do not ask too many questions.
- Listen attentively.
- Use language that is developmentally appropriate and be direct. Use clear language that is not too technical or complex to understand.
- Avoid falsely reassuring the client and do not impose your personal beliefs on the situation.
- Younger adolescents need the presence of a trusted adult to feel secure. Try involving caregivers and other family members in the counseling process.
- Explain confidentiality and 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. Give the adolescent enough time to explain his or her ideas and decisions to you.

Appendix 4C: Basic Counseling Guidance for ALHIV

Appendix 4B provides suggested conversational cues or prompts for introducing some core topics related to HIV care and treatment. It should be noted that this is meant to be a simplified framework outlining main discussion points around care and treatment rather than a comprehensive counseling script.

Counseling ALHIV, Ages 10–12	
Guidance • Remember to incorporate the 7 listening and learning skills described in this module. • Determine disclosure status for younger adolescents and tailor the discussion accordingly. 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 the disclosure process (see Module 7). • Give realistic information about the client’s health status. • At this age, depending on the client’s developmental level, it may be appropriate to begin discussions about HIV. • Emphasize that people with HIV can live meaningful lives and have normal relationships. • Help the client deal with possible stigma.	
Objectives	**Script**
Tell the client that you are here to address his or her specific questions and concerns.	*I want to talk with you about any questions you may have about your HIV result.* or *I want to talk with you about any questions or concerns you may have about your health and about your care here at the clinic.*
Talk about HIV in age-appropriate terms.	*What is HIV?* (Tailor explanation to the client’s response and level of understanding. Key points you may want to include in your explanation follow). *HIV is a germ that lives in your blood and that makes it easier for you to get other germs. That means you could get sick if you don’t take your medicines or if you don’t take them correctly. You should know that you can still grow up to live a good life even though you have HIV.*
Ask about HIV-related discrimination.	*Some people have heard wrong information about HIV. If they think you have HIV, they might treat you differently just because they don’t know any better. Has this happened to you?* (Tailor explanation to the client’s response and level of understanding. Key points you may want to include in your explanation follow). *Some of the things you can do are: talk to someone you trust who can help you manage the bad feelings; know that you have friends and family who love and care for you; and understand that HIV is just a germ.*
Emphasize that ALHIV are normal.	*Having HIV does not make you a bad or different person, it just means you have to take care of your health. If you take care of your health, you will be able to live a healthy life just like other people.*

Objectives	Script
Discuss ART and adherence.	*How many times have you taken your ARVs in the last 3 days? What problems have you had taking your ARVs lately? Which doses did you miss? What can you do to make it easier to remember the doses you tend to miss?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *It is important for you to take your medicines every day and to not skip any doses even if you don't feel like taking them. These medicines will help you to stay healthy. Are you having any problems taking your medicines or problems remembering to take them?*
Talk about ways to stay healthy.	*How do you stay healthy?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *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.*
Discuss confidentiality. Encourage the client to decide with his or her caregivers which people are okay to talk to about HIV.	*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 take care of you. You and your caregivers can decide together who else you feel comfortable talking to about your HIV-status.*
Provide referrals.	*There are doctors who are experts in taking care of people just like you. There are also support groups and services available to you in the community, such as ________________, ________________ and ________________. Our referral team can help you get in touch with these services.*
Comfort the adolescent. **Address any questions and concerns.**	*There are a lot of ways you can stay healthy and we are here to help you.* *What questions do you have? If you think of any questions later on, I will be available to answer them. Let's talk about how you can contact me if you have any more questions.*

Counseling ALHIV, Ages 13–19	
Guidance • Remember to incorporate the 7 listening and learning skills described in this module. • Give realistic information about the client's health status and answer all questions. • The client should know his or her HIV-status by this age. Waiting to disclose makes it much more difficult for the adolescent to accept his or her status. • Emphasize that ALHIV can live meaningful lives and have normal relationships. • Help the client deal with possible stigma and determining how and when to disclose to others. • Include prevention information in pre- and post-test counseling.	
Objectives	**Script**
Tell the client that you are here to address his or her specific questions and concerns.	*I want to talk with you about any questions or concerns you may have about your health, about your care here at the clinic, or about HIV.*
Talk about HIV in age-appropriate terms.	*What is HIV?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *HIV is a virus that lives in your blood and makes it easier for you to get other illnesses. That means you will get sick very often if you don't take your daily medicines or if you don't take them correctly. You should know that you can still have a good life even though you have HIV — you can even get married if you want to.*
Ask about HIV-related discrimination.	*Some people have incorrect information about HIV. If they think you have HIV, they might treat you differently just because they don't know any better. Has this happened to you?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *If you feel you've been discriminated against because you have HIV, talk to someone you trust. Take reassurance in the fact that you have friends and family who love and care for you and who understand that HIV is just a virus.* *If you have been discriminated against by someone who you feel you can talk to and if you feel comfortable doing so, go ahead and address this person's misconceptions. You don't have to disclose to this person, simply address their misinformation with correct, factual information.*
Emphasize that ALHIV are normal.	*Having HIV does not make you a bad or different person, it just means you have to take care of your health. If you take care of your health, which includes taking your medicines, coming to the clinic, and living "positively," you will be able to live a healthy life just like other people.*
Discuss ART and adherence.	*How many times have you taken your ARVs in the last 3 days*? (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *It is important for you to take your medicines every day and to not skip any doses even if you don't feel like taking them. These medicines will help you to stay healthy. What problems have you had taking your ARVs lately? Which doses did you miss? What are you doing now to remember to take your medicines every day?* If appropriate: *Tell me a bit more about why you missed some doses of your medicine? What ideas do you have to improve your adherence (in other words, to remember to take your medicines every day at about the right time)?*

Objectives	Script
Talk about ways to stay healthy.	*How do you stay healthy?* (Tailor explanation to the client's response and level of understanding. Key points you may want to include in your explanation follow). *Knowing that you have HIV will let you take control of your health. To stay healthy, you should take your medicines every day, twice a day, exactly as the health worker described. You can also stay healthy by eating healthy foods, exercising, and getting enough sleep.*
Discuss confidentiality. Encourage the adolescent to decide with his or her caregivers which people are okay to talk to about HIV.	*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 take care of you. You and your caregiver can decide together who else you feel comfortable talking to about your HIV-status.*
Provide referrals.	*There are doctors who are experts in taking care of young people with HIV. There are also support groups and services available to you in the community, such as __________________, __________________ and __________________. Our referral team can help you get in touch with these services.*
Talk about the responsibility to protect others. **When age-appropriate, talk about safer sex.**	*Many adolescents have sex with their partners. Are you having sex? If so, how do you and your partner protect yourselves?* (If client is sexually active and did not use condoms the last time, ask: *When was the last time you used a condom?)* (Tailor discussion to the client's response and level of understanding. Key points you may want to include in your explanation follow). *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.* ***If you are not yet having sex****, it is important that you stay abstinent until you are at an age when you are ready to handle any possible consequences of sex, like getting pregnant or getting a sexually transmitted infection.* *You can pass on HIV to your partner if you have sex without a condom. In fact, having sex without a condom is the most common way that HIV is spread. This means that you should always use a condom when you have sex. This will also help prevent unwanted pregnancies (and we recommend using condoms PLUS another method of contraception to be safe). If you are having sex, it is important that you stay with only one partner and that you talk to your partner about having sex only with you.*
Comfort the adolescent. **Address any questions and concerns.**	*There are a lot of ways you can stay healthy and we are here to help you.* *What questions do you have? If you think of any questions later on, I will be available to answer them. Let's talk about how you can contact me if you have any more questions.*

Adapted from: Zambia Ministry of Health. (2010). *National training package on provider-initiated paediatric HIV testing & counseling in Zambia.*

Appendix 4D: Listening and Learning Skills Checklist

Skill	Specific Strategies, Statements, Behaviors	(√)
SKILL 1: Use helpful non-verbal communication.	• Make eye contact.	
	• Face the person (sit next to him or her) and be relaxed and open with your 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. (Or, if you need to take notes to remember key points, explain this and reassure the client that the notes will be kept confidential in his/her medical file).	
	• Other (specify)	
SKILL 2: Actively listen and show interest in the client.	• Use gestures that show interest (nod and smile) and use encouraging responses (such as *"yes," "okay,"* and *"mm-hmm"*).	
	• Clarify to prevent misunderstanding.	
	• Summarize to review key points at any time during the session.	
	• Other (specify)	
SKILL 3: Ask open-ended questions.	• Use open-ended questions to get more information.	
	• Other (specify)	
SKILL 4: Reflect back what the client is saying.	• Reflect back or paraphrase.	
	• Encourage the client to discuss further (*"Let's talk about that some more"*).	
	• Other (specify)	
SKILL 5: Empathize — show that you understand how the client feels.	• Demonstrate empathy: show an understanding of how the client feels by naming the emotion he or she has expressed.	
	• Avoid sympathy.	
	• Other (specify)	
SKILL 6: Avoid words that sound judging.	• 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)	
SKILL 7: Help your client set goals and summarize each counseling session.	• Work with the client to come up with realistic "next steps."	
	• Summarize the main points of the counseling session.	
	• Set a next appointment date and 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

Appendix 4E: Motivational Interviewing[3]

Motivational interviewing is an approach to counseling that aims to help clients identify and change behaviors that may be putting them at risk of developing health problems or may be preventing optimal management of a chronic condition. Motivational strategies include eight components that are designed to increase the level of motivation the person has toward changing a specific behavior. These components include:

- Giving advice (about specific behaviors to be changed)
- Removing barriers (often removing barriers to accessing help)
- Providing choice (making it clear that if the adolescent chooses not to change, that this is his or her right)
- Decreasing desirability (of the status quo, i.e., how the adolescent currently behaves in a particular situation)
- Practicing empathy
- Providing feedback (from a variety of perspectives — family, friends, health professionals — in order to give the client a full picture of their current situation)
- Clarifying goals
- Active helping (such as expressing caring or facilitating a referral, which convey a real interest in helping the person to change)

The overall aim of motivational interviewing is to encourage and support clients to adopt new behaviors. This should be done in a supportive way with the health worker accepting the client's perspective and reflecting it rather than challenging it.

How to encourage change

Below are the 8 steps to motivational interviewing:

1. **Establishing rapport**: Take the time to get to know the client and reassure him or her of confidentiality.
2. **Setting the agenda:** When embarking on a change program, many people attempt too much and/or too quickly. The client should set the agenda for change using feedback from the health worker regarding priorities, potential difficulties, and strategies.
3. **Assessing readiness to change**: Asking simple questions like, *"On a scale from 1 to 10, how motivated are you to . . . ?"* will give insight into the client's level of motivation. Answers can then be challenged gently: "*You said 4, which is more than 3. Why not 5? Are you sure it is not 5? What makes you sure?"*
4. **Sharpening the focus**: After the initial sessions, which are aimed at identifying what the client wants help with, the following sessions should focus on what exactly the patient wants to change.
5. **Identifying ambivalence**: Ambivalence is normal and is often expressed when clients disagree, argue, deny, or ignore a statement of reflection or a request for elaboration. Ambivalence is not a sign of a client being difficult or unhelpful, but rather an indication that there are reasons for and against change.
6. **Eliciting self-motivating statements**: The health worker should take every opportunity to encourage the adolescent client to phrase things in a positive way and to highlight successes. Asking what would be the best outcome for the client from a particular course of action encourages him or her to see possibilities and visualize success.
7. **Handling resistance**: Reflection is a powerful way of handling resistance. It is important to concretely express what you, the health worker, are observing and hearing.

8. **Shifting the focus**: Helping people get around a barrier can be another way of handling resistance. The health worker should shift the focus to the beliefs underpinning the client's behavior and should help him or her explore those beliefs.

Motivational interviewing: Creating the conditions for change

Motivational interviewing has 5 basic principles:

1. **Expressing empathy**: Demonstrating empathy is conveying a real, informed understanding of the person's predicament and why he or she is responding in a particular way. Expressing empathy demands active listening so the health worker can reflect back what the client is saying (see "Skill 5: Empathize — show that you understand how the client feels" in Session 4.2.).

2. **Avoiding argument**: Arguments are counterproductive. Motivational interviewing itself is challenging and confrontational as it questions how much someone wants to make a change. Rather than arguing with the client, however, the goal of motivational interviewing is to encourage the client to hear themselves say why they want to change.

3. **Supporting self-efficacy**: Belief in one's ability to make a change and to stick to it is fundamental to success. Encouraging the client to make overt positive statements that reflect a sense of self-efficacy will help the client 'reframe' his or her thinking.

4. **Rolling with resistance**: The aim is to not argue with the client, but to carefully challenge the thought processes that underlie the behavior the client wants to change. When done skillfully, this can shift the client's perspective of the situation. A health worker can help the client see the incompatibility between where he or she is and where he or she wants to be through questioning, asking for clarification, and summarizing (and sometimes even by exaggerating a particular position). New perspectives can be offered but should not be imposed.

5. **Developing discrepancy**: Clients need goals to work toward. In addition, they need to be aware that their current situation has consequences. Goals should be generated by the client instead of being imposed on him or her by others. The exercise of getting the client to outline his or her goals gives the health worker insight into how realistic these goals are and what his or her priorities for change.

Appendix 4F: Common Counseling Scenarios

Scenario	What the health worker can do
Silence	- Remember that silence can be a sign of shyness, embarrassment, anger, or anxiety. - If an adolescent client is silent at the beginning of a session, the health worker can say, *"I realize it's hard for you to talk. Talking to someone you don't know can be scary. Many people are scared (or too embarrassed, too angry, too anxious) to share their feelings."*
Anger	- Say, *"You seem angry. It's OK to be angry, but would you like to talk about it?"* Or, if the health 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 for him or her speak. Is that what is going on?"*
Shyness	- Legitimize 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 4-15). Some adolescents simply need time to feel comfortable with someone new. - If the adolescent cannot or will not talk, the health worker should propose another meeting.
Crying	- 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 health worker can give the adolescent permission to express his or her feelings by saying, *"It's okay to cry…it's the normal thing to do when you're sad."* - If the client is using crying as manipulation, the health worker can say, *"Although I'm sorry you feel sad, it's good to express your feelings."* - The health worker should allow the client to freely express emotions and should not try to stop his or her feelings or belittle their importance.
Threat of suicide	- Take all suicide threats very seriously! Refer the adolescent to a qualified counselor, 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	- Discreetly try to find out why the adolescent is refusing help. If the underlying feeling is anger, refer to some of the suggestions under "Anger" listed above). - If the client has been sent against his or her will, the health 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."*

Scenario	What the health worker can do
Difficulty dealing with short stature (Many adolescents with perinatally-acquired HIV feel self-conscious about being "different." These physical differences can interfere with their self-esteem).	• Reassure the ALHIV that most adolescents go through a period of feeling unhappy about themselves. One study from the U.S. suggests that almost 54% of American girls aged 12 to 23 years old are unhappy with their bodies;[4] another study suggests that 9 out of 10 British girls are unhappy with their bodies.[5] Although few of these young people had HIV, these statistics illustrate that adolescents, regardless of HIV-status, often feel self-conscious and even dissatisfied with their looks. • Encourage ALHIV to reframe their difference as not making them "different," but rather as defining them as individuals. A young man who is shorter than the average might feel better about himself if he focuses on the skills and qualities that he sees as positive, e.g., if he is artistic, creative, or naturally outgoing. • It is difficult for young people to reframe their differences as positive. Give them time and encourage them to talk about their differences with friends and within support groups. Support groups can also give adolescents tips on dealing with teasing. • Encourage caregivers of ALHIV to support their children to feel good about themselves. A caregiver's unconditional love and support is the core of self-esteem. Self-esteem is the armor adolescents need to ignore peer teasing.
Need to talk	• It can be a counseling challenge when a client is very vocal and wants an outlet to express concerns that the health worker does not perceive to be directly related to the client's immediate counseling needs. In this situation, the health worker should give the client the opportunity to express his or her needs and concerns. The health worker should then summarize the discussion so far and identify the key issues that need to be discussed further that day. This sets the agenda for the rest of the meeting and gives the health worker permission to pull the session back on track if the client starts discussing tangential issues. • Sometimes the health worker simply does not have enough time to devote to a particularly needy or talkative client. In this case, the health worker should get about partway through the session and should then summarize the session so far, identifying the key points that require further discussion. Assuming that the client agrees the summary is accurate, the health worker should then try to prioritize the client's issues. The health worker should suggest they talk about the first 2 or 3 issues in the time remaining during that day's session and that they tackle the other issues at the next session. Assuming the client agrees with this listing of priorities, the health worker should then make a note of the agenda items to be covered during the next session so they are not forgotten. • Refer client to a peer support group; talkative clients tend to benefit greatly from opportunities to interact with their peers.

References

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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: **Peer Support in Psychosocial Services for Adolescents**

Learning Objectives

After completing this module, participants will be able to:

- List common psychosocial needs of both adolescents in general and ALHIV specifically
- Identify strategies to support adolescent clients and caregivers in dealing with stigma and discrimination
- Recognize psychosocial challenges among most-at-risk ALHIV and provide support and referrals
- Conduct a psychosocial assessment with adolescent clients and caregivers to better determine their specific psychosocial needs and the types of support they require
- Provide adolescents and caregivers with ongoing, age-appropriate psychosocial support services, including referrals
- Understand the importance of peer support in meeting adolescents' psychosocial support needs

Session 5.1 The Psychosocial Needs of Adolescent Clients

Session Objectives

After completing this session, participants will be able to:

- List common psychosocial needs of both adolescents in general and ALHIV specifically
- Identify strategies to support adolescent clients and caregivers in dealing with stigma and discrimination
- Recognize psychosocial challenges among most-at-risk ALHIV and provide support and referrals

Overview of Psychosocial Support

Definition of psychosocial support and well being:

- **"Psycho-"** refers to the mind and soul of a person (involving 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, values (culture), and the influence exerted by one's 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 a person's internal and external needs are met and he or she is physically, mentally, and socially healthy.

Psychosocial well being is part of the mental health spectrum. Psychosocial support for ALHIV and families is discussed in this module and mental health, more generally, is discussed in Module 6.

Psychosocial Support Needs of ALHIV

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

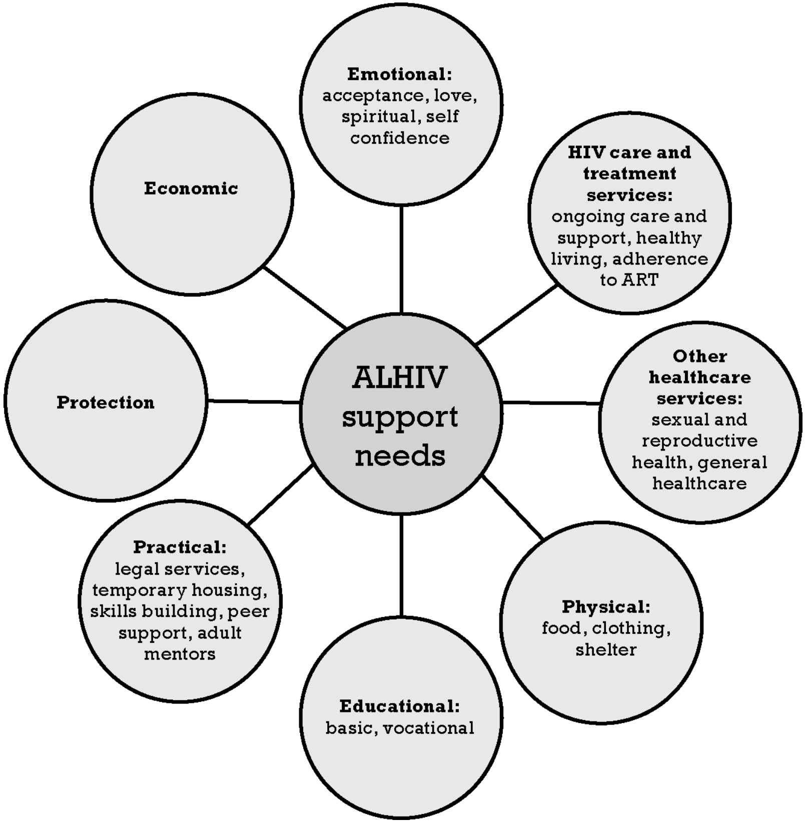
- Significant physical, emotional, and mental changes
- Risk-taking behavior and experimentation
- Sexual desire, expression, and experimentation
- Insecurity/confusion
- Anxiety
- Reactive emotions
- Criticism of caregivers or elders
- A focus on body image
- A sense of immortality
- A need to challenge authority figures while also still needing their support

Remember: ALL adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.

On top of the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors, vulnerabilities, and challenges that can result in the need for extra support. Adolescent clients may require extra support in the following areas, (among others):

- Understanding and coming to terms with their own HIV-status
- Understanding and coming to terms with family members' HIV-status
- Grieving the illness or loss of parents and/or siblings and coping with added responsibilities at home
- Coping with cycles of wellness and poor health
- Long-term adherence to both care and medicines
- Disclosure to friends, family members, and sexual partners
- Sexual and reproductive health, including disclosure to partners, practicing safer sex, using family planning, and making childbearing decisions
- Anxiety over physical appearance and body image
- Developing self-esteem, confidence, and a sense of belonging
- Dealing with stigma, discrimination, and social isolation
- Accessing education, training, and work opportunities
- Managing mental health issues, such as anxiety, depression, and substance abuse (see Module 6 for more information about mental health and ALHIV)

Figure 5.1: Support needs of ALHIV



Note: This figure was adapted from: Uganda Ministry of Gender, Labour, and Social Development. (2005). *Integrated care for orphans and other vulnerable children: A training manual for community service providers.*

Providing psychosocial support to ALHIV and their caregivers is important because:

- All adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.
- On top of the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors and, in some cases, additional vulnerabilities and challenges.
- Psychosocial support can help clients and caretakers gain confidence in themselves and in their coping skills.
- Adequate psychosocial support can increase clients' understanding and acceptance of all comprehensive HIV care and support services.
- Psychosocial well being is associated with better adherence to HIV care and treatment.
- HIV can be a chronic stressor that places ALHIV and their families at risk for mental health problems. Mental health and physical health are closely related (see Module 6).
- Ongoing psychosocial support may help prevent ALHIV from entering the "most-at-risk" category (discussed later in this session) or from developing more severe mental health problems.

Overview of Stigma and Discrimination

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

To stigmatize someone: Labeling or seeing a person as inferior (less than or below others) because of something about him or her. A lot of times people stigmatize others because they do not have the right information or knowledge. People also stigmatize others because they are afraid.

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

There are different kinds of stigma:

- **Stigma toward others:** Having a negative attitude about others because they are different or assumed to be different (for example, a boy with HIV who feels isolated at school because of the stigmatizing attitudes of his 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, H___ is HIV-positive and is afraid of "giving the disease" to her family, so she keeps to herself and eats her meals alone.).
- **Secondary stigma:** When people are stigmatized because of their association with PLHIV. This may include community health workers; doctors and nurses at the HIV clinic; children of parents with HIV; and the caregivers and family members of PLHIV (for example, when a child's friends no longer play with her at school or around the community because people have heard that one of her family members is living with HIV).

There are different forms of discrimination:

- Facing violence at home or in the community
- Not being able to attend school
- Being kicked out of school
- Not being able to get a job
- Being isolated or shunned from the family or community
- Not having access to quality health or other services
- Being rejected from a church, mosque, or temple
- Police harassment
- Verbal discrimination: gossiping, taunting, or scolding
- Physical discrimination: insisting a person use separate eating utensils or stay in a separate living space

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

Effects of Stigma and Discrimination

Stigma and discrimination can:

- Keep ALHIV from accessing care, treatment, counseling, and community support services (because they want to hide their status)
- Cause a great deal of anxiety, stress, and/or depression
- Make adolescents feel isolated and as if they do not fit in with peers
- Make it difficult for ALHIV to succeed in school
- Result in poor adherence to medications
- Make it hard for people to tell their partner(s) their status
- Make it hard for people to discuss safer sex with partners
- Make it hard for parents to disclose their own HIV-status to their children and also 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 health care settings
- Impact some adolescents more than others. For example, orphans living with HIV may encounter hostility from their extended families and community and may be rejected, denied access to schooling and health care, and left to fend for themselves.

Strategies to Deal with Stigma and Discrimination

Individual strategies for dealing with stigma:

- Stand up for yourself!
- Educate others.
- Be strong and prove yourself.
- Talk to people with whom you feel comfortable.
- Join a support group.
- Try to explain the facts.
- Ignore people who stigmatize you.
- Avoid people who you know will stigmatize you.
- Taking and adhering to ART and other medicines reduces stigma around HIV, helps normalize HIV, and allows the community to see HIV as a chronic disease. People who openly take ART can reduce stigma around the disease.

Strategies for dealing with stigma within health care settings:

- Make sure PLHIV and ALHIV, such as Peer Educators, are part of the care team. This includes making sure that 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 health workers.
- Ensure that there are linkages with community-based youth groups and support groups for ALHIV; refer adolescents to these groups.
- Talk openly with other health workers about your own attitudes, feelings, fears, and behaviors. Support each other to address fears and avoid burnout.
- When you witness discrimination in the health care setting, challenge it. For example, if you see a colleague being rude to a client with HIV, talk to this colleague on a one-to-one basis after the client leaves. Tell him or her what you saw and how you think the situation could have been handled differently.
- Report to the manager any discrimination in the clinic setting that is directed toward PLHIV or their families.
- Listen to clients when they talk about their feelings and concerns about stigma and discrimination and report what you learn back to other health 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.

Overview of Most-at-Risk ALHIV[1,2]

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

- Young people's behavior is less fixed than that of adults. Drug use and certain sexual practices are sometimes experimental and may or may not continue.
- Young people are less likely than older adults to identify themselves as drug users or sex workers. This makes them both harder to reach with programs and less responsive to communication addressed to groups with specific identities.
- Young people are more easily exploited and abused.
- Young people, especially girls, are the most common victims of gender-based violence or GBV (see Module 10 for more information).
- Many young women are also vulnerable to transactional sex and its consequences (see box below).
- Young people have less experience coping with marginalization and illegality.
- Young people may be less willing to seek out services — and providers may be less willing to provide them with services — due to concerns about the legality of behaviors and informed consent.
- Young people are often less oriented toward long-term planning and thus might not think through the risks that are related to the choices they make.
- Many adolescents are living without parental guidance or 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 practices, or social values force young people to behave in ways that place them at risk. Examples include the presence of homophobia, female genital cutting, or norms that encourage adolescent girls to have sex with older men.

Transactional sex: putting young women at risk

Transactional sex is the exchange of sex for money, goods, or services. Significant age disparities are common in partners who engage in transactional sex. Among other factors, concerns about HIV have prompted older men to seek younger sexual partners because they assume these partners are less likely to be HIV-infected. Young women are often willing to participate in these partnerships for emotional reasons; perceived educational, work, or marriage opportunities; monetary and other material gifts; or basic survival. They often fail to realize their vulnerability to abuse, exploitation, reproductive health risks, and HIV. **Transactional sex puts girls and young women at risk of physical and emotional abuse, exploitation, and a range of sexual and reproductive health problems.**

Most-at-risk ALHIV include young people who are both HIV-positive and particularly vulnerable or at risk, such as those who are homeless, homosexual or bisexual, trans-gendered, disabled, imprisoned, caregivers, orphans, migrants, refugees, gang members, sex workers, or 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 behaviors, while **"vulnerability"** refers to the circumstances and conditions that make most-at-risk behaviors more likely.

Young people who most need support often have the most difficulty accessing services and adopting behaviors that will protect them from HIV. The behaviors that put them at risk (for example, exchanging sex for money, food, or shelter) are usually heavily stigmatized, frequently take place in secret, and are often illegal.

Existing policies and legislation, lack of political support, and other structural issues often prevent most-at-risk adolescents from receiving the services they need. This contributes to the further marginalization of these young people and undermines their confidence in health and social services, as well as their willingness to make contact with service providers.

Most-at-risk ALHIV may require increased psychosocial support due to extreme challenges, such as:

- Displacement
- Severe social exclusion and isolation
- Stigma and discrimination
- Extreme poverty
- Substance abuse
- Physical or sexual abuse/violence
- Exploitation
- Migration
- Stigma, discrimination, violence, and fear of arrest due to sexual orientation
- Chronic mental health issues, psychiatric disorders, and learning disorders
- Disabilities
- A stressful past: many situations and events that push youth into vulnerable circumstances in the first place (like parental illness and death, lack of substitute parental care, abuse, etc.) may have a lasting impact on their well being

Non-violence: a human right

Ensure that all clients, particularly those who are most-at-risk, recognize that they have a right to say "no" to sex and a right to live in a world without abuse. Encourage them to recognize that violence and forced sex is not only wrong but also unethical and punishable by law.

Session 5.2 Assessing Psychosocial Support Needs

Session Objective

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 the types of support they require

Conducting a Psychosocial Assessment

See *Appendix 5A: Psychosocial Assessment Tool.*

Tips to remember during the psychosocial assessment process:

Family-centered care versus client confidentiality

It is important to ensure the inclusion of caregivers and other family members in care. However, it is equally important that private information discussed during an individual session with an ALHIV remains confidential and is not shared with caregivers (unless the adolescent specifically consents). **Unless clients have a guarantee of confidentiality, they will be unwilling to discuss personal issues.**

- Emphasize that all information is confidential and private, but that health 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 during all phases of the assessment process.
- Respect the dignity and worth of the adolescent at all times.
- Do not talk down to the adolescent. Use good listening and learning skills, as discussed in Module 4.
- Always be positive! Offer lots of encouragement and praise throughout the assessment.
- Be patient! Allow the adolescent to speak for him- or herself. Allow the client to express his or her views and to describe his or her experiences.
- Respect the adolescent's coping skills and his or her ideas and solutions to problems.
- Do not judge! Make adolescents feel comfortable instead of 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.

Overview of Coping Strategies

Health workers should use the 5 "A's" when conducting psychosocial assessment with clients: ASSESS, ADVISE, AGREE, ASSIST, and **ARRANGE**. Note that the 5 "A's" were also covered in Module 3; these are part of the WHO IMAI guidelines on working with clients with chronic conditions, including HIV. See Table 5.1 for a review of the 5 "A's."

Table 5.1: Using the 5 "A's" during clinical visits with adolescents, including psychosocial and counseling sessions (the 5 "A's" were also covered in Module 3)

The 5 "A's"	More Information	What the Health Worker Might Say
ASSESS	• Assess the client's goals for the visit • Asses the client's clinical status, classify/identify relevant treatments, and/or advise and counsel • Assess risk factors • Assess the client's (caregiver's) knowledge, beliefs, concerns, and behaviors • Assess the client's understanding of the care and treatment plan • Assess adherence to care and treatment (see Module 8) • Acknowledge and praise the client's efforts	• *What would you like to address today?* • *What can you tell me about ______?* • *Tell me about a typical day and how you deal with ______?* • *Have you ever tried to _____? What was that like for you?* • *To make sure we have the same understanding, can you tell me about your care and treatment plan, in your own words?* • *Many people have challenges taking their medicines regularly. How has this been for you?*
ADVISE	• Use neutral and non-judgmental language • Correct any inaccurate knowledge and gaps in the client's understanding • Counsel on risk reduction • Repeat any key information that is needed • Reinforce what the client needs to know to manage his or her care and treatment (for example, recognizing 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.)	• *I have some information about ____ that I'd like to share with you.* • *Let's talk about your risk related to ____. What do you think about reducing this risk by ______.* • *What can I explain better?* • *What questions do you have about ________?*
AGREE	• Negotiate WITH the client about the care and treatment plan, including any changes • Plan when the client will return	• *We have talked about a lot today, but I think we've agreed that ______. Is this correct?* • *Let's talk about when you will return to the clinic for ____.*
ASSIST	• Provide take-away information on the plan, including any changes • Provide psychosocial support, as needed • Provide referrals, as needed (to support groups, peer education, etc.) • Address obstacles • Help the client come up with solutions and strategies that work for him or her	• *Can you tell me more about any obstacles you've faced with ______ (for example, taking your medicines regularly, seeking support, practicing safer sex)?* • *How do you think you can overcome this obstacle?* • *What questions can I answer about _____?* • *I want to make sure I explained things well — can you tell me in your own words about _____?*
ARRANGE	• Arrange a follow-up appointment • Arrange for the client to participate in a support group or group educations sessions, etc. • Record what happened during the visit	• *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.* • *What day/time would work for you?*

Sources:
WHO. (2004). *General principles of good chronic care: IMAI. Guidelines for first-level facility health workers.*
WHO. (2010). *IMAI one-day orientation on adolescents living with HIV.*

Note: If, during the "ASSESS" phase, a health worker thinks the adolescent client has serious issues that threaten his or her life or immediate safety (such as homelessness, thoughts of suicide, signs of severe depression, violence, etc.), these issues must be addressed IMMEDIATELY.

- In these emergency cases with most-at-risk adolescents, working through the 5 "A's" should not be the priority.
- Instead, the health worker should focus on the client's immediate safety and well being.
- Note that in these emergency situations, health workers may need to break confidentiality in order to take actions that are in the best interest of the adolescent and that ensure his or her immediate safety.
- Managing emergency situations is discussed further in Module 6.

Once the health worker has assessed that there are no emergency issues threatening the client's immediate safety and well being, the health worker can **suggest coping strategies** to the client and his or her caregivers to help them reduce stress, deal more effectively with challenges, and promote their psychosocial well being.

Examples of coping strategies include:

- Talking about a personal problem with someone trusted, such as a friend, family member, counselor, or Peer Educator
- Seeking help from clinic staff, especially if sad, depressed, or anxious for a long period of time (see Module 6 for more information about mental health and ALHIV)
- Joining a support group
- Changing one's environment, taking a walk, or listening to music
- Seeking spiritual support
- Attending a cultural event, like traditional dancing or singing
- Participating in recreational activities, like sports or youth clubs
- Returning to a daily routine, including doing household chores (e.g. cooking) or going to school
- Doing something to feel useful, like helping a sibling with homework

Helping clients express themselves and encouraging them to tell their stories and to 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 for, and valued
- Develop confidence
- Build self esteem
- Explore options or solutions to make better decisions
- Prevent bad feelings from coming out as aggressive behavior
- Maintain needed support from family members and other adults

An important part of helping adolescents cope with issues is encouraging their caregivers to strengthen their relationship with them. Health workers can suggest that caregivers:

- Spend time with and listen to the adolescent.
- Let the adolescent know that their feelings are normal and "OK." Encourage them to talk and express feelings and thoughts. Listen actively.
- Communicate unconditional love and acceptance.
- Help the adolescent plan daily or weekly activities.
- 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 counselor or social worker.
- Be aware of changes in behavior or mood and look for signs of mental illness, including alcohol and other substance use (discussed more in Module 6).
- Talk to someone; family members may also be depressed and need help.
- Get help from a support organization in the community.
- Continue their regular religious or spiritual practices.

Exercise 1: Assessing Psychosocial Support Needs: Case studies in small groups and large group discussion	
Purpose	To discuss how to the asses the psychosocial needs of adolescents using *Appendix 5A: Psychosocial Assessment Tool* and by applying the 5 “A’s”
Refer to *Appendix 5A: Psychosocial Assessment Tool* and the 5 “A’s” in Table 5.1.	
Case Study 1: A 17-year-old woman named T___ tested positive for HIV 6 months ago. She is currently 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, including refill appointments for ARVs. Her partner is the only one who knows she is HIV-positive, but he himself has not been tested. *How do you proceed with T___ today?* **Case Study 2:** A 12-year-old boy named M___ has comes to the clinic today with his mother. He looks like he is “feeling down.” You sense that he wants to talk to someone, but he seems very quiet and won’t make eye contact with anyone. *How do you proceed with M___?* **Case Study 3:** K___ is a 17-year-old young woman living with HIV. Her mother died when she was 5 years old and she doesn’t know her father. For the last year, K___ has been living with her 28-year-old boyfriend. She has come to the clinic today because she thinks she is pregnant. *How would you proceed with K___?*	

Session 5.3 Peer Support in Psychosocial Services for Adolescents

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

Adolescents generally depend on peers for information, approval, and connection. In addition to the other psychosocial support strategies described in this module, peer support can help ALHIV counter stigma and discrimination, cope with fear and hopelessness after diagnosis, improve adherence to care and treatment services, and deal with issues like disclosure to partners, friends, and family.

The engagement of ALHIV as Adolescent Peer Educators can play an important role in improving adherence and service quality. See Module 12 for more information on the benefits of adolescent peer education programs and on how to implement such programs.

Adolescent Peer Educators can help improve services for ALHIV

Full participation of Adolescent Peer Educators in the health facility and in outreach services can expand the clinic's ability to provide quality care to adolescents by allowing already overburdened health workers to concentrate on more technical tasks.

It should be noted, however, that there are some significant differences between Adult and Adolescent Peer Educators, ranging from their availability to their attention span, brain function, and decision-making. Thus, expectations of Adolescent Peer Educators and their supervisory structures must also be different from those of Adult Peer Educators, expert clients, and lay counselors. Adolescents, usually self-conscious because of their age, inexperience, and outsider status, try hard to fit into adult environments. When they are successful, it can be easy to forget that they are not adults. However, when they are under stress, the mask of adulthood may slip, revealing their youth along with their **need for close supervision and guidance.**

Depending on the context and program, Adolescent Peer Educators can play a number of important roles in HIV service delivery, including but not limited to (see Module 12 also):

- Providing counseling and long-term support (related to adherence preparation, adherence follow-up, disclosure, positive living, positive prevention, etc.)
- Providing psychosocial support to clients and family members
- 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 health workers
- Participating in HIV-related outreach and education activities in the community
- Assisting with the design and delivery of peer support groups for ALHIV and their caregivers

Peer support can help address ALHIV's psychosocial support needs by (see Module 12 also):

- Helping them feel that they are accepted and valuable members of the group, and by reducing their sense of isolation
- Helping them solve their own problems
- Providing them with emotional support
- Promoting learning, sharing, and skill building around disclosure, adherence, and dealing with stigma and discrimination
- Maintaining their motivation and commitment to HIV care and treatment (since peer support can be more powerful 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[3]

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 better manage their situations, to share challenges, and to discuss solutions. Members support each other to implement decisions made to meet their psychological, social, physical, and medical needs.

- Support groups help people meet others living with HIV, which can reduce isolation and provide people with encouragement to live more fully and positively.
- A support group can be a safe place for someone who needs to talk about personal issues, experiences, struggles, and thoughts.
- Adolescents benefit from support groups because they trust information that they get from peers.
- Support groups can help members 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 community-based services. For example, health workers or leaders of community-based organizations can talk about the range of services their organizations offer during support group meetings. Also, support group members typically share with each other their experiences with local service providers and swap advice on how to navigate each program (what the ideal time to arrive is to reduce wait time, which documents to bring to the initial appointment, etc.).
- Support groups may also give income-generating, vocational, or educational assistance; or they may have savings and loan programs that can benefit members.
- Depending on the specific program, Adolescent Peer Educators may play an important role in starting support groups, facilitating support group meetings, and/or helping others organize them and recruit members. Adolescent Peer Educators in any of these roles benefit from support and mentoring (this is discussed more in Module 12).

There are many different types of useful support groups:

- **Adolescent support groups**: ALHIV may want to form their own support groups to discuss some of the special challenges 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 an Adolescent Peer Educator.
- **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 can help mothers understand and access key HIV and PMTCT services. These groups can also 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.
- **Couples support groups:** Couples, including discordant couples as well as those where both partners are living with HIV, may wish to form support groups. Couples can share common concerns and challenges, and can support each other to live positively with HIV.
- **Post-test clubs:** These groups are for anyone who has been tested for HIV; they do not require participants to disclose their status. They often focus on promoting HIV information and education in the community and they also provide a social environment for members to meet each other and to discuss important issues, such as 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 support groups for sex workers, men who have sex with men, street youth, orphans, or other vulnerable groups. 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.

Health education and related topics that can be incorporated into support group meetings:

- Positive living
- Adherence
- Disclosure
- Sexual and reproductive health
- Relationships and sexuality
- Preventing new HIV infections and positive prevention
- Preventing opportunistic infections
- Coping with school
- Finding work
- Strategies to reduce gender-based violence
- Dealing with stigma
- Nutrition
- Getting help for mental health problems
- Dealing with dying and the death of a friend or family member
- Managing disabilities

Module 5: Key Points

- Psychosocial support addresses the ongoing emotional, social, and spiritual concerns and needs of PLHIV, their partners, their family, and caretakers of children living with HIV.
- All adolescents need support coping with normal developmental issues, such as wanting to feel normal and accepted and wanting to fit in with peers.
- In addition to the psychosocial needs and challenges that all adolescents face, ALHIV may also experience HIV-related stressors and additional vulnerabilities and challenges.
- Stigmatizing someone, which means having a negative attitude toward a person we think is not “normal” or “right,” often leads us to treat them unfairly (or discriminate against them). Stigma and discrimination deter many people from accessing HIV prevention, care, and treatment services.
- Health services for young people need to be adapted to identify and meet the needs of most-at-risk adolescents.
- Health workers play a key role in assessing clients’ and caregivers’ psychosocial needs.
- Health workers can use the Psychosocial Assessment Tool (in *Appendix 5A*) to help assess clients’ (and caregivers’) psychosocial needs and to help them come up with their own solutions.
- Health workers should remember the 5 “A’s” when conducting a psychosocial assessment: **ASSESS**, **ADVISE**, **AGREE, ASSIST,** and **ARRANGE**.
- If a health worker thinks an adolescent client has serious issues that threaten his or her life or immediate safety, these issues must be addressed IMMEDIATELY.
- An important part of helping adolescents cope with issues is encouraging their caregivers to strengthen their relationship with them.
- Peer support is an important source of psychosocial support for ALHIV.
- Health workers have a role in initiating and facilitating peer support groups — and in linking ALHIV with existing support groups.

Appendix 5A: Psychosocial Assessment Tool

How to Use This Tool

This Psychosocial Assessment Tool was developed to support a range of providers (trained counselors, lay counselors, doctors, nurses, and others) who work with ALHIV and their families. Conducting a psychosocial assessment with each client (and caregiver, if applicable) helps providers learn more about the client's specific situation, helps them prioritize needs, and helps give direction to ongoing counseling and psychosocial support. This includes referrals for needed community- and home-based services.

A psychosocial assessment should be conducted with each adolescent client **both after enrollment in HIV care and treatment services and annually after that.** Health 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 he or she is facing new challenges or 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 should be kept in the client's file for reference during follow-up visits.

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: These questions allow the health 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 the client's responses in the right-hand column, as this will help you to decide on effective next steps, to decide on important areas for follow-up, and in supporting the client's psychosocial well being over the long term. Also make sure that the client has time to ask questions and that you have time to summarize the session and agreed upon next steps. Record key next steps in the space provided.

REMEMBER:

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

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 an important element of HIV care and treatment programs 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 Adolescent Peer Educators, adherence supporters, ALHIV associations, food support, education and job training programs, gender-based violence services, legal support, etc.) and formal two-way referral systems to these organizations and services. Clients with severe psychosocial and psychological issues (such as depression, alcohol or other substance use disorders, suicidal feelings) will require careful follow-up and immediate referrals to ongoing professional counseling 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 counseling session/clinic appointment: Schedule a follow-up counseling appointment with the client and record this date, as well as any other clinic appointments, in the space provided.

ALHIV Psychosocial Assessment Guide and Recording Form[3]

Client Name: ______________________________ Client File#: ____________________ Date: _____________

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 (or since we last met)? How are you coping? ***Explore and discuss client's coping strategies***	
3. Tell me about your mood now. Do you feel sad or stressed? What changes have you noticed in your mood? What about in your eating and sleeping habits? ***Assess risk of depression and need for referral***	
4. How often in the last week have you used cigarettes, alcohol, or other drugs? ***Assess for harmful coping strategies, such as drug/alcohol use, provide counseling and referrals***	
5. To whom have you disclosed your HIV-status? What was their reaction? Do you want to disclose to anyone else? What concerns do you have about disclosure? ***Counsel on disclosure***	
6. Who do you feel close to? Who can you go to for emotional support? ***Counsel on importance of social support***	
7. Do you belong to a community/religious organization or support group? Would you be willing to join a support group to meet other ALHIV? ***Make referrals as needed***	
8. Tell me about any negative attitudes or treatment you've experienced. Has anyone caused you harm (e.g., been violent, made unwanted sexual advances)? ***Counsel and discuss support services; consider gender-based violence services, if appropriate***	
9. Some adolescents have sex with their partners. It's important for you and your partner to do this safely. Are you having sex? If so, what are you doing to prevent pregnancy and the spread of STIs and HIV? ***Screen for sexual risk-taking and counsel on safer sex, dual protection, etc.; give condoms***	
10. 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? ***Assess living situation*** *If not living with parents, ask:* Where are your parents? When did this happen? How did this affect you?	
11. Tell me what you do most days. Do you, for example, go to school or work outside the home? Where do you go to school/work? How is this going for you? ***Assess school/work situation***	
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 or food? ***Refer to social worker and community-level support***	

13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?	
14. How do you/will you remember to come to this clinic for your appointments and refills? How do you/will you manage it with your school or work? Who can help you? ***Counsel on adherence to care***	
15. How do you/will you remember to take your medications every day? How do you/will you remember when to come back to the clinic? Who can help you? ***Counsel on adherence and briefly discuss:*** • ***WHO will give or manage your medicines?*** • ***WHEN will you take them?*** • ***WHERE will you store them?*** • ***HOW will you remember to take them (review use of reminders, like calendars, pill boxes, etc.)***	
16. What other questions or concerns do you want to discuss today? Would you like to bring someone else into our conversation — today or at another visit (e.g. family member, partner)?	
17. Summarize the session and review immediate plans and next steps, including the next clinic visit date.	

Notes:

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Referrals made:

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Date of next counseling session/clinic appointment: ____________________________________

Health 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[4]

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, counselors, 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, etc.).

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 participant? 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 will the topic(s) be?
- 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, etc.)
- 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 them into the agenda. This can be done through an anonymous questions box.

Appendix 5C: Facilitating a Peer Support Group[4]

Be sure to plan the group session ahead of time and practice what you are going to say.

Set up the room so that everyone can participate:

- Encourage participants to sit in a semi-circle to make it feel less like a classroom and more comfortable to talk.
- The person leading the meeting should be part of the semi-circle rather than standing behind a desk or other furniture.
- 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 discussing their experiences and feelings if they know others will ensure that 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 will not be repeated in the community or elsewhere.

Ask participants to establish ground rules:

- During the first group meeting, ask the participants to brainstorm ground rules for the group. Ground rules might include any of the following: we will 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 counselor 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 it is "their" meeting.
- 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!
- Interact with participants and get them involved by moving around the room, by asking questions, and by asking people to share personal stories/concerns, etc.
- Pay attention to participants who seem shy or quiet and emphasize that everyone's personal experiences, questions, and concerns are important.
- Use visual aids and avoid lecturing.
- At the end of the meeting, ask participants to summarize what they have learned and the actions they plan to take.
- Always leave time for questions and re-explain anything that participants did not understand fully.
- 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 summarize each session.

Note: If a participant is being disruptive:

- Try to understand why he or she is acting this way.
- Do not ignore or argue with him or her.
- During a break, talk to the participant one-on-one and ask what is bothering him or her.

Appendix 5D: Ideas for Peer Support Group Activities

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 eight pieces — papers can be blank or can already have health terms written on them); two baskets, hats, or other containers for the paper; scorekeeping method
- **Play:** Divide the participants into 2 teams and give each team half of the slips of paper. If the pieces of paper are blank, give the teams time to privately consult and write one term, phrase, or concept related to material they are learning on each piece of paper. Choose a neutral timekeeper/scorekeeper or have the teams take turns keeping score. Review the gestures and hand signals that will be used during the game and invent any others, as needed.

  To play, teams take turns having a player choose a piece of paper from the other 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 into 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.

- **Example**: Ask participants to get in pairs and then ask each pair to make a sculpture showing how people treat orphans. Ask them to decide on roles — one person will be the orphan and the other a community member. After all pairs have come up with their sculptures, ask some to show their sculptures in the center 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 any other materials that could be used to decorate the journal. Ask participants to think about the special characteristics (hobbies, traits, talents, strengths, etc.) that make up their identity. Also ask them to think about their future goals and dreams. A counselor or Peer Educator at the clinic may want to write back/respond to clients' journal entries in writing.

Question box

Create a box at the health facility for anonymous questions. Tell clients that they can 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, about positive living, or about reducing stigma.

Plays/drama

Ask participants to work in small groups to create a play about a specific issue, such as combating stigma in schools or in the community.

Arts and crafts games

These games help adolescents 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 and ask participants to discuss their feelings/reactions.

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[4] Schley, A., Colton, T., Schoeneborn, A., and Abrams, E. (2011). *Positive voices, positive choices: A comprehensive training curriculum for adolescent peer educators, Version 1.0*. ICAP.

Module 6 Adolescents, HIV, and Mental Illness

Session 6.1: **The Importance of Mental Health Services for ALHIV and Categories of Mental Illness**

Session 6.2: **Identifying Possible Mental Illness 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 illness and ALHIV
- Define and list basic categories of mental illness
- Describe why ALHIV need access to mental health services
- Discuss the role of primary health workers in providing basic mental health services to ALHIV
- Recognize when an adolescent client may have a mental illness, determine the need for follow-up care, and provide appropriate referrals for mental health services
- Apply screening tools for depression and substance use disorders with adolescent clients
- Provide basic management during mental health emergencies
- Describe how to support clients taking psychotropic medications, including understanding basic interactions between ARVs and psychotropic medications

Session 6.1 Importance of Mental Health Services for ALHIV

Session Objectives

After completing this session, participants will be able to:

- Identify their own beliefs and attitudes about mental illness and ALHIV
- Define and list basic categories of mental illness
- Describe why ALHIV need access to mental health services
- Discuss the role of primary health workers in providing basic mental health services to ALHIV

Exercise 1: Values Clarification: Large group discussion	
Purpose	To discuss attitudes, values, beliefs, and prejudices about ALHIV and mental illness
Remember that, during this exercise, there **are no wrong answers!**	

Overview of Mental Illness[1,2,3,4]

What is mental health?

Mental health refers to a state of psychosocial well being and, for people with mental illness, the adoption of adequate strategies to overcome the debilitating effects of their illness. States of mental health and mental illness fall into a broad spectrum — ranging from, for example, "feeling down" to having severe depression over a period of time.

What is mental illness?

- Mental illness (or mental disorder) is characterized by the presence of one or both of the following *over time*:
  - Persistent and severe subjective distress (or discomfort)
  - Moderate or severe impairment in functioning (not being able to "get through" day-to-day activities)
- *Temporary* states of severe distress and reduced functioning, often in response to stressful life events, are not considered mental illness. Examples might include temporary mood fluctuations, extreme sadness in response to a difficult life event, or not being able to focus in school from time to time.
- Mental health problems that do not meet the threshold for mental illness can be addressed through general counseling (see Module 4), psychosocial support (see Module 5), and support to live positively with HIV (see Module 9).
- Although the exact cause of most mental illnesses is not known, it is becoming clear through research that many are caused by a combination of factors, including genetic predisposition, injuries to or medical conditions that affect the brain, and the long-term impact of adverse life events.

Difficulties defining mental illness:

- To some extent, the line between ordinary variation and distress, and the presence of a mental illness, is an arbitrary one.
- People vary in their personalities, social and intellectual abilities, emotional expression, and coping skills, resulting in a wide range of what is considered "normal."
- Among adolescents, there are also enormous biological and psychological changes taking place. Most adolescents will experience some type of fluctuation in mood or behavior and/or problems that affect their emotional and mental functioning. For example, normal adolescent development includes transient "moodiness" and challenging parental authority.
- The problem of defining mental illness is further complicated by the lack of objective biological tests to make diagnoses.
- Definitions of mental illness are constantly being further refined.

Basic Categories of Mental Illness Seen in Adolescents

Mental illness is a broad term that covers many different disorders — many of which can emerge during late childhood and adolescence. ALHIV are susceptible to a number of mental illnesses, which can be broadly classified into the following categories:

- **Depression:** a feeling of intense sadness — including feeling helpless, hopeless, and worthless — that lasts for days to weeks and is not explained by bereavement (mourning the death of someone close). If severe and untreated, depression can lead to suicide (see box).
- **Alcohol and substance use disorders**
- **Anxiety disorders:** manifested by persistent fear or worry that is out of proportion to a person's current life circumstances
- **Behavioral disorders:** manifested by violent behavior, aggression, and impulsivity (the tendency to do things without adequate forethought)
- **Severe mental illness:** usually refers to schizophrenia or other mental illnesses that have psychotic features (in other words, loss of contact with reality)

Suicide in Adolescents

Suicide, or the act of killing oneself, is one of the most severe consequences of mental illness. While severe depression is the mental illness most commonly associated with suicide, psychosis, anxiety disorders, substance use disorders, and other mental illnesses are also associated with an increased risk of suicide.

These disorders vary in severity and can create barriers to the adolescent achieving self-protection and the expected degree of independence. Mental illness can also interfere with an adolescent's HIV care, including in the areas of retention in care, adherence to ART, positive living, and positive prevention.

Some of the more common mental illnesses are discussed further in the next session.

Importance of Mental Health Services for ALHIV[1,2,3,4]

Recognizing possible mental illness and providing/referring ALHIV for mental health services is important because:

- Primary mental illnesses usually begin in childhood, adolescence, or early adult life.
- Compared to their HIV-negative peers, ALHIV have an increased risk for mental illness as a result of the direct effect HIV has on the brain, the fact that chronic illnesses are associated with higher rates of mental illness, and the impact of stigma and discrimination.
- **A person's mental health significantly influences his or her adherence to HIV care and treatment.** Adolescents with mental health and substance use problems are more likely to forget or decide not to take their medications.
  - Studies in adults have found that, when depression is treated, clients with HIV are more likely to initiate ART, adhere to ART, and have both higher CD4 cell counts and lower viral loads.
- Mental health status influences the course of HIV disease in various ways. For example, depression can limit the energy needed to keep focused on staying healthy and research shows that depression may accelerate the progression to AIDS.
- Mental illness can make it more difficult for an adolescent to engage in positive living and positive prevention, including practicing safer sex to prevent transmission to sexual partners.
- The presence of one mental illness predisposes a person to the onset of other mental disorders (for example, it is not unusual to see a depressed adolescent who also abuses alcohol).
- People who experience mental health problems (for example, depression) are more likely to abuse drugs or alcohol and to engage in risky sexual behaviors.
- Untreated mental illness can disrupt adolescent development in a profound way, by interfering with the ability to work, attend school, and form social relationships.
- Untreated mental illness can result in suicide.

Providing Mental Health Services to Adolescents: Challenges and Solutions[2,5]

Challenges

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

- An insufficient number of mental health specialists to provide services and effective training and supervision to primary health workers
- The limited information on the prevalence of mental health disorders in African countries
- A lack of validated and context-appropriate screening tools
- The few treatment options available in most settings (for example, psychotherapy, psychotropic medications)
- The very limited data available on the treatment of psychiatric disorders in ALHIV
- The high levels of social stigma and discrimination faced by people with mental illness

Solutions

Diagnosing a specific mental illness can be difficult and requires specialized training. Despite this and the many challenges related to providing mental health services to ALHIV, there are many things **health workers** can do, such as:

- Recognize that ALHIV are at risk for mental illness.
- Recognize the array of mental illnesses that are seen in adolescents.
- Include mental health as a part of routine care. This includes conducting regular psychosocial assessments (see Module 5), regularly assessing a client's mental health needs, and checking in with caregivers (when available and involved) about the clients' moods, general behavior, and any changes they have observed — at home, at school, with friends, and with family members.
- Use clinical skills and observation during routine visits to identify if an adolescent might have a mental illness.
- Know the signs that a serious mental illness may be present and know how to refer adolescents for further assessment and care.
- Use simple screening tools to determine if a mental illness may exist.
- Distinguish urgent mental illness that requires emergency management from less pressing mental health concerns.
- Provide appropriate mental health referrals and follow-up care and support to adolescent clients and their family members.
- Consider the impact of mental illness on an adolescents' HIV care (in particular adherence to care and medications).
- Respect and listen to clients' and caregivers' beliefs about the origin and treatment of mental illness. Beliefs concerning the treatment of mental health conditions vary among members of different communities and cultural groups.
- Discourage the use of alcohol and drugs among adolescent clients.

There are also many things **health facilities** can do to support and improve mental health services for adolescent clients and their family members, such as:

- Establish routine approaches and standard internal procedures for mental health screening, referrals, and treatment.
    - This can include **mapping available mental health services** at the level of the health facility (own health facility and others in the area) and the community (e.g. school-based programs for adolescents with learning disabilities; mental health specialists, such as psychologists and psychiatrists within the facility or at other health facilities; public or private inpatient and outpatient psychiatric services; individual or group counseling programs, etc.), formalizing referral linkages with these services, and providing appropriate referrals and follow-up.
    - Health facilities should also **develop and implement standard procedures** for mental health screening, referrals, and treatment. In some facilities, for examples, health workers may be responsible for mental health screening and basic management, while in others, they may only be responsible for initial screening and referral to a mental health professional if possible mental illness is detected.
- Identify a mental health point person on the multidisciplinary HIV team (this may be a social worker, counselor, psychologist, or other).
    - Support the mental health point person to attend relevant mental health trainings and make time for in-service trainings on mental health.
    - A number of mental health resources that may be used for discussion and training in the clinical setting can be found here: http://www.who.int/mental_health/en/.
- Ensure a multidisciplinary team approach to the care of clients with mental illness — for example, that their care is managed jointly by the mental health professional (e.g. psychologist, psychiatrist, social worker) and the nurses and physicians providing HIV care and treatment.
- Ensure that mental health is discussed as a routine part of HIV care in multidisciplinary team meetings and case conferences.

Session 6.2 Identifying Possible Mental Illness and Providing Basic Mental Health Support to ALHIV

Session Objectives

After completing this session, participants will be able to:

- Recognize when an adolescent client may have a mental illness, determine the need for follow-up care, and provide appropriate referrals for mental health services
- Apply screening tools for depression and substance use disorders with adolescent clients
- Provide basic management during mental health emergencies
- Describe how to support clients taking psychotropic medications, including understanding basic interactions between ARVs and psychotropic medications

Recognizing Possible Signs of Mental Illness During Routine Clinic Visits

Remember: Diagnosing a specific mental illness can be difficult and requires specialized training. However, all health workers should know the signs that a serious mental illness may be present and know how to refer adolescents for further assessment and care.

There are many types of information readily available to the health worker that can help determine if an ALHIV may have a mental illness. See also *Appendix 6A: Tips for Health Workers on Identifying Possible Mental Illness.*

1. Use a client's recent and past history

Recent history: An adolescent may self-report symptoms of mental illness. On the other hand, an adolescent suffering from a mental illness may not be aware that something is wrong or may be too afraid to talk about it. Concerns about the changes brought about by possible mental illness may be initially expressed by a client's family members, other adults, or peers. The health worker who knows an adolescent well may also notice these changes over time. For example:

- The adolescent has shown a dramatic change in behavior and/or a major decrease in psychosocial functioning (e.g., used to be friendly, but now only wants to be alone; used to be calm, but is now behaving in a violent way; was a good student, but is now failing in school, etc.)
- The adolescent has been saying things that do not seem plausible (e.g., "my grandmother is trying to poison me," "voices are telling me that I'm a bad person," etc.)

Somatic symptoms: Mental illness, especially depression and anxiety disorders, affect the mind and body and, when severe, are routinely accompanied by physical (or somatic) complaints.

- These may include: fatigue, headaches/migraines, abdominal pain/gastrointestinal problems, backaches, difficulty breathing, changes in appetite and weight, changes in sleep patterns, and chest pains.

Review the client's clinical and ART history:

- If signs of possible mental illness are observed or reported, health workers should review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing or medicine changes) to determine if they are contributing to changes in the client's mental health.
- While rare, some ARVs, including efavirenz, can have neuropsychological side effects that may contribute to mental health problems. In these cases, drug changes may need to be considered in clients with new onset mental health problems.

Past history: Many mental illnesses are persistent or recurrent, and some can begin in early childhood. The client or an accompanying family member or friend may report past events that suggest the presence of a mental illness. These include:

- Past psychiatric hospitalization
- Past use of psychotropic medication (any medication capable of affecting the mind, emotions, and behavior) — this is discussed further later in this session
- History of severe behavioral disturbances
- History of mental illness in the family (e.g., depression, schizophrenia)
- History of school failure

2. Make observations during routine visits (and ask caregivers' about their observations)

Health workers can make observations about the following during their routine visits with clients, which may alert them to the existence of a possible mental illness.

- **Appearance and presentation**: The adolescent's hygiene and grooming are poor; the client comes across as frightening or frightened; the client has alcohol on his or her breath and/or appears intoxicated; the adolescent makes no eye contact or is crying
- **Attitude and behavior**: The adolescent is restless, belligerent, uncooperative; the adolescent is making threats, is unwilling/unable to speak, is behaving in odd and unusual ways
- **Mood and emotions:** The adolescent looks or seems to be frightened, sad, angry
- **Speech, thinking, and perception**: The adolescent is speaking very rapidly or overly loudly or softly; is saying things that make no sense; is saying things that are unlikely to be true (e.g. my grandmother is poisoning me); is reporting hallucinations (hearing or seeing things that are not there)
- **Level of alertness and orientation**: The adolescent is having trouble staying alert and attentive; is drowsy; is confused about things like where he or she is and what time of day it is
- **Social and intellectual skills**: The adolescent does not have the verbal, behavioral, and/or social skills that would be expected of someone his or her age; the adolescent is behaving like a younger child would

If the history and observations reveal problems, it is helpful to ask a few simple follow-up questions that are specific to the problems reported or observed. For example:

- *What is making you cry?*
- *You look frightened today — did something scare you?*
- *What are you feeling angry about?*
- *You are usually so neatly dressed — is something wrong?*
- *Have you noticed how quickly you're speaking?*

If health workers are not afraid to ask this type of simple questions based on their observations, they may quickly learn whether an adolescent client is having serious problems that suggest the presence of mental illness.

As mentioned above, it is also important for health workers to review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications) to determine if they might be contributing to any new mental health issues.

A note about delirium

Delirium is a serious *medical* (i.e., not psychological) condition that can present with signs of mental illness, such as delusions, hallucinations, and agitation. Prior to concluding that an adolescent has a primary mental illness, it is very important for health workers to first assess whether the adolescent has delirium and is in urgent need of medical care. Note that delirium is not as common in adolescents as it is among the elderly, especially hospitalized and critically ill patients.

Causes of delirium:

- Rapidly reversible causes of delirium are hypoglycemia (check blood glucose level), severe dehydration (check for signs of shock, heat stroke, high temperature; provide hydration and cooling), and hypoxia (look for cyanosis and shortness of breath; give oxygen).
- Other causes of delirium include meningitis, cerebral malaria, sepsis from any cause, the direct impact of HIV on the brain, elevated blood sugar, organ failure, metabolic or endocrine abnormalities, alcohol/drug/medication intoxication or overdose, poisoning, status epilepticus, post seizure state, neurotoxic snake bites, and head trauma.

3. Conduct regular psychosocial assessments

As discussed in Module 5, health workers should conduct a psychosocial assessment when an adolescent enrolls in care and treatment and annually thereafter — as well as when there is a significant change in the client's situation. Health workers may find it helpful to use the Psychosocial Assessment Tool in *Appendix 5A* as a guide to conduct and record key points of psychosocial assessments.

- Psychosocial assessment findings can reveal important things about the client's mood, mood changes over time, coping strategies, eating and sleeping habits, drug and alcohol use, and support systems.
- Information gained from psychosocial assessments can help health workers identify areas for additional follow-up and support, as well as possible signs of mental health problems that require further assessment by a trained mental health provider.

Remember: The way mental illnesses present in clients varies from culture to culture and person to person. There are also differences in younger versus older adolescents. For example:

- It is common for younger children to manifest mental health issues through acting out behaviors 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. Mental illness interferes with their sense of well being and/or the ability to carry out usual activities.

<table>
<tr><th colspan="2">Exercise 2: Mental Illness in ALHIV: Small group work and peer teaching</th></tr>
<tr><td>Purpose</td><td>To learn more about the major categories of mental illness, including common signs and symptoms that health workers should watch out for and suggested next steps health workers can take if they think an adolescent client may have a mental illness</td></tr>
<tr><td colspan="2">This exercise consists of 2 parts:
• Part 1: Small Group Work
• Part 2: Large Group Discussion

Refer to Tables 6.1-6.5.</td></tr>
<tr><td colspan="2">For Part 1, prepare to teach your peers about the category of mental illness assigned to your group, including:
• Basic information about the mental illness (the definition, locally used terms, etc.)
• Possible signs and symptoms
• What the health worker should do
• Screening tools that health workers can use to get more information (note that examples of screening tools for depression, alcohol abuse, and drug use are included in Appendices 6B, 6C, and 6D, respectively).</td></tr>
</table>

Mental Illness in ALHIV: Signs and Symptoms and Tips for Health Workers[2,6]

The content and tables below summarize basic information on common categories of mental illness, including basic definitions, possible signs and symptoms health workers should watch out for, and suggestions for what health workers should do if they observe these signs and symptoms.

Depression

Depression is the most common mental illness seen in ALHIV.

Table 6.1: Depression - Tips for health workers

Possible Signs and Symptoms of Depression	• Depressed mood, feelings of helplessness or hopelessness • Really tired with no energy • Cannot find good in anything • Does not enjoy things (loss of interest or pleasure) • Sleeps too much or not enough • Gets angry for no reason • Cannot eat or eats too much • Does not feel like being social with friends or family • Feelings of guilt or low self-worth • Poor concentration • Talks about running away • Thinks about suicide • Talks of self-injury or has had prior episode(s) of self-injury • Prior attempts or expressions of suicide
What the Health Worker Can Do	• Symptoms of depression are very common among adolescents. They are often transient and respond to support from friends, family, and health workers. • If problems are mild, try psychosocial counseling and support strategies (see Modules 4 and 5). • Refer client to trained counselor or other mental health provider, peer support group, and group/individual therapy, if available. • Ask about alcohol and drug use (see below). • Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications). • Screen the client for depression; for example, using the screening tools in ***Appendix 6B: Sample Screening Tools for Depression and Suicide*** • If depression is severe, does not improve, or worsens, refer client to a mental health provider. **Screen for suicide risk. Clients require urgent intervention if:** • They indicate they might hurt themselves or another person, or if they show any evidence of self-harm. • Their families cannot cope with them anymore. • They are thinking about, threatening, or have attempted to kill themselves. ◦ If suicidal, ensure immediate safety and refer to the nearest psychiatric hospital; provide constant supervision during transfer (see the section on "Managing Psychiatric Emergencies" below for more information).

Alcohol and substance use disorders

Experimentation is common among adolescents (this will be discussed further in Module 9). However, there are patterns of use that warrant the diagnosis of an alcohol or substance use disorder. Note that, in addition to alcohol, some commonly used drugs include marijuana, glue (sniffing), chat, and methamphetamines. In some places, efavirenz is also crushed and smoked.

Table 6.2: Alcohol and substance use disorders - Tips for health workers

Possible Signs and Symptoms of Alcohol and Substance Use Disorders	• Sudden changes in personality without another known cause • Loss of interest in favorite 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 behavior, anger, nervousness, or giddiness • Increased secretiveness, heightened sensitivity to being asked questions • Sudden changes or unexplained problems with adherence to medications or missed appointments
What the Health Worker Can Do	• Provide general education and counseling on risk reduction and behavior change. For example, assess the safety of the client and others while client is under the influence of alcohol or drugs (if operating a motor vehicle, having sex, etc.) and provide risk reduction counseling. • Provide referrals for individual and group counseling and treatment (e.g. Alcoholics Anonymous). • Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications). • Screen for alcohol misuse and drug use and abuse upon initial intake and whenever suspected, based on medical history, reports from family/partner, client's behavior in the clinic, or findings from psychosocial assessments. **See *Appendix 6C: Screening for Alcohol Dependency with the CAGE Questionnaire* and *Appendix 6D: The Drug Abuse Screening Test (DAST).*** • Be patient and accepting of the client's situation; recovery can be a gradual process. • Provide ongoing support and follow-up at every visit. • See Module 9 for more information

Anxiety disorders

Anxiety disorders are different from the normal, everyday anxiety that is commonly seen among adolescents. Anxiety disorders are more intense (e.g., panic attacks), last longer, and/or interfere with daily life.

Table 6.3: Anxiety disorders - Tips for health workers

Possible Signs and Symptoms of Anxiety Disorders	• Cannot eat • Cannot breathe or has frequent shortness of breath • Panic attacks (may include shaking, sweating, fast heartbeat, difficulty breathing) • Tingling in the hands or feet • Chronic headaches • Trouble sleeping; nightmares • Cannot concentrate on anything • Feels jumpy, stressed out, or restless • Feels overwhelming sense of worry • Fearful of participating in normal activities
What the Health Worker Can Do	• Symptoms of anxiety are very common among adolescents. They are often transient and respond to support from friends, family, and health workers. • If problems are mild, try psychosocial counseling and support strategies (see Modules 4 and 5). • Refer client to peer support group and group/individual therapy, if available. • Teach client relaxation techniques and explore other coping mechanisms to manage anxiety. • Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications). • If anxiety is severe, interferes with the client's functioning, and/or does not improve or worsens over time, refer client to a mental health provider.

Behavioral disorders

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

Table 6.4: Behavioral disorders - Tips for health workers

Possible Signs and Symptoms of Behavioral Disorders	• Frequent defiance of authority • Arguing and refusing to obey rules at home and at school • Failure to take responsibility for bad behavior or mistakes • Resentment, looking for revenge • Regular temper tantrums **In older children/adolescents:** • Aggressive behaviors that threaten/harm people or animals • Behaviors that destroy property • Stealing, bullying, or lying • Serious violations of rules at home or at school **Adolescents with attention deficit hyperactivity disorder (ADHD) often exhibit the following symptoms:** • Trouble paying attention and concentrating • Difficulty in organizing activities • Easily distracted and fails to finish tasks • High activity level • Cannot sit still • Impulsivity • Cannot wait for a turn • Interrupts when others are talking or doing something
What the Health Worker Can Do	• Counsel the client, focusing on self-regulation. • Counsel caregivers, focusing on improving parenting skills and giving advice on how to create a structured home environment. • Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications). • Talk with a mental health specialist about prescribing medication • Provide referrals to local support services.

Severe mental illness

Severe mental illness usually refers to schizophrenia, schizoaffective disorder, or other mental illnesses that can have psychotic features (in other words, loss of contact with reality).

Table 6.5: Severe mental illness - Tips for health workers

Possible Signs and Symptoms of Severe Mental Illness	• Bizarre delusions • Auditory or visual hallucinations (client reports hearing or seeing things) • Paranoia • Agitation • Suspiciousness • Hostility • Exaggerated sense of self
What the Health Worker Can Do	• First, rule out delirium, a serious *medical* (i.e., not psychological) condition that can present with signs of mental illness, such as delusions, hallucinations, and agitation. Always check for fever — an agitated adolescent who is febrile should always be presumed to be medically ill. See the content about delirium in the previous section for more information. ◦ Adolescents suspected of delirium should be referred for urgent medical evaluation and treatment. • Review the client's HIV history, recent changes in disease status, and ART regimen (including any dosing changes or new medications). • If delirium is ***not*** suspected, refer to a psychiatrist or other mental health professional for assessment and treatment. • Clients with severe mental health disorders should not be discriminated against when ART is considered. Stabilization of psychiatric symptoms and directly observed treatment by a caregiver will likely improve adherence.

Managing Psychiatric Emergencies[6]

Sometimes an adolescent may present in a violent or agitated way, making it necessary to provide immediate management prior to emergency medical treatment (if the cause is delirium, for example) or transfer to a psychiatric hospital.

Each health facility should develop standard operating procedures on the management of psychiatric emergencies, should train all health workers on these procedures, and should ensure that they are implemented.

How to manage a client who is violent or very agitated

Calm and protect:

- Protect the client from harming him- or herself, you, or others.
- Ensure that you are in a quiet area where there is no audience.
- Use space to protect yourself.
- Get help from other colleagues, security, or family members who can help mediate the situation and calm the client down, for the safety of both the client and staff.
- Approach the client in a calm and confident manner.
- Speak in a calm and reassuring way.
- Be non-confrontational, non-judgmental, and deflect criticism.
- Keep your own emotions in check. Do not let yourself be affected by verbal abuse or threats.
- Be aware of potential weapons and remove unsafe objects.
- Consider sedation with diazepam or haloperidol if these medications are available on-site with instructions for use in adolescents.

A note on restraining patients: In some places, it is currently or was previously customary practice to restrain violent or agitated patients, such as by using hand and feet restraints. The global community recognizes such extreme restraint as both cruel and unnecessary. Health workers should not restrain patients in this way unless it is absolutely necessary to protect the patient.

How to manage a suicidal or self-harm client
Sometimes an actively suicidal adolescent may present and require immediate management prior to transfer to a psychiatric hospital.

Evaluate whether the client has attempted a medically serious act of self-harm or suicide:

- Ask the client and any accompanying friends or family about any past self-harm attempts.
- Look for signs of poisoning, intoxication, or self-injury.
- Medically treat as necessary. Engage mental health experts to help with this.
- Ensure that the client is closely monitored to prevent further self-harm.
- Do not leave the client alone or unsupervised.

Evaluate whether there is an imminent risk of self-harm or suicide:

- Ask the client about current thoughts or plans to commit suicide or self-harm, and about means to follow through on those thoughts or plans.
- Look for signs of severe emotional distress, hopelessness, agitation, uncommunicative behavior, or social isolation.

If risk of suicide or self-harm is imminent:

- Remove access to means of self-harm.
- Create a secure and supportive environment and ensure that the person is not left alone.
- Transfer the client to a psychiatric hospital, with accompaniment by a family member or other reliable escort, including, if available, a health worker.

Psychotropic Medications and ARVs [2]

Key points about the use of psychotropic medications in ALHIV

Psychotropic medications: Any medication capable of affecting a person's mind, emotions, and behavior.

- Health workers should learn the basics about interactions between psychotropic medications and ARVs.
  - Most ARVs are not affected by psychotropic medications.
  - There is one important exception: carbamazepine is used to treat both seizures and mania (a state of abnormally elevated or hyperactive mood/mental state). It can lower the levels of certain ARVs in the body, which can result in failure of 1st and 2nd line ART regimens. Therefore, another medication should be used in place of carbamazepine if at all possible.
  - It is more common that ARVs change the levels of psychotropic medications. In general, most psychotropic medications can be used, but the following rule should be followed: *"start low and go slow."*
- Like all medications, psychotropic medications — including antidepressants — can have side effects and require careful monitoring. It is important to be aware that the use of antidepressants in adolescents is sometimes associated with an increased risk of suicide.
- Any behavioral changes in a client require further assessment for possible medical problems.
- If medication for mental illness is prescribed to a client, it should, whenever possible, be combined with counseling and psychotherapy.
- In cases of clients who are mentally ill, an important consideration is adherence to both HIV and any other medication regimens. Health workers should assess each client's adherence to ALL prescribed medications at every visit.
- It is especially important to use a multidisciplinary team approach for the care of ALHIV with mental illness, including those clients taking psychotropic medications.

Exercise 3: Mental Health Case Studies: Large group discussion

Purpose	To apply the information covered in this module to specific case studies

Case Study 1:

M___ is an 18-year-old client who was recently diagnosed with HIV. M___ missed his last appointment 2 weeks ago, but has come to the clinic today. He tells you that he is too busy with "life" to come to the clinic and he appears shaky and nervous. You conduct a psychosocial assessment, during which you learn that M___ recently got fired from his job and spends most nights getting drunk with his friends to "forget about everything."

Case Study 2:

N___ is 16 years old. She has been on ART and has been coming to the clinic for many years. As a child, she maintained good grades in school and was described by her grandmother as being helpful around the house. Recently, however, N___'s relationship with her family has deteriorated. She is not eating or sleeping regularly, she goes through periods of extreme anger followed by periods of complete withdrawal, and she has run away from home to live with her boyfriend twice in the past year. N___ says, *"life is not worth living if I can't be with my boyfriend."* Her grandmother is very concerned that N___ is going to do something to hurt herself.

Case Study 3:

P___ is a 14-year-old boy with HIV. He and his aunt arrive at the clinic for a routine checkup. P___'s aunt tells you that she is worried about her nephew because he often seems to get agitated and "jumpy." He does not want to go to school or play with his friends like he used to. He also has "episodes," usually at night or right before he is supposed to leave for school in the morning, where he has trouble breathing and sweats. P___ was living with his mother until she died two years ago.

Case Study 4:

B___ is 13 years old and comes for a routine visit with her mother. When you do a clinical checkup with B___, you notice that she is having trouble paying attention, that she is suspicious when you ask her questions, and that her clothes and hair are unkempt (which is unusual). At one point, she mentions "a voice" that is telling her to do bad things that she doesn't want to do and then she starts crying. You then meet with B___'s mother, who tells you that B___ has "turned into a different person" during the last few months. She cannot focus at school, she seems suspicious when anyone wants to talk with her, she hides her medications, she does not care about her appearance any more, and her behavior in general just seems "off."

Module 6: Key Points

- People with mental illness are often stigmatized, discriminated against, and excluded from school, social activities, and, at times, even health care services. Health workers can combat this stigma and discrimination by setting an example and treating people with mental illness respectfully.
- It is very important to include mental health services as part of comprehensive care for ALHIV.
- Mental illness is a broad term that covers many disorders characterized by persistent and severe subjective distress and/or moderate to severe impairment in functioning over time.
- Many mental illnesses may emerge during late childhood and adolescence.
- Adolescents are susceptible to a range of mental illnesses that can be classified into these broad categories: depression; alcohol and substance use disorders; anxiety disorders; behavioral disorders; and severe mental illness.
- Mental illness can influence the course of HIV disease, impact adherence to care and treatment, increase the likelihood of drug and alcohol use, and lead to risky sexual behavior.
- Untreated mental illness can disrupt adolescent development and, in the most extreme cases, result in suicide.
- Although there are barriers to providing mental health services in many settings, there are many things health workers and health facilities can do to establish routine approaches and standard procedures to recognize possible mental illness and provide basic care, referrals, and follow-up.
- There are many ways that health workers can recognize signs of a possible mental illness during routine clinic visits with ALHIV (and caregivers), including: the client's recent and past history; basic observations of the client; and findings of routinely conducted psychosocial assessments.
- Health workers should know the basic categories of mental illness, be alert to their signs and symptoms, and know the steps to take if a client exhibits these signs and symptoms. Simple screening tools are available to assist health workers.
- If a client is behaving violently or is very agitated, the most important priorities are to calm and protect him or her. Clients who are suicidal, who have harmed themselves, or who have an intention of self-harm require **immediate emergency care**.
- Most ARVs are not affected by psychotropic medications. Exceptions include the use of carbamazepine (used to treat seizures and mania), which can lower ARV levels in the body.

Appendix 6A: Tips for Health Workers on Identifying Possible Mental Illness

√	Categories	Signs of a possible mental illness that require follow-up
1. Ask the client and caregiver about:		
	Present history (reported by client or caregiver)	• Reports symptoms of mental illness or mental distress • Reports new problems functioning at home, school, work, or new problems with friends and family • Reports a dramatic change in behavior and/or a major decrease in psychological functioning (e.g., used to be very calm, now violent; used to do well in school, now falling behind; used to be friendly, is now withdrawn, etc.) **Note:** Review the client's HIV history, recent changes in disease status, and ART regimen (including dosing or medicine changes)
	Past history (reported by adolescent client or caregiver)	• Reports a past history of mental distress; problems functioning at home, school, work; or problems with friends and family • History of psychiatric hospitalization, treatment, or psychotropic medication use • History of school failure • History of severe behavioral disturbances • History of mental illness in the family
2. Observe and ask for the caregivers observations of the client's:		
	Appearance and presentation	• Hygiene and grooming are poor • Comes across as frightening or frightened • Has alcohol on his or her breath or appears intoxicated • Does not make eye contact • Crying, shouting, or laughing uncontrollably
	Attitude and behavior	• Restless, belligerent, or uncooperative • Making threats • Unwilling or unable to speak • Behaving in odd and unusual ways
	Mood and emotions	• Seems frightened, sad, or angry • Unusually happy for no apparent reason
	Speech, thinking, and perception	• Speaking very rapidly or overly loud • Whispering or speaking very softly • Saying things that make no sense • Saying things that are unlikely to be true • Claiming to hear voices or to see visions of people/things that are not there
	Level of alertness and orientation	• Having trouble staying alert and attentive • Drowsy • Confused about things such as where he or she is or the time of day
	Social and intellectual skills	• Lacks verbal, behavioral, and/or social skills that would be expected of someone his or her age • Behaving like a much younger child/adolescent
3. Conduct regular psychosocial assessments and document major findings (see Module 5)		
	Conduct a psycho-social assessment (at enrollment, annually, and when the client's situation changes significantly)	• Major changes in mood • Experiencing chronic sadness or anxiety • Changes/problems in sleeping, eating, or other routines • Harmful coping strategies, including use of alcohol or drugs • Problems in school, with friends, or with family members

Appendix 6B: Sample Screening Tools for Depression and Suicide

Patient Health Questionnaire-2 (PHQ-2)

This simple questionnaire can be used as an initial screening test for a major depressive episode.

Over the past two weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things
0 = Not at all
1 = Several days
2 = More than half of the days
3 = Nearly every day

Feeling down, depressed, or hopeless
0 = Not at all
1 = Several days
2 = More than half the days
3 = Nearly every day

Total point score: ____________

Score interpretation:

PHQ-2 score	Probability of major depressive disorder (%)	Probability of any depressive disorder (%)
1	15.4	36.9
2	21.1	48.3
3	38.4	75.0
4	45.5	81.2
5	56.4	84.6
6	78.6	92.9

Source: Kroenke, K., Spitzer, R.L., & Williams, J.B. (2003). *The Patient Health Questionnaire-2: Validity of a two-item depression screener*. Med Care, *41,* 1284-92.

PHQ-9 Questionnaire, Modified for Adolescents

Name ______________________________ Clinician ________________________

Medical Record or ID Number ___________ Date _____________

How often have you been bothered by each of the following symptoms during the past two weeks?

	(0) Not at all	**(1) Several days**	**(2) More than half the days**	**(3) Nearly every day**
1. Feeling down, depressed, irritable, or hopeless?				
2. Little interest or pleasure in doing things?				
3. Trouble falling asleep, staying asleep, or sleeping too much?				
4. Poor appetite, weight loss, or overeating?				
5. Feeling tired or having little energy?				
6. Feeling bad about yourself or feeling that you are a failure or that you have let yourself or your family down?				
7. Trouble concentrating on things like school work, reading, or watching TV?				
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you were moving around a lot more than usual?				
9. Thoughts that you would be better off dead or thoughts of hurting yourself in some way?				

10. *In the* ***past year****, have you felt depressed or sad most days, even if you felt okay sometimes?*

☐ Yes ☐ No

11. *If you are having any of the problems on this form, how* ***difficult*** *have these problems made it for you to do your work, take care of things at home, or get along with other people?*

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

12. *Has there been a time* ***in the past month*** *when you have had serious thoughts about ending your life?*

☐ Yes ☐ No

13. *Have you* ***ever, in your whole life,*** *tried to kill yourself or made a suicide attempt?*

☐ Yes ☐ No

Score: _____________

Administering the PHQ-9 Questionnaire:

- This questionnaire can be used with patients between the ages of 12 and 18 and takes less than 5 minutes to complete and score.
- It can be administered and scored by a nurse, medical technician, physician assistant, physician, or other office staff.
- Patients should be left alone to complete the questionnaire in a private area, such as an exam room or a private area of the waiting room.
- Patients should be informed of their confidentiality rights before administering this questionnaire.
- Depression screening should be conducted annually.

Scoring:

- For every X:
  Not at all = 0
  Several days = 1
  More than half the days = 2
  Nearly every day = 3
- Add scores of all "X"ed boxes.
- Total score of 11 or above indicates a positive screen.
- Regardless of the total score, endorsement of serious suicidal ideation OR past suicide attempt (questions 12 and 13) should be considered a positive screen.

Total score: depression severity

1-4:	Minimal depression
5-9:	Mild depression
10-14:	Moderate depression (score of 11 or above = positive score)
15-19:	Moderately severe depression

Interpreting the screening results:

- Patients who score positive on the questionnaire should be evaluated by their primary provider to determine if the depression symptoms they expressed on the screen are significant, causing impairment, and/or warrant a referral to a mental health specialist or follow-up treatment by the provider.
- It is recommended that the provider inquire about suicidal thoughts and previous suicide attempts with all patients that score positive, regardless of how they answered these items on the questionnaire.
- For patients who score negative, it is recommended that the provider briefly review with the patient the symptoms marked as "more than half days" and "nearly every day".
- The questionnaire indicates only the likelihood that a youth is at risk for depression or suicide; its results are not a diagnosis or a substitute for a clinical evaluation.

Depression severity:

- The overall score provides information about the severity of depression, from minimal to severe depression.
- The interview with the patient should focus on their answers to the screen and the specific symptoms with which they are having difficulties.
- Additional questions also explore dysthymia, impairment of depressive symptoms, recent suicide ideation, and previous suicide attempts.

Source: Spitzer, R.L., Williams, J.B., Kroenke, K., et al. (2005). *Patient Health Questionnaire modified for teens (PHQ-9).*

Appendix 6C: Screening for Alcohol Dependency with the CAGE Questionnaire

✓	**Screening for alcohol dependency**
	1. Use the CAGE questionnaire
	• Have you ever felt that you should **C**ut down on your drinking?
	• Have people **A**nnoyed you by criticizing your drinking?
	• Have you ever felt bad or **G**uilty about your drinking?
	• Have you ever had an **E**ye-opener — a drink first thing in the morning to steady your nerves or get rid of a hangover?
	2. If the client responded "yes" to 2 OR MORE of the above questions, then he or she may have alcohol dependency.
	3. Give feedback about the results of the screening; provide support and referrals.
	• Provide information about the hazards of drinking (including poor adherence to HIV care and treatment). • Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent. • Emphasize the benefits of changing and assess the client's level of motivation to change. • If the client wants to change his or her drinking behavior, discuss goals and provide advice and encouragement. • Provide referrals to a support group and for further counseling. 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).

Source: Ewing, J.A. (1984.) *Detecting alcoholism: The CAGE Questionnaire.* J. Am. Med. Assoc, *252,* 1905-1907.

Appendix 6D: The Drug Abuse Screening Test (DAST)

✓	**Screening for drug abuse**
	Use the DAST questionnaire. Ask: *In the last 12 months…:*
	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 program, especially related to drug use?*
	Score the questionnaire.
	• Score 1 point for each "yes" response, EXCEPT for the following two questions: ○ *Can you get through the week without using drugs (4)?* ○ *Are you always able to stop using drugs when you want to (5)?* For these two questions, score 1 point for "no" responses. • **If the client's score is 6 OR MORE, then he or she may have a substance use problem.** • **If the client's score is 16 OR MORE, this may indicate very severe substance abuse.**
	Give feedback about the results of the screening; provide support and referrals.
	• Supply information about the hazards of drug use (including poor adherence to HIV care and treatment). • Involve the adolescent's caregiver(s), if appropriate and if the adolescent gives consent. • Emphasize the benefits of changing and assess the client's level of motivation to change. • If the client wants to change his or her behavior related to drug use, discuss goals and provide advice and encouragement. • Provide referrals to a support group and for further counseling. If needed, find a facility that may be able to help the patient overcome physical dependency and provide counseling and support.

Source: 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.* Brit J Addict, *84(3),* 301-307.

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[5] WHO. (2010). *mhGAP intervention guide for mental, neurological, and substance use disorders in non-specialized health settings.* WHO.

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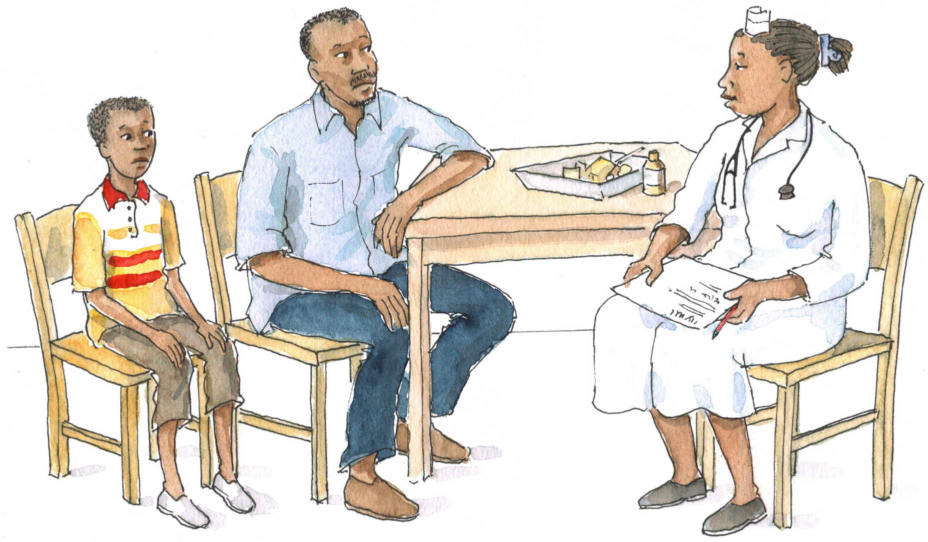
Module 7 Providing Disclosure Counseling and Support

Session 7.1:	**The Disclosure Process: A Developmental Approach**
Session 7.2:	**Disclosure Preparation, Counseling, and Support for Children, Young Adolescents, and Caregivers**
Session 7.3:	**Disclosure Counseling 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
- Understand the reasons to disclose to children and young adolescents
- Discuss common barriers that health workers and caregivers have to disclosure and possible solutions for each
- Work with caregivers to understand the importance of disclosure and to prepare for and move through the disclosure process with children and adolescents
- Work through the disclosure process with children and young adolescents
- Provide counseling and support to adolescents on disclosing their HIV-status to others



Session 7.1 The Disclosure Process: A Developmental Approach

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[1,2]

What is disclosure?

- Disclosure should be seen as a process — not a one-time event — of telling a child/young adolescent that he or she has HIV and helping him or her 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 child/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 do so
- Helping the young person prepare to disclose to others and providing follow-up support during the process

Through the process, the child/young adolescent should come to know about:

- The diagnosis, the infection and disease process, and health changes that could occur
- Strategies to lead a healthy life (in particular adherence to ART) and his or her responsibilities now and in the future
- How to cope with the possible negative and positive reactions of others

Using a developmental approach to disclosure for children and adolescents:

- Decisions about when to start talking to children about their health should be based on the readiness of the caregiver and the developmental stage of the child.
- Each phase of childhood development has characteristic features. Understanding a child's/adolescent's developmental stage and needs is vital to disclosure. A young person's understanding of his or her HIV diagnosis will evolve as his or her brain becomes more equipped to absorb complex information and as his or her level of emotional maturity increases.
- Understanding childhood and adolescent development will help health workers and caregivers better guide the disclosure process, ensuring that appropriate information is presented at a time 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 his or her development is the same as that of others in his or her age group. Therefore, it is essential that health workers ask questions to assess each young person's understanding.

See *Appendix 7A: Guidance for Developmentally Appropriate Disclosure* for additional information.

Session 7.2 Disclosure Preparation, Counseling, and Support for Children, Young Adolescents, and Caregivers

Session Objectives

After completing this session, participants will be able to:

- Understand the reasons to disclose to children and young adolescents
- Discuss common barriers that health workers and caregivers have to disclosure and possible solutions for each
- Work with caregivers to understand the importance of disclosure and to prepare for and move through the disclosure process with children and adolescents
- Work through the disclosure process with children and young adolescents

Disclosure of HIV-Status to ALHIV

To improve the chances that the disclosure process will proceed as smoothly as possible, health workers should start talking about disclosure with caregivers, and should start working with older children to prepare them for disclosure and assess their readiness for disclosure, WELL before a particular child becomes an adolescent. It is recommended that partial disclosure (see "Partial and Full Disclosure" on the next page) begin by the time the child is 6 years old. Ideally, the young person will already know about his or her HIV-status by the time he or she is a young adolescent. However, there are challenges associated with the disclosure process and health workers play an important role in helping families work through these barriers.

What are the reasons to disclose a child's HIV-status?

- A literature review conducted by the WHO concluded that disclosing to HIV-infected children can result in health and psychological benefits. Also, there is little evidence of psychological or emotional harm caused by disclosing to a child. In most cases, initial emotional reactions to disclosure wear off over time and respond to adequate emotional support.[3]
- 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
    - Have poor adherence.
- Disclosure may help improve social functioning and school performance due to a decrease in stress.
- When children/young adolescents learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, they overhear health workers and caregivers talking about their health as if they were 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 is especially critical for orphaned or other vulnerable and most-at-risk children/young adolescents because they may wonder why they have lost a parent or been rejected by their family. Disclosure also helps them seek the services they need, especially in the case of 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 children, adolescents, and their caregivers. Non-disclosure does not protect children and adolescents. 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.

Partial and Full Disclosure

Disclosure to children and young adolescents should depend on their stage of development. Young children may only need to know that they are sick, that they have to go to the doctor, and that they need to take medicines to feel better **(partial disclosure)**. Older children/young adolescents, on the other hand, should know that they have HIV, should understand the disease and their medications, and should actively participate in their own care and treatment **(full disclosure)**. As a child/young adolescent develops, caregivers and health workers should eventually move from partial to full disclosure, gradually helping the child/young adolescent understand and cope with knowing his or her diagnosis.

Partial disclosure:

Children develop the ability to think logically around 6 years of age. It is at this time that they are able to begin understanding 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 creating a context in which full disclosure can be more meaningful for the child

Full disclosure:

"Full disclosure" is when a child/young adolescent is specifically told that he or she is HIV-infected and is given further HIV-related details, such as how HIV is transmitted and how he or she may have contracted it.

- Families and caregivers are ideally the ones who should decide at which point full disclosure is necessary. However, health workers should also assess the child's readiness for disclosure, prepare him or her for disclosure, and provide follow-up information and support.
- It is generally recommended that children/young adolescents be fully disclosed to when they are developmentally ready to receive this information, which is typically by the time they are 10–12 years old.[2]
- A particularly important indication that full disclosure should be considered is when the child/young adolescent starts asking specific questions about his or her illness (for example, asking how he or she got the sickness) and no longer seems satisfied with the responses previously given.
- Full disclosure is easier for children/young adolescents 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 by caregivers and health workers, including Adolescent Peer Educators if possible.

There are occasional times when it may be more appropriate to delay the disclosure process with a child/young adolescent, such as:

- When the child/young adolescent has severe cognitive and developmental delays
- When the child/young adolescent is grappling with serious health or mental health conditions
- When one or both parents/the caregiver has an acute health problem or mental health crisis

Barriers to Disclosure

Health worker barriers

- Health workers experience some of the same barriers faced by caregivers, such as not knowing where to start or being concerned about harming the child/adolescent (see next section).
- Training is essential to equip health workers to support caregivers, children, and adolescents throughout the disclosure process. In addition, it is important that health workers ask the advice of peers who have been through this process with caregivers, children, and adolescents, and that they observe peers that have more experience.
- Knowing caregivers' backgrounds, resources, and limitations will help improve health workers' sense of understanding and comfort assisting and supporting the disclosure process.
- Table 7.1 includes a list of health worker barriers along with suggested solutions for each.

Table 7.1: Solutions to health worker barriers to disclosure

Health worker barrier	Suggested solutions
Health worker is unsure about his or her role or thinks that the disclosure process is not his or her responsibility	• All members of the multidisciplinary team can support the disclosure process in various ways. • Discuss and define health workers' roles in the disclosure process in order to promote effective coordination. • Make assessment of disclosure status a routine part of clinical review and multidisciplinary team case discussions about clients – the same way, for example, that CD4 count and growth/development are reviewed. • Use Adolescent Peer Educators and establish support groups for both caregivers and children/young adolescents.
Differences of opinion between health workers and caregivers	• Remember that disclosure is a process that takes time. • Try to prevent these situations by helping caregivers understand that as children become adolescents they have a greater need to know their HIV-status. This is to avoid accidental disclosure and unprotected sexual activity, and also so they can actively participate in their own care. • Carefully assess barriers to disclosure and work with the caregiver to reach an agreement on when and how to disclose to the adolescent. • Respect the caregiver's decisions, but remember that health workers may have to directly assess and prepare the child/young adolescent for disclosure if they feel it is in the best interest of the client. • Discuss these situations with other members of the multidisciplinary team.
Differences of opinion among health workers — generally or related to a specific client	• If the differences of opinion were triggered by a specific client, convene a multidisciplinary case conference to bring together all the opinions about disclosure surrounding this client. If possible, invite an expert on disclosure to the meeting to add to the discussion. Use the eventual consensus as a precedent to inform future cases. • Discuss disclosure as an agenda item in the next multidisciplinary team meeting. • Invite adolescent clients, including Adolescent Peer Educators, to a discussion about the importance of disclosure during a regular team meeting or as a separately scheduled in-service training. • Identify which health workers on the team feel most confident in their abilities to work through the disclosure process with young clients and caregivers, and have these health workers train and mentor others. • Hold an in-service training on child/adolescent disclosure (using all or a portion of this module if desired) so that all members of the multidisciplinary team have the same information as well as a chance to discuss disclosure together.

Caregiver barriers

Caregivers may not want to disclose their child's HIV-status for a number of reasons, all of which should be explored and respected. Health workers should never judge a caregiver for their unwillingness to disclose, their fears about disclosure, or their "performance" during the disclosure process. Table 7.2 includes a partial list of caregiver barriers and suggested health worker responses for each. The health worker's role in supporting caregivers and children/adolescents is discussed more in the next section.

Table 7.2: Addressing caregiver barriers to disclosure

Caregiver barrier	Suggested health worker responses/solutions
Fear that disclosure will cause psychological harm to the child (e.g. reduce will to live, make the child feel abnormal)	• Reassure caregivers of the positive psychological benefits of disclosure for children/adolescents and caregivers (e.g. higher self-esteem among young people who know their status, less depression among caregivers, etc.). • Connect caregivers to peers who have gone through the disclosure process and who are willing to share their experiences.
Concern that topic is too complicated for the child/adolescent to understand	• Reassure caregivers that health workers will work with them to ensure that all disclosure-related conversations are appropriate to the adolescent's age and developmental status. Health workers can assess the client's readiness and report impressions back to the caregiver. • The aim of the various conversations that should take place over many years is to help the child/adolescent become "appropriately aware of his or her illness" rather than to explain everything at once. • In some cases, health workers can play an active role in the actual disclosure process and in conversations with the child/young adolescent. This can reassure caregivers that they have support.
Uncertainty about where to start or how to respond to questions	• Begin talking to caregivers very early about the disclosure process — long before anything has been to the child/young adolescent. • Help caregivers plan where, when, and how to begin the process. • If requested by caregivers, health workers should be prepared to take a more active role in the disclosure process.
Lack of knowledge/comfort with topic	• Provide caregivers with the background information they need to discuss HIV with their children. Use job aides and offer take-away materials. • Ensure that caregivers' questions are answered throughout the process. • Provide caregivers with possible answers to questions they anticipate the child/adolescent will ask. • Role play various disclosure scenarios to give caregivers practice. • Decide with caregivers what is appropriate/necessary to tell the child/young adolescent at each stage of development. • As above, sometimes health workers may need to take an active role in the disclosure process if caregivers feel uncomfortable.
Fear of stigma and discrimination against the child/adolescent and other family members	• Support caregivers to provide guidance to their children/adolescents about the people with whom they may safely speak about their illness. • Suggest that caregivers identify one or more trustworthy person to be a "safe" person — someone with whom the child can discuss his or her HIV-status, concerns, and treatment (this may be the health worker). • Involve caregivers and other family members early in the disclosure process to ensure that misinformation about HIV is corrected. • Refer the child/young adolescent and caregivers to support groups where others can provide advice on dealing with stigma. • Maintain a continuous open line of communication with the child/young adolescent to help him or her deal with his or her changing feelings about HIV and any negative reactions from society.
Parental guilt regarding transmission	• Remember that disclosure of HIV-status to children/young adolescents is often a family issue due to its relation to one/both parents' HIV-status. • Help parents understand that they should not blame themselves. • Encourage parents to take care of themselves by going to the clinic regularly, taking their medication, etc. • Encourage parents to model positive living for their children. Healthy behaviors reflect a positive attitude toward life, thereby encouraging children to see their own lives with optimism.

Table 7.2 adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; 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 18years of age living with HIV.*

The Health Worker's Role in the Disclosure Process: Overview

- The health worker plays a number of important roles in the disclosure process. Each of these roles is discussed in more detail in the sections that follow but, in summary, the health worker's role may include:
- Encouraging open dialogue and disclosure
- Offering practical and developmentally-appropriate strategies
- Assessing the child/young adolescent's readiness for partial or full disclosure and communicating impressions with caregivers
- Working with the caregiver/family to develop and follow a disclosure plan
- Preparing the child/young adolescent for disclosure
- Facilitating disclosure discussions — ideally with the caregiver but, in some cases, the health worker may have to take a more active role and lead these discussions
- Supporting the client and caregiver throughout the disclosure process
- Advocating for the needs of the child/young adolescent (which may, in some cases, put them in conflict with the caregiver)

It can be helpful for health workers to work as a team and to consult with each other to get suggestions on how to best support children, adolescents, caregivers, and families through the disclosure process.

The Health Worker's Role in Supporting Caregivers with Disclosure

Supporting the caregiver during the disclosure process begins with his or her initial visits to the clinic. The health worker should:

- Build trust by getting to know the caregiver; find out what HIV means to him or her.
- Assess the caregiver's readiness for the disclosure process, his or her psychosocial situation, and his or her ability to cope. Health workers can answer the caregiver's questions and identify his or her sources of support.
- Discuss the implications of disclosure with the caregiver and family to help them consider in advance the reactions of the child, other family members, friends, and teachers.
- Assess the child's readiness for disclosure and share your impressions with the caregiver, especially if he or she seems hesitant to disclose. Help caregivers consider the adolescent's stage of development and the implications thereof:
  - Children may only need to know that they are sick and have to go to the doctor and take medicines to feel better.
  - Young adolescents should know that they have HIV, should understand the disease and the medications they take, and should actively participate in their own care and treatment.
- Help the caregiver develop a disclosure plan for the child/young adolescent. The plan should:
  - List any preparations they need to make before starting the disclosure process
  - Include who will be involved in different stages of the disclosure process (and define the role of the health worker), what they will say, and how and where they will have disclosure discussions
  - Include plans for ongoing support throughout the disclosure process (from health workers, family members, peers, etc.)
- Arrange to see the caregiver (and the child/young adolescent) again to review where he or she is in the process.
- If there is disagreement between family members about the timing and process of disclosure, try to assess all family members' concerns, discuss the benefits and risks of disclosure, and discuss the potential harm of long-term non-disclosure. Collaborate with caregivers to make a plan tailored to meet 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 sense of partnership and can prevent an adversarial relationship from developing between caregivers and members of the health team.

Remember: If the caregiver is not ready to disclose, the process cannot be forced. However, the health worker should always advocate for what is in the best interest of the child/young adolescent.

Caregivers will also need ongoing support — from health workers, family members, and peers — as the disclosure process proceeds over time. Health workers should remember to use a developmental approach to disclosure, incorporating the techniques in *Appendix 7A: Guidance for Developmentally Appropriate Disclosure.*

Once the disclosure process has begun and the client knows more about his or her HIV-status (ideally well before the child has reached adolescence), health workers should ask the ***caregiver*** at each visit about support needs from health workers, family members, and peers:

- *Have you noticed any changes in your child's behavior since he or she learned about his or her HIV-status?*
- *Who else at home knows about the child's status?*
- *What kind of help, support, or information do you still need?*
    - Refer him or her to a caregiver support group if possible.
- *What feelings or concerns do you have about the disclosure process with your child?*
- *Who does your child have to talk with if he or she has questions?*
    - Remind the caregiver to offer support to the child/adolescent to cope with his or her emotions and feelings after disclosure.
- *What questions do you have?*
- *When will we meet again?*
    - Plan for a follow-up counseling session at the clinic with the child/adolescent and caregiver.

The Health Worker's Role in Supporting Children and Young Adolescents with Disclosure

In addition to helping caregivers prepare for and move through the disclosure process, health workers also play an important role in supporting children and young adolescents through this process.

- Health workers can **prepare the child/young adolescent** for disclosure through youth-friendly counseling and information sessions (see Module 4 for tips on communicating with children/adolescents) and by linking clients with peer support groups and Adolescent Peer Educators.
- Health workers can actively **assess the child/young adolescent's readiness** for partial or full disclosure by asking questions about his or her understanding of why he or she takes medicines and comes to the clinic. They can share impressions of the client's readiness for disclosure with caregivers and other members of the care team and work with them to make and implement an appropriate disclosure plan.
- In some cases, health workers may actually **be part of the disclosure discussions** with children/young adolescents. Ideally, these would be joint conversations with the health worker, client, and caregiver, but in some cases, the health worker may need to lead these discussions. It is always helpful to have the support of other members of the multidisciplinary team.
- Health workers should provide **post-disclosure and ongoing support** to the child/young adolescent. This is discussed more in the next section.

Health workers should remember to use a developmental approach to disclosure, incorporating some of the techniques in *Appendix 7A: Guidance for Developmentally Appropriate Disclosure.*

Remember: Health workers can and should be advocates for the needs of their child/adolescent clients, including their disclosure needs.

Disclosure does not begin or end with a single conversation. As children/adolescents grow and develop, they need to be able to continue to ask questions and discuss their feelings. Multiple forms of support — from health workers; caregivers and family members; and peers — are helpful. Once the disclosure process has begun (ideally well before the child has reached adolescence), health workers should ask the ***client*** at each visit (adjust to the age and developmental status of 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 do you talk to about HIV and who do you ask if you have questions?*
  - Offer support to the young client to cope with his or her emotions and feelings after disclosure. Refer him or her to a peer support group and/or Adolescent Peer Educator if possible.
  - Make sure the client is given a chance to express his or her feelings — for example, through talking, role play, or drawing.
- *Who else knows about your HIV-status? What do you think about disclosing your status to (other) people you are close to?* (see the next session for more on supporting adolescents during their disclosure process to others)
- *What are some of the ways you are taking care of yourself? How do you think you can live positively with HIV?*
- *How are you doing with your medications?*
- *What other questions do you have?*
- *When should we meet again to talk more?*

Working with children and adolescents who do not have caregivers

Sometimes children and adolescents do not have caregivers or do not have caregivers who play an active or consistent role in their care. Adolescents may be heads of households, they may be living with a sexual partner, or they may be homeless. In such situations, particularly if the client is coming to the clinic alone, the health worker (and if possible, more than one member of the multidisciplinary team) may have to take a more active or "parental" role in the disclosure process. This includes deciding when and how to begin and move forward with the disclosure process according to the client's unique situation and developmental stage.

Working with children and adolescents in institutional care

Sometimes children and adolescents live in institutional care instead of with a primary caregiver at home. This includes those who live in orphanages, foster homes, or education- or employment-related housing programs. In these cases, health workers should identify the person who is legally responsible for the child or adolescent and, if possible, invite that person (with the consent of the adolescent client) to the clinic for an educational and counseling session related to disclosure. As with children and adolescents who do not have primary caregivers, the health worker may have to take a more active or "parental" role in the disclosure process.

Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion

Purpose	To give participants an opportunity to develop the knowledge, skills, and confidence to support caregivers and clients during the disclosure process

Refer to *Appendix 7A: Guidance for Developmentally Appropriate Disclosure.*

Start-Stop Role Play - Case Study 1:
A mother named E___ has been caring for her HIV-infected 10-year-old son, T___. T___ keeps asking you why he has to take these pills and says he wants to know when he will be done with them. When you ask his mother what T___ knows about his health, she becomes quiet. *How would you proceed?*

Start-Stop Role Play - Case Study 2:
A___ is 11 years old. She has lived with her grandmother since her mother died three years ago. A___ and her grandmother have been coming to the clinic since A___ started to become symptomatic and the doctor wants her to start ART soon. The grandmother is having problems giving A___ her CTX. You believe that A___ 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 everyday lives. The grandmother thinks A___ is too young to know her status and insists she does not need to know yet. *How would you proceed?*

Start-Stop Role Play - Case Study 3:
G___ is a 12-year-old boy living with HIV and taking ART. He lives with his mother, uncle, and 5 older siblings and cousins. G___ has come to the clinic with his mother today. She tells you that before she thought she was doing the right thing by moving from partial to full disclosure with her son over the last couple of months. Now, however, she thinks she might have done the wrong thing by fully disclosing because her son hasn't asked any questions about his status, seems sad all the time, doesn't want to take his medicines, and is acting out in school. Today, G___ seems very withdrawn even though he tells you, "I am fine." *How would you proceed?*

Session 7.3 Disclosure Counseling and Support for Adolescents Who Know Their Status

Session Objective

After completing this session, participants will be able to:

- Provide counseling and support to adolescents on disclosing their HIV-status to others

Providing Disclosure Support to ALHIV

Health workers can work with ALHIV to help them to understand why disclosure is important and to decide to whom they should disclose. Health workers can also help ALHIV prepare for disclosure and can provide them with follow-up support.

Advantages of disclosure may include:

- Avoiding the burden of secrecy and the feeling of hiding
- Avoiding anxiety about accidental or unwanted disclosure
- Gaining access to emotional and practical support from peers or family members, including the freedom to talk about symptoms and concerns
- Gaining easier access to health care
- Enhanced adherence to care and medication
- Enhanced ability to discuss safer sex and family planning choices with one's partner(s)
- Enhanced ability to refer partners for HIV counseling and testing, and to care and treatment if needed
- Gaining the freedom to ask a friend or relative to be a treatment buddy
- Gaining access to peer support groups and community organizations
- Serving as a disclosure role model for other people

Disadvantages of disclosure may include:

- Receiving blame by partner or family for "bringing HIV into the household"
- Distancing, fear, rejection, or abandonment by partners, family, or friends/classmates
- Discrimination or rejection at school
- Discrimination or rejection in the community
- Discrimination or rejection at work, including possible loss of job
- Others making assumptions about one's sexuality, promiscuity, or lifestyle choices
- Reluctance on the part of partners 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 counseling:

- Should not include pressure to disclose
- Is a confidential conversation that helps clients 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 clients should disclose their 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 counseling approach — since each adolescent is unique
- Is an ongoing process that requires preparation, practice, and follow-up support

Adolescents should make their own decisions about disclosure, but health workers can assist ALHIV in the disclosure process by:

- Using good communication and counseling skills (for example, the 7 Listening and Learning Skills from Module 4)
- Talking about the client's feelings and fears around disclosure
- Discussing the advantages and disadvantages of disclosure specific to the client's life
- Supporting clients to make their own decisions about disclosure
- Helping clients decide whom to disclose to, when, and where
- Helping clients 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 to disclosure
- Talking about current and past sexual partners who need to be notified of their HIV risk
- Offering reassurance and emotional support
- Identifying sources of support and referring clients to peer support groups
- Encouraging clients to take the time needed to think things through
- Practicing disclosure through role plays, including providing practical suggestions about how they can start the conversation. For example, health workers can suggest the following "conversation starters" to clients who are unsure 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 checkup. They told me 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 throughout the disclosure process

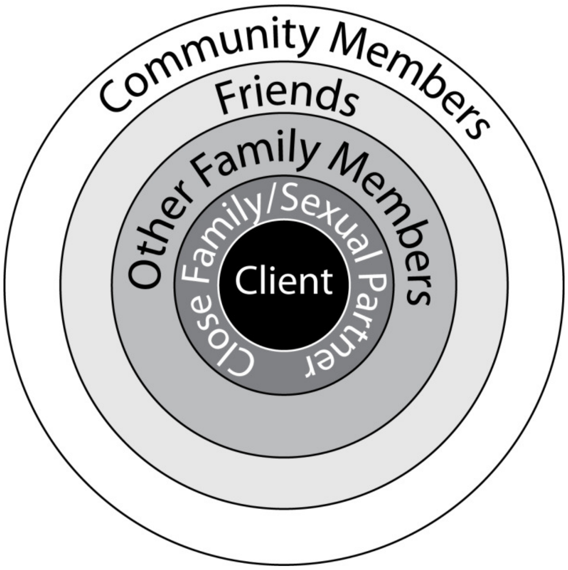
Peer support and disclosure

- Peer support can be an excellent resource for adolescent clients who are making decisions 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 benefit from talking with other families or with a health worker in a support group setting.

Deciding about disclosure

- A good way to understand disclosure and to help adolescents decide who they will disclose to is by creating "disclosure circles" (see Figure 7.1).
- The center of the circle is the adolescent (self).
- The next circle out is a person or people the adolescent is very close to, such as his or her 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 circles).
- 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 levels to the circles of disclosure.
- Each level of disclosure represents a process in itself — preparing for disclosure, the actual disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure — there will likely be ongoing discussions over time between the client and the person to whom he or she disclosed.
- The goal is NOT that all people will eventually disclose to all of the people included in the circles. Instead, the circles provide a way of discussing the disclosure process, of considering the risks and benefits of disclosing to different people, and of helping to prioritize disclosure activities.

Figure 7.1: Disclosure circles



Source: Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0*. ICAP.

Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion	
Purpose	To provide participants with an opportunity to discuss strategies for assisting ALHIV with the disclosure process

Case Study 1:
C___ is 15 years old and found out that he is HIV-infected at a VCT clinic 2 months ago. Today, he has returned to the ART clinic for a second visit 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 C___?*

Case Study 2:
L___ is a 16-year-old girl who was perinatally infected with HIV. L___ mentions that she really wants to disclose her status to one of her male friends at school. L___ 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 L___ has been avoiding him. She asks your opinion about what to do. *How do you proceed?*

Case Study 3:
J___ is a 14-year-old female orphan with HIV who lives with her maternal aunt and uncle. J___ 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 J___?*

Case Study 4:
An 18-year-old named I___ tested positive for HIV about 2 years ago. He got tested because his girlfriend at that time found out she was HIV-infected. He has since changed girlfriends, however, and has not yet told his new girlfriend about his HIV-status. He takes good care of himself and feels fine. He has come to the clinic today for his regular appointment and wants to talk with you about how to tell his girlfriend that he is living with HIV. *How would you help I___ prepare for the process of disclosing to his girlfriend?*

Module 7: Key Points

- Disclosure is an ongoing process, not a one-time event. Most children, adolescents, and caregivers need support planning for disclosure as well as with the actual disclosure conversation and with post-disclosure follow up.
- Disclosure can help young clients access prevention, care, treatment, and support. It can also help improve adherence; help reduce stigma and discrimination by bringing HIV out into the open, and help slow the spread of HIV by helping people protect themselves and their partners.
- There is little evidence that disclosing to HIV-infected children/young adolescents results in psychological or emotional harm. Rather, studies suggest that disclosure can result in health benefits for the child/adolescent and caregiver.
- Health workers and caregivers may face barriers to disclosure, such as not knowing where to start or feeling concerned about harming the child/adolescent. Training, working together as a multidisciplinary team, and understanding the backgrounds, limitations, and resources of caregivers can help health workers overcome these barriers.
- Health workers play several important roles in the disclosure process, including assessing the client's and caregiver's readiness, working with the caregiver to develop and follow a disclosure plan, preparing the client for different stages in the disclosure process, and supporting the client and caregiver throughout the process.
- Health workers should advocate for the best interests of the child/adolescent and, in some cases, — such as when the caregiver does not want to/will not disclose or when there is no active participation of a primary caregiver — they may have to take a more active or "parental" role in the disclosure process.
- Health workers can support adolescents decide to whom to disclose their HIV status, when, and where; they can help them weigh the advantages and disadvantages of disclosure; and they can help them anticipate likely responses.

Appendix 7A: Guidance for Developmentally Appropriate Disclosure

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent may have	Possible responses to questions or ways of explaining things to the adolescent
Younger adolescents (approximately 10–13 years old)			
• Beginning to understand cause and effect, but still struggle with abstract concepts • Have growing vocabulary, but struggle to express ideas and feelings in words • Enjoy activities that give them a chance to control, organize, and order things • May regress and want help from adults if feeling insecure or unsure	• Be truthful. • Ideally, the disclosure process will have already started by this age. • Give more detailed information using concrete examples. • If they ask for more information (for example, "*What's the germ called?*" or "*How did the germ get in my body?*"), give short, clear answers. • Help them deal with possible stigma. • Reassure them that they can ask further questions or share any of their concerns with you now or later.	• *Why do I have to go to the clinic (so much)?* • *Why am I sick?* • *Why do I have to take medicine?* • *Am I going to die?* • *How did I get HIV?* • *Who knows that I have HIV?* • *Do I have to tell people I have HIV?* • *What will happen if people find out I have HIV?*	• *Going to the clinic will help you stay well.* • *You have a virus in your blood called HIV. It attacks the germ fighters in your body. This is why you get sick sometimes.* • *You and I* (if mother or caregiver is also HIV-infected) *both have HIV in our bodies.* • *You have to take medicine so the germ fighters can work and so you won't get sick as much.* • *You (and I,* if appropriate*) take medicine to keep you/us strong.* • *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.* • *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.* • *You can talk to me about it at any time.* • *Maybe we should keep this within the family for now?*
Older adolescents (approximately 14–19 years old)			
• Beginning to be able to think in more abstract terms • Want solid, well-thought-out explanations • Body changes may create feelings of insecurity	• Ideally, they will have been fully disclosed to by this age. • Accurate and more detailed information can be given in response to questions. • Realistic information about health status should be given and all questions should be answered.	• *What is HIV?* • *Why do I have HIV?* • *Can I give HIV to my (girl/boy) friend? How?* • *Why do I have to go to the clinic so often?* • *What are the health workers looking at in my blood?*	• *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 will be sick all the time.* • *Health workers look at your blood to see how many healthy cells (called CD4 cells) are in it. The higher your CD4 count, the better.*

Age group characteristics	**Disclosure considerations and guidance**	**Possible questions the adolescent may have**	**Possible responses to questions or ways of explaining things to the adolescent**
• Forming a sense of identity — peer approval and social acceptance very important	• Be sure to ask about and discuss their feelings and fears about HIV. • Ask questions about their understanding and address misperceptions, for example, *"What have you heard about HIV?"* • Ways to live meaningfully with HIV are a common concern (including having relationships). Issues like risk reduction and living positively with HIV should be discussed. • It is very important that they are assured that their status and what they say is confidential. • Normal adolescent striving for independence may complicate the response to disclosure (for example, it might result in a decline in adherence). • Issues of disclosure to others should be discussed but adolescents should make their own decisions about this matter. • Assurance of support and willingness to help should be given without seeming intrusive.	• *What if I want to get married and have children? Is that possible for people living with HIV?* • *Who should I tell that I have HIV?* • *Why are people mean to people with HIV?*	• *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.* • *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.* • *Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and to not pass HIV to other people.* • *People with HIV can and do live long lives, have relationships, and get married.* • *If you have sex, it is important that you and your partner use a condom. 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.* • *You can have a baby in the future, but there 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 will get HIV. Taking your ARVs the right way, every day, will help lower the chance of passing HIV to either your partner or your baby. We can talk more about this whenever you like.*

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; 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 years of age living with HIV.*

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[1] Adherence Networking Group. (2006). *Kids count: Guide for trainers, Children's ART adherence resource pack.*

[2] The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; 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 years of age living with HIV*.

[3] WHO. (2011). *Guidance on HIV disclosure counselling for children 12 years of age and younger: A look at the evidence (Draft).*

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 health workers and health facilities can support ALHIV's retention in and adherence to care
- Conduct adherence preparation sessions with ALHIV and their caregivers
- Use tools to provide adherence counseling and to help clients and caregivers make a personal adherence plan
- 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

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

Definition of retention:

- Retention refers to keeping (or "retaining") clients in the care program, which in this case means that clients continue accessing lifelong HIV care and treatment services.
- A goal of all HIV care and treatment programs is to retain clients in care and treatment. The onus of retention is on health workers and managers, as they are the ones who can offer quality services and set up systems that support the retention of ALHIV.
- For ALHIV, supporting retention also means supporting their transition to adult care and treatment (see Module 13).

Definition of adherence:

Previously, the standard clinical definition of adherence was 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:

Adherence

Adherence describes how faithfully a person sticks to and participates in his or her HIV prevention, care, and treatment plan.

- It 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)
- It includes adherence to both medicines and care
- It depends on a shared decision-making process between the client (and caregivers) and health workers
- It determines the success of HIV prevention, care, and treatment programs
- Adherence not static — in other words, it changes over time and as ALHIV age and go through different developmental stages and life changes

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 health education and counseling
- Picking up medicines when scheduled and before running out
- Recognizing when there is a problem or a change in health and coming to the clinic for care
- Adopting a healthy lifestyle and trying to avoid risky behaviors (as much as is possible given the client's life situation)

Adherence to treatment includes:

- Taking (or giving) ART correctly, as prescribed, for a person's whole life — even if he or she 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 center, lab, or pharmacy
- Not following the care plan
- Missing a dose or doses of medicine
- Sharing medicines with other people
- Stopping medicine for a day or many days (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 medicines do their job, which is to increase the client's CD4 cell count and to decrease the amount of HIV in his or her body
- To make sure people get all the benefits that ART has to offer, such as feeling better, not getting sick as often or as badly, living a longer life, etc.
- To reduce the risk of spreading the virus to others, which can be called *"altruistic adherence"*
  - According to recent studies, PLHIV who are taking and adhering to ART are much less likely to pass HIV to their sexual partners than those who are not on ART.
  - Adherence to ART also reduces mother-to-child transmission of HIV.
- To help ALHIV grow and develop into healthy adults
- To keep people looking and feeling good so they can get back to "normal" life, including going to school, working, socializing, and being an active family and community member
- So the virus does not become resistant to certain medicines

Remember, no one is perfect. It is important not to judge adolescent clients (or caregivers) if they are non-adherent. Instead, we should try to understand why they do not adhere and help them and their caregivers find ways to resume good adherence as soon as possible.

Factors Affecting ALHIV Retention and Adherence

The following are lists of some of the common factors that can affect adolescents' retention and adherence.

Health service factors:
The following health service factors can affect adolescent clients' adherence to treatment and retention in care:

- Availability of youth-friendly services
- Level of confidentiality
- Provider attitudes
- Existence of drug stock-outs
- Distance to the clinic/transportation costs
- Convenience of clinic hours
- Strength of patient record and tracking systems
- Number and type of health workers
- Provider language
- Length of waiting times
- Availability of space for private counseling
- Level of staff turnover at the clinic
- Strength of linkages between services, including linkages to social and material support in the community and home-based care
- Strength of referral systems
- Existence of support groups
- Level of PLHIV involvement, including ALHIV
- Cost of health services or medicines

Individual factors:
Adolescence often brings with it new issues that can negatively affect adherence to care and medicines. Some adolescents go through rebellious or risk-taking stages, during which they want to define who they are and take more risks. Adolescents also generally have a desire to "fit in" with peers and appear "normal." In addition, young adolescents who have been managing well with HIV and adhering to their care and treatment (because their parents or caregivers took primary responsibility for their care) often encounter new adherence challenges as they move through adolescence and begin to take on more responsibility for their own care.

Other individual factors that can affect adolescent clients' adherence to treatment and retention in care include:

- Feeling self-conscious about taking medicines (particularly in the case of older adolescents)
- Forgetting to take their medicine, or forgetting because of alcohol or drug use
- Experiencing side effects:
    - If they feel sick from the medicine, they more likely to stop taking it.
    - If they begin to notice unwanted body changes caused by the medicine (such as lipodystrophy, which are changes in fat distribution on different parts of the body), they may stop taking it.
- Forgetting to go to the pharmacy at the end of the month and running out of tablets
- Having difficulty accepting their HIV-status
- Facing stigma and discrimination from peers, family, and/or others in the community can affect their willingness to take HIV medicines or to go to an HIV clinic because of fear that these behaviors 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. a treatment "buddy" or supporter)
- How sick or well they feel
- If they migrate or relocate, which often disrupts the continuity of their care
- Whether or not they can take time away from home, school, or work to go to clinic appointments
- Having a mental illness, like depression

Community and cultural factors:
The following environmental factors (related to families, communities, culture, etc.) can affect adolescent clients' adherence to treatment and retention in care:

- Lack of family support or help from caregivers with decision-making (particularly in the case of 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
- Extent of disclosure within the family, at school, and/or at work — for example, non-disclosure resulting in a lack of peer support or if they fear that taking medicines or leaving early to go to the clinic will inadvertently disclose their HIV-status
- Social support at home and in the community, including at school
- Inability to find child care for their younger siblings (if youth-headed household) or for their own children (if a young parent)
- Inability to take time off from school or work to go to clinic appointments
- Gender inequality: In some places, young women are less likely to have access to adequate nutrition to support their treatment, they may depend on men economically, they may 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 decrease perceived need for ART or negatively interact with HIV-related medications
- Political instability or war
- Physical environment (for example, if living in a place with mountains, seasonal flooding, etc.)

Medication factors:
The following things about ART and other HIV-related medicines can affect adolescent clients' adherence to treatment and retention in care:

- Side effects
- Changing pediatric doses
- Changing regimens
- Number of pills in their regimen
- Dose timing
- Availability of reminder cues — pill boxes, calendars, alarms, etc.
- Taste
- Changes in drug supplier — labeling, pill size, color, formulation, etc.

Session 8.2 Supporting Retention and Adherence to Care

Session Objective

After completing this session, participants will be able to:

- Discuss ways that health workers and health facilities can support ALHIVs' retention in and adherence to care

Improving Retention in and Adherence to Care

The following are suggestions for health workers to improve retention in and adherence to care among ALHIV:

- Ensure that HIV services are youth-friendly and that adolescent clients are treated respectfully and non-judgmentally by health workers.
- Ensure that services are provided on days and times that are convenient for adolescents.
- Use counseling and education approaches that correspond to adolescents' 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 counseling and adherence support sessions and ensure confidentiality.
- Ensure that there are appointment systems in place.
- Ensure that all clients are given reminder cards to help them remember upcoming appointments. If possible, send clients appointment reminders via SMS.
- Ensure that there are systems to track adolescent clients who miss clinic appointments or pharmacy refills.
  - When adolescent clients miss an appointment, contact them through phone calls or SMS messaging. If that does not work or if this is not an available option, send an outreach worker to their home to provide counseling and education and to set up an appointment for their next visit.* (see note on next page)
- Check in with clients frequently after they start or change medicines (if not through in-person clinic visits, then through phone or outreach).
- Make sure to review each client's drug regimen to assess whether changes can be made to facilitate adherence (for example, changing the client to a once-daily regimen.
- Use fixed dose combinations of ARVs when possible to reduce clients' pill burden.
- If possible, provide transportation stipends to clients who are unable to pay for their own transportation to the clinic.
- Consider establishing a formal mechanism, such as an adolescent consumer (or client or community) advisory board (CAB), to obtain client feedback. CABs are autonomous bodies that advise the clinic on how to improve the quality of services and on addressing gaps in care. CABs are discussed further in Module 12.

Also refer to *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services* in Module 2, which is a tool for auditing services that can provide additional suggestions for making a clinic friendlier for adolescents.

***Permission to call or visit clients at home**

During the baseline intake and at key times thereafter (at least annually), make sure personal client information like addresses and phone numbers are updated. Also, request permission to follow up by SMS, phone call, or home visit if clients miss a clinic visit. Clients who have not disclosed their HIV-status to others in the home may give special instructions regarding what to say to caregivers or siblings about the nature of the visit.

Session 8.3 Providing Adherence Preparation Support to ALHIV and Caregivers

Session Objective

After completing this session, participants will be able to:

- Conduct adherence preparation sessions with ALHIV and their caregivers
- Use tools to provide adherence counseling and to help clients and caregivers make a personal adherence plan

Adolescent-Friendly ART Adherence Preparation

Overview of adherence preparation and support for adolescent clients and caregivers:

- In most places, individuals starting ART are required to participate in a series of adherence preparation sessions. These are conducted in groups, as individual sessions, or as a combination of the two. Depending on the program and national guidelines, this may include between 1–4 adherence preparation sessions that take place over a number of days or weeks. Nurses, counselors, or Peer Educators may conduct these adherence preparation sessions. See Table 8.1 for a suggested list of topics to cover during adherence preparation sessions.
- It is important to follow national guidelines for adherence preparation and to always keep in mind that ongoing adherence assessment and support is necessary for adolescents (and caregivers).
- Group education/peer support sessions are useful for giving many people information at one time.
- Individual sessions can be used to find out what the client (and caregiver) learned from any previously attended group education sessions, to identify the areas in which they need extra support, and to develop an individual adherence plan.
- At minimum, ALHIV initiating care and treatment should have time to speak to a counselor, health worker, and/or Adolescent Peer Educator alone and in private in order to discuss their questions and concerns and to get information tailored to their situation, care plan, and developmental stage.
- Individual counseling session(s) should include talking with the client (and caregiver or treatment buddy) about any adherence challenges he or she may face and making an individual adherence plan.

Remember: while providing as much support as possible, the multidisciplinary care team should be flexible when addressing ART readiness. The preparation process should always facilitate ART initiation and should never act as a barrier to it.

What is a treatment buddy?

A **treatment buddy** or **treatment supporter** is someone who is chosen by a client to provide him or her with 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 who is a trusted person to whom the client can disclose his or her status. Younger adolescents may have one of their primary caregivers as a treatment buddy, while older adolescents may prefer to have a friend or peer as their treatment buddy. This depends on each individual client. **Remember, not having a treatment buddy should not act as a barrier to any client initiating ART.**

It is important for health workers, including Adolescent Peer Educators, to explain the importance of having a treatment buddy to ALHIV and to make sure that treatment buddies have the information and skills needed to support the client's adherence and positive living. All treatment buddies should be encouraged and welcomed to accompany the adolescent client on clinic visits and, to the extent the client wants, to participate in education and counseling sessions.

Table 8.1: Suggested topics for adherence preparation education and counseling with adolescents and caregivers

Key Topics to Discuss in Group Education and Individual Counseling Sessions with Clients Starting ART (and their Caregivers)

HIV Care and Treatment Basics

- Understanding the diagnosis
- How HIV is transmitted and prevented
- How HIV affects the immune system
- The meaning of CD4 count
- Who needs ART
- Benefits of ART
- Importance of ongoing care and regular clinic visits
- Positive living
- HIV and sexual initiation, safer sex, dual protection, and prevention and treatment of STIs
- OI prophylaxis (especially CTX)
- TB prevention and treatment
- Importance of disclosure (own disclosure, disclosure to peers, sexual partners)
- Family testing and enrollment

Adherence to Care and Treatment

- Beliefs and attitudes about ART
- ART = lifetime commitment
- Importance of adherence to care plan and to treatment for own health and to prevent HIV transmission to sexual partners
- What happens when a person does not adhere
- Importance of social support for adherence, including having a treatment buddy and/or directly observed therapy (DOT)
- Understanding the treatment plan (explanation of each medicine, the dosing schedule, missed/late doses, adjustments according to school hours, etc.)
- How medicines are to be taken (and for young adolescents, how to measure and give medications, tips for children on swallowing pills)
- Preventing and managing side effects
- Previous adherence experiences (CTX, TB medicines, etc.), strategies, and challenges
- Adherence strategies, tips, and tools
- Problem-solving around adherence barriers, including the use of tools like medicine diaries, pill boxes, watches, cell phones, etc.
- How to make one's care and treatment plan part of one's everyday life and developing an individual adherence plan
- What to do if there is a problem or question
- Planning 2-week and subsequent follow-up visits
- Linkages and referral to support groups and community support services

Adherence Preparation and Planning

Helping clients develop a personal adherence plan
During the individual counseling session, work with clients to develop a personal adherence plan. This plan should address the ARE YOU COMMITTED? question and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines:

- ***ARE YOU PLANNING TO TAKE YOUR MEDICINES?*** 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 of each and how often will you take each medicine? 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 medicines?* (Establish a routine.)
- ***WHERE*** *will you take your ART (for example, at school, home, work, etc.)? Where will you store your ART?*
- ***HOW*** *will you remember to take your medicines at the same time, every day? What about 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? How will you know that you have taken your doses so that you don't miss any or take them twice?*

See *Appendix 8A: Adherence Support Tree*, which is a useful tool to help health workers and clients discuss these questions and develop a personal adherence plan. Specific instructions to use the Adherence Support Tree are also included.

Assessing a Client’s Readiness for Adherence

Use the plan agreed upon during the WHO, WHAT, WHEN, WHERE, and HOW discussions when completing the “Guide for Assessing Adolescents’/Caregivers’ Readiness for ART” questionnaires in *Appendix 8B: Adherence Preparation and Support Guides.* These assessment guides are standardized tools that can help health workers assess clients’ and caregivers’ readiness for ART. The guides can also:

- Support health workers to increase their clients’ understanding of the importance of lifelong adherence to HIV care and treatment
- Ensure a shared understanding of the client’s care and treatment plan
- Identify potential adherence challenges and help to brainstorm practical solutions

Instructions for administering the guides are also included in *Appendix 8B.*

Note that it may take 1, 2, or even more individual counseling sessions before a client is ready to start ART. Upon completion of the adherence preparation visits and the individual counseling session(s), the client should be ready to initiate ART. If the client is not ready, the multidisciplinary team may advise that the client delay initiation until the next visit or may discuss reservations with the client and/or caregiver and allow them to choose whether to start immediately or to delay temporarily.

Keep in mind that, as with any other one-to-one counseling session, health workers should remind clients that all sessions are confidential. When counseling adolescents, also remind them that the commitment to confidentiality means that health workers will not share any information discussed during individual counseling sessions with their caregiver or partner.

Exercise 1: Conducting an Adherence Readiness Assessment: Case studies in small groups and large group discussion

Purpose	To practice conducting adherence preparation counseling with adolescent clients and caregivers, including using the Adherence Support Tree *(Appendix 8A)* and the Adherence Preparation and Support Guides *(Appendix 8B)*

This exercise consists of 3 parts:

- Part 1: Trainer Demonstration and Role Play
- Part 2: Small Group Work
- Part 3: Large Group Discussion

Refer to *Appendix 8A: Adherence Support Tree* and *Appendix 8B: Adherence Preparation and Support Guides.*

Case Study 1 (for Part 1):

B___ is 11 years old and is supposed to start taking ART today. B___ and her auntie have already gone through the group education sessions and today is B___'s adherence preparation visit. B___'s auntie is her primary caregiver and will be responsible for giving B___ her medicines every day. B___ understands that she has HIV and that she needs to take medicines every day, but her auntie is still worried how she will manage.

- *How would you help B___ and her auntie prepare today for adherence?*
- *What questions would you ask to assess their understanding of adherence and B___'s readiness to start ART?*

Case Study 2:

S___ is 17 years old and lives by himself. He needs to start taking ART and, now that he has attended the group adherence preparation sessions, the doctor asks you to counsel him individually to further prepare him for ART adherence. S___ 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 since he has not disclosed to anyone and works long hours.

- *How do you help S___ prepare to start taking ART?*
- *What questions would you ask to assess S___'s readiness for ART?*

Case Study 3:

L___ 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 group adherence preparation sessions, you have been asked to help prepare her and make an adherence plan. L___ is at the clinic with her older cousin and says that she does not talk much with her mother and father about HIV. Instead, her cousin has agreed to be her treatment supporter.

- *How would you prepare L___ and her cousin for good adherence?*
- *What questions would you ask to assess their readiness and understanding?*

Case Study 4:
J___ is 14 years old and, based on her CD4 results, she is eligible to start ART. She has come to the clinic today with her father for adherence preparation and ART initiation (she has already attended group preparation sessions). Her mother passed away recently, so her father will be her main treatment supporter. While conducting adherence preparation counseling with J___ and her father, her father expresses some concern that ART might be bad for children. He says that his daughter feels fine without medicine, adding that he works long hours so J___ spends a lot of time at home with her older brother.

- *How would you proceed in preparing J___ and her father?*

Case Study 5:
N___ is 16 years old and lives with his mother and 4 younger siblings. N___ is still in school, but only because his mother makes him to go. N___ would prefer to spend his time with his friends, which he does as soon as school ends. He is rarely home before 21.00hrs and he is failing nearly half of his classes. He has not told his mother or siblings about his HIV-status, but he has told his best friend and partner, A___. A___ is 17 and she also has HIV.

- *How do you help N___ prepare to start taking ART (he has already attended group adherence preparation sessions)?*
- *What questions would you ask to assess his readiness for ART?*

Session 8.4 Assessing Adherence and Providing Ongoing Adherence Support

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

Assessing adherence is very challenging and there is no perfect way to do it. We can really only learn about adherence through ongoing, individual adherence assessment and counseling combined with other adherence measures (and review of the client's response to ART over time). It is very important to assess adherence at every visit, but we must also take the next step of offering clients ongoing, individual adherence support.

- The purpose of ongoing adherence monitoring and support is to encourage clients (and caregivers) to express challenges and to be open about any problems they are facing so the multidisciplinary team can provide them with ongoing support.
- **Assess adherence at every visit.**
- All members of the multidisciplinary team should ask questions about adherence (nurses, counselors, pharmacists, doctors, peer educators, etc.).
- If the caregiver or treatment buddy is available, ask him or her about adherence as well.
- Adolescents and caregivers may have different reports and understandings of adherence, so it is important to conduct separate adherence assessment sessions with older adolescent clients and their caregivers.
- In cases where answers to parallel questions differ greatly, discuss these responses with the client and caregiver together to see if they can explain. When asking for an explanation, make sure questions are appropriate and non-accusatory. For example: "*Interestingly, in response to my question, 'How did the medicines make you feel?,' you said that the medicine gives you headaches every day. Your mother responded that the medicine has no effect on how you feel. I am sure you're both being honest, but maybe one of you can explain a bit more about how your responses might seem, on the surface, to be so different?*"
- Do not judge! Make clients feel comfortable and let them know that they will not be punished or judged if they openly discuss adherence challenges.
- Let clients know 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 health worker is to work WITH clients, not against them!
- Refer clients to peer support groups or link them to an Adolescent Peer Educator.
- Talk about clients' adherence at multidisciplinary team meetings.

Adherence Red Flag

For a client on ART, missing pharmacy refills or clinic appointments is a RED FLAG indicating poor adherence that should be addressed immediately.

- Use tools to help assess and improve adherence, such as:
  - Pill counts
  - Review of clinical findings and laboratory tests
  - Review with clients of medicine diaries or calendars

Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. *Appendix 8C: Adherence Assessment Guides* includes two standardized adherence assessment tools. These 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 in which the client and/or caregiver may need additional information and support.

Providing Ongoing Adherence Support

When providing adherence support, it is important that health workers build on the trust and rapport they have with the client and caregiver, that they maintain a safe space to discuss any problems, and that they give ongoing encouragement.

If the health worker feels, after discussing adherence with a client, that he or she is adhering well:

- Praise the client (and the caregiver, if present) for good adherence.
- Remind the client to come back if there are any problems.
- Talk about how important it is to be open with health workers and to solve challenges together.

If the health worker or multidisciplinary team has determined that an adolescent client is experiencing challenges with adherence, provide individual counseling and:

- Praise the client for sharing his or her challenges.
- Identify the client's specific challenges and how these challenges affect his or her adherence.
- Help the client resolve each challenge.
- Discuss the importance of adherence.
- Refer the client to an Adolescent Peer Educator, adolescent support group, and other organizations that works with youth in the community.
- Refer difficult cases to a counselor, social worker, or other available mental health worker.
- Plan for next steps, including the clinic return date.
- Record the session on the patient record.
- Follow up at the next visit.
- Share observations 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: Small group work, role play, and large group discussion

Purpose	To practice conducting adherence assessments with adolescent clients and caregivers and to practice providing ongoing adherence support

This exercise consists of 3 parts:

- Part 1: Role Play
- Part 2: Small Group Work
- Part 3: Large Group Discussion

For part 1, refer to *Appendix 8C: Adherence Assessment Guides.* For part 2, work in your small groups to answer the following questions:

A. *What are the client's/caregiver's main adherence challenges? What are some possible solutions?*

B. *What are some age-appropriate techniques a health worker could use to build the client's/caregiver's confidence and knowledge about adherence?*

C. *Are there any community-based services that might help the client? What suggestions or referrals would you make?*

Case Study 1: J___ and his uncle

- **The client (J___) introduces himself to the health worker:** I am J___, I am 17 years old, and I have had HIV since I was little. My parents died a long time ago. I live with my uncle and his family. My uncle came with me today.
- **Background:**
  - **J's uncle's says:** J___ is often out all night and comes home drunk. The family is upset with his behavior and is afraid for him. J___ used to be a good student and did well in school. Recently, he has not been taking his ART regularly, and maybe he is not taking it at all. I found medicines thrown away in the outhouse — I am angry with my nephew. I need the clinic staff to scare J___ into taking his medicines. I also have HIV, but J___ does not know.
  - **J___ says**: I think I have taken about half of my ART doses over the past week, mostly because I've been too busy.

Case Study 2: N___ and his mother

- **The client (N___) introduces himself to the health worker:** I am N___, I am 12 years old, and I have been coming to the clinic for a long time. My mother is here with me today.
- **Background:**
  - **N___'s mother says:** N___ always used to cooperate and take his medicines with no problems. But now he is fighting me with every dose — he runs away and spits out his ART. I am planning to tell N___ his diagnosis, but right now he is still too young to know. I haven't used the word "HIV" with him yet.
  - **N___ says:** My mother forces me to take my medicine every morning and every evening. But I don't want to take it anymore — I just want to be normal and not take medicine. My friends don't take medicine, so why do I have to?

Case Study 3: P___

- **The client (P___) introduces herself to the health worker:** I am P___ and I'm 14 years old. I am feeling bad and I want to stop taking ART. My best friend is with me today.
- **Background:**
    - **P___ says:** I've missed about 3 doses of my ART this month, but I think that taking my doses most of the time is good enough. I think the pills are making me look fat. There is a boy in my class that I really like, but I'm sure he thinks I'm ugly. I get teased when I go to school and I only have one friend. She is with me today — in the waiting room.

Case Study 4: M___ and her mother

- **The client (M___) introduces herself to the health worker:** I am M___, I am 16 years old, and I have come in today for my 3-month checkup. As always, my mother is here with me. The doctor told me to give this to you (M___ should hand over her pretend medical record with the results of her last 2 CD4 tests, which show a decrease in her CD4 count).
- **Background:**
    - **M___'s mother says:** M___ has taken 100% of her medicines on time this month.

M___ says: I've taken 100% of my medicines on time this month.

Module 8: Key Points

- Retention and adherence are closely related and are key components of comprehensive adolescent HIV care and treatment.
- Retention refers to keeping (or "retaining") clients in the care program, which in this case means that clients continue accessing lifelong HIV care and treatment services. In terms of 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 their necessary doses to achieve the conditions for therapeutic success. Therefore, it is our aim as health workers to support clients to achieve and sustain this rate of adherence to their regimens, both for their own health and to protect their sexual partners ("*altruistic adherence*").
- Although it is ultimately the responsibility of clients to adhere to their care plans, there are many steps health workers can take to make it easier for clients to adhere to care. One of the most important steps to improve retention is to ensure that services are youth- friendly.
- ART preparation usually includes group education sessions, individual counseling sessions, and an adherence readiness assessment. Follow your national guidelines and adapt them as needed to the unique needs of adolescents.
- Ideally, adherence readiness assessment and counseling should begin early during HIV care, but they should NOT be a reason to delay initiation of ART for most ALHIV.
- Each client should have AT LEAST one individual adherence preparation counseling session with a health worker before starting ART. Caregivers and treatment buddies, when available, should also participate in these preparation sessions.
- In addition, health workers can help the client develop a personal adherence plan by:
  - Asking the ARE YOU COMMITTED? question and then the WHO, WHAT, WHEN, WHERE, and HOW of the medications. Health workers can use the Adherence Support Tree in *Appendix 8A* to help clients and caregivers work through these questions.
  - Administering a standardized assessment tool to help determine a client's and caregiver's readiness for ART and to help them develop an adherence plan. Health workers can use the Adherence Preparation and Support Guides in *Appendix 8B.*
- Assessing adherence and providing adherence support to clients and caregivers are important, yet challenging, tasks. The best way is to use several methods, such as a standardized adherence assessment combined with a patient/caregiver self-report, pill count, and review of clinical and laboratory records. Health workers can use the Adherence Assessment Guides in *Appendix 8C* to ask clients and caregivers about adherence at **each clinic visit.**
- Adherence support services should be ongoing — not one-time events — and the entire multidisciplinary team, not just counselors or Peer Educators, is responsible for providing these services.
- Ongoing adherence support is especially important for adolescents because their adherence to care and medications is not static (meaning it will change over time).

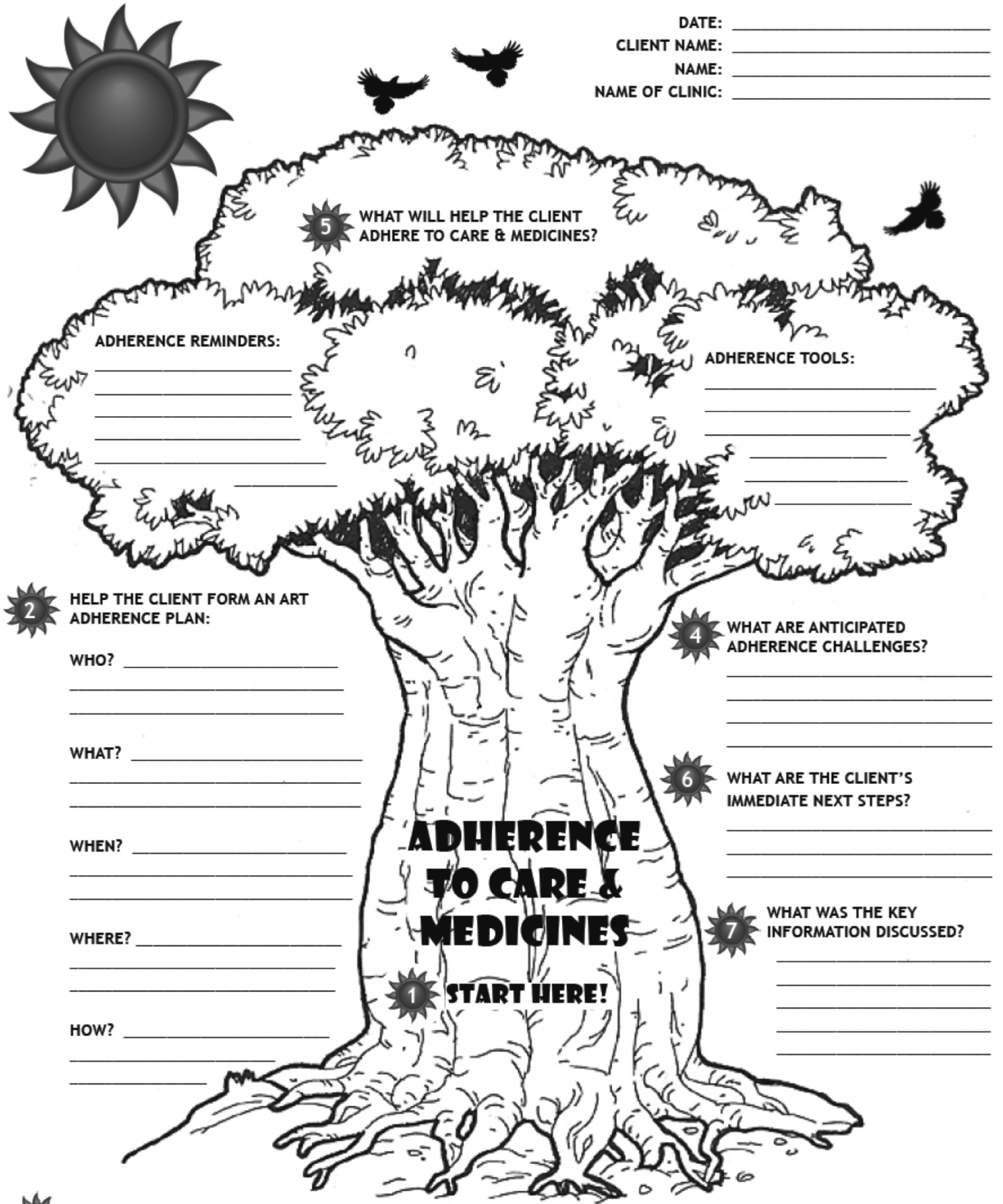
Appendix 8A: Adherence Support Tree[1]

Instructions for the Adherence Support Tree:
Each instruction below goes with a number on the Adherence Support Tree. The health worker should follow these instructions in order.

1. Start on the trunk. Begin by explaining what we mean by adherence to treatment and why near-perfect adherence is important.
2. Continue by helping the client make an ART adherence plan: address the ARE YOU COMMITTED? question and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. The lines to the left of the tree are spaces for writing down important information related to the client's adherence plan.
   - ✓ ***ARE YOU PLANNING TO TAKE YOUR MEDICINES?*** 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 of each and how often will you take each medicine? 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 medicines?* (Establish a routine.)
   - ✓ ***WHERE*** *will you take your ART (e.g. at school, at home, at work, etc.)? Where will you store your ART?*
   - ✓ ***HOW*** *will you remember to take your medicines every day and at the same time? 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? How will you know that you have taken your doses so you don't miss any or take them twice?*
3. Ask the client to imagine him- or herself as a tree. His or her roots are "*where you come from, your home, your family, and your community,*" they are "*what support and ground you.*" Ask the client who will support him or her with the adherence plan and write this under "peers, family, and community" in the roots of the tree. Also write down if the client has a treatment buddy.
4. Discuss the possible challenges to adherence in the client's (and caregiver's) life. Write these under "what are the anticipated adherence challenges?"
5. The branches are the client's adherence strategies. These are things he or she can do to have perfect adherence, like using reminders, having routines, having a treatment buddy, etc. Give the client practical suggestions and help him or her plan ways of remembering to take medicines and to come to the clinic for appointments.
6. Always plan a follow-up session and record any action points under "immediate next steps." Tell the client that you will always be available to talk more with him or her. Adherence and follow up to the adherence plan should be discussed during every clinic visit.
7. Lastly, summarize the main points that were discussed during the adherence support session, talk about any necessary referrals, and arrange another time to talk (if necessary).

ADHERENCE SUPPORT TREE

DATE: ______________________
CLIENT NAME: ______________________
NAME: ______________________
NAME OF CLINIC: ______________________



5 WHAT WILL HELP THE CLIENT ADHERE TO CARE & MEDICINES?

ADHERENCE REMINDERS:
____
____
____
____
____
____

ADHERENCE TOOLS:
____
____
____
____
____
____

2 HELP THE CLIENT FORM AN ART ADHERENCE PLAN:

WHO? ______________________
____
____

WHAT? ______________________
____
____

WHEN? ______________________
____
____

WHERE? ______________________
____
____

HOW? ______________________
____
____

4 WHAT ARE ANTICIPATED ADHERENCE CHALLENGES?
____
____
____
____

6 WHAT ARE THE CLIENT'S IMMEDIATE NEXT STEPS?
____
____
____

ADHERENCE TO CARE & MEDICINES

1 **START HERE!**

7 WHAT WAS THE KEY INFORMATION DISCUSSED?
____
____
____
____
____

3 WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:	PEERS:	COMMUNITY:
______________________	______________________	______________________
______________________	______________________	______________________
______________________	______________________	______________________
______________________	______________________	______________________

Appendix 8B: Adherence Preparation and Support Guides

How to use these guides:

These adherence preparation and support guides were developed to assist a range of providers (trained counselors, lay counselors, Adolescent Peer Educators, doctors, nurses, pharmacists, community health workers, and others) who work with 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. In some cases, adolescents are referred to adult ART clinics — which may not be youth-friendly — for adherence counseling and preparation. Many programs stipulate that clients participate in a series of group and individual counseling and preparation sessions before starting ART.

Included here 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 counseling 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 health 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 begin ART. 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 to decide on next steps, to identify important areas for follow up, and to support the client's adherence over the long term.

Client/caregiver requires more counseling and support in these areas:

In this space, write down specific areas in which the adolescent client/caregiver needs ongoing adherence counseling and support. Refer to this section of the form during follow-up counseling 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 ART. Instead, these issues should be viewed as important areas for ongoing counseling 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:	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 ART?	
3. Who have you spoken to/who knows about your HIV-status?	
4. What do you expect from taking ART?	
5. How do you feel about taking medicines every day for your lifetime?	
6. Can you tell me the names of the medicines 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 ART? What will you do if you have side effects?	
8. Can you explain what happens if you do not take all of your ART 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 his or her name and contact information?	
9a. Has he or she been to the clinic with you?	
9. What might make it difficult for you 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, like 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 and your medicines?	
17. Do you feel ready to start taking these medicines?	

Client requires more counseling and support in these areas (LIST):

Signature of person completing assessment: ___________________________ **Date:** ___________

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 ART?	
3. Who knows about your child's HIV-status?	
4. What do you expect from your child taking ART?	
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 medicines 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 ART? 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 ART 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?	
10. What might make it difficult for your child to come to this clinic for his or her appointments?	
11. How will your child remember to come for his or her clinic appointments?	
12. How will your child remember to take his or her medicines the right way, at the same time, every day?	
13. 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)?	
14. Where will you store your child's medicines?	
15. 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, like when he or she is at school?	
16. What will you do if your child misses a dose of the medicine?	
17. What questions do you have about the plan for your child's care and medicines?	
18. Do you feel that you and your child are ready to start taking these medicines?	

Caregiver requires more counseling 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 8C: Adherence Assessment Guides

How to use these guides:

These adherence assessment guides were developed to support a range of providers (trained counselors, lay counselors, Adolescent Peer Educators, doctors, nurses, pharmacists, community health 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 here is one adherence assessment guide to be used with 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 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 health 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 to decide on next steps, to identify important areas for follow up, and to support the client's adherence over the long term. If possible, the health worker should meet with the client and caregiver separately to identify and address any discrepant responses. Meeting separately is especially important as young clients enter middle and late adolescence.

Other assessment measures and next steps:

This is the section where health workers will make a 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 health 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 health 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 organization, such as a youth support group or a home-based care program, 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 organization 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, like for an appointment with a trained counselor or for a session with the pharmacist to explain dosing.
- **Next steps and follow-up plan:** Identify which solutions and next steps the client/caregiver thinks are feasible and manageable. For each solution, list the necessary steps the client or health worker will need to take and a timeline 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 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 medicines 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?	
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? For twice daily regimens, was it the morning or the evening dose(s) that you took late?	
3. How many pills did you **miss** in the last 7 days? What were the main reasons you missed them? For twice daily regimens, was it the morning or the evening dose(s) that you missed?	
4. How did the medicines make you feel? For example, did you have any side effects?	
5. Can you tell me about any changes you noticed (such as in your health) or challenges you had with your medicines?	
6. What support or reminders do you have to help you take your medicines at the same time, every day?	
7. 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 health worker: (discuss possible solutions to each)	
Referrals made:	
Next steps and follow-up plan:	Next appointment date: _______________

Notes:

Signature of person completing assessment: ___________________________ **Date:** ___________

Adherence Assessment for Caregivers of 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 caregiver:	Notes
1. Can you tell me more about how your child took his or her medicines 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?	
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? For twice daily regimens, was it the morning or the evening dose(s) that he or she took late?	
3. How many pills did your child miss in the last 7 days? What were the main reasons he or she missed them? For twice daily regimens, was it the morning or the evening dose(s) that he or she missed?	
4. How did the medicines make your child feel? Did your child have any side effects from the medicines? Can you describe them?	
5. 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?	
6. What support or reminders does your child have to help him or her take his or her medicines at the same time, every day?	
7. What questions do you have about your child's care or 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.*

References

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[1] Schley, A., Colton, T., Schoeneborn, A., and Abrams, E. (2011). *Positive voices, positive choices: A comprehensive training curriculum for Adolescent Peer Educators, Version 1.0*. ICAP.

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 ALHIV
- Support ALHIV to achieve and maintain a healthy mind – having a positive outlook toward living and life
- Provide ongoing support and counseling to adolescent clients on maintaining a healthy body
- Provide basic nutritional recommendations to ALHIV and their family members
- Help adolescent clients prevent or recover from alcohol and other substance use problems

Session 9.1 Supporting ALHIV to Live Positively and Maintain a Healthy Mind

Session Objectives

After completing this session, participants will be able to:

- Define positive living and describe the key components of positive living for ALHIV
- Support ALHIV to achieve and maintain a healthy mind – having a positive outlook toward living and life

What is Positive Living?

- **Positive living includes:**
  - Keeping one's mind healthy (having a positive outlook toward living and life)
  - Keeping one's body healthy
  - Keeping one's soul and spirit healthy (for example, the things we do to feel good on the "inside" and to feel a sense of peace and contentment)
  - 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 health workers at the clinic and also by caregivers and family members.
- Health workers play a key role in helping ALHIV live positively and follow the "**recipe for positive living**" (see box below).

Recipe for positive living:

KNOWLEDGE + DETERMINATION TO LIVE

with actions for a

HEALTHY MIND + HEALTHY BODY + HEALTHY SOUL

= A LONG, HEALTHY LIFE

Source: Orr, N.M. (2004). *Positive health*. Cape Town: Double Storey Books.

Because adolescent clients' questions about and understanding of living with HIV changes over time, it is important that health workers talk to them about topics related to positive living on an ongoing basis.

Information on positive living should be communicated often and through multiple channels, such as:

- Individual counseling 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, and books)
- TV shows or videos about living positively
- Web sites and youth-friendly Internet resources (see *Appendix 9A: Web Resources for ALHIV* for a list of web-based resources on positive living that are geared toward young people)

Supporting Adolescents to Have Healthy Minds and a Positive Outlook

Health workers should always try to build trusting, positive, and respectful relationships with their adolescent clients.

Ensure that ALHIV have access to adolescent-specific support groups and peer support (see Module 5)

- Health 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. It can also help improve their access and adherence to HIV prevention, care, and treatment services.

Ensure that psychosocial support (see Module 5) and mental health referrals (see Module 6) are part of comprehensive HIV care and treatment

- ALHIV face additional challenges and stressors as a result of living with a chronic, highly stigmatized disease. It is important that health workers conduct routine psychosocial assessments and provide needed psychosocial support as an integral part of HIV care and treatment. Adolescents will likely need extra support during challenging times, like when they are preparing to disclose their status, when they lose a loved one, when they face discrimination, etc.
- Health workers should watch out for the presence of mental health problems, including substance abuse, among their adolescent clients, and provide needed referrals and support as needed. Health workers should be able to recognize when an adolescent may be in danger or may have a severe mental illness requiring immediate, emergency steps.

Ensure that adequate attention is paid to ongoing disclosure support for ALHIV and their caregivers (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.
- Health workers can help ALHIV overcome their fear of disclosure to others by helping them see the advantages of 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 of disclosure; and to help them anticipate likely responses.

Ensure that ALHIV and their caregivers receive ongoing adherence support (see Module 8)

- There are many barriers and challenges to retaining adolescents in care and to supporting them to adhere to their ART regimen. Although health workers may not be able to address all of a client's barriers to adherence, there are many factors that can be addressed, including minimizing health service barriers by improving the quality of counseling and ensuring access to youth-friendly services.
- There is no one specific way to monitor adherence. Instead, the best way is to use many different methods, including routine adherence assessment, ongoing adherence counseling, 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 ALHIV 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 adolescents with a chance to make friends and develop life skills.

Talk with ALHIV about their spiritual, religious, and cultural beliefs and practices

- Health workers should encourage both ALHIV and their families to continue their regular spiritual, religious, and cultural practices.
- For ALHIV 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 counseling to help them face issues related to mental health, disclosure, and positive living.

Encourage ALHIV to develop life skills to help them live positively with HIV (see below).

Supporting Adolescents to Develop Life Skills

Having life skills helps adolescents 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 who are equipped to cope with the demands and pressures of everyday life and living with HIV. Developing 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.

Health workers are not responsible for teaching adolescent clients all of these life skills, but they should:

- Keep them in mind when working with adolescents and providing them with psychosocial support
- Encourage life skills trainings and discussions as part of peer activities and support groups
- Link their adolescent clients, when possible, with formal or informal life skills trainings, such as those offered by youth groups, schools, and faith- or community-based organizations

See *Appendix 9B: Life Skills Training Resources* for more information.

Table 9.1: Examples of adolescent life skills

Communication and Interpersonal Skills	Decision-making and Critical Thinking Skills	Coping and Self-Management Skills
Interpersonal communication skills: • Verbal communication • Non-verbal communication • Expressing feelings • Giving and receiving feedback **Negotiation/refusal skills:** • Negotiation and conflict management • Assertiveness skills • Refusal skills **Empathy:** • Ability to listen and understand another's needs and circumstances and express that understanding **Cooperation and teamwork:** • Expressing respect for others' contributions and styles • Assessing one's own abilities and contributing to the group **Advocacy skills:** • Influencing skills and persuasion • Networking and motivation skills	**Decision-making and problem solving skills:** • Information gathering skills • Evaluating future consequences of present actions for self and others • Determining alternative solutions to problems • Analysis skills related to the influence of values and attitudes on motivation (of self and others) **Critical thinking skills:** • Analyzing peer and media influences • Analyzing attitudes, values, social norms, and beliefs and factors affecting these • Identifying relevant information and sources of information	**Skills for increasing internal locus of control:** • Self-esteem/confidence-building skills • Self awareness skills, including awareness of rights, influences, values, attitudes, strengths, and weaknesses • Goal-setting skills • Self-evaluation, self-assessment, and self-monitoring skills **Skills for managing feelings:** • Anger management • Dealing with sadness, grief, and anxiety • Coping skills to deal with loss, abuse, illness, and trauma **Skills for managing stress:** • Time management • Positive thinking • Relaxation techniques

Source: UNICEF. (2004). *Which skills are life skills?* Available at: http://www.unicef.org/lifeskills/index_whichskills.html

Session 9.2 Supporting ALHIV to Live Positively and Maintain a Healthy Body

Session Objectives

After completing this session, participants will be able to:

- Provide ongoing support and counseling to adolescent clients on maintaining a healthy body
- Provide basic nutritional recommendations to ALHIV and their family members
- Help adolescent clients prevent or recover from alcohol and other substance use problems

Key Points for Positive Living

Healthy behaviors

Health workers should actively encourage ALHIV to live healthy lives. Some of the activities that constitute "living healthfully" or "living positively" are summarized in Table 9.2.

Table 9.2: Positive living

“Living positively” with HIV includes…
Health care
• 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 health workers if taking any traditional remedies or supplements
• Telling a nurse or doctor if there have been any health-related changes, even small ones
Sexual health
• If sexually active, using condoms and practicing safer sex every time; using a family planning method in addition to condoms (dual protection)
• Going to the clinic for pregnancy testing, counseling, early antenatal care, and PMTCT services if pregnancy is suspected or confirmed
• Getting screened for STIs and getting immediate treatment for self and partner
Staying active and socially engaged
• Doing 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 prioritizing education/career
Rest
• Getting enough rest
• Sleeping and resting under an insecticide-treated mosquito net if in a malarial area
Personal hygiene
• Washing hands with soap often, especially: • After using the toilet, touching the genitals, or touching any body fluid • Before preparing food or eating • After sneezing or coughing • After handling garbage • After touching animals
• Bathing regularly
• Practicing good hygiene during menstrual period: • Changing sanitary pads or cloths regularly • Washing hands before and after changing sanitary products • Bathing daily during monthly period (note: there is never a need to clean inside the vagina, not even during the monthly period) • Safely disposing (by putting into a pit latrine or burning) or washing used sanitary pads/cloths

Oral health
• Keeping your mouth clean by brushing teeth, mouth, and tongue at least twice a day
• Treating severe oral lesions with gauze soaked in salt water to clean the mouth
Nutrition
• Eating enough healthy food and taking multivitamins
• Drinking at least 8 glasses (250 mls/glass) of **clean** water each day. It is important to ensure that drinking water is clean – depending on what is locally available, this may include boiling or filtering water, treating water with chlorine tablets or liquid, or placing water in plastic bottles out in the sun for a day.
Food hygiene
• Washing food preparation, cooking, eating, and storage utensils with soap and water (hot water is best, if available)
• Washing raw fruits and vegetables well with clean water
• Covering food to prevent both flies and dust from contaminating it; not storing raw and cooked foods together
• Eating food as soon as it is cooked and not storing leftovers unless they can be kept in a refrigerator or a cool place
• Cooking food thoroughly, particularly meat, poultry, and fish (meat should have no red juices), but remember that overcooking vegetables causes them to lose nutritional value
• Keeping the house and compound clean — getting rid of any still water; keeping garbage covered and disposing of it at least once per day
• Keeping all food preparation surfaces clean. Use a germ-killing bleach solution (like Jik, Gentian Violet, or whatever bleach is locally available) diluted with water to keep household surfaces clean. Note that the bleach to water ratio may change, depending on the brand of bleach.

Unhealthy behaviors
Health workers should talk with ALHIV about avoiding practices or behaviors that are not healthy. These include:

- Drinking alcohol
- Smoking cigarettes
- Using drugs (marijuana, *khat*, heroin, glue, prescription drugs, etc.)
- Having unsafe sex
- Sharing medicines, stopping medicines without talking to a doctor, or missing medication doses
- Taking traditional medicines that have not been discussed with a doctor or nurse
- Missing appointments at the clinic
- Not eating enough healthy foods or eating too many sugary or fatty foods
- Avoiding social contact, staying alone too much, and being inactive

Remember: Education and counseling on positive living may not result in immediate behavior change among adolescent clients. Changing behavior takes time, self-confidence, and a supportive environment! Be sure to praise clients when they recognize the need to change their behaviours and for even the smallest efforts to adopt healthier behaviors.

Helping Clients Practice Positive Prevention

Positive prevention is a key component of positive living. Health workers should help ALHIV understand how 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 11)
- Prevention of blood-borne HIV transmission, including transmission through injecting drug use or sharing sharp instruments to cut or pierce the skin

Review of General Nutrition Information[1]

It is critically important that health workers provide regular weight and nutrition monitoring as part of ALHIV's routine care.

Common nutritional issues for adolescents:

- Many adolescents — especially the most vulnerable adolescents like 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 because of busy lifestyles.
- Some ARVs may cause adolescents to lose their appetite and some may cause changes in physique, 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." Health 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. It is always best to eat fresh, natural foods, which are also usually cheaper than packaged and pre-prepared foods.

Eating a "balanced diet"

Eating a "balanced diet" means eating a variety of foods from each of the 3 food groups (see *Appendix 9C: Basic Food Groups*) and eating enough food every day. It is always best to eat foods grown at home or produced locally instead of eating foods that have been imported or processed, which do not have as many nutrients.

For additional information on healthy eating for people living with HIV, see the "Resources" section on the first page of this module and also refer to your national nutrition and HIV guidelines.

General Nutrition Recommendations for ALHIV

Health workers can counsel and educate adolescent clients and their family members about good nutrition. Advise them to:

- Eat a well-balanced diet that includes a variety of fresh foods and that is based on what is locally available and affordable. See *Appendix 9C: Basic Food Groups*.
    - Make "energy giving foods" ("GO" foods/starches) the biggest part of every meal.
    - Eat "body building foods" ("GROW" foods) with every meal. Whenever possible, a meal should contain some meat, fish, or other foods from animals. When properly combined, plant proteins (beans, peas, soya beans, peanuts, and other nuts) also provide good quality protein.
    - Eat "protective foods" ("GLOW" foods), which include all kinds of fruits and vegetables, every day.
    - Use fats and oils in moderation.
    - Avoid junk food and processed foods.
- Increase caloric intake, especially with "GO" and "GROW" foods.
    - Asymptomatic ALHIV may need 10–15% more energy intake than people without HIV.
    - 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 due to their busy lives).
- Have their weight routinely monitored and recorded. If there are changes or other indications of nutritional problems, the health worker should conduct a nutritional assessment (see next section).
- Receive nutritional education and counseling (along with their caregivers) as a part of all HIV care appointments.
- Take a daily multivitamin supplement as a routine part of care in order to prevent micronutrient deficiencies.

Many of the activities listed above in Table 9.2 will enhance appetite (for example, exercising), aid digestion (for example, drinking plenty of water), and prevent food-related illness (for example, practicing good food hygiene).

Conducting a Nutritional Assessment

Health workers should follow their national guidelines and be sure to:

- Weigh adolescent clients at each visit, record their weight in the patient chart, plot it on a growth curve (for adolescents who are not yet full grown), 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 interpretations is included in *Appendix 9D: Key Components of a Nutritional Assessment*.

> **Weight monitoring**
>
> It is important to weigh **EVERY** client at **EVERY** visit. Their weights should be plotted on growth curves (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!**

The goal of nutritional assessments is to determine if nutritional problems exist and, if so, the severity and probable causes. Health workers should consider the high incidence of food insecurity for families in the region, 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 counseling, education, and advice should always be adapted to the realities of a particular client's situation.

Common Nutritional and Eating Problems and Advice for Adolescent Clients and Caregivers

Health workers should try to support adolescent clients with nutritional problems and work with them and/or their caregivers to address these problems 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 9E: 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

One of the most common challenges ALHIV and their families face is lack of food. Some ways health workers can help ALHIV and their families get or grow enough good foods to eat are:

- Provide practical counseling 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 establish formal linkages between the clinic and agricultural and food support organizations, including by initiating food distribution to clients at the health facility level.
- Link clients with agricultural support programs, nutrition support programs, and animal husbandry and other income-generating activities in the community.

Helping Clients Avoid Alcohol and Drugs[2,3]

Substance use versus abuse

Not everyone who uses drugs becomes addicted, but alcohol and other substance use can cause problems for ALHIV, 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

Health workers can help adolescents avoid alcohol and other substance use in the first place and can also help clients already using or abusing drugs and alcohol by providing support and referrals. This includes risk reduction counseling and referrals to more intensive treatment if needed and available (see Module 6).

Drugs and alcohol: A part of 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, coping with sadness or stress by using drugs or drinking alcohol will only make people feel physically and emotionally worse in the long term, even if it makes them feel better at first.
- When people take drugs or alcohol, they may become addicted. This 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. Drug and alcohol use can also affect people's appetite.
- Helping adolescents learn about the risks of drugs, alcohol, and cigarettes before they start using them helps prevent addiction and harmful effects. This education can be done through individual counseling and health education sessions or group health education sessions with adolescents (and caregivers).
- Screening adolescent clients for alcohol and drug abuse and providing counseling, referrals, and treatment to those 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. Genetic risk factors for developing addiction contribute to this risk. 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 alcohol and drugs is perhaps the strongest predictor of adolescent substance use and abuse.
- **Mental health problems:** There is a strong link between mental health problems and substance abuse.

- **Response to stress:** Alcohol and other drug abuse in adolescents may be the result of feeling out of control, feeling hopeless, or having a lack of direction in life. Adolescents may use drugs to feel better about life events that they see as being out of their control.

Consequences of adolescent alcohol and other substance use

Adolescents face unique risks and problems associated with alcohol and substance use, including:

- **Poor adherence to HIV care and treatment:** Alcohol/substance use can have a significant negative impact on an individual's adherence to HIV care and medications.
- **School-related problems:** Adolescent alcohol/substance use 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 use reduces their ability to practice safer sex, they are at greater risk for unplanned pregnancies, transmitting HIV, and transmitting or acquiring other sexually transmitted infections.
- **Delinquent behavior and juvenile crime:** Drug use can lead to selling drugs, stealing, and violent behavior.
- **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:** Alcohol and other substance use has negative effects on the user's mind and body.
  - Some of these effects are short-term, such as memory loss due to a drinking binge that results in a blackout.
  - Severe long-term use can cause problems such as certain cancers (for example, upper digestive tract and liver cancers from alcohol abuse, lung cancer from smoking, etc.), heart or respiratory failure, stomach ailments, central nervous system damage, and sexual impotence.
  - Alcohol use also interacts with conditions like depression and may contribute to suicide.
  - Some studies have shown that drinking alcohol may accelerate HIV disease progression, as both HIV and alcohol suppress the body's immune system.
  - Alcohol and other substance use also increases a person's risk of violence and accidental death from trauma.

Prevention of alcohol and substance use

Prevention strategies should be linked to the overall goal of prevention or less harm/safer use. Substance use prevention education strategies health workers may use include:

- Ensuring ALHIV have positive peer support networks and are linked to support groups
- Counseling clients to increase their awareness of the consequences of alcohol and drug use
- Counseling clients on risk reduction to enhance their 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 are referred for support and treatment (see Module 6)

Identifying and Treating Alcohol and Substance Use Disorders

The use of alcohol and other substances can become severe enough to constitute the diagnosis of a mental disorder. See Module 6 for more information, including *Appendix 6C: Screening for Alcohol Dependency* and *Appendix 6D: Screening for Drug Abuse*.

<table>
<tr><th colspan="2">Exercise 1: Supporting ALHIV to Live Positively: Case studies and large group discussion</th></tr>
<tr><td>Purpose</td><td>To work through case studies that will help participants think about how to best handle challenging situations with adolescent clients</td></tr>
<tr><td colspan="2">Case Study 1:
During a routine visit, A___, 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. <i>How would you proceed with A___?</i>

Case Study 2:
E___ 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 Adolescent Peer Educators mentioned that he saw her hanging out with some older men outside of a store. She was smoking a cigarette and sharing some beer. <i>How do you plan to talk to E___ about positive living when she comes for her next clinic visit?</i></td></tr>
</table>

Module 9: Key Points

- The concept "positive living" encompasses not only maintaining one's physical health but also taking care of one's mind and soul.
- Health workers should routinely address positive living with their adolescent clients, using a variety of channels.
- Although adolescents ultimately have to reach within themselves to ensure that their minds are healthy, there is a lot health workers can do to help them find and maintain emotional and psychosocial health.
- As ALHIV develop and age, so does their need for information about staying healthy. Examples of healthy living include: using condoms and family planning, adhering to care and medicines, staying active, making friends, getting rest, eating healthy foods, and exercising regularly.
- "Positive prevention" is also a part of positive living. This refers to preventing the further transmission of HIV.
- Good nutrition is an important component of positive living. Health workers should provide regular weight and nutritional monitoring and counseling as part of ALHIV's routine care.
- Health workers can help adolescents avoid alcohol and other substance use and can also help clients already using alcohol or other substances by providing counseling and referrals to treatment.
- Health workers should remember that education and counseling may not result in immediate behavior change among adolescent clients. Remember that behavior change takes time, self-confidence, and an enabling environment.

Appendix 9A: Web Resources for ALHIV[4]

Avert.org: An online resource with easy to understand information on HIV transmission prevention, treatment, care, epidemiology, pathology, politics, and more. Available at: http://www.avert.org

The Body: An online HIV and AIDS resource that aims 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. Available at: http://www.thebody.com

Body and Soul Charity: A UK-based organization supporting people living with HIV. Its Teen Spirit section (for people living with HIV aged 13-19) provides comprehensive information and resources geared specifically toward young people living with HIV. Available at: http://www.bodyandsoulcharity.org

"Does HIV Look Like Me?": This campaign was conceived of by YLHIV from Hope's Voice (see below) and aims to target stigma, discrimination, and ignorance about the HIV and AIDS pandemic using mass media. 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. Available at: http://www.doeshivlooklikeme.org

Go Ask Alice!: Columbia University's web portal for young people's questions about sex, sexuality, and more. Available at: http://www.goaskalice.columbia.edu

Global Network of People Living with HIV and AIDS (GNP+): An organization with several regional networks working to improve the quality of life for all people living with HIV and AIDS. Available at: 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 prioritizes 1) Networking and sharing of best practices; 2) Capacity building and technical assistance; 3) Political advocacy; and 4) Preparation for international conferences. This site can be used to find other young people, mentors, donors, funders, scholarships, trainings, and event opportunities related to HIV, AIDS, and sexual reproductive health. Available at: http://www.youthaidscoalition.org – please note that, at the time of writing, this site was down

Hope's Voice: A YLHIV-led organization committed to decreasing stigma around HIV and AIDS through education and campaigns. Hope's Voice aims to empower HIV positive youth to be leaders in educating their communities and to be catalysts for change around the globe. Available at: http://www.hopesvoice.org

International Community of Women Living with HIV (ICW): A global community of women living with HIV. Available at: http://www.icw.org

My Sex Life: Info for Poz Youth: A youth-friendly, informative guide on safer sex and sexuality for YLHIV created by the AIDS Committee of Toronto and Positive Youth Outreach, Canada. Available at: http://www.actoronto.ca/home.nsf/pages/mysexlife

Youth R.I.S.E.: An international youth network for reducing drug-related harm. Available at: http://youthrise.org/

Appendix 9B: Life Skills Training Resources

Advocates for Youth. (1995). ***Life planning education: A youth development program.*** This manual details activities that people can use to help youth develop relationships, communication skills, plans for the future, and a better understanding of sexual health and risk behavior. Available at: http://www.advocatesforyouth.org/publications/555?task=view

Alliance. (2006). ***Our future: Sexuality and life skills education for young people.*** This is a series of workbooks developed by the Government of Zambia that contain information on sexual health and HIV education for youth in and out of school. The workbooks are divided by grade (grades 4-5, 6-7, and 8-9). Available at: http://www.aidsalliance.org/publicationsdetails.aspx?id=211

Botswana Teen Club. ***Teen club life skills curriculum.*** This curriculum, which is still under development, includes topics such as feelings and emotions; financial literacy; grief and bereavement; love, sex, and dating; and adherence. Available at: http://botswanateenclub.wordpress.com/resources/teen-club-life-skills-curriculum/

Family Care International. (1999). ***Get the facts: A flipchart for adolescents.*** This flipchart was developed in collaboration with IPPF/Africa Region to help generate discussion; provide accurate information; and stimulate actions related to healthy relationships, improving communication with parents, condom negotiation, HIV/AIDS, STIs, and other important reproductive health issues for adolescents. Available at: http://www.familycareintl.org/en/resources/publications/38

Office of Sustainable Development Bureau for Africa. (2003). ***Life skills and HIV education curricula in Africa: Methods and evaluations.*** This report pulls together what is known about existing classroom-based life skills programs. Several previously evaluated African programs described, along with research findings and lessons learned. Available at: pdf.usaid.gov/pdf_docs/PNACT985.pdf

Office of Sustainable Development Bureau for Africa. (2002). ***Tips for developing life skills curricula for HIV prevention among African youth: A synthesis of emerging lessons.*** This document offers practical guidance for those planning, implementing, or strengthening life skills curricula for young people in sub-Saharan Africa. Available at: sara.aed.org/multisectoral/publications/developing_life_skills.pdf

PATH. (2003). ***Life planning skills: A curriculum for young people in Africa.*** This curriculum is designed to help youth face the challenges of growing up. It includes a facilitator's manual and a workbook for participants.
Botswana version is available at: http://www.path.org/publications/detail.php?i=1590
Tanzania version is available at: http://www.path.org/publications/detail.php?i=1593
Uganda version is available at: http://www.path.org/publications/detail.php?i=1592

Peace Corps. (2001). ***Life skills manual.*** This manual consists of over 50 versatile lesson ideas that are grouped according to 3 basic life skills: communication, decision-making, and relationship skills. Available at: http://www.peacecorps.gov/multimedia/pdf/library/M0063_lifeskillscomplete.pdf

The Youth Health and Development Program, Government of Namibia & UNICEF. (1999). ***My future is my choice: Extra curricular life skills training manual for adolescents 13 to 18 years of age.*** This is a 10-session program that aims to give young people the information and life skills they need to make decisions about their future. Available at: http://www.unicef.org/lifeskills/files/mfmc_facilitator_manual.pdf

Appendix 9C: Basic Food Groups[5,6]

The basic food groups are:

- **Energy giving (or "GO") foods**, which give us energy and make us **GO**. They include rice, maize meal, 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, help us gain weight, and make foods taste better. However, they should be eaten together with healthy foods and in moderation. "Good fats" include things like avocados and groundnuts.
    - **Roughage, also known as fiber**, is important for bowel movements and, therefore, helps prevent constipation.

- **Body building (or "GROW") foods** provide protein, helping to build our bodies and keep our muscles strong. They include meat, poultry, fish, 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). These foods 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 "GO" foods (starches)	**Body building "GROW" foods (proteins and dairy)**	**Protective "GLOW" foods (fruits and vegetables)**	
• Maize meal • Rice • Bread • Cassava • Matoke • Porridge • Yams • Millet • Sorghum • Potatoes • Chapati • Plantains • Arrowroots • Crackers • Pasta (noodles)	• Beans • Lentils • Peas (cow, garden, pigeon, etc.) • Groundnuts • Sesame • Eggs • Fish • Beef • Lamb • Goat • Chicken • Pork • Insects • Milk • Yogurt • Cheese	• Carrots • Cabbage • Tomatoes • Okra • Kale • Spinach, leafy greens • Sweet potato and cassava leaves • Pumpkin leaves • Eggplant • Mushrooms • Cauliflower • Cucumber • Capsicum/peppers	• Avocadoes • Pineapple • Mango • Oranges • Lemons/limes • Papaya/pawpaw • Ripe bananas • Pears • Plums • Peaches • Apples • Jack fruit • Watermelon • Passion fruit • Guavas

Appendix 9D: Key Components of a Nutritional Assessment

Measures	Interpreting results and next steps
Anthropomorphic assessment	
Weight and Height	• In patients who have lost 10% of body weight or 6–7 kg in a month: **Assess ART eligibility** • If loss >5% of body weight over 2-3 months associated with OIs: **Treat underlying conditions** • If loss of >10% of body weight over 2-3 months associated wasting syndrome (WHO Stage 4): **Start ART.**
BMI = Weight (Kg) / Height (M^2) • BMI 18.5–24.9: **Normal weight** • BMI 25–29.5: **Overweight** • BMI 30 and above: **Obese** (Does not apply to pregnant women)	• If BMI <18.5: **Provide counseling and supply therapeutic food supplements** • If BMI >30: **Recommend weight loss without compromising nutrition status**
MUAC (mid-upper arm circumference) Recommended for adolescents and adults who cannot stand up for weight and height measurements and for pregnant women	**Adults** • <16 cm: **Severe malnutrition** • 16–18.5 cm: **Moderate malnutrition Pregnant Women** • < 17 cm: **Severe malnutrition** • 17–21.9 cm: **Moderate malnutrition**
Clinical assessment: what to look for	
• GI problems (diarrhea, nausea, vomiting) • OIs that may interfere with food intake and absorption • Concurrent medical conditions (diabetes, hypertension, lipid problems) • Medication profile (medications taken, side effects that may affect food intake or absorption)	
Dietary assessment: what to ask about	
• Eating patterns, food regularly consumed, and frequency of meals • What foods are available and affordable • Food intolerance, allergies, and aversions • Dietary problems (for example, poor appetite, difficulty chewing and swallowing) • Food preparation and handling practices • Psychological factors that may contribute to inadequate food intake (for example, depression) • Physical activity • Use of mineral or vitamin supplements • Living environment and functional status	
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 (e.g., anemia)	• If hemoglobin (Hb)<10: **Advise diet high in iron and folic acid**
• Glucose and lipid profile	• If abnormal blood glucose: **Profile for diabetes** • If abnormal lipid profile: **Do further clinical evaluation**

Appendix 9E: Nutritional Management of Common Symptoms Related to Advanced HIV Infection[5,6]

Note: All of the recommendations for nutritional support and management of symptoms should be combined with routine clinical care and treatment, including ART.

Sign/symptom	Nutritional recommendations and management
Major weight loss (sometimes called "wasting")	• Eat small meals often. Try to include "body building" foods (protein) with each meal. • Eat snacks during the day if possible (such as groundnuts, boiled eggs, and avocados). • Eat more "energy giving" foods (like rice, maize meal, bread, and porridge). • Eat more beans, lentils, peas, and groundnuts. • Try to eat more meat, fish, and eggs. • Use more fats and oils in food, especially "good fats" like avocados and nuts. • Eat more dairy foods (like milk and yogurt). • Add dry milk powder or pounded groundnuts to foods (like porridge and cereals). • Add sugar, honey, syrup, or fruit jam to foods. • Try to eat more of your favorite foods. • Adhere to your care and treatment plan, including ART. • 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 may lose fat in their face, arms, and legs. These side effects may be confused with weight gain or weight loss.
Diarrhea	• Eat soups and drink safe water, rice water, thin porridge, and weak tea to avoid dehydration. • Drink oral rehydration solution (ORS). • Eat small amounts of food many times a day. • Eat foods like millet, bananas, peas, and lentils to help retain fluids. • Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes, and crackers, which are easy to digest. • Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-paws, mashed sweet potatoes, and mashed carrots. • Eat eggs, chicken, or fish for protein. • Adhere to your care and treatment plan, including ART. **Stay away from:** • Strong citrus fruits (like oranges and lemons) • Dairy products, such as milk — try fermented products instead, like yogurt or sour milk • Caffeine (coffee and tea) • Alcohol • Fried foods • Very sugary foods • Extra oil, butter, or lard • Gas-forming foods (like cabbage, onions, and carbonated soft drinks)

Sign/symptom	Nutritional recommendations and management
Nausea and vomiting	• Drink fluids (especially clean water) to prevent dehydration. • Eat bland soups. • Eat fruit, such as bananas. • Eat lightly salty and dry foods (like crackers or bread) to calm the stomach. • Drink herbal teas and lemon juice in hot water. • Eat small amounts of food many times a day. • Adhere to your care and treatment plan, including ART. **Stay away from:** • Spicy or fatty foods • Caffeine (coffee and tea) • Alcohol
Mouth and throat sores or infection	• Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet potatoes, bananas, soup, paw-paws, and porridge. • Eat cold foods or foods at room temperature. • Drink liquids, such as beef broth or lentil/pea soup. • Rinse the mouth with clean, warm salt water before and after eating. • Use cinnamon tea as a mouthwash. • Suck on clean ice, if available, to relieve pain. • For thrush, eat fermented foods (like plain yogurt and sour milk). Sucking on a lemon and eating garlic can also help. • See the nurse or the doctor, and adhere to your care and treatment plan, including ART. **Stay away from:** • Spicy or salty foods, which can irritate mouth sores • Strong citrus fruits and juices, which can irritate mouth sores • Sugary foods and drinks • Rough foods like toast and raw vegetables • Alcohol
Loss of appetite	• Eat small, frequent meals throughout the day. • Eat nutritious snacks between meals. • Take walks before meals if possible — fresh air helps to stimulate appetite. • Avoid smoking — it reduces appetite. • Add seasonings, especially herbs, to food to give it more flavor. • Try rinsing out the mouth after meals. • Use lemon, raw tomatoes, or tonic water to stimulate the taste buds. • Chew food well and move it around the mouth to stimulate taste buds. • Avoid strong-smelling foods. • Eat with others as much as possible. • Adhere to your care and treatment plan, including ART.
Taste changes (can sometimes be caused by ARVs and other medications)	• Change the sweetness, saltiness, or sourness of food by adding sugar, salt, jam, or lemon (which also increases the taste). • Try different herbs and spices. • Eat more fish or chicken, as meat can often have a metallic taste. • Eat lentils, beans, or split peas. • Brush teeth after eating to remove any aftertaste. • Adhere to your care and treatment plan, including ART.

References

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[2] Program for Appropriate Technology in Health (PATH). (2006). *Tuko pamoja adolescent reproductive health and life skills curriculum.*

[3] United Nations Children's Funds. (2006). *Life skills – based education for drug use prevention training manual.* UNICEF.

[4] 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

[5] 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.

[6] 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 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 Practice Safer Sex**
Session 10.4:	**Integrating Sexual Risk Screening, Risk Reduction Counseling, and STI Services into Adolescent HIV Services**

Learning Objectives

After completing this module, participants will be able to:

- Reflect on their own attitudes, values, and beliefs about 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 adolescents' sexuality
- Define safer sex and discuss how to empower adolescent clients to practice safer sex
- Conduct sexual risk screening and reduction counseling with adolescent clients
- Explain the importance of and provide STI screening and treatment to adolescent clients
- List ways to make sexual and reproductive health (SRH) and other clinical examinations more adolescent-friendly

Session 10.1 Values Clarification and Introduction

Session Objectives

After completing this session, participants will be able to:

- Reflect on their own attitudes, values, and beliefs about adolescent sexuality, and discuss how these may affect their work with adolescents

Adolescent Sexuality – Introduction

Sexuality emerges during adolescence and, for many people, mid-late adolescence is also a time when sexual activity begins.

- Health workers should never assume that adolescent clients are not sexually active. Instead, they should assume that adolescent clients already are sexually active (or will become sexually active at some point in the future).
- It is important that all members of the multidisciplinary team feel comfortable talking about sexuality and sexual and reproductive health (SRH) with adolescent clients, and that they be able to offer them non-judgmental sexual education and SRH counseling and services.

Exercise 1: SRH Values Clarification: Large group exercise	
Purpose	To help participants begin to explore their values, attitudes, and prejudices related to adolescent sexuality and SRH, and to also help them think about how these might affect their work with adolescent clients
The trainer will read out a series of statements out loud. After each statement is read, move to the “agree” or “disagree” sign, depending on your opinion. If you are not sure whether you agree or disagree with a particular statement, you can somewhere in-between the 2 signs.	

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	
Purpose	To provide participants with the definitions of words used to describe sexual expression and sexual orientation
This exercise consists of 2 parts: • Part 1: Small Group Work • Part 2: Large Group Discussion	

Sex and Sexuality

Sex (as in sexual activity)

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 his or her partner's penis, vagina, or anus)
- Inserting fingers or objects into the vagina or anus
- Masturbating (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 a person's sexual partners at risk of getting a sexually transmitted infection (STI), including HIV, or unwanted pregnancy.
- It is very important for health workers to be comfortable talking about sex and reproduction with their adolescent clients. Honest, factual discussions about sex and sexuality can provide adolescents with the information they need to protect themselves and their partners from STIs and unplanned pregnancy.
- Some adolescents acquire HIV, or are at risk of acquiring HIV, because of sexual abuse. Although sexual abuse is often unsafe, unsafe sex due to sexual abuse is not something that the victim has control over. Therefore, when discussing sexual abuse with adolescents, the focus of the discussion must be on stopping the abuse, counseling the victim, identifying ways to support healing and possibly punishing the perpetrator, instead of on unsafe sex.

Sexuality

- Is more than sex and sexual feelings
- Includes all the feelings, thoughts, and behaviors of being a girl, boy, man, or woman, including feeling 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 a part of us from birth until death
- Is constantly evolving as we grow and develop

See *Appendix 10A: Journal Article,* which presents data on sexual behaviors and desires among perinatally infected ALHIV in Uganda.

Sexuality: Key Terms

The following are some aspects of sexuality. Each of these aspects is connected to one other and contributes to making a person who he or she is.

- **Body image:** How we look and feel about ourselves and also 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
- **Intimate relationship**: A romantic and/or sexual involvement with another person
- **Intimacy:** Sharing thoughts or feelings in a close relationship, with or without physical closeness
- **Love:** Feelings of affection and the ways we express those feelings for others
- **Sexual arousal:** The arousal of sexual desires and the state of sexual readiness in preparation for sexual behavior. Sexual arousal has mental and physical components.
- **Social roles:** How we contribute to and fit into society
- **Genitals:** The reproductive and sexual organs: the testicles and penis of a male or the labia, clitoris, and vagina of a female
- **Sexual abuse:** Sexual abuse is forced, unwanted, improper, or harmful sexual activity inflicted on another person. Sexual abuse will be discussed further in the next section.
- **Ways we can express our sexuality:** Through dancing, talking, wearing attractive clothes, experiencing sexual dreams or daydreams, feeling sexual near others, masturbating, etc.

Remember:

- In many places, “sex” is often thought to mean only penis-vagina sex between a man and a woman. However, sexual behaviors include much more than just penis-vagina sex.
- If health workers do not talk about sex and sexual behaviors with clients, they may not get the information, skills, and supplies they need to protect themselves and their partners and to reduce their risk of HIV, STIs, sexual violence, discrimination, and unplanned pregnancy.
- While we all hold our own opinions about different sexual behaviors, we cannot — as health workers — project our own values onto clients. Adolescent clients should always be made to feel comfortable talking about their sexual concerns, questions, and behaviors — and that there is no risk of judgment.

Sexual Orientation and Identity

- Adolescence is a time of sexual experimentation and defining one's sexual identity.
- Health workers need to stress that homosexual, bisexual, and transsexual/transgendered behavior is NORMAL (regardless of their own personal views).
- Adolescence is a period of change — and an adolescent's sexual identity may not be his or her permanent identity.
- Adolescence is a period when sexual identity starts to be defined. An adolescent who realizes that he or she may be gay, bisexual, or transgendered may feel isolated and depressed. It is the health worker's responsibility to help the adolescent cope with his or her sexual orientation and accept his or her feelings.
- The health worker does not have to be an expert on sexual orientation. The most important thing is that the health worker be willing to listen to adolescent clients in a non-judgmental way and provide them with any necessary referrals.

Creating a gay-friendly atmosphere

Although most adolescents are heterosexual, some are homosexual or bisexual. Adolescents who are not heterosexual are particularly vulnerable because they often 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 at an early age with tobacco, alcohol, and illegal drugs. It is important that health workers make sure homosexual and bisexual youth know they will not be judged and that they are welcome in the clinic. Health 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 counseling). If clinic staff do not feel qualified to counsel gay youth about homosexuality, they should know where to refer them for peer support or other forms of support and counseling.

Sexual Orientation and Identity: Key Terms

- **Sex (as a noun):** Refers to the physiological attributes that identify a person as male or female (e.g. 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 behavior 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, while retaining his penis and sexual functioning).

Effects of HIV on Sexuality Among ALHIV

HIV affects everyone differently and depends on how long a person has been infected, how others respond to the person and his or her diagnosis, his or her level of self-esteem, etc. Some of the effects of HIV on sexuality are listed below. Some ALHIV may experience 1 or more of these effects, and others may not experience any. Also, many of these effects are experienced only in the months following diagnosis, as a necessary phase in a person's journeys to redefine who he or she is.

- 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.
- ALHIV may have lower self-esteem than their peers.
- ALHIV may have increased anxiety about their sexuality, sexual relationships, and sexual and reproductive health.
- ALHIV often have concerns about whether/how they can have sexually intimate relationships. They also often have fears related to disclosing their status to sexual partners and the possibility of transmitting HIV to them.
- ALHIV may have concerns and questions about being able to have safe sexual relationships and, in the future, children.
- Not 'fitting in' can be very traumatic for adolescents, especially when it involves 'looking different.'
- ALHIV, especially those who were perinatally infected and those who went a long time without HIV treatment, may begin puberty later and may 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, and short stature). These physical characteristics and changes may affect an adolescent's body and self-image.
- Adolescents who acquired HIV through sexual abuse may have unresolved issues from the trauma related to the abuse (see next section).

Sexual Abuse[1]

Many victims of sexual abuse are adolescents. Research in many countries has documented that 7–34% of girls and 3–29% of boys experience sexual abuse (ranging from harassment to rape and incest). Sexual abuse can happen inside or outside the home; it can be perpetrated by a partner, family member, family friend, or stranger. It can also include domestic violence.

Health workers should teach young people that it is a basic human right to grow up and live in an environment that is free of physical and sexual violence. Violence should never be considered a "normal" part of everyday life.

Recognizing sexual abuse can be difficult and is rarely a straightforward task:

- Sexual abuse in young people requires careful investigation and assessment because there are very few conclusive signs and symptoms of sexual abuse.
- Often, there is no physical evidence that an adolescent has been sexually abused — changes in the adolescent's behavior are a far more common result.

- The most reliable and common indicator of sexual abuse is an adolescent's disclosure of the abuse. 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, including signs and symptoms of abuse, how to interview an adolescent who may have been abused, and follow-up, is further discussed in *Appendix 10B: Adolescent Sexual Abuse*.

Sexual abuse should be investigated using a multidisciplinary team approach:

- The team should consist of at least 3 people and, when possible, should include a representative from law enforcement, a person from social welfare, and a health 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.

See box on the following page for additional information on sexual and gender-based violence (SGBV) and what health workers can do to support a victim of SGBV.

Sexual and gender-based violence (SGBC)

- SGBV is a problem throughout the world.
- The most frequent victims of coerced sex are adolescent girls.
- Reducing the frequency of coerced sex requires efforts in the community to promote non-violent norms, to pass and enforce laws against sexual violence, to encourage the reporting of sexual violence, and to teach self-defense skills to girls.
- When the perpetrator is an adult, sexual assault of an adolescent is also considered child abuse.
- Following an episode of sexual assault, a comprehensive package of SGBV services is needed to address the acute medical needs of the victim. This includes:
  - HIV testing and post-exposure prophylaxis (PEP), following national guidelines (note that if the adolescent is already known to be HIV-infected and on ART, this is not necessary)
  - A medical examination that includes the collection of forensic evidence and an assessment for STIs
  - The provision of needed medical treatment
  - Pregnancy testing and the provision of emergency contraception (for females)
  - Counseling and support
  - A temporary place to stay, if needed for safety
  - A link to the police for an investigation of the assault

Exercise 3: OK For Me?: Large group exercise and discussion	
Purpose	To allow participants to examine their own values about sexual behaviors, and to discuss how these values and attitudes can affect the services they provide to adolescents
This exercise consists of 2 parts: • Part 1: Individual Work • Part 2: Large Group Discussion	

Session 10.3 Supporting Adolescent Clients to Practice Safe Sex

Session Objectives

After completing this session, participants will be able to:

- Define safer sex and discuss how to empower adolescent clients to practice safer sex

Understanding Risk

HIV is transmitted from 1 person to another through **4 body fluids**: semen, vaginal secretions, blood, and breast milk. Any activity during which 1 or more of these body fluids is passed from 1 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

Given the mechanism by which HIV is transmitted from 1 person to another, sexual activities that present no risk of transmission are those during which none of these 4 body fluids (semen, vaginal secretions, blood, or breast milk) is exchanged. Sexual activities that present a risk involve semen, vaginal secretions, or blood.

Applying this to counseling sessions, health workers should encourage clients who are sexually active to abstain from activities that are high risk and probably even medium risk. They should encourage ALHIV to substitute any risky activities with others that are considered "no risk" or low risk. If a client is sexually active, it is probably inappropriate to expect that he or she will avoid all physical contact, but only practicing no or low risk activities may actually be a very achievable goal.

No risk

There are many ways to share sexual feelings that are not risky. These include:

- Hugging
- Kissing (even "French kissing," or kissing with the tongue, carries no risk of HIV transmission)
- Holding hands
- Massaging
- Bathing or showering together
- Rubbing against one other with clothes on
- Sharing fantasies
- Self-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 during **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
- Sharing sexual toys (rubber penis, vibrators) without cleaning them

Medium risk

- Oral sex without a latex barrier (some STIs, like gonorrhea, 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?"

Safer sex includes the range of ways that people can protect themselves and their partner(s) from HIV (or HIV "re-infection"), other STIs, and unintended pregnancy.

- Safer sex involves choosing sexual practices and protection methods that prevent body fluids from passing from 1 person to another.
- Because ARVs reduce the amount of virus in body fluids (including blood, semen, vaginal secretions, and breast milk), safer sex includes maintaining excellent adherence to ART.
- Safer sex reduces the risk of transmitting HIV without reducing intimacy or pleasure.
- Safer sex includes the activities listed under "No risk" and "Low risk" in the previous section.

ART and safer sex

- An important study was released in 2011 (referred to as HPTN 052)[2] that showed that people living with HIV who are taking ART are much less likely to pass HIV to their uninfected partners than those who are not on ART. The study showed a 96% reduction in risk of HIV transmission when the partner living with HIV was taking ART.
- *"**Altruistic adherence**"*: Now there is yet another important reason to adhere to ART — to protect sexual partners from HIV.
- PLHIV on ART should still practice safer sex — even when taking ART, there is still a risk of HIV transmission.

Role of health workers:

- During adherence counseling, health workers should inform clients of the additional benefits of excellent adherence: not only does good adherence improve the quality and length of the client's life, but it reduces the risk of transmission to his or her uninfected sexual partner(s).

More on condoms

- Not having sex at all (abstinence) is one way to be completely safe. However, 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, like that they are only for sex workers or promiscuous people. Health workers should promote condoms as a way for young people to protect themselves and their partners from HIV and other STIs.
- Some people feel that condoms make sex less enjoyable. Health workers should respect everyone's personal experiences with condoms, but should also try to reframe condoms as part of pleasurable foreplay and sex. They should emphasize that condoms can relieve worries about an unplanned pregnancy or guilt related to risking HIV transmission.
- Some people think that if both partners are living with HIV, they do not need to use condoms. It is important that health workers explain to clients that even if both partners are living with HIV, they should still use condoms to reduce the risk of transmitting new strains of HIV to one another (re-infection). Such transmission is particularly risky if the strain of HIV that is transmitted is resistant to the ART regimens used locally.
- Some health workers may think that giving young people condoms encourages them to have sex. However, 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, offered by Peer Educators, etc. Remember: health workers must remove as many barriers as possible to condom use among adolescents.

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 previously in this session. Other strategies include:

- Dual method use — i.e., using male or female condoms to protect against STIs **and** a second method to protect against unplanned pregnancy (often a hormonal method). This is a very reliable method of dual protection.
- Being in a monogamous relationship in which both partners have been tested and know they do not have any STIs, and in which at least 1 partner is using effective contraception
- Using male or female condoms

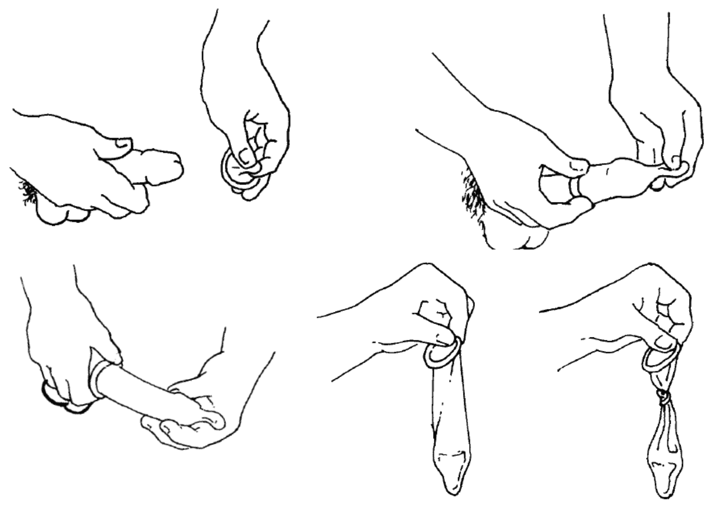
"If we're both HIV-positive, why do we need to use a condom?"
"What is re-infection?"

Some people think that if a PLHIV has a partner who is also HIV-infected, he or she does not need to worry about protection with condoms anymore. However, this assumption is incorrect. It is important that PLHIV practice safer sex, even if their partner also has HIV.

- Using condoms prevents both unwanted pregnancy and the transmission of other STIs.
- Different strains or types of HIV can be passed between two HIV-infected people. This transfer of a particular HIV strain from one HIV-infected person to another is called **re-infection.** Being re-infected can make treatment more difficult because the new strain of HIV might not respond to the ART regimen the person is currently taking (in other words, the strain might be drug resistant).

How to use a male condom

These are the basic steps you should know in order to use or demonstrate how to use a male condom. If penis models are not available, you can use a banana, corncob, or bottle for the demonstration. Only condoms made out of latex protect against HIV.



Steps to use a male condom:

- Look at the condom package to make sure it is not damaged and check the expiration date to make sure the condom is still good.
- 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 tip will hold the semen and prevent the condom from breaking.
- Hold the condom so that the tip is facing up and so the condom 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), hold the rim of the condom 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 any spilling. Throw it away in a latrine or bury it. Do not put it in a flush toilet.

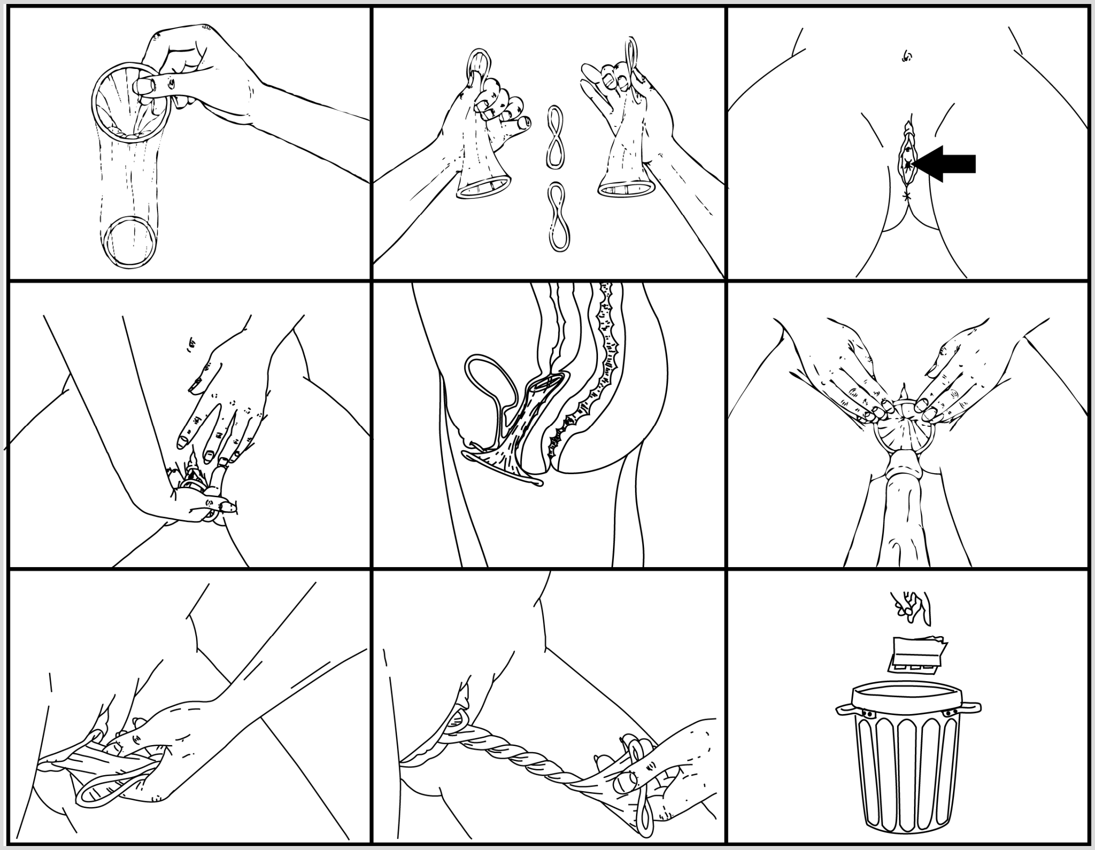
Also, it is important to:

- Use a condom every time you have sex — whether it is oral, anal, or vaginal sex. Use a new condom every time! Never reuse a condom!
- Only use water-based lubricants (instead of oil-based lubricants).
- Store condoms in a cool, dry place that is away from the sun. Do not keep them in a wallet.
- Do not use condoms that seem to be sticky, a strange color, or damaged in any way — instead, 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 using female condoms because these condoms give them more control over their own bodies and over sex. Some men like using them because then they do not have to use a male condom. The female condom is becoming more affordable and available. These are the basic steps you should know in order to use or demonstrate how to use a female condom. If no vaginal model is available for demonstration, 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 expiration date to make sure the condom 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 your thumb and middle finger.
- Guide the inner ring all the way into the vagina with your fingers. The outer ring should stay outside the vagina, covering the vagina's lips.
- 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) and 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.

Exercise 4: Condom Demonstration: Return demonstration and large group discussion	
Purpose	To help participants feel comfortable demonstrating how to use a male and female condom
This exercise consists of 3 parts: • Part 1: Male Condom Demonstration • Part 2: Female Condom Demonstration • Part 3: Large Group Discussion	

Reasons Why Adolescents May Not Practice Safer Sex[3]

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 know 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 often reluctant to provide practical information about sex to adolescents. Some believe that providing such information encourages sexual activity, even 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 contraceptive methods and their side effects.
- They do not know that methods are available or know 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 use condoms correctly.
- They have heard myths about the dangers of using contraceptive methods, which are common and difficult to defuse.
- They are not aware of pleasurable alternatives to risky sex, such as mutual masturbation, etc.

Denial

- "*It 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 do not think they will get pregnant or an STI, or think that there is only a small chance of passing HIV to a partner during sex.

Lack of access

- Access to contraceptive services for adolescents is often limited by law, custom, or clinic/institutional policy.
- Availability and cost of contraceptive methods may restrict access.
- There may be an irregular supply of contraceptive methods available.
- Sex happened spontaneously and a contraceptive method was not available when needed.
- Health worker attitudes toward 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.
- One of the partners has the attitude that condoms ruin sex or are unromantic.
- There is pressure from family members to conceive.

The "I don't care" 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 may have lost hope. This may cause them to think: *"I don't care, I already have HIV, so why not take risks?"*

Fear

- They fear rejection by their partner.
- They fear people knowing their HIV-status (if they use condoms or request that their partner use condoms).
- They fear a lack of confidentiality at the place methods can be obtained.
- They fear using something new — they fear the unknown.
- They fear side effects.
- They fear not being able to find a place to keep protective methods so that no one sees them.
- They fear something going wrong if they start using a certain contraceptive method, like oral contraceptive pills, too early in life.
- They fear that their parents will find out they are having or planning to have sex.
- They fear that their peers or parents will know they are sexually active.
- They fear being asked questions by a pharmacist or health worker if they request condoms or other contraceptive methods.
- They fear being labeled "cheap" or "loose."

Embarrassment

- Service providers and pharmacists are sometimes judgmental and/or moralistic about adolescent sexual activity. This is especially true for ALHIV, since 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 communication and negotiation skills and/or expertise to discuss protection or 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 suggesting using protection implies mistrust of their 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, for a married couple, both partners may want to start a family.
- They think their partner "is taking care of the 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 Counseling, and STI Services into Adolescent HIV Services

Session Objectives

After completing this session, participants will be able to:

- Conduct sexual risk screening and reduction counseling 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

Although information alone cannot be expected to change the sexual behavior of adolescents, health workers can support 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.
- Health workers can help adolescent clients understand the transmission risk of certain activities and provide guidance to help them reduce risky behavior, to maintain good SRH, and to prevent new HIV infections. (See Session 9.2 in Module 9 for more information on positive prevention)
- In general, adolescents want their health provider(s) to give them accurate information and to sensitively, confidentially, and without any judgment ask them personal questions about HIV-related risk behavior.
- In order for these discussions to be effective, adolescent clients must feel that their providers will talk to them in a comfortable and supportive way about any topic, no matter how uncomfortable it may seem.
- Young people can sense when health workers are out of their element or are passing judgment while talking about sensitive issues and this perception will likely prevent honest communication about risk behaviors.

Sexual Risk Screening and Counseling

The process

- Start asking adolescent clients routine screening questions as early as possible.
- Build trust with clients:
  - Start addressing sexuality with them before they become sexually active.
  - Begin with safer topics, such as the physical changes of puberty. Educate clients 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 the caregivers and the adolescent client.
- By the time clients are 12 years old, begin meeting with them separately from their caregivers 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 health workers will protect client confidentiality unless there is an emergency or a health risk that requires intervention.
  - A health worker might need to disclose information about a patient if this information needs to be shared with another health worker, so that appropriate care can be provided to the client.
  - Local law may require disclosure under other circumstances. For example, most countries require that discussions about child sexual abuse be reported to authorities. Also, some countries/localities (but not all), require health workers to disclose their client's HIV-status to the client's sexual partner, if the partner is known to the health worker.
- Use good communication and counseling skills (see Module 4).
- Avoid making assumptions about the client, including about his or her knowledge, behavior, sexual orientation, etc.
- Always ask about sexual behavior, rather than sexual identity.
- Avoid using any labels not first used by the client.
- If a discussion is awkward, respect a client's cues that further talk is unwanted.
- Table 10.1 summarizes the elements of a sexual risk screening.
- Table 10.2 summarizes the risk reduction counseling session, which should follow the sexual risk screening.

Table 10.1: Sexual risk screening

✓	Questions for the client:
	1. Is the client sexually active?
	- *Some adolescents have sex with their partners. Are you having sex?* If the response is "no," go to Table 10.2. If "yes," proceed to section 2 of this table.
	2. If yes, with whom?
	- *Are you having sex with males, females, or both?* - *How many partners do you have right now? How many partners have you had in the past year?* - *What is the HIV-status of your partner(s)?* - *Does your partner know you have HIV?*
	3. What are the client's sexual practices?
	- *Do you have vaginal sex? Oral sex? Anal sex?* - *What family planning method did you use the last time you had sex?* - *When was the last time you used a condom?* - *Has anyone caused you harm in the past; for example, hurt you physically or made you have an unwanted sexual encounter?* - *Have you ever used cigarettes, alcohol, or other drugs? If so, how often in the last week have you used cigarettes, alcohol, or other drugs?*

Table 10.2: Risk reduction counseling

✓	Questions for the client:
	1. Assess knowledge
	• *How is HIV transmitted from one person to another?* • *How can a person prevent transmission of HIV during sex?* • *What is your plan to protect your partner from getting HIV when you have sex?* • *Did you know that even if both partners have HIV, it is important to practice safer sex and use condoms? Do you know why?*
	2. Discuss options for sexual risk reduction
	• *There are a number of ways to your reduce risk of HIV, other STIs, and unwanted pregnancy, including:* ◦ *Abstinence* ◦ *Intimate touching without exchange of bodily fluids* ◦ *Reducing your number of sexual partners* ◦ *Disclosing your HIV-status and negotiating sexual practices* ◦ *Correctly and consistently using condoms (for male-female couples, ideally with another form of hormonal contraception)* ◦ *STI screening and treatment (HIV is transmitted more easily in the presence of other STIs)* ◦ *Maintaining maximal suppression of HIV through excellent adherence to ART, if eligible* ◦ *Avoiding alcohol, marijuana, party drugs, and other substances that impair good judgment and prevention*
	3. If an option, discuss abstinence
	• *Abstinence means not having sex. If you are abstinent, you cannot get STIs or get re-infected with HIV, and you cannot have an unplanned pregnancy.* • *Is abstinence an option for you?* • *If you choose abstinence, you should have a backup plan as well, just in case you change your mind. What will be your backup plan?*
	4. Discuss condoms
	• Demonstrate steps for putting on a condom (male and female) and offer to supply the client with condoms • Help client improve condom negotiation skills by: ◦ Responding to the clients questions and concerns ◦ Reassuring the client that it can be difficult to bring up the topic of condoms with a partner ◦ Suggesting that he or she discuss condoms BEFORE they are needed (rather than in the heat of the moment)
	5. Role play to encourage condom use
	• If partner asks: "*But you have never suggested we use condoms before.*" • Client can say: "*I went to the clinic today and my health worker told me that I really need to use condoms for my health and so that we can prevent an unintended pregnancy.*" (Or, the client may have another reason to explain changing his or her mind.) • If partner asks: "*You don't love me enough to have sex without a condom?*" • Client can say: "*It is because I love you and I love myself that I want to keep us both safe.*" • If partner says: "*You must want to use a condom because you have been messing around with other people.*" • Client can say: "*Before we met, we both had other partners and I want to be sure that neither of us brings anything into this relationship.*"

✓	Questions for the client:
	6. Encourage disclosure
	• 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).

What Makes Adolescents Vulnerable to STIs?[4]

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, including:

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 who have low CD4 counts may have weakened immune systems, which make them more susceptible to STIs.
- Females often do not show signs or symptoms of chlamydia and gonorrhea, so infection may go untreated, which increases the risk of HIV acquisition.

A 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. They often think adolescents should not be having sex in the first place.

Factors related to adolescence

- For adolescents, sex is often unplanned and spontaneous. This makes condom use less consistent and increases the risk of STIs. Adolescents may also have multiple, short-term sexual relationships, which further increases their STI risk.
- Young women are more at risk of sexual violence and exploitation and are more likely to lack formal education (including SRH education), the ability to negotiate safer sex with partners, and access to SRH information and services.
- Adolescents may be subject to high-risk behaviors that increase the risk of STIs, such as anal sex to preserve virginity, dry sex, and scarification.
- Young men may have their first sexual experiences with commercial sex workers and young women may have their first sexual experiences 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 because they fear 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[4]

There are many ways health workers can make physical examinations less stressful for adolescent clients. Health workers should 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 he or she needs to remove clothing or change into a gown. Try and expose only the parts of the body you are examining and leave 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-judgmental manner. For example, *"I see you have a small sore here, does it hurt?"*
- If possible, offer to have the exam performed by a doctor or nurse who is the same sex as the client. Otherwise, offer to have someone of the same sex in the room during the examination.
- Conduct pelvic exams only when recommended. Pelvic exams are recommended annually for sexually active females and for young virgins (under 21 years of age) only if there is a medical indication. If not sexually active by age 21 (or as recommended in national guidelines), start annual pelvic exams. Regardless of age or sexual history, pelvic exams are indicated if there is suspected abuse, abnormal vaginal discharge, vaginal bleeding, amenorrhea, trauma, unexplained pelvic pain, etc.
- If a pelvic exam is necessary, address all of the client's concerns. For example, adolescent girls who are virgins may fear that the procedure will be uncomfortable or tear their hymen. Health 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 before touching the client with your hand or the speculum. Take great care to carry out all parts of the exam gently and smoothly, so as to minimize the client's discomfort and anxiety. Remind the client to breathe deeply and to try to relax during the exam.

STI Screening and Treatment for ALHIV

Screening and physical examination

At every visit, ask adolescent clients who are sexually active adolescents (and **ALL** older adolescents clients — health workers should assume they are sexually active or will be sexually active soon) about STI symptoms (see *Appendix 10C: Screening and Examining Adolescent Clients for STIs*). If the answer to any of the screening questions is *'yes,'* conduct a physical examination that includes the steps outlined in *Appendix 10C*. Ensure that there is privacy during all physical examinations and follow the tips provided in the previous section to make examinations more adolescent-friendly.

Health workers should provide routine cervical screening (using PAP or visual inspection of acetic acid, as per national guidelines) to 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 national STI guidelines for additional information.

Diagnosis and treatment

A thorough physical examination is key to diagnosing STIs. Health workers should use information from the physical examination, in combination with the client's history, to make a ***syndromic diagnosis*** and should manage and treat according to the flow charts included 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) that they should seek medical care so they can be evaluated and treated for STIs.
- Conduct risk reduction counseling to help adolescent clients avoid STIs in the future, including counseling on safer sex and consistent condom use during every sexual encounter.

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 this, health workers must be comfortable talking about sexuality and SRH with their clients, and must be knowledgeable about the common SRH issues faced by adolescents.
- Health workers need to stress that all types of sexual orientation — heterosexual, homosexual, bisexual, and transsexual/ transgendered — are NORMAL (regardless of the health worker's personal views). Health 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 reduce the risk of STIs (including HIV) and protect against unintended pregnancy. Safer sex includes sexual practices and protection methods that prevent body fluids (semen, vaginal secretions, blood, and breast milk) from passing from 1 person to another.
- Using condoms is a reliable way to practice safer sex and to prevent HIV, other STIs, and unwanted pregnancy. For people who are living with HIV, condoms also prevent re-infection.
- ALHIV should have free, easy, and non-embarrassing access to condoms in the clinic setting.
- Safer sex also includes excellent adherence to one's ART regimen — a study released in 2011 showed that people living with HIV who are taking ART are much less likely to pass HIV to their partners than those who are not taking ART.
- Sexual risk screening should start before a client is sexually active and includes questions to help the health worker assess if the client is sexually active and, if so, with whom and what risks he or she is taking.
- Risk reduction counseling focuses on reducing clients' risk of HIV, other STIs, and unwanted pregnancy by helping them choose a strategy that is right for them.
- All adolescents who are sexually active should be screened for STI symptoms. If there is suspicion of an STI, the health worker should conduct a physical examination and follow national STI guidelines.

Appendix 10A: Journal Article

(2009). Journal of Adolescent Health *44,* 184–187.

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.

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 organized 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 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 10.3: Distribution of Study Respondents by Sociodemographic Characteristics

Characteristic	**Male (n = 263)**	**Female (n = 469)**	**Both genders (n = 732)**
Mean age (y)	**17**	**16**	**17**
Age, y (%)			
15	35	33	34
16	14	17	16
17	8	10	9
18	25	23	24
19	18	17	17
District (%)			
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 10.3). 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.[1]

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[1] 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.

Results

Key findings are summarized in Table 10.4. 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 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 10.4: Percent distribution of respondents by their views about sex and sexual experiences

	All respondents			
	Male (n=263)%	Female (n=469)%	Significance test[e]	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[a]	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[b]				
• 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[f]				
• Had consensual first sex[c]	89 (n=98)	63 (n=144)	**	73 (n=242)
• Used a method to prevent HIV infection/re-infection at first sex	35 (n=98)	39 (n=138)	NS	37 (n=236)
• Currently using a condom to prevent[d]	(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.

[a] Proportion of respondents who believed that there is no reason why a person living with HIV should not have sex.

[b] Participants who reported preference for HIV-negative partners. This was an open-ended question whose responses were re-coded after data entry.

[c] Both partners were willing or wanted to have sex.

[d] Multiple responses were allowed.

[e] Significance test of difference between male and female proportions: *p <.05; **p <.01.

[f] 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.

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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, often 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; of urinary tract infections
- Hints, indirect comments, or statements about the abuse
- Problem sexual behaviors: Some adolescents who have been sexually abused may become sexually provocative and copy adult behavior, displaying sexual knowledge (through language or behavior) beyond what is normal for their age. Others may merge sexual behavior and aggression and become the victimizers of others.

Some of these symptoms can result from consensual sexual activity. When pregnancy or sexually transmitted infections are found in adolescent clients, the age of the adolescent should be taken into consideration. In many countries, the age of consent for sexual activity is 16 years; however, adolescents younger than 16 may also have consensual sex (sex in which they willingly engage). In some cases, therefore, it may be necessary for health workers to make a judgment call about whether the sexual activity was forced or not. 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 adolescents), the determination of whether or not abuse occurred may require interviewing the client and making a clinical judgment.

Recognizing the signs and symptoms of sexual abuse in adolescents

The table below presents a checklist of physical and behavioral 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. Also remember that the absence of any of these signs or symptoms does not indicate that no sexual abuse occurred. Each individual survivor of sexual abuse reacts differently and a determination of sexual abuse cannot be based on signs or symptoms alone. Behavioral signs of sexual abuse, for example, are more common than physical signs, but they can also be indicators of other types of trauma. Therefore, it is always necessary to gather information beyond just signs and symptoms 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 or bruises		
Signs of physical abuse (for example, punch marks, restraint marks on the wrist, torn eardrums — all should be investigated as a possible indication abuse)		
Complaints of pain with urination or with 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, or ulcers in genital area		
Unusual or offensive odors from genital area or anus		
Fresh or healed tears of the hymen or vaginal mucosa		
Development of frequent, unexplained health problems		
Changes in behavior	**Yes**	**No**
Nonsexual indicators		
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		
Sexual indicators		
Age-inappropriate knowledge of sex		
Imitating sexual acts or copying adult sexual behavior with younger children, toys, or pets		
Excessive masturbation		
Sexual experimentation with age-inappropriate partners		
Note: This is not a diagnostic tool — these signs and symptoms may result from other causes.		

Additional signs of sexual abuse that may be present in older adolescents include:
- Drug or alcohol use
- Delinquency
- Running away
- Depression
- Early sexual involvement/activity
- Promiscuity
- Criminal activity
- Self-destructive behavior (for example, attempting suicide or self-mutilation)
- Eating disorders (anorexia/bulimia)

As adolescents mature, they become aware of societal responses to their sexual activity and overt sexual indicators, such as those listed in the table above, become less common. In addition, some level of sexual activity is considered normal for older adolescents. **There are three sexual indicators, however, that *may* signal sexual abuse in this population:**
- Among girls, sexual promiscuity
- Among girls, being sexually victimized by peers or nonfamily members — in other words, repeated victimization when an adolescent is older may be evidence of earlier unrecognized 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 had been sexually abused at some point in their lives.[5] Although there has not been comparable research on adolescent male sex work*, clinical observation suggests that adolescent males also become involved in the exchange of sexual services for goods or money as a result of sexual abuse.[6]

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 the adolescent's 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, he or she is 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 is upsetting you.[7] It is also important that health workers not to appear to lead clients to answer their questions in a particular way. Be careful not to plant ideas in an adolescent's mind or to suggest what you expect to hear because then he or she will be more likely to give you the answers he or she thinks you want. Instead, encourage clients to be open and honest.

Above all, reassure adolescents that the abuse was not their fault. Tell them that there is nothing that they did to deserve what happened. Help clients understand that it is all right to feel angry and help them express their anger in ways that are healthy for themselves and others.

Health workers will get further, and will get a more accurate account, if they ask open-ended questions. An open-ended question requires an explanation/description for an answer, instead of 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, health workers should not ask questions that start with "why" because they may come across as accusatory. See Module 4 for more information on open-ended questions.

* Please note that UNAIDS Editors' Notes for authors (August 2006) preferred the term "juvenile prostitution" for this group.

How to begin questioning related to suspected sexual abuse[8]

Always introduce the principle of shared confidentiality and explain your obligations as a health worker if disclosure of sexual abuse occurs during the conversation.

Try to make the adolescent comfortable by explaining that you would like to ask him or her some questions. Explain that he or she should be honest and should not be afraid. Begin by normalizing the topic. For example: *"Because I want to help my clients, I ask everyone about issues 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-judgmental way and 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 if someone has ever touched you in a way you didn't like? How did they touch you?*
- *Has anyone ever hurt you or made you feel bad? How so?*
- *Has anyone ever touched your private areas? Where?*
- *What happened?*
- *Tell me more.*
- *When was last time this happened?*

Other possible questions for younger adolescents:

- *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 that you didn't like ever happen to your private parts? What?*

For older adolescents:

- *How long have you been sexually active?*
- *Has anything sexual that you didn't like ever happen between you and a friend, date, or someone you know? How about something 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?*

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 the present-day level of danger, other violence, drug or alcohol use, and health habits. Mention the adolescent's disclosure again during another visit and continue to ask about his or her needs. Request a 1- to 2-week follow-up appointment with the adolescent.

Use a multidisciplinary team approach:

- Health workers should always seek the counsel and support of multidisciplinary team members when working with clients who have experienced sexual abuse. Discuss sexual abuse cases and how they can best be managed in multidisciplinary team meetings.
- Ensure that health workers know where to seek and refer clients for additional expert help, advice, counseling, and resources.

Other clinical follow-up after the interview

If an adolescent discloses sexual abuse, a thorough physical and gynecological examination should be conducted, with the adolescent's consent (procedures described in Session 10.4).

Respect for privacy during physical examinations is extremely important for adolescents who have experienced sexual abuse. Health workers can demonstrate this respect and can help the adolescent regain a sense of control over his or her body by covering the client with a sheet and allowing him or her to stop the examination at any time if feeling uncomfortable. Health workers should also model sensitive, respectful physical examination techniques to other members of the clinical team.

Follow national testing guidelines when providing HIV counseling and testing to adolescents of unknown HIV-status who have experienced sexual abuse.

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. As above, it is important to take a multidisciplinary approach with clients who have experienced sexual abuse. Health workers should know where to refer clients for additional counseling, peer support, and community-based services.

At a minimum, health workers should conduct a psychosocial assessment to determine the impact the abuse had on the adolescent, the level of family support available to assist him or her with coping, and the ability and willingness of the family to ensure the adolescent's continued safety. The initial assessment should be accompanied by a 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. Helping the adolescent and caregiver understand what behaviors 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 cope more effectively with the impact of the abuse.

Provide follow-up for assessment and treatment of mental health issues. Follow-up should take place at 7 days and 1, 2, 3, and 6 months after the abuse, or according to national policy. Health workers should be knowledgeable of the resources available within the facility and the community to treat the adolescent. If the facility does not have the capacity to provide mental health services, the adolescent should be referred to a facility that does have mental health resources. For more information about assessment and treatment of mental health problems and disorders, refer to Module 6.

Legal follow-up

Health workers must understand any relevant laws and must report cases of sexual abuse in accordance to these laws. Having formal referral linkages to police and legal services is recommended.

In most countries, the police are required by law to be notified of suspected cases of abuse or neglect of adolescents under the age of 16 years. The police are responsible for working with representatives from social welfare and health services as part of a multidisciplinary team. Their duties include investigating the report, determining whether abuse has occurred, ensuring the continued safety of the adolescent, and prosecuting the person who committed the abuse. Where sexual abuse is a criminal offense, health workers may be responsible for reporting findings in a court of law. Therefore, it is vital that health workers who have had contact with the adolescent or with evidence gathered from the adolescent 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
For adolescent women:	
• Do you have vaginal discharge that is not normal for you (color, amount, smell)? • Do you have any pain when you urinate (pee)? • Do you have any sores or bumps in or around your genitals? • Do you have any pain in your lower abdomen?	Ask the young woman to undress from the waist down and to 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. **External exam:** • ***Skin exam:*** 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. • ***External genital exam:*** Inspect and palpate the external genitalia, then inspect the perineum and anus. Look for ulcers, vesicles, warts, and discharge. • ***Inguinal exam:*** Examine the inguinal area and palpate for lymph nodes. • ***Abdominal exam:*** Palpate the abdomen, checking for guarding, tenderness, rebound tenderness, and masses. **Internal exam:** • ***Internal genital exam:*** 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. • ***Bimanual pelvic exam:*** 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. * Some health workers prefer to not use a speculum, or to use a smaller speculum, in women who are virgins.
For adolescent men:	
• Do you have any discharge from your penis? • Do you have any pain when you urinate? • Do you have any sores or bumps around your genital area or your anus?	Ask the man to undress from the waist down and to lie on an exam table. Be sure to cover him with a sheet and only expose the parts that you examine. • ***Skin exam:*** Inspect the skin of the genitals, perineum, anus, inguinal areas, thighs, lower abdomen, buttocks, chest, back, soles of feet, and palms of hands. Look for vesicles, ulcers, warts, other growths, and rashes. • ***External genital exam:*** 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 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. • ***Inguinal examination:*** Palpate the groin, feeling for enlarged lymph nodes and the presence of buboes.

Adapted from: WHO (2003). *Guidelines for the management of sexually transmitted infections.* Available at: http://whqlibdoc.who.int/publications/2003/9241546263.pdf

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Module 11 Family Planning and PMTCT Services for Adolescents

Session 11.1: **Family Planning Counseling for ALHIV**

Session 11.2: **PMTCT Counseling for ALHIV**

Learning Objectives

After completing this module, participants will be able to:

- List the risks of adolescent pregnancy
- Discuss childbearing choices and safe childbearing with adolescent clients
- Understand the contraceptive issues and challenges faced by ALHIV
- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT)

Session 11.1 Family Planning Counseling for ALHIV

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 the contraceptive issues and challenges faced by ALHIV

Risks of Adolescent Pregnancy[1]

Health risks:

- Pregnancy complications — because adolescents are not fully developed and their bodies may not be prepared to handle childbearing. Pregnant adolescents have a greater risk of obstructed delivery and prolonged labor, which increases their risk of hemorrhage, infection, and fistula.
- Pre-eclampsia (hypertension during pregnancy), which can progress if left untreated to extreme hypertension, seizures, convulsions, and hemorrhage
- Anemia
- Complications associated with unsafe abortion
- Premature birth and low birth weight
- Spontaneous abortion and stillbirth, especially among adolescents under the age of 15
- Mother-to-child transmission — ART and ARVs reduce but do not eliminate the risk of a pregnant adolescent transmitting HIV to her fetus or baby (see Session 11.2 for more information on PMTCT)

Psychological, social, and economic risks:

- Pregnant adolescents, especially those living with HIV, may face intense stigma from family, friends, community members, and health workers. This can cause emotional distress and can create a barrier to receiving needed HIV and PMTCT care and medicines.
- Pregnancy often means the end of an adolescent's formal education. If not expelled from school during the pregnancy, young women — and young men — often have to drop out to care for their infant.
- Adolescent pregnancy can change a young woman's and a young man's academic aspirations and choice of career. For young women, adolescent pregnancy can affect future marriage prospects.
- With limited career prospects, some young mothers resort to low-paying and risky jobs (such as prostitution) or marriage in order to support their children.
- Early marriages that result from an unplanned pregnancy are frequently unhappy and unstable.
- Some men refuse to take responsibility for their partner's pregnancy, which can contribute to hardship for the mother and child.
- Young parents are often not prepared to raise a child, which, in extreme cases, can lead to child-rearing problems like child abuse or neglect.

- Fathers of children born to adolescent mothers are more likely than other fathers to experience:
    - Decreased earnings[2]
    - Less education[3]
    - Depression[4]
- Compared to older fathers, adolescent fathers are:[3]
    - Less likely to have plans for a future job
    - More likely to have anxiety
    - More likely to be homeless or living in very unstable households

Counseling Adolescents on the Safest Times to Have Children in the Future

Many ALHIV have questions about whether or not they can safely have children in the future. Health workers should provide adolescent clients with education and counseling 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-related, psychological, social, and economic risks associated with having a baby during adolescence (see above).
- The safest time to get pregnant is when the woman with HIV:
    - Has a CD4 cell count above 500
    - Is healthy — she does not have any opportunistic infections (including TB) or advanced AIDS
    - Is taking and adhering to her ART regimen, and her ART regimen is **NOT** EFV-based
- If her partner is HIV-infected, then the safest time to get pregnant is when he also:
    - Has a CD4 cell count above 500
    - Is healthy —he does not have any opportunistic infections (including TB) or advanced AIDS
    - Is taking and adhering to his ART regimen
- It is healthiest for a mother to wait until her child is at least 2 years old before getting pregnant again.

EFV and pregnancy

Because of the theoretical risk of EFV causing neural tube defects:

- Women at risk of conception or women for whom contraception is not ensured should be given an ART regimen that does **not** include EFV.
- EFV should **not** be initiated in the first trimester of pregnancy, but it may be initiated in the second or third trimester.
- If a woman on an ART regimen containing EFV is diagnosed as pregnant before 28 days of gestation, EFV should be stopped and substituted with NVP or a PI. If a woman is diagnosed as pregnant after 28 days of gestation, EFV should be continued.
- There is no indication for termination of pregnancy in women exposed to EFV in the first trimester of pregnancy.[5]

It is important that ALHIV 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 counseling sessions. Adolescent clients should be encouraged to talk with health workers about pregnancy and PMTCT if they are thinking of having children. Health workers should also encourage the partners of these adolescent clients to come to the clinic for education and counseling on these topics.

Providing Contraceptive Services to Adolescents: Important Considerations

"One-stop shopping" (as discussed in Module 3) is particularly important for adolescents seeking contraceptive counseling and/or a contraceptive method. When adolescents are provided with contraceptive services as part of another service (in this case HIV care and treatment), they are able to access these services conveniently and in confidence (without having to go to a family planning clinic, which may be uncomfortable for them).

Key screening questions for family planning counseling sessions with ALHIV are included in *Appendix 11A: Family Planning Screening Questions and Counseling Points*.

When discussing family planning methods with adolescents, it is important to remember:

- Adolescents have special needs when choosing a contraceptive method and social, behavioral, and lifestyle issues need to be considered. For example, because of adolescents' unpredictable sexual activity and their common need to conceal intimacy and contraceptive use, methods that do not require a daily regimen may be more appropriate for adolescents. 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.
- In general, 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 their contraceptive acceptance and use. Proper education and counseling — both before and at the time a method is selected — can help adolescents make informed, voluntary decisions.
- At a minimum, all adolescents should be counseled on correct condom use and clearly instructed that condoms or abstinence are the only ways to prevent HIV transmission.
- Every effort should be made to prevent the cost of services or the cost of contraceptive methods from limiting adolescents' options.

Additional Issues for ALHIV, Including Use of Hormonal Contraceptive Methods

- Women living with HIV can safely use most forms of hormonal contraceptives. However, ARVs may adversely affect the efficacy of combined oral contraceptives (COCs) and hormonal implants and/or increase their side effects. Further information about family planning considerations specific to clients living with HIV, including contraindications with ARVs and common opportunistic infection drugs, can be found in *Appendix 11B: Family Planning Considerations for People Living with HIV*.
- Health workers prescribing hormonal contraceptives should:
  - Counsel their HIV-infected clients who are on ART about possible interactions between hormonal contraceptives and certain ARV drugs. Clients should understand that the clinical significance of these interactions is unclear and that adherence to the hormonal method of contraception is very important.[6]
  - **Recommend the use of hormonal methods WITH condoms.**
  - Provide women taking rifampicin for TB with a back-up method of contraception, such as condoms. Rifampicin can lower the efficacy of some hormonal contraceptives (pills, monthly injectables, and implants).

Always follow national guidelines when providing family planning counseling and when prescribing family planning methods.

Contraceptive Options

Table 11.1 provides a summary of common contraceptive options for ALHIV. A more detailed description of contraceptive options, which includes special considerations for adolescent clients and advice on counseling adolescent clients about condoms, can be found in *Appendix 11C: Survey of Family Planning Methods for Adolescents*.

Note: In countries where abortion is legal and safe, adolescents who have an unplanned and unwanted pregnancy should be informed of the option of having a first trimester abortion.

Table 11.1: Summary of contraceptive options for ALHIV

<table>
<tr><th colspan="3">Male and female condoms</th></tr>
<tr><th>Advantages</th><th>Disadvantages</th><th>Summary</th></tr>
<tr><td>• Provides protection from both pregnancy and STI (including HIV) transmission and acquisition
• Highly effective when used consistently and correctly</td><td>• Correct and consistent condom use may be difficult to achieve and failure rates can be high.
• Partner involvement is required; need to negotiate their use
• Does not interfere with medications</td><td>• Good method for adolescents
• Requires demonstration on proper use</td></tr>
<tr><th colspan="3">Combined oral contraceptives (COCs) and progestin-only oral contraceptive pills (POPs) — pills taken daily*</th></tr>
<tr><th>Advantages</th><th>Disadvantages</th><th>Summary</th></tr>
<tr><td>• Highly effective when taken daily and on time
• POPs may be a good choice for adolescents who cannot tolerate the estrogen in COCs or who are breastfeeding
• Does not interfere with sex</td><td>• Failure rates are highest for adolescents due to confusion about how to take pill
• Side effects can include nausea, weight gain, breast tenderness, headaches, spotting
• Cannot be taken by clients on rifampicin
• ARVs may adversely affect the efficacy of low-dose COCs and/or increase their side effects</td><td>• Women taking ARVs who want to use COCs should be counseled about the importance of taking COCs on time, every day and about consistent condom use
• POPs are safe for adolescents but because they must be taken at exactly the same time every day, they are not the best choice</td></tr>
<tr><th colspan="3">Injectables — “shot” given every 2–3 months*</th></tr>
<tr><th>Advantages</th><th>Disadvantages</th><th>Summary</th></tr>
<tr><td>• Highly effective when used correctly
• Does not interfere with sex
• As it is an injection, there are no pills to take (i.e., reduced pill burden)</td><td>• Side effects can include spotting at first, then amenorrhea and weight gain</td><td>• Can be used by ALHIV without restrictions
• Remind adolescent when to return for next injection</td></tr>
<tr><th colspan="3">Emergency contraceptive pills (ECP) — 2 doses of pills taken within 120 hours of unprotected sex</th></tr>
<tr><th>Advantages</th><th>Disadvantages</th><th>Summary</th></tr>
<tr><td>• Reduces risk of pregnancy after unprotected sex by 75%
• Safe for all women, including those living with HIV and those taking ART</td><td>• For emergency use only!
• Side effects can include nausea, vomiting, cramps, headache, breast tenderness, and changes in the menstrual cycle</td><td>• Should be widely and easily available to ALHIV
• Provide counseling on adopting a regular contraceptive method as well as on condom use for dual protection</td></tr>
</table>

Hormonal implants — small rods inserted under skin, last 3–7 years*

Advantages	Disadvantages	Summary
• Highly effective • Can be reversed • Does not interfere with sex	• Effectiveness of implants may be reduced by ARVs • Side effects can include nausea, weight gain, and changes in the menstrual cycle • Usually need to be inserted and removed at a family planning clinic	• Can be used by ALHIV who do not take ART • Can be used by ALHIV on ART, but they should use condoms as a back-up method • Provide counseling to prepare client for possibility of irregular bleeding

Intra-uterine device (IUD) — device inserted into uterus, lasts up to 12 years*

Advantages	Disadvantages	Summary
• Highly effective • Does not interfere with sex	• Should not be initiated in a woman with AIDS who is not taking ART • Side effects can include heavy bleeding, discharge, cramping, and pain during the first months • Usually needs to be inserted and removed at a family planning clinic	• Appropriate for adolescents in stable, mutually monogamous relationships • Not recommended for ALHIV with advanced HIV disease or AIDS, especially if not on ART

Male and female sterilization — surgery*

Advantages	Disadvantages	Summary
• Safe and effective • Free of side effects • Does not interfere with sex	• Permanent and requires surgery	• Permanent methods are not recommended for adolescents

Lactational amenorrhea method (LAM)*

Advantages	Disadvantages	Summary
• Temporary, natural contraceptive option for women who are less than 6 months postpartum, who are exclusively breastfeeding, and whose periods have not yet returned	• Most adolescents will not be breastfeeding (unless they have infants), so this is not a likely option for ALHIV	• Appropriate only for adolescents who have given birth within the past 6 months and who are exclusively breastfeeding

Fertility awareness methods*

Advantages	Disadvantages	Summary
• No health risks or side effects	• Requires a woman to identify her fertile days, which takes time and effort • Requires considerable commitment, calculation, and self-control, both by the woman and her partner	• A difficult method for most adolescents to implement correctly and consistently • Not reliable for pregnancy prevention • Do not recommend

* Health 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.

Contraceptive Side Effects

Some adolescents may experience side effects from contraceptive methods (for example, weight gain, spotting, menstrual changes, etc.). 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 health workers:[1]

- Treat all client complaints with patience and seriousness.
- Offer clients an opportunity to discuss their concerns.
- Reassure clients that side effects are manageable and reversible.
- Help clients differentiate between normal contraceptive side effects and 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 counseling.

Session 11.2 PMTCT Counseling for ALHIV

Session Objective

After completing this session, participants will be able to:

- Counsel adolescent clients on prevention of mother-to-child transmission of HIV (PMTCT)

PMTCT Services for Adolescents

Health workers should follow national PMTCT guidelines when providing services to pregnant ALHIV, their partners, and their family members. Where there are no national guidelines, health workers should follow the WHO's guidelines. Key PMTCT concepts are summarized below.

Table 11.2: Key PMTCT concepts[*]

Key Concept 1 — Keep mothers healthy

- 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 her baby will acquire HIV during pregnancy, labor, delivery, or breastfeeding. Conversely, the sicker the mother (the more virus she has in her blood and the lower her CD4 cell count), the more likely it is that her baby will become HIV-infected.
- 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!

Key Concept 2 — Reduce risk at every stage

The risk of passing HIV from a mother living with HIV to her baby depends on timing:

- **During pregnancy, labor, and delivery,** about 20-25 out of every 100 babies will get HIV in the absence of PMTCT services, including ARVs.
- **During breastfeeding,** about 12-15 out of every 100 babies will get HIV from their mothers in the absence of PMTCT services, including ARVs. Risk of transmission depends on how the baby is fed (mixed feeding in the first 6 months of life dramatically increases risk), how long the baby is breastfed, and if the mother or infant is on ARVs.

Breastfeeding exclusively during the first 6 months of life (not giving the baby any food or drink other than breast milk) can lower the risk of HIV transmission.

It is important to help mothers reduce the risk of transmission at every stage.

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[*] Note to training managers: this table should be revised to reflect national PMTCT guidelines and the WHO options deleted.

Key Concept 3 — All mothers need ARVs

- One of the best ways to lower the amount of HIV in a mother's body, to increase her CD4 cell count, and to make her healthy and less likely to pass HIV to her baby is to provide her with the care and treatment she needs to be as healthy as possible. All pregnant women living with HIV need to take ARVs.
- If the mother has a CD4 cell count **at or below 350**, her baby is at high risk of getting HIV. According to WHO PMTCT guidelines, she should start ART as soon as possible and should stay on ART for life.
- If the mother has a CD4 cell count **above 350**, her baby has a lower risk of getting HIV. According to the WHO, she should be started on ARV prophylaxis at 14 weeks gestation or as soon as feasible thereafter to prevent the baby from acquiring HIV. The WHO describes 2 options and national ministries of health decide which option is preferred. These 2 options are:
  - **Option A:**
    - Twice daily AZT starting from as early as 14 weeks gestation and discontinued at delivery **<u>and</u>**
    - sd-NVP at onset of labor combined with initiation of twice daily AZT + 3TC "tail" for 7 days postpartum (Note: Some countries omit the sd-NVP and AZT + 3TC tail in mothers who receive more than 4 weeks of AZT.)
  - **Option B:**
    - Triple ARV prophylaxis starting from as early as 14 weeks gestation and continued until delivery or, if breastfeeding, continued until 1 week after all infant exposure to breast milk has ended

Key Concept 4 — All babies of HIV-infected mothers need ARVs and CTX

- All babies need to take ARV prophylaxis at the time of birth and for the first 4–6* weeks of life to help prevent them from becoming HIV-infected:
  - If the mother is on an **ARV prophylaxis** regimen that is stopped at delivery or 7 days postpartum and…
    - **She is <u>breastfeeding</u>:** then baby will take once daily NVP from birth until 1 week after all exposure to breast milk has ended
    - **She is <u>formula feeding</u>:** then baby will take once daily NVP or sd-NVP + twice-daily AZT* from birth until 4–6* weeks of age
  - If the mother is on **ART or triple ARV prophylaxis that will be continued postpartum,** her baby will take once daily NVP or twice daily AZT* for the first 4–6* weeks of life
- Either the mother or the baby needs to take ARV prophylaxis for the **entire time the baby is breastfeeding and should stop 1 week after cessation of breastfeeding**. This helps protect the baby from getting HIV during breastfeeding.
- HIV-exposed babies need to have HIV virological testing at 4–6 weeks of age or as soon as possible thereafter. Babies who test HIV-positive and who are under the age of 12 months** should begin ART as soon as possible.
- HIV-exposed babies need to take CTX starting at 4–6 weeks of age to prevent other infections that may make them very sick or lead to a rapid death. Babies should take CTX until it is certain they are not HIV-infected.

* The actual regimen (whether NVP or AZT) and duration of regimen (whether 4 weeks or 6) is stated in the national PMTCT guidelines.

** Some countries recommend automatically starting ART in all children who test HIV-positive and are under the age of 24 months.

Challenges Adolescents May Face with PMTCT

Pregnant adolescents and new adolescent mothers (and **their** partners) face many of the same challenges adults face with PMTCT. However, health workers should keep in mind particular challenges that could constitute barriers to adolescent clients in PMTCT programs, including:

- Difficulty adhering to ART or ARV prophylaxis
- Difficulty giving the baby medicines every day
- Challenges with safe infant feeding, especially exclusive breastfeeding for the first 6 months of life
- Fears about having a baby who is HIV-infected and guilt about possibly passing HIV to the baby
- Facing stigma for having HIV and becoming pregnant — and for being pregnant at a young age (especially if unmarried)
- Difficulty foreseeing the future adhering to lifelong HIV care while also caring for a child
- Lack of emotional and financial support from family and/or the child's father
- Financial instability and the possibility of dropping out of school
- Inadvertent disclosure of HIV-status to others
- Lack of access to youth-friendly PMTCT information and services

Safety of ARVs during pregnancy

Pregnant adolescents should be reassured that, with the possible exception of EFV, ARVs are safe to use during pregnancy. The benefits of using ARVs far outweigh the risks of not initiating ART.

Exercise 1: Providing Family Planning and PMTCT Services to Adolescent Clients: Case studies, role play, and large group discussion

Purpose	To provide participants with an opportunity to discuss and role play strategies to provide ALHIV with childbearing, contraceptive, and PMTCT information, counseling, and services

Case Study 1:
P___ is a 19-year-old young man who comes to the ART clinic regularly. You learn from one of the Adolescent Peer Educators at your clinic that P___ has been bragging that he has been with "about 10 women" but never uses condoms because they are “good girls” who don’t insist on using them. When you offer him some condoms at the end of his next appointment, he says he doesn’t need them. He says that he has a steady girlfriend now because he is feeling pressure from family to "get serious." *How do you proceed with P___?*

Case Study 2:
K___ is a 17-year-old young woman living with HIV. She is on ART and is doing very well. She has a boyfriend who knows about her HIV-status and who is accepting of it. K___ used to take oral contraceptives, but stopped taking them recently because she said they made her feel nauseous and gain weight. Now K___ and her boyfriend usually use condoms, but they have had sex a few times without them. K___ 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. K___ 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 K___?*

Case Study 3:
Z___ is a 21-year-old woman who has been living with HIV since she was 16. She has been in a stable relationship with R___ since she was 18. R___ is also living with HIV. Although Z___ attends the adult ART clinic now, she comes back every now and again to visit you, the health worker, at the adolescent clinic. Today you get the feeling that there’s something she wants to talk about so you invite her into the counseling room. You ask her how she’s doing and then ask her about R___. After some small talk, she finally tells you that she and R___ have decided that they would like to have a baby. After asking her some more questions, you realize that she is very serious about this and you agree that this was a mature, well-thought through decision that the two of them made together. *How would you proceed with Z___?*

Case Study 4:
E___ 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 checkup and, during the visit, she tells you that she thinks 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 — who is not infected with HIV — told her to stop taking them so they wouldn’t hurt the baby. *How would you proceed with E___? (Assume her pregnancy test is positive.)*

Module 11: Key Points

- Given the risks of adolescent pregnancy, it is important that health workers counsel their young clients to delay childbearing, if possible, until they are adults and to use contraceptive methods if they are sexually active.
- Health workers can provide adolescent clients with counseling on the safest times to become pregnant, such as when they have reached physical adulthood, when their CD4 cell count is high (above 500), when they are well, and when they are stable on and adhering to ART.
- Good education and counseling both before and at the time a contraceptive method is selected can help adolescents make informed, voluntary decisions that they are more likely to adhere to in the long term. Counseling should always include a discussion of side effects.
- The following contraceptive 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 whether they will be used for dual protection.
- Ensure that all adolescent clients know about emergency contraceptive pills, including where they can get them and when they should be used.
- Provide counseling on PMTCT and refer all pregnant ALHIV to the ANC clinic for PMTCT services (if they cannot be provided directly in the adolescent HIV clinic).
- Pregnant adolescents should be reassured that, with the possible exception of EFV, ARVs are safe to use during pregnancy.
- The aim of PMTCT services is to reduce the risk that a pregnant woman will transmit HIV to her baby during pregnancy, labor, delivery, or breastfeeding.
- PMTCT services include care, treatment, and support for mothers with HIV, including ARVs for the mother; safer infant feeding information, counseling, and support; ARVs for the infant; and infant testing.

Appendix 11A: Family Planning Screening Questions and Counseling Points

Family Planning Screening Tool

ART ID#: ________________________ On HAART: ☐ YES ☐ NO Date of Visit: ____/____/_____

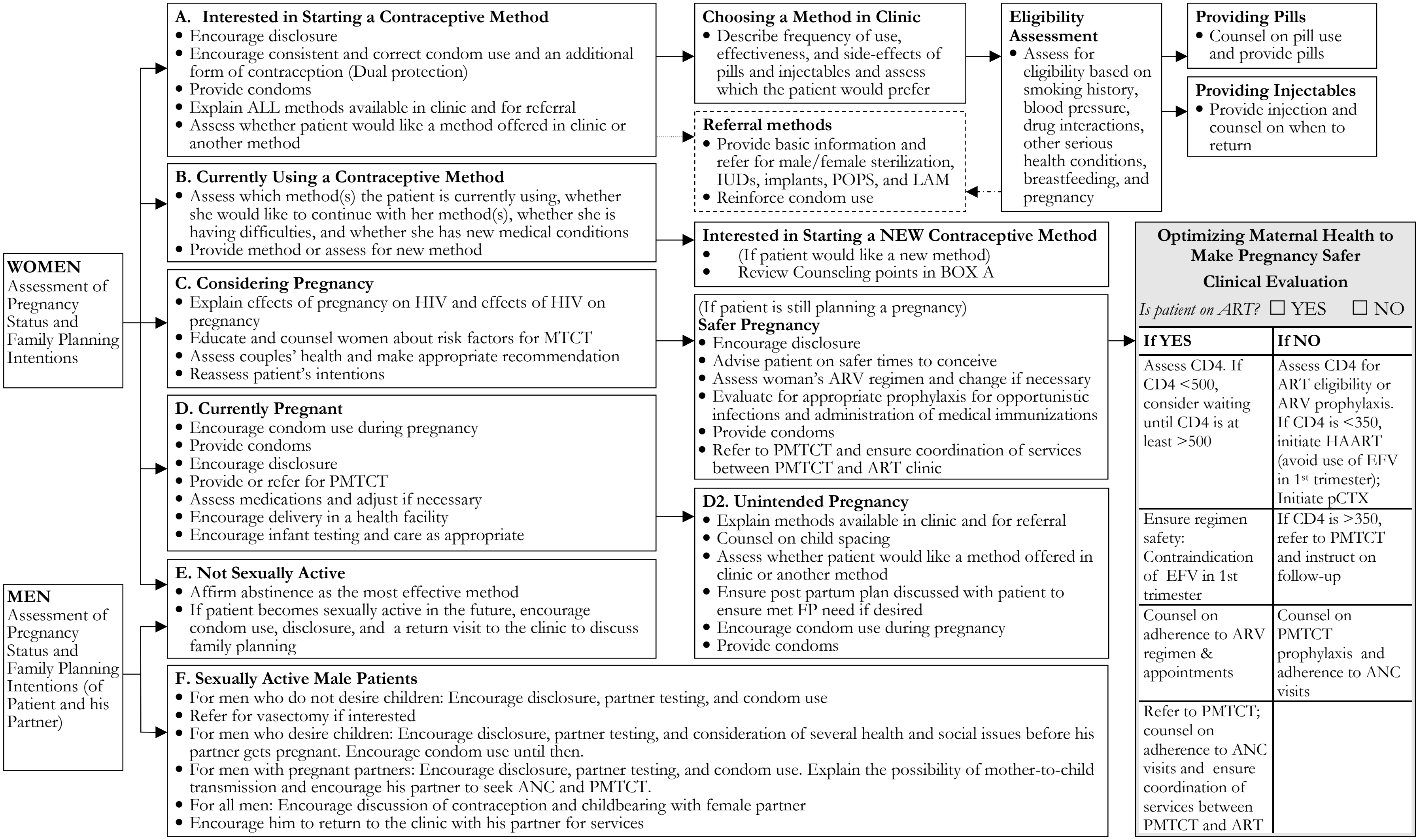
Gender: ☐ Male ☐ Female → *If female, Date of Last Menstrual Period (LMP) (dd/mm/yy):* ____/____/_____

INSTRUCTIONS:

- **For Females:** Assess pregnancy status and pregnancy intentions at every visit. Depending on patient's pregnancy status and intentions, you will provide contraceptive services or referrals, or advise on the safest times and ways to become pregnant.
- **For Males:** Ask about pregnancy status of their partners and about their and their partner's pregnancy intentions. Encourage male clients to discuss contraception with their partners and, when possible, recommend couple to come to clinic for couples counseling around family planning.

1. Are you sexually active? ☐ **Yes** ☐ **No**	**2. Are you (or your partner) pregnant or could you (or your partner) be pregnant?** ☐ **Yes** ☐ **No**	**3. Do you (and/or your partner) desire to have a baby in the next 6 months?** ☐ **Yes** ☐ **No**	**4. Are you (and/or your partner) currently using a modern method of contraception?** ☐ **Yes** ☐ **No**	**5. Conclusion**
If YES → Go to Question 2.	**If NO** → Go to Question 3. **If Don't Know** → Go to Question 3. **If YES** → Was this an intended pregnancy? ☐ **Yes** →Tick **"(a)"** in column 5 **Action:** Review counseling points **D&D2;** Refer to PMTCT. STOP **questionnaire** ☐ **No** →Tick **"(b)"** in column 5 **Action:** Review counseling points **D&D2;** Refer to PMTCT. STOP **questionnaire**	**If NO** → Go to Question 4. **If Don't Know** → Go to Question 4. **If YES** → Tick **"(a)"** & **"(d)"** in column 5 **Action:** Review counseling point **C.** STOP **questionnaire**	**If NO** → If not using a FP method but want to delay or prevent a future pregnancy, can you tell me why are you not using a method? (Do not read response categories) a) Cannot get pregnant – tick **"(a)"** in column 5 b) Menopausal – tick **"(a)"** c) Has had hysterectomy – tick **"(a)"** d) No sex – tick **"(a)"** e) If none of the above answers mentioned — tick **"(b)"** **Action:** Review counseling point **A.** STOP **questionnaire** **If YES** → Tick **"(c)"** in column 5. Which methods are you using? (do not read options out loud): a) Female sterilization b) Male sterilization c) Pill d) IUD e) Injectables f) Implants g) Condom h) Female condom i) Diaphragm j) Foam/jelly k) Lactational amenorrhoea method l) Rhythm method m) Withdrawal n) Other _______________ Are you comfortable with your current FP method: ☐ **Yes** ☐ **No** **Action:** Review counseling point **B.** STOP **questionnaire**	☐ **(a) No current FP Need** ☐ **(b) Unmet FP Need** ☐ **(c) Met FP Need** ☐ **(d) Pregnancy intention** *Met need is defined as women that are at risk for pregnancy and wanting to space or limit their childbearing who are currently using a modern method of contraception.* *Unmet need is defined as women that are at risk for pregnancy and wanting to space or limit their childbearing who are not using modern method of contraception.*
If NO → Tick **"(a)"** in column 5. **Action:** Review counseling point **E.** STOP **questionnaire**				

Family Planning Counseling Points



WOMEN
Assessment of Pregnancy Status and Family Planning Intentions

MEN
Assessment of Pregnancy Status and Family Planning Intentions (of Patient and his Partner)

A. Interested in Starting a Contraceptive Method
- Encourage disclosure
- Encourage consistent and correct condom use and an additional form of contraception (Dual protection)
- Provide condoms
- Explain ALL methods available in clinic and for referral
- Assess whether patient would like a method offered in clinic or another method

B. Currently Using a Contraceptive Method
- Assess which method(s) the patient is currently using, whether she would like to continue with her method(s), whether she is having difficulties, and whether she has new medical conditions
- Provide method or assess for new method

C. Considering Pregnancy
- Explain effects of pregnancy on HIV and effects of HIV on pregnancy
- Educate and counsel women about risk factors for MTCT
- Assess couples' health and make appropriate recommendation
- Reassess patient's intentions

D. Currently Pregnant
- Encourage condom use during pregnancy
- Provide condoms
- Encourage disclosure
- Provide or refer for PMTCT
- Assess medications and adjust if necessary
- Encourage delivery in a health facility
- Encourage infant testing and care as appropriate

E. Not Sexually Active
- Affirm abstinence as the most effective method
- If patient becomes sexually active in the future, encourage condom use, disclosure, and a return visit to the clinic to discuss family planning

F. Sexually Active Male Patients
- For men who do not desire children: Encourage disclosure, partner testing, and condom use
- Refer for vasectomy if interested
- For men who desire children: Encourage disclosure, partner testing, and consideration of several health and social issues before his partner gets pregnant. Encourage condom use until then.
- For men with pregnant partners: Encourage disclosure, partner testing, and condom use. Explain the possibility of mother-to-child transmission and encourage his partner to seek ANC and PMTCT.
- For all men: Encourage discussion of contraception and childbearing with female partner
- Encourage him to return to the clinic with his partner for services

Choosing a Method in Clinic
- Describe frequency of use, effectiveness, and side-effects of pills and injectables and assess which the patient would prefer

Referral methods
- Provide basic information and refer for male/female sterilization, IUDs, implants, POPS, and LAM
- Reinforce condom use

Eligibility Assessment
- Assess for eligibility based on smoking history, blood pressure, drug interactions, other serious health conditions, breastfeeding, and pregnancy

Providing Pills
- Counsel on pill use and provide pills

Providing Injectables
- Provide injection and counsel on when to return

Interested in Starting a NEW Contraceptive Method
- (If patient would like a new method)
- Review Counseling points in BOX A

(If patient is still planning a pregnancy)
Safer Pregnancy
- Encourage disclosure
- Advise patient on safer times to conceive
- Assess woman's ARV regimen and change if necessary
- Evaluate for appropriate prophylaxis for opportunistic infections and administration of medical immunizations
- Provide condoms
- Refer to PMTCT and ensure coordination of services between PMTCT and ART clinic

D2. Unintended Pregnancy
- Explain methods available in clinic and for referral
- Counsel on child spacing
- Assess whether patient would like a method offered in clinic or another method
- Ensure post partum plan discussed with patient to ensure met FP need if desired
- Encourage condom use during pregnancy
- Provide condoms

Optimizing Maternal Health to Make Pregnancy Safer

Clinical Evaluation

Is patient on ART? ☐ YES ☐ NO

If YES	**If NO**
Assess CD4. If CD4 <500, consider waiting until CD4 is at least >500	Assess CD4 for ART eligibility or ARV prophylaxis. If CD4 is <350, initiate HAART (avoid use of EFV in 1st trimester); Initiate pCTX
Ensure regimen safety: Contraindication of EFV in 1st trimester	If CD4 is >350, refer to PMTCT and instruct on follow-up
Counsel on adherence to ARV regimen & appointments	Counsel on PMTCT prophylaxis and adherence to ANC visits
Refer to PMTCT; counsel on adherence to ANC visits and ensure coordination of services between PMTCT and ART	

Flow Chart Adapted from: CDC. (2008). *Family planning and safer pregnancy counseling for people living with HIV/AIDS: A tool for health care providers in HIV care and treatment settings.*

Appendix 11B: Family Planning Considerations for People Living with HIV

(Including contraindications with ARVs and common opportunistic infection drugs)

Essential Principles of FP Counseling in HIV Services:	Key Messages for FP Counseling in HIV Services:
• Every HCT, ART, and PMTCT client should be assessed for FP need. • Quality FP counseling and services should reinforce clients' ability to limit HIV transmission to HIV-negative partners and infants. • HCT, ART, and PMTCT clients have the right to make their own FP choice, including safer pregnancy for HIV-positive women (using risk reduction measures like ARVs and exclusive breastfeeding), if desired.	• Dual method use — using condoms and a contraceptive method for good protection from infection and unintended pregnancy — should be included in FP counseling for clients living with HIV. • Generally, HIV-positive clients can use most contraceptive methods (even if on ART).

	HIV-Related Treatments and Conditions								
	NNRTIs		NRTIs (AZT, D4T, 3TC, ABC, TDF)	Ritonavir or Ritonavir-Boosted Protease Inhibitors	Rifampicin (common for TB)	Certain Anti-Convulsants (Carbamazepine, Phenytoin, Barbituates)	Systemic Anti-Fungals (Azoles)	Untreated Chlamydia and/or Gonorrhea	Clinical AIDS/not doing well on ART
FP Options	**NVP**	**EFV**							
Male/Female Condoms									
COCs	▨	▨		X	X	X			
POPs	▨	▨		X	X	X			
Implants	▨	▨		▨	▨	▨			
EC									
DMPA Injectables									
NET-EN Injectables	▨	▨		▨	▨	▨			
IUD Insertion								X	X
Tubal Ligation									▨
Vasectomy									▨
Natural Family Planning									
Fertility Awareness									
Client Desires Safer Pregnancy		X				X	X	X	X

Legend:

☐	Method appropriate for client; No reservation of drug interaction
▨	Possible reduced contraceptive effect or increased side effects of hormonal method; Recommend dual method use with condoms and perfect use of method
X	Do not use the method

Adapted from: Pathfinder International. *FP/HIV Integration provider reference tool: Family planning considerations specific to HIV-positive clients.* Watertown, MA: Pathfinder International.

Appendix 11C: Survey of Family Planning Methods for Adolescents

Barrier Methods

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 and some people (more often men than women) report diminished sensation when using condoms during sex.
- Condom use does not interfere with medications and there are no common side effects for male or female condoms unless a person is allergic to latex.

- **Special considerations for adolescent clients:** Male and female condoms are safe and appropriate for ALHIV. They are a good method for adolescents because condoms are available without a prescription and are the only method that offers dual protection. It is important that condoms are always available to adolescents for free and without having to ask an adult for them. Adolescents require skill development and practice to learn how to use condoms and to 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 counseling and peer support to feel empowered to negotiate condom use and to 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.

- **Counseling adolescent clients about condoms:** Always demonstrate, step-by-step, how condoms are used and explain how to dispose of them correctly. Tell clients to return to the clinic if there is any problem, if 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 adolescent clients to repeat the instructions back to you so you can check their understanding.

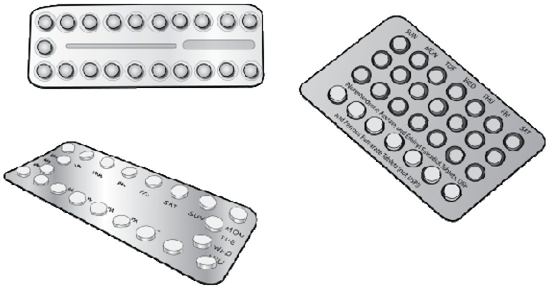
Spermicides and diaphragms with spermicides:

- These methods are NOT recommended for adolescents or adults living with HIV because they may increase the risk of HIV transmission.

Hormonal Methods

Hormonal contraceptives, including combined oral contraceptives (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 non-contraceptive health benefits.

COCs and POPs:



- These are pills that a woman takes once a day to prevent pregnancy.
- They contain the hormones estrogen and progestin (in the case of COCs) and progestin only (in the case of POPs).
- Both types are very effective at preventing pregnancy when taken on schedule.
- **Special considerations for adolescent clients:** Low-dose COCs are appropriate and safe for ALHIV. Many adolescents choose to use a type of COCs because of the low failure rate, the 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 the pills. Health workers should stress that COCs can prevent pregnancy but that they should always be used in combination with condoms to provide STI/HIV protection. Health workers can help adolescent clients decide where to 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 28-day regimens because it makes it 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 estrogen and should be counseled about the importance of taking COCs on time every day (without missing pills) and about consistent condom use.

  POPs are also safe for adolescents, but since they must be taken at exactly the same time every day to be effective, 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.

- **Counseling adolescent clients about oral contraceptive pills:** The most important counseling issue is to make sure adolescents understand the importance of taking the pills correctly. Show the client the pill packet and explain in detail when to start taking the pills and how to take them. Explain that if she forgets to take her pills, she may become pregnant. Instruct her on what to do if she misses pills (for example, if she misses one, to take it as soon as she remembers and, if she misses 2, to take 2 pills as soon as she remembers and to use a back-up method, etc.). Always review possible side effects, including that breakthrough bleeding may be common during the first cycles, but that it is not a reason to stop taking the pills. Like with ARVs, the client should be encouraged to talk with a health worker about any side effects (nausea, weight gain, breast tenderness, headaches, spotting, etc.) and should be told that these will usually decrease over time. Review the times when she should return to the clinic, including if she thinks she may be pregnant or if she has chest pain, shortness of breath, severe headaches with blurred vision, or swelling/severe leg pain. Make sure the client understands when to come back for re-supply and that she should not wait until she is out of pills (just like with ARVs). Always ask the client to repeat information back to you so you can check her understanding and always promote dual protection with male or female condoms.

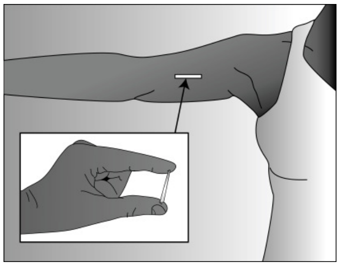
Injectables:

- Progestin-only injectable contraceptives, such as Nur-Isterate and Depo-Provera (depot medroxyprogesterone acetate, aka DMPA or '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 and then amenorrhea and weight gain.
- Injectables do not offer protection from STIs/HIV, so they should always be used with male or female condoms.

- **Special considerations for adolescent clients:** Injectables are safe and appropriate for adolescents. Many adolescents like this method because they do not 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 next injection and, ideally, this can be combined with their routine HIV care appointments.

- **Counseling adolescent clients about injectables:** Health 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 they 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 they continue on this method. Some women may also experience weight gain or headaches. Health 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 clients repeat this information back to you to check their understanding. As with all hormonal methods, health workers should recommend and provide condoms for dual protection.

Hormonal implants:

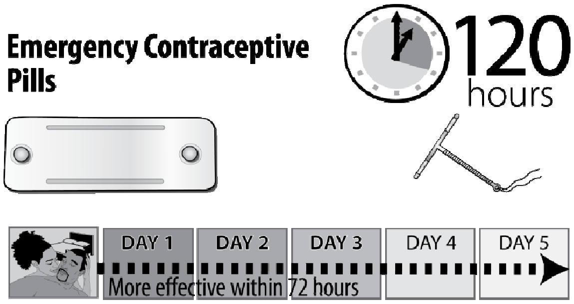


- Progestin-only implants (e.g., Implanon, Norplant) consist of hormone-filled, matchstick-like rods that are inserted under the skin in a woman's upper arm. Depending on the type of implant, there may be only 1 rod or as many as 6 rods.
- Hormonal implants can prevent pregnancy for between 3–7 years, depending on the type.
- Highly effective at preventing pregnancy, implants are a long-term contraceptive method that can easily be 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 case the effectiveness of the implants is reduced by the ARVs.
- Side effects of implants may include nausea, weight gain, and changes in monthly bleeding. As with all hormonal methods, women should be encouraged to use condoms for dual protection.

- **Special considerations for adolescent clients:** Hormonal implants are safe for adolescents. The main reason adolescents discontinue their use of implants is irregular bleeding, so it is important that health workers counsel clients to prepare them for this potential side effect. Programs must ensure that adolescents have access to services to remove the implants whenever they need or want them to be removed.

- **Counseling adolescent clients about implants:** Health 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 counseled on care of the insertion area and the possibility of bruising or swelling after insertion. Adolescents should know where to go if they have problems or questions, or if they want the implants removed. Health workers should give clients information on common side effects and on serious side effects 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):



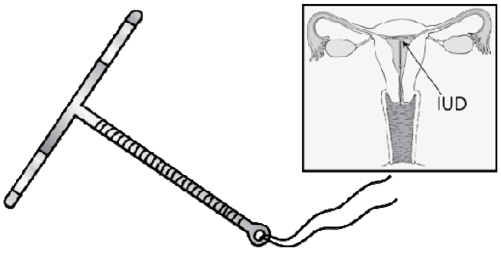
- ECP are used to prevent pregnancy after unprotected sex.
- ECP can be used if no contraceptive method was used during sex or if a contraceptive method failed, for example, if a condom broke.
- ECP should be taken as soon as possible after unprotected sex (although it can be taken up to 120 hours after sex).
- When used correctly and in a timely fashion, ECP can reduce the risk of pregnancy by 75%.
- ECP are usually a combination of oral contraceptives, taken in 2 doses.
- ECP do not cause an abortion, they prevent an egg from implanting in the uterine wall.
- ECP are 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 counseled on adopting a regular contraceptive method and on condom use for dual protection.

- **Special considerations for adolescent clients:** 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 ECP are taken after unprotected sex, the more effective they will be in preventing pregnancy. ECP can be provided in advance to adolescents who are at high-risk of unprotected sex, but these clients should be counseled that ECP are for emergency use only. ECP do not provide dual protection and all adolescents using ECP should be counseled on more effective contraceptive methods and condom use for dual protection.

- **Counseling adolescent clients on ECP:** Health workers should explain how ECP work and how the client should take them (for example, the first dose should be taken as soon as possible after unprotected sex, up to 120 hours afterward, and 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. Health workers should review what adolescents can expect after taking ECP — 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 she expected it, she should return to the clinic because she could be pregnant.

Long-term and Permanent Methods

Intra-uterine devices (IUDs):



- This small device, which is 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.
- IUDs that release hormones are becoming more widely available. These IUDs work differently than the copper IUD and may cause side effects different from those listed below.
- 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.

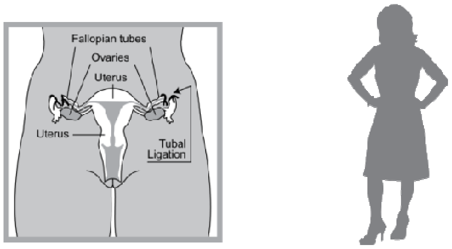
- **Special considerations for adolescent clients:** IUDs are appropriate for adolescents in stable, mutually monogamous relationships. Careful screening for STIs before insertion is critical and IUDs are not recommended for ALHIV with advanced HIV disease or AIDS (especially if they are not on ART).

- **Counseling adolescent clients 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. Health workers may have to refer adolescent clients for IUD insertion, but they should provide counseling and follow up within the HIV clinic. It is important that adolescent clients understand how the IUD works and how to check for the strings. Health workers should explain side effects, including cramping and pain after insertion, a 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, but 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. Ask the client to repeat this information back to you so you can check her understanding. It is very important that clients using an IUD use condoms to prevent STIs, which can cause infection and complications.

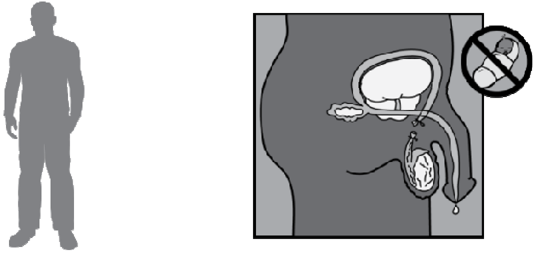
Male and female sterilization

- These permanent methods are not usually recommended for adolescents, who may change their mind about wanting to have children in the future.
- Some ALHIV may request sterilization, in which case counseling should be provided and all options explored.

Female Sterilization (Tubal Ligation)



Vasectomy (Male)



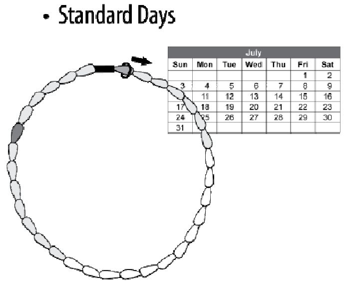
Traditional and Other Methods

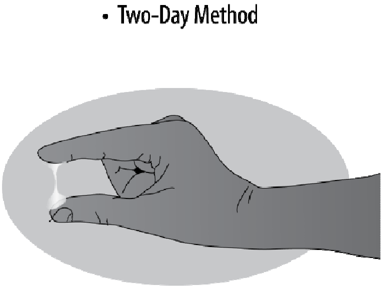
Natural methods do not require any materials (for example, the withdrawal method or a woman learning to recognize when she is fertile and agreeing with her partner to avoid sex during that time). In general, natural methods are not as effective in preventing pregnancy as "modern" methods. In some places, there are also **traditional methods**. These mostly include using traditional herbs to prevent pregnancy. They are not reliable because the dosage is not controlled and their effectiveness has not been 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 period has not yet returned.
- Any clients practicing 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 the time identified.
- To do so, she can observe fertility signs like 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 during fertile days.
- 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.

Illustrations courtesy of: Karen A. Forgash, François-Xavier Bagnoud Center, School of Nursing, University of Medicine and Dentistry of New Jersey. (2011).

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[5] WHO. (2010). *Antiretroviral therapy for HIV infection in adults and adolescents: Recommendations for a public health approach.*

[6] See also: Panel on Antiretroviral Guidelines for Adults and Adolescents. U.S. Department of Health and Human Services. (October 14, 2011). *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.* "Table 15a. Drug Interactions between PIs* and Other Drugs," page 135. Available at: http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf.

Module 12 Community Linkages and Adolescent Involvement

Session 12.1: **The Importance of Facility-Community Linkages**
Session 12.2: **Creating a Community Resource Directory**
Session 12.3: **Adolescent Participation and Peer Education Programs**

Learning Objectives

After completing this module, participants will be able to:

- Discuss common challenges to creating strong facility-community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
- 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 behind meaningful adolescent involvement and describe effective strategies of involving adolescents in service delivery
- Understand the key components of implementing a successful Adolescent Peer Education program

Session 12.1 The Importance of Facility-Community Linkages

Session Objectives

After completing this session, participants will be able to:

- Discuss common challenges to creating strong facility-community linkages in support of ALHIV and their caregivers, and strategies to overcome these challenges
- Describe community-based support services that ALHIV and their caregivers may need

Improving Facility-Community Linkages

Challenges to establishing facility-community linkages

Some key challenges to establishing facility-community linkages include:

- Health workers may not be aware of community-based services or there may be no mechanism to exchange information or to formalize two-way referrals.
- Community organizations and leaders may not be aware of adolescent HIV services at the health facility.
- Teachers may not be familiar with HIV or the needs of ALHIV.
- Community organizations and leaders may not trust facility-based services or they may prefer traditional medicine/healing.
- There may not be any community services specifically for ALHIV.
- Adolescents may get treated poorly when they go to the health facility and this type of information spreads among members of 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 improve facility-community linkages

Strategies to improve facility-community linkages and to develop a more coordinated and collaborative approach to ALHIV service delivery include:

- Learn what community organizations and services are available in the areas where adolescent clients live (and where they go to school or work). Make an appointment and go to these organizations. Meet with the staff to find out what services they offer, to discuss the services offered at your facility, and to set up formal or informal "two-way" referral systems. This means that the health facility can refer adolescents to the community organization and the community organization can refer adolescent clients to the health facility. Invite representatives of the organization to visit the health facility for an informal meeting or a formal tour and "open house."
- Facilitate regular (for example, monthly or quarterly) meetings that include health facility managers and staff, the staff of community-based youth groups, Adolescent Peer Educators, PLHIV associations, community health workers, school teachers/headmasters, teachers, and others. The meetings should aim to share insights and information about the special needs of ALHIV, about the services available at health facilities and in the community, and about how to facilitate interagency linkages and referrals.
- Meet with community leaders to talk with them about ALHIV and the importance of HIV care and treatment services. Also try to clarify common myths about HIV, ALHIV, and ARVs.
- Participate in community meetings and community gatherings to discuss HIV, ALHIV, and HIV care and treatment.
- Train/orient existing community-based Peer Educators, youth group members and leaders, and community health workers to identify adolescents in the community 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 health workers and youth outreach 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 in strengthening facility-community linkages; for example, by starting an Adolescent Peer Education program (see Session 12.3).

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 adolescence) and associations
- Disclosure support (for both caregivers and adolescents)
- Nutritional and food support
- Spiritual guidance and support
- Transportation to get to the clinic
- Education and counseling 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, help with school fees/tuition) and life skills training
- Job preparation and placement
- Income-generating activities and savings and loan programs
- Home-based care
- Home-based adherence support
- Home-based infant feeding support
- Legal advice and support
- Others…

Continuum of care

Remember: no single person or organization 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 within the health facility, in the community, and at home.

Session 12.2 Creating a Community Resource Directory

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

In order to provide effective referrals, health 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 12A: Community Resource Directory Template)*. This makes it easier to refer clients to needed services.
- Each facility should have an up-to-date community resource directory and established, formal two-way referral systems to and from these organizations and services. The resource directory should include days/times services are offered, fees, documentation required at the initial visit, address, phone number, contact person, etc. The community resource directory should be posted in the clinic waiting room and should also be available in all of the examination and counseling rooms for easy reference.
- Health workers can also work together with youth (for example, Adolescent Peer Educators) to map available resources in the community for ALHIV and their families. They can then 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 changes in personnel, addresses, phone numbers, etc. It is a good idea for one person to be responsible for keeping up to date with these changes and adjusting the directory accordingly.

Exercise 1: Creating a Community Resource Directory: Small group work and large group discussion	
Purpose	To provide an opportunity for participants to brainstorm and create their own resource directory
Refer to *Appendix 12A: Community Resource Directory Template.*	

Session 12.3 Adolescent Participation and Peer Education Programs

Session Objectives

After completing this session, participants will be able to:

- Describe the rationale behind meaningful adolescent involvement and describe effective strategies of involving adolescents in service delivery
- Understand the key components of implementing a successful Adolescent Peer Education program

Adolescent Involvement[1,2]

The meaningful involvement of PLHIV and affected communities in service delivery contributes powerfully 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 programs 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 are:

- The engagement of ALHIV as Adolescent Peer Educators
- The establishment of ALHIV consumer (or community or client) advisory boards (CABs)

Both are discussed below.

Adolescent Peer Educators

Adolescent Peer Educators can complement the work of health workers and they play an important role in improving client adherence and service quality. Adolescent peer education offers many benefits to HIV care and treatment programs, including:

A safe environment:

- People trust others in similar situations. Adolescent Peer Educators provide ALHIV with the opportunity to discuss their personal circumstances in a safe environment, with someone who can relate to their situation.

Improved retention in care and adherence to treatment:

- Adolescent Peer Educators can support clients' retention in care and adherence to treatment because they are likely to have a deep understanding of the challenges faced by ALHIV as well as practical solutions to those challenges.
- Youth involvement and the availability of Adolescent Peer Educators often make HIV care and treatment services more attractive to adolescents, thus improving their retention in care.

Improved linkages:

- Adolescent Peer Educators can draw on their own knowledge and experiences to help other ALHIV navigate health facilities and to strengthen linkages between the clinic and community-based services.

Increased positive living:

- Building on their own experiences, Adolescent Peer Educators can serve as role models to encourage positive living and positive prevention.
- Peer Educator Programs can empower and create positive changes in the lives of the Adolescent Peer Educators themselves, they can help decrease stigma and discrimination against ALHIV in the community, and they can encourage other adolescents in the community to access HIV services.

Improved service quality:

- Adolescent Peer Educators can help programs become more youth-friendly. They can also help identify and address program barriers to reaching young people.
- Adolescent Peer Educators are in a unique position to contribute to quality assurance activities, making suggestions based on their own experiences as clients in the program and based on feedback solicited from their peers.
- Adolescent Peer Educators can make services more accessible to youth by helping to plan and facilitate peer support groups and activities, including art, drama, music, sports, and other youth-friendly activities.

Increased community participation and advocacy:

- Adolescent Peer Educators can play a role in community mobilization by serving as positive role models, by decreasing stigma, and by increasing support for ALHIV.

Job opportunities:

- The training and work experience that comes with the Adolescent Peer Educator job prepares adolescents for future job opportunities in the formal economic sector.

Increased access to services:

- When young people such as Adolescent Peer Educators conduct outreach and advocacy work in their communities, more adolescents are reached with information about clinical services.
- Adolescent Peer Educators can play a role in identifying and reaching most-at-risk adolescents in their communities.

A closer sense of connection for adolescent clients:

- Young people are a vital source of information about youth needs.
- Programs that utilize youth staff tend to address young clients' needs and concerns more sensitively and accurately than programs that do not.
- Adolescent Peer Educators may hear of client challenges or successes that have not come to the attention of other team members.
- Young people often speak the "same language" and Adolescent Peer Educators can help explain things in terms and language that their peers will understand (instead of using, for example, explaining things using formal or clinical language).

Client/Consumer/Community Advisory Boards (CABs)

Some health care programs may be interested in establishing a formal mechanism to facilitate feedback from clients through the establishment of a CAB (client/consumer/ community advisory board). CABs are autonomous bodies that advise the clinic on service quality and gaps in care. They also make recommendations on how to improve service provision. CABs:

- Include 5–20 members. 7–9 is typical, most or all of whom are clients or caregivers. Members should represent a wide range of the clients served by the clinic.
- Typically meet every other week at first and monthly once established
- Have a direct line of communication with clinic management. Typically, a clinic manager attends every meeting.
- Are guided by a set of by-laws developed by members and approved by the clinic they advise

Avoid Tokenism

Adolescents should be recognized, integrated, and supported as the vital human resource they are. Tokenism is NOT the same as 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 their skills and capacity.
- Asking youth their opinions but not taking these opinions seriously or incorporating them into program decisions or planning
- Assigning tasks to youth that adults do not want to do, like filing or cleaning

Ensure Expectations Are Appropriate

Remember: health facilities should always use a developmental approach when involving adolescents in program delivery:

- Keep expectations and assigned responsibilities and tasks realistic. Expectations should always match adolescents' developmental capacity and responsibilities should always be appropriate for their age and ability. For example, an Adolescent Peer Educator should not be expected to provide professional-level counseling or mental health screening and management.
- Provide follow-up training and ongoing mentoring and supervision. If Adolescent Peer Educators are not well trained, this will compromise the quality and effectiveness of their work. Adolescent Peer Educators also need ongoing support, mentoring, and supervision. They need an experienced supervisor to:
  - Observe their work frequently at first and regularly thereafter (for example, weekly progressing to monthly) and to provide constructive feedback. The supervisor should observe both one-to-one interactions as well as those in a support group setting.
  - Provide 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 Adolescent Peer Educators may need extra support.
  - Answer questions.
  - Not "look over their shoulder," as this can undermine their self-confidence and the confidence of clients in their work.
- It is important to make the boundaries very clear to Adolescent Peer Educators and CAB members, and to enforce them in a transparent way. Make sure that the program has explicit policies and rules for addressing what is appropriate and inappropriate behavior and make sure that Adolescent Peer Educators are appropriately supervised and supported to adhere to these policies.

Key Steps to Implementing a Facility-based Adolescent Peer Education Program

Before implementing an Adolescent Peer Education program, it is important to consider how Adolescent Peer Educators will function within the existing program framework. In other words, how will Adolescent Peer Educators assist other adolescent clients and how will they become part of the multidisciplinary team as a whole? Neglecting to consider these factors can result in unclear job descriptions, mismatched expectations, poor peer performance, and, ultimately, compromised client service.

Table 12.1: Key steps to implement an effective Adolescent Peer Educator Program[1, 2]

Step	Description
1.	**Conduct a participatory situational analysis and needs assessment:** Ask colleagues, adolescent clients, and caregivers how youth are currently involved, how they could be involved in the future, and how they are involved in planning, implementing, and evaluating services at other organizations.
2.	**Engage stakeholders in participatory program design:** Ask adolescents and their caregivers how they would like the peer involvement project structured. What should the Adolescent Peer Educators do? How should they be trained and managed? See *Appendix 12B: Template for Adolescent Peer Educator Job Description*.
3.	**Define program indicators, set targets, and develop tools:** Indicators and targets include: "To train 12 Adolescent Peer Educators by April 1, 2012" or "To engage 6 Adolescent Peer Educators by May 1, 2012." Tools might include supervisory tools, job descriptions (see *Appendix 12B*), personal criteria, etc.
4.	**Develop a detailed budget and workplan:** This budget and workplan should include the cost and activities involved in recruiting, training, and engaging Adolescent Peer Educators.
5.	**Recruit Adolescent Peer Educators, based on selection criteria** (see below for examples).
6.	**Adapt or develop an Adolescent Peer Educator training curriculum.**
7.	**Train Adolescent Peer Educators.** (Note: A useful, publically available curriculum exists to train Adolescent Peer Educators: *Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators*. See *Appendix 12C* and the "Resources" section at the beginning of this module for further information.)
8.	**Engage health facility teams to roll out peer education activities.**
9.	**Provide ongoing support, supervision, and mentoring** to Adolescent Peer Educators.
10.	**Continuously monitor, evaluate, and adjust the program.**

Peer Educator Selection, Roles, and Responsibilities

A sample job description for Adolescent Peer Educators is included in *Appendix 12B: Template for Adolescent Peer Educator Job Description.*

Sample selection criteria for Adolescent Peer Educators

Some suggested selected criteria for Peer Educators include:

- Is an older adolescent
- Is living positively with HIV
- Is adherent to care and medications
- Has an open-minded and non-judgmental attitude (for example, is respectful and tolerant of different perspectives, cultural backgrounds, and lifestyles)
- Has basic literacy and numeracy skills
- Has good interpersonal and oral communication skills
- Is committed to working with other ALHIV
- Demonstrates self-confidence
- Has the ability to be self-disciplined and to work both independently and as part of a team
- Has the availability to work at the clinic (in a way that does not conflict with school or work attendance)
- Represents the 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/or suggested by young people

For additional information on setting up and managing Peer Education programs and on training Adolescent Peer Educators, see *Appendix 12C: Resources for Peer Education Programs and CABs.*

For more information on starting or planning a peer support group, see *Appendix 5B: Starting/Planning a Peer Support Group.* For more information on facilitating a peer support group, see *Appendix 5C: Facilitating A Peer Support Group.*

For detailed materials that can be used to train Adolescent Peer Educators, refer to the publically-available *Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators.*

Module 12: 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, including organizing informal and formal meetings with community and youth group leaders; orienting community organizations 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 organizations working with PLHIV, ALHIV, and youth in general.
- Health workers should stay up-to-date on which services are available for ALHIV and their caregivers/families and should maintain a directory of these services to facilitate the making of referrals. This directory should then be shared with community organizations so that they also have a current list of the community- and health facility-based services for adolescents.
- PLHIV participation in all aspects of HIV programs is critical to ensure that programs are designed and implemented to meet client needs.
- Two important ways of including adolescents are through Adolescent Peer Education programs and through CABs.
- As ALHIV and service recipients themselves, Adolescent Peer Educators can give meaningful feedback to health care programs, offering insights into the best ways to retain young people in care and support their adherence to treatment.
- Adolescent peer education can be a powerful approach to improving the youth-friendliness and quality of adolescent HIV care and treatment services. However, such programs require careful planning, clear objectives, regular supervision, and good communication.

Appendix 12A: Community Resource Directory Template

DISTRICT NAME:___________________________ **FACILITY NAME:**___________________________ **DATE:** __________________________

NAME OF ORGANIZATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEORGAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
1.					
2.					
3.					
4.					
5.					
6.					
7.					

NAME OF ORGANIZATION	SERVICES PROVIDED FOR YOUTH/FAMILIES	GEORGAPHIC AREAS COVERED	CONTACT PERSON	PHONE NUMBER AND ADDRESS	OTHER*
8.					
9.					
10.					
11.					
12.					
13.					
14.					

* "Other" could include, for example, hours of opening, fees, documentation needed at the initial visit, information about how to get there (transportation, bus line, directions if difficult to find), etc.

Appendix 12B: Template for Adolescent Peer Educator Job Description

***SAMPLE* Adolescent Peer Educator Job description**

Adolescent Peer Educators are expected to (fill in/adapt as needed):

- Participate as active members of the multidisciplinary care team in the clinic, including attending required meetings and trainings
- Openly disclose their HIV-status to clients
- Help conduct/co-facilitate support groups and other psychosocial support activities for ALHIV (and caregivers/family members, when needed)
- Conduct peer education sessions with ALHIV and provide support on the following topics:
  - Basic information about HIV and HIV care and treatment
  - Retention in HIV care
  - Adherence to HIV treatment
  - Disclosure
  - Basic emotional and psychosocial support
  - Positive living and positive prevention
  - Safer sex
  - Others, as decided by the program
- Help ALHIV with referrals within the health facility
- Help link ALHIV with needed community support services
- Be positive living and adherence role models to other ALHIV
- 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 work at the clinic at least 2–3 days per week.
- Adolescent Peer Educators may, as needed, be expected to attend meetings or refresher trainings on weekends or during holidays — 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 they will receive the following incentives, supplies, and stipends: (fill in).

Appendix 12C: Resources for Peer Education Programs and CABs

ICAP. (2011). ***Positive voices, positive choices: A comprehensive training curriculum for Adolescent Peer Educators.*** This easy-to-use, youth-friendly curriculum was designed to train Adolescent Peer Educators to become active members of multidisciplinary HIV care teams in health facilities.

The training course consists of a Trainer Manual and an illustrated Participant Manual containing 15 Modules that can be adapted to a range of country, program, and organizational settings and that can be used to start, scale-up, or improve the involvement of ALHIV as Adolescent Peer Educators. Available at: http://www.columbia-icap.org/resources/peresources/index.html

ICAP. (2011). ***Comprehensive peer educator training curriculum. Version 2.0.*** To share lessons learned and experiences more widely, ICAP developed and has recently updated per the new WHO guidelines a set of generic Peer Educator materials that can be adapted by organizations and implementing partners wishing to start or scale-up peer education programs.

Training content areas were selected to prepare adult Peer Educators for integration into the multidisciplinary HIV care team and to 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 program 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 and 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 is meant to guide Ministries of Health, PLHIV Associations, or NGOs initiating or expanding facility-based Peer Education programs. It provides practical advice on planning, managing, and monitoring Peer Education programs. The appendices of the Manual also include a number of generic tools that can be adapted.

Available at: http://cumc.columbia.edu/dept/icap/resources/peresources/PE.html

FHI. (2005). ***Youth peer education toolkit.*** The Youth Peer Education Toolkit is a group of resources designed to help program managers and master trainers of Peer Educators. Collectively, these tools are meant to help develop and maintain effective Peer Education programs. 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 was the result of 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:

1. Training of Trainers Manual
2. Standards for Peer Education Programs
3. Theatre-Based Techniques for Youth Peer Education
4. Performance Improvement
5. Assessing the Quality of Youth Peer Education Programs

Available at: http://www.fhi.org/en/Youth/YouthNet/Publications/peeredtoolkit/index.htm

IMPAACT. (2007). ***IMPAACT community advisory board (ICAB) training curriculum: 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. Available at: https://impaactgroup.org/icab-trainer-manual

References

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[1] 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*. ICAP.

[2] Schley, A., Colton, T., Schoeneborn, A., and Abrams, E. (2011). *Positive voices, positive choices: A comprehensive training curriculum for Adolescent Peer Educators, Version 1.0*. ICAP.

Module 13 Supporting the Transition to Adult Care

Session 13.1:	**Key Considerations for Health Care Transition**
Session 13.2:	**Preparing and Empowering Adolescents to Transition into Adult Care**

Learning Objectives

After completing this module, participants will be able to:

- Understand the key considerations when transitioning a client from pediatric/adolescent care to adult care
- Prepare adolescents for and support them during the transition to adult care

Session 13.1 Key Considerations for Health Care Transition

Session Objective

After completing this session, participants will be able to:

- Understand the key considerations when transitioning a client from pediatric/adolescent care to adult care

Key Considerations for the Transition to Adult Care[1]

There are parallels between the maturation of adolescents into adults and the transition from pediatric to adult HIV programs. ALHIV may face challenges in their transition to adult care and in learning to independently manage their own care. These challenges affect both health workers in pediatric and adult clinics as well as adolescents and their caregivers.

The role of the health worker is to provide ALHIV and their caregivers with adequate support and to help ALHIV increase their capacity to manage their own care and to advocate for themselves in the clinical setting.

Goal of transition

The goal of transition is to ensure the provision of uninterrupted, coordinated, developmentally- and age-appropriate, and comprehensive care before, during, and after the transition.

Some key challenges for ALHIV during the transition process may include:

- **Balancing complicated care:** Adolescents have to manage multiple medications and appointments and must deal with many different health workers and health services.
- **Leaving a familiar care network:** Adolescent clients may feel reluctant to leave a familiar care setting, which often means losing contact with support networks and friends there. They may also be fearful and uncertain about how to manage a new clinic setting with new providers.
- **Psychosocial and developmental challenges:** Adolescents are coping with the typical changes, feelings, and worries of adolescence (which may include relationships, employment, education, etc.) and they may be struggling with disclosing their HIV-status to peers and family. Given the number of life changes happening all at once, adherence to ART and visits to the clinic may become less of a priority. Health 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, youth-friendly services for adolescents as well as an understanding of and appreciation for adolescents' needs and issues.

Transition is applicable to every ALHIV as they mature into adulthood — all adolescents require support both within and outside of the clinic setting to take greater ownership over their health care, behavior, lives, and adherence to care and treatment.

- The transition to adult care generally occurs in parallel with an adolescent's emotional and physical maturation into adulthood. Effective transition must allow for the fact that adolescents are undergoing changes that impact much more than just their clinical care. Adolescents' psychological maturation may be influenced by how and when they assume responsibility for their own care and vice versa.
- Health workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognizing their increasing maturation, capacity to make choices, and independence.
- Leading up to the transition, health workers should encourage ALHIV to develop as much independence as possible, both from their families and from health workers. This will help bridge the gap to adult services and help adolescents make informed decisions about their own care.
- Reaching the overall goal of helping adolescents achieve independent management of their own care is a gradual process and should, whenever possible, involve the caregivers and family.
- Some caregivers will need assistance understanding their changing role as the focus of care moves away from always having a caregiver present at appointments, and toward a confidential relationship between the adolescent and the health worker.

Note: Not every adolescent will be able to reach 100% independence from his or her caregivers. This is particularly true for adolescents who have moderate or severe developmental delays. In such cases, caregivers will likely need to stay involved in the adolescent's care after transition to the adult clinic. Pediatric/adolescent and adult clinics will need to consider special arrangements to accommodate developmentally or otherwise disabled clients.

Session 13.2 Preparing and Empowering Adolescents to Transition into Adult Care

Session Objective

After completing this session, participants will be able to:

- Prepare adolescents for and support them during the transition to adult care

Helping ALHIV Prepare for the Transition[1]

A successful transition involves a client-centered process and a developmental approach — it is not a one-time event. The following principles can help ensure a smooth transition from pediatric/adolescent to adult care programs:

- The health worker should begin the process early, working as a team with the adolescent client, his or her caregivers, and other members of the multidisciplinary team.
- The transition process should enhance the adolescent's 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 individualized and should consider each adolescent's developmental stage and readiness for transition.

There are many innovative strategies that health workers and programs can undertake to support transition. These may include:

- Orienting adult HIV providers on adolescent-friendly services and the needs of adolescent clients
- Bringing adult providers (nurses, counselors, etc.) to the pediatric/adolescent clinic for a joint weekly clinical session so that they can get to know more about adolescent clients and their unique needs (this is an especially helpful strategy when working with pregnant adolescents)
- Having a provider (doctor, nurse, counselor, etc.) from the pediatric/adolescent clinic attend the adult clinic on a regular basis for "transition sessions"

Health workers and Adolescent Peer Educators can support ALHIV and help them prepare for the transition process by:

- Reviewing the client's medical history together with the client, encouraging him or her to ask questions about his or her care and medicines, and discussing possible future changes
- Ensuring that the adolescent understands his or her diagnosis, his or her needed medications, the importance of adherence to care and medicines, and ways to prevent new HIV infections and to live positively (see Module 9 for more information about living positively with HIV)
- Promoting linkages to adolescent peer support groups and support groups at the adult clinic (for example, programs can consider having Adolescent Peer Educators make visits to both adolescent and adult clinics to organize support group meetings for transitioning adolescents)
- Transitioning adolescents to adult care in cohorts or groups if possible so that adolescents can support each other
- Organizing health talks for transitioning adolescent clients (consider having the talks led by an older adolescent who has already successfully transitioned to adult care)
- Encouraging older adolescents to take responsibility in making and keeping appointments and adhering to medicines (for example, by ensuring that they maintain a calendar of clinic appointments and a medication calendar)
- Identifying and orienting adult providers on the necessity of youth-friendly services, including providing 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 health workers (including the adult Peer Educators or other lay counselors), and to discuss the client's specific concerns and questions
- Transferring the client's medical records to the new clinic and holding a case conference to discuss key issues in the adolescent's care
- Involving Peer Educators, social workers, and counselors when planning for a client's 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 (see *Appendix 13B: Transition Resources for Health Workers and ALHIV*), in which the adolescent records 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.

Health workers can help older ALHIV be more involved in their own HIV care and treatment and can help prepare them for the transition to adult care. Ideally, adolescents should be able to do the following before transitioning:

- Make, cancel, and reschedule appointments
- Arrive to appointments on time
- Call ahead of time to schedule urgent visits
- Request prescription refills correctly and allow enough time for refills to be processed before medications run out
- Know when to seek medical care for symptoms or emergencies
- Identify symptoms and describe them
- Negotiate multiple providers and different types of clinic visits
- Establish a good working relationship with a case manager at the pediatric clinic, which will enable them to work effectively with the case manager at the adult ART clinic
- Ask questions and ask for help when needed
- Have a full understanding of their care and treatment plan, including the medicines they are taking
- Get the results of every test and understand the results
- Join an ALHIV association and support group
- Follow up on all referrals

Health workers can use *Appendix 13A: Transition Checklist for Health Workers* and Table 13.1 as tools to support ALHIV in the transition process. There are also a number of additional resources listed in *Appendix 13B: Transition Resources for Health Workers and ALHIV*. Please note that these resources can be adapted to many clinical or program settings.

Table 13.1: A self-care and transition timeline for ALHIV

10–12 years old	13–16 years old	17–19 years old
• Encourage caregivers to fully disclose to the child • Solicit direct conversation with the adolescent • Increase one-to-one meetings and counseling sessions with the adolescent • Begin to explain medications and adherence • Deal with early adherence issues and challenges • Link adolescent to support groups	• Assist adolescent with a calendar for appointments and medicines • Ensure adolescent understands diagnosis, needed medications, adherence, health precautions, positive living, and positive prevention	• Enforce responsibility in making and keeping appointments • Provide ALHIV with copies of medical records and any other forms or documents required by the adult clinic • Review medical history with the client • Encourage questions about adolescent's care plan, treatment regimen, and possible changes • Transfer medical records to new provider, highlight key issues • Visit the adult clinic with the adolescent client

Adapted from: AETC National Resource Center; New York/New Jersey AETC; Texas/Oklahoma AETC and Florida/Caribbean AETC. (2003). *The HIV perinatally-infected adolescent: A developmental approach, Practitioner transition checklist and timeline.* Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272

Exercise 1: Supporting ALHIV in Their Transition to Adult Care: Case studies and large group discussion	
Purpose	To discuss particular issues related to ALHIV's transition to adult care and how health workers can help make the transition process smoother
Refer to *Appendix 13A: Transition Checklist for Health Workers.*	

Case Study 1:
P___ is a 16-year-old ALHIV. In a few months, he is moving to a new town with no pediatric clinic and he will have to start getting care and treatment at an adult clinic. He is nervous about this change because he does not know the staff there and because he will now have to deal with a large, crowded clinic.

Case Study 2:
M___ is an ALHIV who is 19 years old. She has been receiving services from the adult clinic for the past year. Today, M___ has returned to the adolescent clinic to see you. When you ask her about her care and treatment, she tells you that she stopped taking her ARVs 3 weeks ago. When you try and discuss this situation with her in more detail, she cries and tells you that she doesn't like the people at the adult clinic.

Case Study 3:
B___ is 20 years old and is a client at the pediatric clinic where you work. Her auntie supports her and usually brings her for clinic visits. B___ has been diagnosed with some learning problems and developmental delays and, 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.

Module 13: Key Points

- In some places, adolescents attend pediatric clinics where they may have been getting services since birth, or for many years. After a certain age, however, they usually have to transition to the adult ART clinic.
- This care transition can be difficult for adolescents, caregivers, and health workers because, during this period, adolescents have to adjust to a new, less nurturing environment and to new health workers. They also have to adjust to adult clinics, which usually expect their clients to take responsibility for their own care.
- Taking on a greater role in self-care and self-advocacy may be challenging for adolescents, depending on their level of development and maturation. Not all adolescents, especially those with developmental delays, will be able to achieve 100% transition and independence.
- Health workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognizing their 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. Health 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 to receive adolescent-friendly services at the adult clinic. This requires planning and preparation for transition with the adolescent and ensuring that adult clinic staff understand the special needs of ALHIV.

Appendix 13A: Transition Checklist for Health Workers

This checklist contains the key points related to preparing older adolescents to transition to adult care. This checklist is meant to assist health workers and all 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 an individual adolescent's needs. In the 'Actions' section, the health worker should record major actions undertaken, referrals made, or information given to the adolescent or caregiver during the discussion.

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	1. Introduce the transition	
	Introduce and discuss transition during adolescent support group meetings and group sessions.	
	Discuss transition during clinical checkups and individual counseling sessions with adolescent clients.	
	Discuss transition with caregivers during group or individual sessions.	
	2. Encourage the adolescent to assume increasing responsibility for his or her own health care management	
	Make sure the adolescent understands his or her own health condition, care plan, and medications.	
	Talk about the transition and transfer to the adult clinic, discuss expectations, and answer any questions.	
	Talk about general coping, positive living, and building supportive relationships.	
	Give caregivers an opportunity to discuss their feelings about transition and any concerns.	
	3. Assess the client's ability to make independent health care decisions, assess his or her readiness for the transition, and determine additional support needs	
	Assess the client's understanding of his or her own care and the transition process.	
	Assess the caregiver's understanding of the client's care and the transition process.	
	Encourage the adolescent to make his or her own next clinic appointment and refill appointment.	
	Initiate any needed referrals, including to support groups.	
	4. Provide anticipatory guidance	
	Review plans for the client's continued adherence to care.	
	Review the client's adherence to medicines and ensure that he or she has a medicine calendar.	
	Ensure the client knows where to access help if he or she has questions about the new clinic.	

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	5. Implement the transfer to an adult clinic	
	Give copies of reports and tests to the adolescent and his or her caregivers so they have their own copies.	
	Transfer medical records to the adult clinic and ensure that the client also has a copy.	
	Discuss the adolescent's care with health workers at the adult clinic.	
	Provide orientation to the adolescent, ideally together with a health worker at 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, etc.).	
	6. Other activities that may help health workers and ALHIV plan for the transition process	
	Arrange for ALHIV to meet with adolescent clients who have already transitioned to adult care.	
	Schedule a visit to the adult clinic so adolescents can learn more about the services and health workers there before the transfer takes place.	
	Invite adult providers to the pediatric clinic for a weekly session so they can get to know more about adolescent clients and their needs. And/or, have providers from the pediatric clinic hold regular transition sessions at the adult clinic.	
	Refer ALHIV to attend a support group session with other transitioning adolescents.	
	Suggest that the adolescent start journaling or using a transition workbook.	
	Use a comprehension assessment tool (for example, a quiz, questionnaire, etc.) about HIV and adherence to care and treatment to assess transition readiness.	

Appendix 13B: Transition Resources for Health Workers and ALHIV

Resources for Health Workers:

- **New York State Department of Health AIDS Institute. (2011).** ***Transitioning HIV-infected adolescents into adult care: HIV clinical guidelines and best practices from New York State.*** Available at: http://www.hivguidelines.org/clinical-guidelines/adolescents/transitioning-hiv-infected-adolescents-into-adult-care/

- **AIDS Education & Training Centers (AETC). (2004).** ***HIV perinatally-infected adolescents: A developmental approach.*** This curriculum slide set is designed to provide an introduction to issues faced by adolescents who have acquired HIV infection perinatally. It uses a developmental approach to explore issues from the perspective of the adolescent, the family, and the health provider. Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272

- **Jacob, S. & Jearld, S. (2007).** ***Transitioning your HIV+ youth to healthy adulthood: A guide for health care providers.*** This is a comprehensive guide for health providers. It includes many tools and resources and although it is designed for perinatally infected youth, it is broadly applicable. Available at: http://hivcareforyouth.org/pdf/TransitioningYouth.pdf

- **AIDS Training and Education Centers National Resource Center*****. Practitioner transition checklist and timeline.*** Available at: http://www.aids-ed.org/aidsetc?page=et-adol-checklist

- **Birnbaum JM.** ***Transitional care for HIV and AIDS from adolescence to adulthood. Slide presentation.*** Available at: http://www.hivguidelines.org/Admin/Files/ce/slide-presentations/trans-care.ppt

- **HRSA Care ACTION. (2007).** ***Transitioning from adolescent to adult care.*** Available at: ftp://ftp.hrsa.gov/hab/june2007.pdf

Resources for ALHIV and Families:

- **Life Skills Subgroup of the AETC Adolescent HIV/AIDS Workgroup. (2006).** ***Adolescent transition workbook.*** Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-269

- ***Adolescent Health Transition Project: A Resource for teens and young adults with special health care needs, chronic illness, physical or developmental disabilities.*** [website] Available at: http://depts.washington.edu/healthtr

- **USAID, AED, and collaborating organizations.** ***Adolescents living with HIV (ALHIV) toolkit.*** Available at: http://www.k4health.org/toolkits/alhiv

- **AIDS Alliance for Children, Teens, and Families.** ***Transitions in health care: A guide for teens with HIV/AIDS and their families.*** Available at: http://www.aids-alliance.org/resources/publications/transitionshealthcare.pdf

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Module 14 Monitoring, Evaluation, and Quality Improvement

Session 14.1:	**Monitoring, Evaluation, and Data Collection**
Session 14.2:	**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 (M&E) can be used to support program improvement
- Describe the purpose of quality improvement (QI)
- Define and describe supportive supervision

Session 14.1 Monitoring, Evaluation, and Data Collection

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 (M&E) can be used to support program improvement

Monitoring

Monitoring is the routine process of data collection and measurement of progress toward program objectives. Monitoring involves COUNTING what we are doing. It also involves routinely checking the quality of services. 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 analyzed on a routine basis.

Health workers play a vital role in the monitoring process by regularly collecting (i.e. recording), compiling, and reporting data to determine, for example, the number of adolescents enrolled in HIV care, the number receiving ART, the number 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 programs can help to:

- Assess whether a program is meeting its targets
- 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 care and treatment **program outcomes**, such as:

- *Is the program retaining adolescent clients in care?*
- *Are all eligible adolescents receiving ART?*
- *Are routine lab tests and clinical follow-up visits being conducted on schedule?*

Program outcomes are usually the cumulative tally of individual outcomes and can give insight into the strengths and the areas needing improvement within an individual facility or across an entire district.

Often, when reporting outcomes, programs separate data into only two age groups: under 15 years and over 15 years. However, **disaggregating data (or further separating the data)** into more age groups allows for more meaningful interpretation of program outcomes.

It is recommended that data be collected and analyzed using these age categories:

- Ages 10-15 years (early adolescence)
- Ages 16-19 years (late adolescence)
- Ages 20-25 years (early adulthood)

Indicators

Indicators are summary measures used to help indicate the status of a program'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 14.1 for more examples of indicators.
- Pediatric and adult HIV care and treatment indicators are established at the national level according to the needs, resources, and standards of the specific program. 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.
- Although indicators are identified at the national level, they can be calculated at the facility, district, or national level depending on need and how these data will be used.
- Some facilities have their own indicators in addition to the nationally-established indicators. Facility-level indicators can help to identify progress, problems, challenges, and solutions in the delivery of adolescent HIV care and treatment services at specific facilities. For example, facility level indicators could show how many adolescents are missing appointments and, of those, 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 program or services being monitored).
- Indicators reflect a certain timeframe — for example, over the course of a month, a quarter, or a year.
- It is important to measure changes in indicators over time. For example, if the number of HIV-infected adolescent enrolled in care is 20 in 2000, 40 in 2002, and 30 in 2004, we would want to explore reasons why the number of enrolled adolescents decreased from 2002 to 2004. One possible explanation could be that the program did not have enough physical space or provider time to continue expanding services to more than 40 adolescents per year, the maximum obtained in 2002.

Table 14.1: Examples of adolescent HIV care and treatment indicators

- Number HIV-infected adolescents (aged 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

In addition to absolute numbers, it is good to calculate **proportions** (e.g. the proportion of adolescents who have discontinued care, the proportion who have transferred out, the proportion who have died, etc.) as this gives more useful and comparative information than raw numbers alone. However, since measuring proportions is often difficult to do, programs may wish to select a small number of priority proportions to measure. Some examples are given below and in *Appendix 14A: ICAP's Adolescent Standards of Care.*

Targets

Targets are specific goals established before a new program 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." See Table 14.2 for examples of priority targets for adolescent HIV care and treatment programs.

Table 14.2: Priority targets for adolescent care and treatment programs

Priority Indicator 1: **95% of adolescent patients in HIV care and treatment receive Cotrimoxazole (CTX) prophylaxis**

Measured by: Proportion of adolescent patients in HIV care and treatment receiving cotrimoxazole (CTX) during the quarter

Numerator: Number of adolescent patients in HIV care and treatment receiving cotrimoxazole (CTX) prophylaxis during the quarter

Denominator: Number of adolescent patients receiving HIV care during the quarter

Priority Indicator 2: **90% of adolescent patients enrolled remain in care for at least 6 months**

Measured by: Proportion of adolescent patients enrolled in care who remained in care for 6 months

Numerator: Number of adolescent patients still in care at 6 months after enrollment (e.g. April-June)

Denominator: Number of adolescent patients enrolled in care in a given 3 month period (e.g. Oct-Dec)

Priority Indicator 3: **95% of all adolescent patients in HIV care and treatment receive TB screening**

Measured by: Proportion of adolescent patients in HIV care and treatment receiving TB screening at enrollment by symptom check list during the quarter

Numerator: Number of adolescent HIV patients screened for TB at enrollment into HIV care during the quarter

Denominator: Number of new adolescent HIV patients enrolled in HIV care during the quarter

Evaluation

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 help take a closer look at the outcomes of interest and can help answer questions about what outcomes mean and what differences the program is making.

- 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.
- At its simplest, an evaluation of routinely collected data from the adolescent HIV care and treatment program will demonstrate to what extent planned activities are actually realized by comparing targets with indicator measurements. So, for example, an evaluation might help to answer the following questions:
    - *What percent of the target for ART initiation was reached by the program last year?* (In other words, did we initiate as many people on ART as we had planned or expected to enroll?)

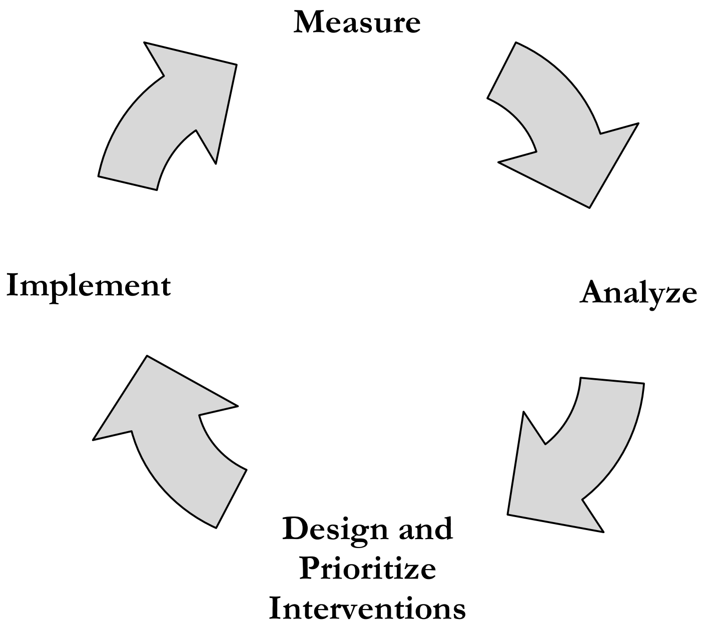
Evaluations can also involve research methods to systematically investigate a program's effectiveness. In this case, evaluation may involve special studies and specific research design, and may require a control or comparison group. One might use evaluation to answer the following program questions:

- *Are adolescents enrolled in a peer support group more likely to return for scheduled appointments compared to adolescents who do not participate in peer support groups?*
- *Are adolescents enrolled in the program experiencing a better quality of life?* (Use patient surveys to collect these data)
- *Has the program reduced the number of adolescents hospitalized for HIV-related illnesses?* (Compare hospitalization rates before and after the adolescent program started, using chart review)

Evaluations should be conducted regularly to look at changes that occur as the adolescent HIV program is implemented and maintained. For example, *has the percentage of adolescents who receive TB screening improved since the start of the program? What about the percentage of adolescents who are retained in care for at least 6 months? If so, can these changes be attributed to our program?* This will enable program staff to identify areas of program strength and weakness, and to respond to weaknesses by investigating and correcting problems.

The monitoring and evaluation process is a continuous one, as shown in Figure 14.1, below.

Figure 14.1: Monitoring and evaluation as a continuous process



Adapted from: ICAP. (2007). *Clinical systems mentorship: The ICAP guide to site support*. Available at: http://www.columbia-icap.org/resources/supporttools/files/SSG.Draft%201.1.pdf

Reporting

There are numerous steps in the reporting process and each step is important:

1. Individual client data are recorded in facility-held patient charts, patient-held records, and/or nationally standardized **registers**.
2. Data in these registers are tallied and the totals are recorded on nationally standardized **monthly summary forms**. These totals summarize a facility's progress on key indicators (such as those listed in Table 14.1).
3. These monthly summary forms are submitted to the district level.
4. Districts collate the monthly summary forms (in other words, they put together the forms from all of the district clinics) and submit the collated data to the national level.

The data summarized on each monthly summary form should also be compiled into a **monthly report** so staff can review how the program is doing. The monthly report for the facility might include that which was reported to the district as well as additional data, such as data collected on retention or quality indicators (see Session 14.2).

All staff must be aware of the importance of completing registers in an accurate way. Monthly summary forms and reports will only be accurate if registers are completed correctly and consistently. This is discussed further in the next session.

Program Modification

At every level of the system — facility, district, and national — monthly summary forms should lead to discussion on how the program can be modified or improved to better meet targets. (This activity is referred to as "design and prioritize interventions" in Figure 14.1)

- For example, if the most recent monthly report indicated that 10 out of 50 (20%) newly enrolled HIV-infected adolescents with CD4 cell counts less than 350 were initiated on ART this month, but that the target was to initiate at least 80% of those who were eligible on ART, we would want to identify ways that the program could be modified or improved in order to reach the target.

Such program improvements will require discussion of the following:

- **What is the problem?**: *What are the barriers to rapid ART initiation for adolescents? Can ART adherence training be streamlined? If many of our adolescent clients are orphans, is there a problem identifying treatment buddies or caregivers who are responsible for supporting ART adherence? Are there delays in getting CD4 test results from the laboratory prior to initiating ART?*
- **How will we address the problem?**: *Once the key problems have been identified, how will these problems be addressed?*
- **What is our 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 know if the plan is working?**: *How will we know if the new initiative is working? Will we look at this year's first few monthly reports (or quarterly summary report, if available)? If so, what improvement do we expect to see? Will we consider the program modifications successful if our ART initiation increases to 40%? 65%? 80%?*

This process is discussed in more detail in the "Quality Improvement" section in Session 14.2.

Adolescent HIV Care and Treatment Data Collection and Forms

Standard data collection and accurate recording of activities and outcomes are essential. Data collection for adolescent HIV care and treatment is usually done through the existing national M&E system, using existing national HIV care and treatment forms and registers. **There is not usually a separate system with adolescent-specific forms.**

- In most cases, adolescent data will be captured in the national forms for pediatric HIV, meaning that the same system and tools can be used to describe, monitor, and evaluate both the pediatric HIV program and the adolescent program.
- This is why it is particularly important that data are appropriately disaggregated by age, as described previously.
- 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 pediatric services are unavailable), then facilities should use the national forms for adult HIV care and treatment to report activities related to the ALHIV.

Characteristics of effective M&E systems

Effective monitoring and evaluation systems require record keeping that is:

- **Accurate** — in other words, correct and true. So, if a client's CD4 count is 401, make sure that "401" is entered correctly in the appropriate cell, along with his or her identifying code or name.
- **Reliable** — completed the same way every time (for example, recording the adolescent's age in years and months at every visit)
- **Standardized** — recorded using the same tools (for example, using the same registers, abbreviations, formulas, and definitions) in every clinic across the district or country
- **Recorded** following established guidelines

Be mindful of adolescents who have transitioned to adult care:

- In facilities with established adolescent programs, adolescents may need to be "transferred out" of pediatric registers and monthly summary forms as they age and "transferred in" to adult HIV program reporting forms and registers.
- There should be national guidelines for this procedure, but if they cannot be identified, facilities should have their own consistent procedure for counting enrollment and retention of adolescents who have begun to meet the definition of "adult" HIV patients.
- Care taken with these data issues will be rewarded with more accurate data on retention of adolescents in the program.

Remember these important points:

- Systems for documenting care and treatment activities must **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 who complete registers or summary forms to **ensure that data are 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 at the clinic.

The following is a list of some of the key registers and forms facilities use to monitor activities in their adolescent programs (note that this list assumes adolescents are being captured on pediatric registers and forms; adapt as needed if adolescents will only be seen in adult clinics):

- Ward or clinic register
- General HIV counseling and testing register
- Patient care card
- HIV care summary sheet
- Pediatric clinical follow-up form
- Pediatric ART eligibility form
- Pediatric adherence form
- Pharmacy logbook/register
- Patient status form
- TB diagnostic worksheet and TB screening tool
- Pediatric patient locator form

Tracking Missed Appointments

Health facilities should use an **appointment book** to keep track of upcoming and missed appointments. A follow-up system should also be developed to contact those who have missed appointments (and their caregivers) to try to bring them back into care.

A follow-up system requires:

- A working appointment system whereby health workers can readily track missed appointments and contact clients (and caregivers) who have missed an appointment in order to bring them back to the clinic.
- In urban areas, contact may involve the use of cell phones (making phone calls or sending SMS messages). In rural areas, contact may involve the efforts of community workers, NGOs, Peer Educators, family members, or friend networks.
- Contacting clients and families when appointments have been missed, either by phone or home visit, requires the consent of the adolescent client and/or the caregiver. Therefore, a system should be in place to obtain contact information at enrollment, to update this information at each subsequent visit, and to routinely request consent to follow up missed appointments.

Exercise 1: Using Data for Decision-Making: Small group work and large group discussion

Purpose	To review adolescent HIV care and treatment data and to analyze the data for use in program decision-making

This exercise consists of 3 parts:

- Part 1: Small Group Work
- Part 2: Small Group Work
- Part 3: Small Group Presentations and Large Group Discussion

Part 1: Small Group Work

Review Table 14.3 and, based on the data provided, calculate the "% of Target" in the last column. Then discuss the following questions:

A. *For which indicators is Clinic Make Believe doing well and meeting its targets? How do you know?*
B. *For which indicators is Clinic Make Believe NOT meeting its targets? How do you know?*
C. *If the number of adolescents enrolled in care in Q4 (the 4th quarter) of 2009 was 450 and the number of adolescents receiving ART was 290, would you say the clinic is doing better or worse enrolling clients in ART in 2010?*
D. *Which areas should the staff of Clinic Make Believe focus on improving?*

Part 2: Small Group Work

Identify one of the areas that needs improvement at Clinic Make Believe and discuss:

A. *What is the problem?*
B. *How should we (assuming we are the managers at Clinic Make Believe) address the problem?*

Table 14.3: Sample data for Exercise 1

Quarterly adolescent HIV care and treatment summary report for Clinic Make Believe			
Number of adolescents enrolled in care	**2010, Q4**	**Target***	**% of Target**
• Females, aged 10–14	100		
• Males, aged 10–14	95		
• Females, aged 15–19	150		
• Males, aged 15–19	165		
• Total	510	550	
Number of adolescents receiving ART	**2010, Q4**	**Target***	**% of Target**
• Females, aged 10–14	75		
• Males, aged 10–14	70		
• Females, aged 15–19	102		
• Males, aged 15–19	120		
• Total	367	350	
Number of new adolescent clients	**2010, Q4**	**Target***	**% of Target**
• Females, aged 10–14	1		
• Males, aged 10–14	2		
• Females, aged 15–19	22		
• Males, aged 15–19	12		
• Total	37	40	
Number of adolescent clients who missed appointments	**2010, Q4**	**Target***	**% of Target**
• Females, aged 10–14 (75 had appointments this quarter)	20 (27%)		
• Males, aged 10–14 (70 had appointments this quarter)	23 (33%)		
• Females, aged 15–19 (95 had appointments this quarter)	37 (39%)		
• Males, aged 15–19 (105 had appointments this quarter)	42 (40%)		
• Total (345 had appointments this quarter)	122 (35%)	10% of those in care, max.	
Number of adolescent clients attending support group meetings	**2010, Q4**	**Target***	**% of Target**
• Females, aged 10–14	55		
• Males, aged 10–14	45		
• Females, aged 15–19	120		
• Males, aged 15–19	130		
• Total	350	50% of those in care	
Number of support group meetings held at the clinic	**2010, Q4**	**Target***	**% of Target**
• For 10–14 year olds	6		
• For 15–19 year olds	10		
• For caregivers	3		
• Total	19	9	
Number of active Adolescent Peer Educators at the clinic	**2010, Q4**	**Target***	**% of Target**
Number of active Adolescent Peer Educators at the clinic	15	6	
* If a cell is blank, it means that sub-targets have not been stated.			

Session 14.2 Quality Improvement and Supportive Supervision

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 (QI)

Quality Improvement is the means by which activities are routinely evaluated to check whether services offered by the multidisciplinary team are following established guidelines and standard operating procedures (SOPs). QI may also be referred to as quality assurance (QA). The purpose of QI is to identify problems so they can be corrected, thereby improving services for adolescent clients and their caregivers.

QI is different from monitoring and evaluation. Monitoring can tell us how many clients attended the clinic or how many received ART last month. QI, on the other hand, can tell us whether those clients were happy/satisfied with the services they received and whether they were provided with sufficient education and appropriate adherence counseling.

QI should be a routine, ongoing part of the normal functioning of health facilities. It should incorporate procedures in which all staff at all levels — not just supervisors — are involved.

Methods to Assess Quality

It is often necessary to use a variety of methods to assess program quality. Standard monitoring tools, such as patient forms and registers, capture only a fraction of the services provided to adolescents and they 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 youth-friendliness of clinical services; on the quality of psychosocial support, adherence, and other counseling sessions; or on the quality of referrals made to community-based support services.

QI activities might examine and evaluate:

- The quality and youth-friendliness of services (see Module 2)
- Compliance with national guidelines, standard operating procedures, and protocols for HIV care and treatment
- The adequacy of space and the attention to privacy and confidentiality
- Linkages to ongoing support and community-based services

QI activities may vary to some extent from one facility to another, based on the type of facility and the facility's experience with adolescent HIV care and treatment services.

QI activities might include:

Adolescent Standards of Care (SOCs)

ICAP has developed **Standards of Care** for different HIV program areas. These SOCs are tools to help programs measure key standards over time, in order to improve quality. See *Appendix 14A*.

- Periodic reviews of records followed by staff feedback — reviewers should check for the accuracy, completeness, and consistency of the entries in various forms, registers, and patient files used in the clinic.
- Defining and regularly measuring adolescent SOCs (see box to the right)
- Direct observation of clinical procedures and counseling sessions
- Periodic assessments of the youth-friendliness of services, including the level of youth participation (the checklist presented in *Appendix 2B* may be used)
- Interviews with staff either directly or indirectly involved in the adolescent care and treatment program, in order to obtain feedback on specific indicators. Case conferences may be used as a forum to highlight current challenges, systems that are working, and systems that need improvement, and to propose 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 were provided during counseling sessions? Did they feel welcomed at the clinic? Were they treated non-judgmentally by health workers? Was it clear what would be expected of them, for example, how and when they should 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?*
- Exit interviews or surveys completed anonymously by clients. A sample client satisfaction survey for youth is included as *Appendix 2C*. Client satisfaction surveys, which are typically given to clients as they complete their clinical visit, are a mechanism for clients to give their opinions about the services they received without fear that their honest feedback might affect their care. Client satisfaction surveys are typically administered either to all clients or to a random selection of clients for 1 to 2 weeks, 3 or 4 times a year.
- 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 they may have received from adolescents regarding the facility's services.

How often should QI be conducted?

During initial implementation, daily or weekly QI activities allow for immediate follow-up aimed at correcting problems that have been identified. As services become established, reviews should become a formal part of overall adolescent HIV care and treatment program monitoring activities at designated intervals (monthly progressing to quarterly reviews). For example, ICAP recommends measuring SOCs on a quarterly basis (see *Appendix 14A*). Although supervisors have the ultimate responsibility for QI, QI-related activities should be shared among all members of the team.

It is important to establish a time for multidisciplinary team members and managers to discuss QI findings and issues, and to jointly come up with ideas and solutions for quality improvement. This may be accomplished as part of routine, monthly multidisciplinary team meetings or through quarterly meetings dedicated to QI review.

Supportive Supervision

QI activities are not complete without assessing the results of each QI review and planning a response. Often, weaknesses discovered through QI activities require supervisors to work directly with staff (including Adolescent Peer Educators) to address underlying problems. It is important that supervisors explain to their staff that QI activities are not simply the responsibility of supervisors, but rather that all service-improvement activities conducted by any staff member are a part of the continuous QI process.

The Focus of QI

QI is most effective when the focus is on providing guidance and mentorship, as well as using group problem solving techniques, to help health workers correct problems and overcome barriers to quality service provision.

An important component of responding effectively to QI findings is providing **supportive supervision**.

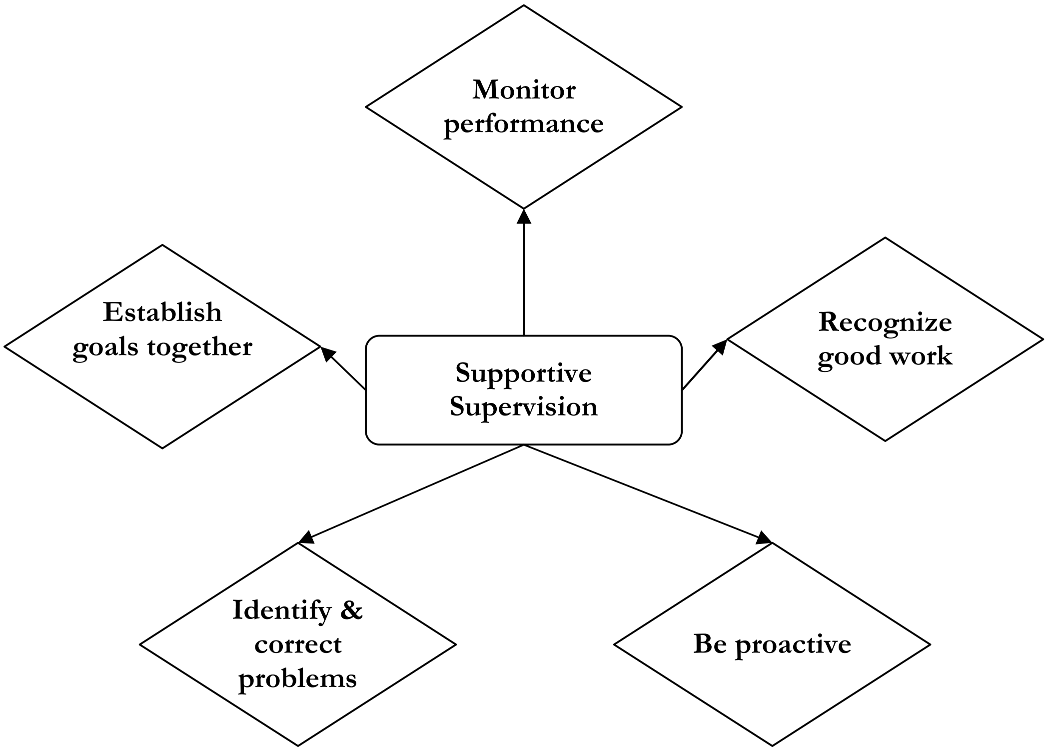
- Supportive supervision is an approach in which supervisors work with staff to establish goals, monitor performance, identify and correct problems, and proactively improve the quality of adolescent HIV care and treatment services through training, one-to-one support, mentoring, and coaching.
- Supportive supervision methodologies can also be extended to other contexts beyond QI, for example as a component of training.

Supportive supervision aims to:

- Obtain valuable information on program functioning and quality
- Improve health worker performance by providing one-to-one support to address an identified deficiency and to build health workers' skills
- Acknowledge good practices by providing positive feedback and noting health workers' (and Peer Educators') contributions to the success of the program
- Involve supervisors, health workers, and volunteers (such as Adolescent Peer Educators) to improve service provision — this is not the sole responsibility of the supervisor. It is also important to encourage health workers and Peer Educators to support each other through peer mentoring.
- Facilitate on-site, participatory problem-solving. Health workers should be encouraged to become comfortable participating actively in addressing weaknesses along with their supervisor.
- Involve youth in giving feedback and improving service provision
- Assure that the program is successful in meeting the needs of ALHIV and their caregivers and families
- Motivate staff and volunteers

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 14.2 illustrates the concept of supportive supervision.

Figure 14.2: Supportive supervision process



Module 14: Key Points

- Monitoring and evaluation (M&E) is the standardized process by which data related to the delivery of services are collected and evaluated.
- M&E is a continuous process that informs the planning and implementation of adolescent HIV care and treatment services.
- Indicators are calculated using routinely collected data. They can be calculated at the facility, district, or national level.
- Targets are specific goals established before a new program or service is implemented or at other specific times.
- Standard national forms and registers are used to collect key data on adolescent HIV care and treatment services.
- If possible, program data should be collected, disaggregated (or separated), and analyzed by the following groups: ages 10-15; ages 16-19; and ages 20-25.
- Key staff should review their facility's monthly forms/reports to ensure that activities will meet targets and goals. Program successes and weaknesses, along with a monthly data summary, should be reviewed at multidisciplinary team meetings in order to initiate discussion on how weaknesses will be addressed.
- Patient confidentiality must be always be maintained.
- Quality Improvement (QI) is the means by which activities are routinely evaluated to check whether services offered are following established guidelines and SOPs.
- QI should be a routine, ongoing part of the normal functioning of health facilities. A variety of methods may be used to conduct QI.
- 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, and identify and correct problems.

Appendix 14A: Adolescent Standards of Care

ICAP Standards of Care (SOCs) for Pediatrics (Adolescents)[1]		Quarterly Measure of SOC	Numerator	Possible Source of information	Evaluation of Program Quality		
			Denominator		Result of Quarterly measure of SOC		
					Possible Actions		
1.	All HIV-infected adolescents should receive CD4 testing at enrollment in HIV care.	% of HIV-infected adolescents with CD4 test result within 1 month of enrollment	# of adolescents enrolled in the past 6 months with CD4 recorded within 1 month of enrollment	Adolescent charts	<75%	75-94%	≥95%
			# of adolescents enrolled in the past 6 months		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**
2.	All HIV-infected adolescents should be screened for TB at enrollment.	% of adolescents screened for TB at enrollment	# of adolescents enrolled in the past 6 months and screened for TB at the enrollment visit	Adolescent charts	<75%	75-94%	≥95%
			# of adolescents enrolled in the past 6 months		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**
3.	All eligible adolescents should initiate ART within 1 month of determination of eligibility.	% of eligible adolescents on ART within 1 month of ART eligibility	# of adolescents on ART within 1 month of determination of eligibility	ART register; Adolescent charts	<70%	70-90%	≥90%
			# of HIV-infected adolescents eligible for ART		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**

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[1] An adolescent refers to a child aged between 10 and 19 years.

ICAP Standards of Care (SOCs) for Pediatrics (Adolescents)[2]		Quarterly Measure of SOC	Numerator	Possible Source of information	Evaluation of Program Quality		
			Denominator		Result of Quarterly measure of SOC		
					Possible Actions		
4.	All HIV-infected adolescents should be educated on secondary prevention every 6 months.	% of HIV-infected adolescents with documented education on secondary prevention	# of HIV-infected adolescents seen in the past 6 months who have documented education on secondary prevention	Adolescent charts	**<75%**	**75-94%**	**≥95%**
			# of HIV-infected adolescents seen during the past 6 months		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**
5.	All HIV-infected adolescents should be screened for substance abuse[3] every 6 months.	% of HIV-infected adolescents with documented screening for substance abuse	# of HIV-infected adolescents seen in the past 6 months who were screened for substance abuse	Adolescent charts	**<75%**	**75-94%**	**≥95%**
			# of HIV-infected adolescents seen during the past 6 months		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**
6.	All HIV-infected adolescents should be screened for depression every 6 months.	% of HIV-infected adolescents with documented screening for depression	# of HIV-infected adolescents seen in the past 6 months who were screened for depression	Adolescent charts	**<75%**	**75-94%**	**≥95%**
			# of HIV-infected adolescents seen during the past 6 months		**Evaluate this month**	**Prioritize and evaluate next quarter**	**On target**

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[2] An adolescent refers to a child aged between 10 and 19 years.

[3] Alcohol, tobacco, and illicit drugs

Module 15 Supervised Clinical Practicum

Session 15.1: **Practicum Planning and Preparation**

Session 15.2: **Supervised Clinical Practicum and Debrief**

Learning Objectives

After completing this module, participants will be able to:

- Describe the core competencies required to provide adolescent HIV care and treatment services
- Demonstrate core adolescent HIV care and treatment competencies in a clinical setting
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services

Session 15.1 Practicum Planning and Preparation

Session Objective

After completing this session, participants will be able to:

- Describe the core competencies required to provide adolescent HIV care and treatment services

Core Competencies

Participants will be asked to practice and demonstrate a number of skills learned during the training. Refer to *Appendix 15B: Practicum Checklist* for more information on these core competencies.

Preceptors will be available to help and mentor participants as they master the skills learned during training.

Conduct During the Practicum Session

- Remember that we are guests at the health facility and must respect the wishes of the health workers and managers who work at 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 clients 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 health workers and clients. Tell them that you are currently completing a course about HIV 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 for you to observe or practice skills. 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 concern.

Preceptors will be using *Appendix 15B: Practicum Checklist* to assess participant performance during the practicum. Become familiar with the content of this form, including how preceptors will make their final evaluations.

Session 15.2 Supervised Clinical Practicum and Debrief

Session Objectives

After completing this session, participants will be able to:

- Demonstrate core adolescent HIV care and treatment competencies in a clinical setting
- Identify their own strengths and weaknesses in providing adolescent HIV care and treatment services

Exercise 1: Supervised Clinical Practicum and Daily Practicum Debrief	
Purpose	To practice core competencies needed to provide adolescent HIV care and treatment services in a clinical setting
See *Appendix 15B: Practicum Checklist*.	

Exercise 2: Final Practicum Debrief : Small and large group discussion

Purpose To share experiences and lessons learned during the multi-day practicum

This exercise consists of 2 parts:

- Part 1: Small Group Discussion
- Part 2: Large Group Discussion

For part 1, discuss the following questions in your small groups and write down your responses on flip chart:

- *What was your overall experience during the practicum?*
- *What skills did you find the most difficult to perform?*
- *What skills did you find the least difficult?*
- *In which areas would you like more mentoring in the future?*
- *What did you learn during the practicum that you did not expect to learn?*
- *What was your most memorable experience during the practicum?*
- *Once the training is over, how can participants and preceptors continue to support each other in building their skills?*

Appendix 15A: Tips on Mentoring and Coaching with Preceptors[1]

What Are the Qualities of a Good Preceptor?

- Has strong knowledge, skills, and experience related to adolescent HIV care and treatment
- Professional
- Understands the importance of skill sharing and capacity building and is willing to teach and mentor others
- Respects others
- Conscientious and trustworthy
- Accountable for his or her work and responsive to feedback
- Upholds confidentiality at all times
- Makes decisions that are ethically sound
- Has leadership skills

Preceptor Do's and Don'ts

Do:

- Make participants feel welcome and valued.
- Set shared achievable goals.
- Put yourself in the participant's shoes.
- Ask questions that show an interest in developing participants' skills.
- Monitor progress and give feedback frequently.
- Provide guidance, encouragement, and support.

Don't:

- Arrive unprepared.
- Be vague about your expectations.
- Confine participants to passive roles.
- Wait to give feedback until the final assessment.
- Embarrass or humiliate participants.
- Accept behavior 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 carried out, without giving commentary.
3. Repeat the demonstration, this time describing each step.
4. Have the participant "talk through the skill" by describing each step.
5. Observe and provide feedback to the participant as he or she performs the skill.

Appendix 15B: Practicum Checklist

This checklist includes many of the core competencies taught during this training. The checklist can be used during the practical sessions of the training and can also be a useful tool after the training for supervisors and health workers in the adolescent clinic. It is unlikely that participants will be able to demonstrate and practice all of the competencies included on this checklist during the 2-day practicum, but the checklist can also be used as part of supportive supervision and mentoring activities when participants return to their sites after the training.

Preceptor instructions: Use 1 checklist per participant in your group. As you observe the participant using a specific skill, tick your rating as GOOD, FAIR, or POOR. Record any comments or recommendations in the "Comments" column and be prepared to share these comments with the participant. Then use this checklist to complete the final evaluation for each participant. **Participant instructions**: Complete this checklist during the practicum, assessing your own performance. In the "Comments" column, record areas where you feel you need 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 follow-up medical and social history				
Demonstrates familiarity with national HIV guidelines; identifies criteria for ART initiation/failure/prophylaxis i				
Assesses growth (weight, height) for at least 1 client				
Assesses WHO clinical stage of at least 1 client				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	**FAIR**	**POOR**	
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				
Communication and counseling skills				
Effectively presents a 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				
Uses gestures and responses to show interest when talking with adolescent clients				
Uses open-ended questions when communicating with and counseling adolescent clients				
Empathizes with the adolescent client and shows understanding				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	**FAIR**	**POOR**	
Avoids words that sound judging when communicating with adolescent clients				
Uses reflection skills during counseling sessions				
Summarizes main points of a counseling session and helps the adolescent client set goals				
Tailors counseling according to age and developmental stage of the adolescent				
Psychosocial support for ALHIV				
Conducts at least 1 psychosocial assessment and completes a psychosocial assessment form (*Appendix 5A*)				
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				
Mental health and ALHIV				
Uses patient history, clinical observation, and information from client/caregiver to evaluate for possible mental illness				
Recognizes signs of depression and uses screening tools				
Identifies potentially serious mental health problems, provides support, and refers appropriately				
Applies standard operating procedures to provide immediate management and referral for psych emergencies				
Recognizes signs of alcohol and other substance use, uses screening tools, and provides counseling and referrals				
Disclosure support				
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				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
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 throughout the disclosure process				
Adherence support				
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 his or her caregiver				
Conducts all components of the standard adherence preparation visits with adolescent and/or caregiver				
Provides individualized counseling to make an adherence plan with client and caregiver				
Provides follow-up adherence support and counseling to at least 1 client on ART and to at least 1 caregiver				
Positive living				
Provides accurate, age-appropriate, and comprehensive positive living counseling to ALHIV				
Provides accurate information and counseling on positive prevention				
Provides practical nutrition counseling and support to at least 1 adolescent client (and caregiver, if available)				
Provides accurate information and counseling on alcohol and substance use prevention to at least 1 adolescent client				
Sexual and reproductive health				
Provides non-judgmental counseling about adolescent sexuality and SRH issues				
Conducts an SRH risk assessment and provides non-judgmental, accurate sexual risk reduction counseling				
Provides accurate, non-judgmental counseling and information on ways to practice safer sex				

CORE COMPETENCIES	PRECEPTOR or SELF-RATING (TICK ONE)			COMMENTS
	GOOD	FAIR	POOR	
Provides condoms to clients and accurately demonstrates male and female condom use				
Provides adolescent-friendly STI counseling, screening, and treatment for male and female clients				
Childbearing choices, contraception, and PMTCT				
Discusses childbearing choices and safe childbearing with adolescent clients				
Provides accurate, non-judgmental contraceptive counseling and supplies (and/or referrals)				
Provides accurate, non-judgmental PMTCT counseling and services, including referrals for pregnant ALHIV				
Community linkages				
Understands how to establish linkages with other agencies, including community-based organizations				
Uses a community resources directory to make referrals for adolescent client and family members				
Provides appropriate referrals to adolescent Peer Educators, if available				
Transition to adult care				
Provides counseling and support to ALHIV to prepare them to take on a greater role in their self-care in preparation for their transition to adult care				
Monitoring and evaluation				
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:** ____________________________

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References

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[1] Adapted from: George, J.H., & Doto, F.X. (2001). *A simple five-step method for teaching clinical skills*. Family Medicine, 33, 577-8.

Module 16 Action Planning, Course Evaluation, and Closure

Session 16.1:	**Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning**
Session 16.2:	**Reflection on Training Objectives and Concerns, Expectations, and Strengths**
Session 16.3:	**Post-Test, Training Evaluation, and Closing**

Learning Objectives

After completing this module, participants will:

- Have reviewed the key steps and considerations of initiating or scaling up 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 started developing a site-specific action plan to initiate or improve adolescent HIV care and treatment services
- Have discussed whether or not the training objectives were 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 16.1 Site-Specific Adolescent HIV Care and Treatment Implementation and Action Planning

Session Objectives

After completing this session, participants will:

- Have reviewed the key steps and considerations of initiating or scaling up 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 started developing a site-specific action plan to initiate or improve adolescent HIV care and treatment services

Key Steps to Initiate or Scale up Adolescent HIV Care and Treatment Services

As you have learned during this training, there are many different aspects involved in the successful provision of HIV care, treatment, and support services to 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 aspects in mind.

As you learned in Module 2, there are many things that health 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 necessarily creating additional workload or incurring any additional costs. Here are some suggestions:

- Conduct a needs assessment, gathering information about the adolescent services currently being provided at the health facility. These services may be provided within the pediatric HIV clinic or the adult clinic. Do not forget to involve young people in the assessment so as to ensure that their views and opinions are reflected in the results. See Module 2 for more information. The needs assessment should identify existing gaps and problems based on what you know about the characteristics of a youth-friendly clinic.
- Develop an action plan to prioritize activities that will fill the identified gaps and solve the identified problems. Each action item should have a timeline and should include clear documentation of those responsible for the item. The action plan should also document any other needed resources. Remember, making services youth-friendly does not have to cost a lot of money — you can work with what you have!
- Present the action plan to the managers, health workers, and youth who will be involved in the program and be sure to regularly revisit the action plan to see what progress has been made and what adjustments are needed.

Remember that setting up youth-friendly HIV care and treatment services is a start, but in order to really meet the needs of adolescent clients, **quality, evidence-based HIV care** must be provided within the context of youth-friendly services.

Characteristics of Youth-Friendly Services

Try to think back to the discussion about youth-friendly services in Module 2. The point was made that, in order to serve adolescent clients with HIV prevention, care, treatment, support, and related health services, clinics and programs must be able to attract, meet the needs of, and retain those clients. The clinics that are most likely to attract and retain adolescent clients are those that are youth-friendly. Table 16.1 summarizes the key characteristics of youth-friendly services, whether they be for HIV, reproductive health, or other types of care. Please note that this table was also included in Module 2 (as Table 2.3).

Table 16.1: Characteristics of youth-friendly services

Health worker characteristics	Health facility characteristics	Program design characteristics
• Specially trained/oriented staff* • All staff display respect for youth • All staff maintain privacy and confidentiality • Enough time for health worker-client interaction	• Separate space for young people • Special times when young people can receive services • Convenient hours • Convenient location • Adequate space and privacy • Comfortable, youth-friendly surroundings • Peer Educators available	• Youth involvement in program design and monitoring • Drop-in clients welcomed • Short waiting times • Set up to provide chronic disease management, including multiple appointments and medications • Appointment systems in place as well as tracking systems for clients who miss appointments • Affordable rates or no fees for services • Publicity, marketing, or recruitment materials that inform and reassure youth • Friendly to both male and female clients • Wide range of services available —"1-stop shopping" • Referrals available to clinical and community-based services • Youth-friendly educational materials available to take away • Youth support groups • Peer Educators available
* Including training in the following areas: • Clinical HIV care for adolescents • How to build trust with and counsel adolescents • Providing psychosocial support to adolescents • Mental health assessment, counseling, and referrals • Disclosure counseling • Adherence counseling • Positive living counseling • Sexual and reproductive health counseling and services • Preparing adolescents for the transition to adult care		

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.

Exercise 1: Action Planning: Small group work and large group discussion	
Purpose	To create an action plan to initiate or improve adolescent HIV care, treatment, and support services at participants' individual facilities
Refer to *Appendix 16A: Adolescent HIV Care and Treatment Action Planning and Implementation Template* and also *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services.*	

Session 16.2 Reflection on Training Objectives and Concerns, Expectations, and Strengths

Session Objectives

After completing this session, participants will:

- Have discussed whether or not the training objectives were 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

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

1. Describe the stages and characteristics of adolescence and the unique needs and challenges of adolescent clients
2. Implement strategies to make HIV-related services youth-friendly
3. Define and implement the package of HIV-related care and treatment services for adolescents
4. Implement effective communication and counseling skills with adolescent clients
5. Conduct a psychosocial assessment and provide ongoing psychosocial support services to adolescent clients
6. Describe the importance of mental health services for adolescent clients, recognize when a mental health problem may exist, and provide appropriate referrals and support
7. Recognize the signs of and be able to screen for alcohol and substance use disorders among adolescents, and provide support and referrals
8. Provide developmentally-appropriate disclosure counseling and support to adolescents and, where appropriate, their caregivers
9. Provide developmentally-appropriate adherence preparation and ongoing adherence support to adolescent clients and caregivers
10. Support adolescents to live positively with HIV
11. Conduct sexual risk screening and provide non-judgmental, comprehensive counseling on sexual and reproductive health to adolescent clients
12. Provide basic, non-judgmental contraceptive counseling and services to adolescent clients
13. Describe the key components of PMTCT services for adolescents and provide referrals and support along the continuum of PMTCT care
14. Describe ways of linking adolescents with needed facility and community-based support services
15. Describe and implement activities to meaningfully involve adolescent clients in clinical services, such as through adolescent peer education programs
16. Prepare and support adolescent clients throughout the transition to adult care
17. Describe how monitoring and evaluation can be used to support adolescent HIV program improvements
18. Demonstrate core competencies in adolescent HIV care and treatment services in a clinical setting
19. Develop a site-specific action plan for implementing adolescent HIV care and treatment services

Session 16.3 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

See *Appendix 16B: Post-Test.*

Exercise 2: Training Evaluation: Individual work	
Purpose	To get participants' feedback on the training
Refer to *Appendix 16C: Training Evaluation Form.*	

Appendix 16A: Adolescent HIV Care and Treatment Action Planning and Implementation Template

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Conduct a needs assessment of adolescent HIV services currently being provided	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Provide training/ orientation to staff and volunteers	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Make the health facility more friendly to adolescent clients	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Involve youth in program design and service delivery	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Improve the quality of adolescent clinical care and treatment services	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Provide “1-stop shopping” to adolescent clients	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop and/or improve appointment and tracking systems	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop peer support programs and support groups for ALHIV	1.				
	2.				
	3.				
Anticipated challenges to implementing this objective and possible solutions: **1.** **2.**					

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop strong referral systems and establish linkages	1.				
	2.				
	3.				

Anticipated challenges to implementing this objective and possible solutions:

1.
2.

Objective	What is the specific activity?	Who is responsible?	What resources or support are needed?	When will the action happen?	Means of verification
Develop and implement data collection, reporting, monitoring, and evaluation systems	1.				
	2.				
	3.				

Anticipated challenges to implementing this objective and possible solutions:

1.
2.

Appendix 16B: Post-Test

Participant identification number: ____________________ **Score: ____**/25

1) Which of the following statements are factors to be considered in the scale up of adolescent HIV care and treatment services? (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) Health workers need specific knowledge and skills to meet the needs of adolescent clients.
    d) Programs and clinical services need to be youth-friendly to attract and retain adolescent clients.

2) Adolescence is a unique stage of life that is characterized by:
    a) Challenging caregivers or elders
    b) A focus on body image
    c) A sense of immortality
    d) Significant physical, emotional, and mental changes
    e) All of the above

3) Which of the following are characteristics of "youth-friendly" services? (select all that apply)
    a) There are special days/times set aside for young people to receive services.
    b) Young clients can only come to the clinic when they have a scheduled appointment.
    c) Young people are involved in designing and monitoring programs.
    d) Multiple services are available in one clinic, known as "one-stop shopping."
    e) Health workers mainly use group counseling sessions in order to save time.

4) To be effective, the adolescent package of care must ensure: (select all that apply)
    a) The integration of services
    b) That services are age- and developmentally-appropriate
    c) That the needs of both perinatally infected adolescents and those infected later in childhood or adolescence are met
    d) That services encourage adolescents to take responsibility for their own health
    e) That adolescent clients receive care in the pediatric clinic for life

5) The adolescent package of HIV care closely resembles the package of HIV care for adults; however, the way services are delivered can impact their success among adolescents.
    a) True
    b) False

6) Adolescent clients should be started on ART when their CD4 cell count is:
    a) 200 or less
    b) 250 or less
    c) 300 or less
    d) 350 or less
    e) None of the above

7) How frequently should CD4 cell count be monitored in adolescent clients?
   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

8) Counseling includes which of the following? (select all that apply)
   a) Solving another person's problems
   b) Helping another person make informed decisions
   c) Telling another person what to do
   d) Respecting everyone's needs, values, culture, religion, and lifestyle
   e) Recording key points of the counseling session in the client's clinic file

9) Family-focused care means that health workers can talk openly with caregivers about any information shared by the adolescent client.
   a) True
   b) False

10) Which of the following are coping strategies that health workers should suggest to adolescent clients to help them reduce stress and promote their psychosocial well being? (select all that apply)
   a) Talking with a Peer Educator
   b) Joining a support group
   c) Exercising
   d) Disclosing their HIV-status to all of their friends
   e) Participating in recreational activities, like sports or youth clubs

11) Which of the following statements about mental illness are correct? (select all that apply)
   a) Mental health problems are very rare among adolescents living with HIV.
   b) Mental illness and substance abuse are closely related.
   c) Only trained psychologists and psychiatrists can recognize the signs of possible mental illness in adolescents.
   d) Adolescents are susceptible to depression, anxiety disorders, behavioral disorders, and alcohol/substance use disorders.
   e) All clinics should have standard procedures on how to manage adolescent clients with possible or confirmed mental illness.

12) Disclosure to a child or adolescent is a one-time event for which the caregiver must be well-prepared.
   a) True
   b) False

13) Which of the following statements about disclosure are true? (select all that apply)
   a) Health workers can work with caregivers to develop and implement a disclosure plan; they can also play a supportive role throughout the disclosure process.
   b) Research shows that disclosing a child/young adolescent's HIV-status often results in psychological problems, emotional harm, and difficulties with adherence.
   c) There are times when health workers may need to facilitate disclosure discussions with children/young adolescents.
   d) It is recommended that children/young adolescents be fully disclosed to when they are developmentally ready — typically by the time they are 10–12 years old.
   e) Health workers should encourage older adolescents not to disclose to their friends because they may face stigma and discrimination.

14) Adherence preparation and ART initiation can usually be completed in 1 visit.
   a) True
   b) False

15) The only reliable way to assess client adherence is with pill counts.
   a) True
   b) False

16) Positive prevention includes which of the following? (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
   d) Prevention and treatment of STIs
   e) Washing hands and bathing regularly
   f) Preventing mother-to-child transmission (PMTCT)

17) Which of the following statements is correct?
   a) Health workers need to stress that ONLY heterosexual behavior is normal.
   b) Health workers should understand different sexual behaviors and sexual orientations and talk openly and non-judgmentally about them with clients.
   c) Health workers need to stress that homosexual and bisexual behavior is abnormal.
   d) Health workers need to stress that transsexual/transgendered behavior should not be tolerated.

18) 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) Using a latex condom during every act of vaginal or anal intercourse
   c) French/deep kissing
   d) Mutual masturbation
   e) Oral sex without a latex barrier

19) The adolescent female genital tract is less susceptible to STIs than that of adult women.
   a) True
   b) False

20) What advice would you give an adolescent client living with HIV who wants to get pregnant? (select all that apply)
   a) It is safest to wait until adulthood to become pregnant.
   b) There are many health, psychological, social, and economical risks of adolescent pregnancy.
   c) Stop having sex because it is dangerous for you and your partner.
   d) It is important to continue to talk with health workers to know the facts and risks about getting pregnant and to understand the facts about PMTCT services.
   e) Switch to or start taking efavirenz before trying to become pregnant.
   f) Make sure you (and your partner, if HIV-infected) are adhering to your ART regimen and have a CD4 count over 500 before trying to get pregnant.

21) Which of the following are usually good contraceptive options for adolescents living with HIV? (select all that apply)
   a) Male and female condoms
   b) Oral contraceptive pills
   c) Spermicides and diaphragms with spermicides
   d) Male and female sterilization
   e) Injectable contraceptives
   f) Hormonal implants

22) Which of the following statements are true? (select all that apply)
   a) Dual protection and dual method use mean the same thing.
   b) Condoms provide dual protection.
   c) Dual protection refers to the practice of taking ART <u>and</u> cotrimoxazole.
   d) Dual method use should be recommended for sexually active adolescents. This means they use condoms and another method of contraception (such as oral or injectable contraceptives).

23) In reference to transitioning to adult care, which of the following statements is true? (select all that apply)
   a) All adolescent clients should be ready to transition to adult care by age 16.
   b) In helping prepare an adolescent to transition, the health worker should support him or her to develop self-care and self-advocacy skills.
   c) In preparation for transition, adolescents should visit and tour the adult HIV clinic.
   d) Adolescent clients should be encouraged to rely more and more on their caregivers to ensure that they adhere to their ART regimen.

24) Which of the following statements about adolescent involvement are true? (select all that apply)
   a) Adolescent peer education programs and community advisory boards are useful mechanisms to involve adolescents in services.
   b) Adolescent peer educators can take on the same responsibilities as adult peer educators.
   c) Adolescent peer educators can help create a safe clinic environment, improve adherence and positive living among clients, and improve service quality.
   d) Asking adolescents to help with clinic filing and cleaning are examples of meaningful involvement.
   e) It is important to have a clear training and supervision plan in adolescent peer educator programs.

25) Which of the following are examples of indicators? (select all that apply)
   a) Number of adolescents who initiated ART in the quarter
   b) Percentage of adolescent clients lost to follow-up in the year
   c) To ensure that 95% of eligible adolescent clients initiate ART this year
   d) All adolescent clients should be screened for TB at enrollment
   e) % of adolescent clients screened for TB at enrollment in the quarter

Appendix 16C: Training Evaluation Form

Name (optional): ___________________________________

Your position (optional): ____________________________________

Health facility where you work (optional): ________________________________

INSTRUCTIONS: *Please rate the following statements on a scale from 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 (i.e., interesting).	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 the 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 Counseling 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 Illness	1	2	3	4	5
Module 7: Providing Disclosure Counseling 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
Module 11: Family Planning and PMTCT Services for Adolescents	1	2	3	4	5

	☹ Not helpful				☺ Very helpful
Module 12: Community Linkages and Adolescent Involvement	**1**	**2**	**3**	**4**	**5**
Module 13: Supporting the Transition to Adult Care	**1**	**2**	**3**	**4**	**5**
Module 14: Monitoring, Evaluation, and Quality Improvement	**1**	**2**	**3**	**4**	**5**
Module 15: Supervised Clinical Practicum	**1**	**2**	**3**	**4**	**5**
Module 16: Action Planning, Course Evaluation, and Closure	**1**	**2**	**3**	**4**	**5**

What was the best part of this training?

How could we improve this training?

Other comments:

Thank you for your participation and for your commitment to adolescents and families!