

# Module 8      Supporting Adolescents' Retention in and Adherence to HIV Care and Treatment

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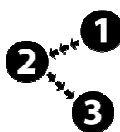
**Total Module Time:** 240 minutes (4 hours)

## 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

## Methodologies



- Interactive trainer presentation
- Brainstorming
- Large group discussion
- Pair work
- Small group work
- Case studies
- Role play

## Materials Needed



- Slide set for Module 8
- Flip chart and markers
- Tape or Bostik (adhesive putty)
- Any adherence support tools that are available to adolescents, such as pill boxes, medicine calendars or diaries, etc.
- Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

## Resources



- 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.
- ICAP. (2010). *Improving retention, adherence, and psychosocial support within PMTCT services: A toolkit for health workers*. ICAP.
- Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0*. ICAP.
- Panel on Antiretroviral Therapy and Medical Management of HIV-Infected Children. (2011). *Guidelines for the use of antiretroviral agents in pediatric infection*. pp. 1-268. Available at: <http://aidsinfo.nih.gov/ContentFiles/PediatricGuidelines.pdf>
- WHO. (2010). *Antiretroviral therapy for HIV infection in infants and children: Towards universal access, Recommendations for a public health approach*. Geneva, WHO Press.
- WHO. (2006). *Antiretroviral therapy for HIV infection in adults and adolescents, Recommendations for a public health approach*. Geneva: WHO Press.

## Advance Preparation



- Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies.
- Review the appendices so that you can refer to them and integrate them into your presentation.
- Make photocopies of the tools in *Appendix 8A, 8B, and 8C* for each participant to use during the exercises.
- Review the national adult/adolescent and pediatric ART guidelines and be prepared to discuss the recommended number and content of adherence preparation sessions for adolescents initiating ART, as well as any national recommendations and guidelines for adherence assessment and follow-up counseling. Make photocopies of any national adherence counseling guidelines and checklists for each participant and be prepared to incorporate them into the discussion.
- Exercises 1 and 2 require advance preparation.

### Session 8.1: Introduction to Retention and Adherence

Activity/Method	Time
Interactive trainer presentation, brainstorming, and large group discussion	25 minutes
Questions and answers	5 minutes
Total Session Time	30 minutes

### Session 8.2: Supporting Retention and Adherence to Care

Activity/Method	Time
Interactive trainer presentation, brainstorming, and large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	25 minutes

### Session 8.3: Providing Adherence Preparation Support to ALHIV and Caregivers

Activity/Method	Time
Interactive trainer presentation, large group discussion, and pair work	50 minutes
Exercise 1: Developing an Adherence Plan: Trainer demonstration, case studies in small groups, and large group discussion	50 minutes
Questions and answers	5 minutes
Total Session Time	105 minutes

### Session 8.4: Assessing Adherence and Providing Ongoing Adherence Support

Activity/Method	Time
Interactive trainer presentation and large group discussion	15 minutes
Exercise 2: Assessing Adherence and Providing Support: Small group work, role play, and large group discussion	50 minutes
Questions and answers	5 minutes
Review of Key Points	10 minutes
Total Session Time	80 minutes

## Session 8.1

# Introduction to Retention and Adherence



**Total Session Time:** 30 minutes



### Trainer Instructions

Slides 1-5

#### Step 1:

Begin by reviewing the Module 8 learning objectives and the session objectives, listed below.

#### Step 2:

Ask participants if there are any questions before moving on.

## 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



### Trainer Instructions

Slides 6-12

#### Step 3:

Explain to participants that retaining ALHIV in care and supporting their adherence to both HIV care and treatment is one of the most important, yet challenging, tasks health workers face.

#### Step 4:

Write “**RETENTION**,” “**ADHERENCE TO HIV CARE**,” and “**ADHERENCE TO TREATMENT**,” each on 1 piece of flip chart. Ask participants to brainstorm what we mean by each of these terms or phrases. Ask for a volunteer to record participants’ answers on the flip charts and fill in using the information below and in the slides.

Next, write “**NON-ADHERENCE**” on a piece of flip chart and ask participants to discuss what this phrase means. Ask for a volunteer to record participants’ responses on the flip chart and fill in using the content below and in the slides.

Lastly, ask participants to discuss this question:

- *Why is excellent adherence to care and treatment important for ALHIV?*

Fill in using the content below.

**Step 5:**

Debrief by reminding participants that retention and adherence are closely related and are key components of comprehensive adolescent HIV care and treatment. Explain that health workers and health systems play an important role in retaining clients in care. Also explain that adherence support for ALHIV and their caregivers should be ongoing — not one-time events — and that the entire multidisciplinary team is responsible for providing these services.

**Make These Points**

- 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 adolescent clients, this also means transitioning them to adult care and treatment.
- Adherence means how faithfully people stick to their care and treatment plan.
- Adherence to treatment is important to lower the amount of HIV in a person’s body and to make sure he or she gets all the benefits that OI medicines and ART have to offer (feeling better, not getting sick, etc.).
- 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, i.e. clients should “stick to” at least 95% of their drug schedule. Therefore, it is our aim as health workers to support clients to achieve and sustain this rate of adherence.
- Non-adherence to treatment can lead to drug resistance, preventing ART from working and causing people to get very sick. Non-adherence can cause CD4 counts to decrease, opportunistic infections to occur, resistance to emerge, and viral replication to continue.
- Retention and adherence are closely related. Good retention and adherence can be achieved through partnerships between caregivers, ALHIV, treatment buddies, and the entire multidisciplinary care team.

## Overview of Retention and Adherence

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**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:**

- 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**

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

**Adherence to care includes:**

- Entering into and continuing on a lifelong care and treatment plan
- Attending appointments and tests, such as regular CD4 tests, as scheduled
- Taking (or giving) medicines to prevent and treat opportunistic infections
- Participating in ongoing 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.**



#### Trainer Instructions

Slides 13-19

#### Step 6:

Post 4 pieces of flip chart around the training room, each with one of the following labels: “**HEALTH SERVICES FACTORS,**” “**INDIVIDUAL FACTORS (about the adolescent),**” “**COMMUNITY AND CULTURAL FACTORS,**” and “**MEDICATION FACTORS.**”

Ask participants to brainstorm key factors affecting ALHIV's retention and adherence. Ask:

- *What are the most common retention and adherence issues for ALHIV?*
- *What are the most common factors affecting retention and adherence among younger adolescents?*
- *How about among older adolescents?*

For each response, ask participants which category (health services, individual, community and cultural, or medication-related) their response fits under. Record responses on the appropriate flip chart and fill in using the content below and in the slides.

Remind participants that most clients **do** want to adhere to their care and treatment plan, but that there are often barriers that get in the way.

#### Step 7:

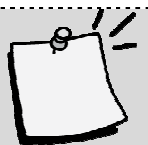
After this brainstorming activity, ask participants:

- *Which of these issues do you think has the greatest impact on an adolescent's retention and adherence? Why?*

Explain to participants that in the next session we will talk about specific actions that health workers can take to support retention and adherence.



(optional) If willing and comfortable, ask the adolescent co-trainer to offer his or her opinion and to respond to the discussion question above.



### Make These Points

- There are many barriers and challenges to retention and good adherence, including factors related to clients' lives, factors related to the medicines they take, and factors related to the health care system and HIV program.
- There are many challenges to adherence that are more common in ALHIV: they engage in more risk-taking behaviors, they have a desire to “fit in” with peers and appear “normal,” they may not take their medicines as a way of demonstrating defiance or because of a need to define their identity, etc.
- We often blame clients for not adhering to care and treatment, but not having access to quality, youth-friendly health services is often one of their biggest barriers to retention and adherence.

## 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.

	<p><b>Trainer Instructions</b> Slide 20</p>
<p><b>Step 8:</b></p>	<p>Allow 5 minutes for questions and answers on this session.</p>

## Session 8.2

# Supporting Retention and Adherence to Care



**Total Session Time:** 25 minutes



### Trainer Instructions

Slides 21-22

- Step 1:** Begin by reviewing the session objective listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### 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



### Trainer Instructions

Slides 23-28

- Step 3:** Explain that while we, as health workers, are not always able to address all of the client's barriers to adherence, there are many factors that we CAN address in order to support his or her retention and adherence to care.
- Ask participants to brainstorm:
- *What are some of the ways that health workers can minimize barriers to retention and adherence to care?*
- (Refer to the flip chart on “**HEALTH SERVICES FACTORS**” from the last session). Encourage participants to brainstorm actions that individual health workers can take as well as actions taken at the facility or systems level.
- Record answers on flip chart and fill in using the content below and in the slides.
- Step 4:** Ask participants to think about the facility where they work. Lead a discussion about the specific actions that could be taken to improve retention at the facility, using the following questions as a guide:
- *Which of the areas discussed are lacking at your facility?*
  - *How could these areas be improved to better support ALHIV's retention in care at your facility?*

- *What are some of the challenges of implementing these actions? What are some of the solutions?*

Participants should feel free to refer to their partially completed *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services*, which was discussed in Module 2. This assessment tool can provide some insight into making services more youth-friendly, which directly affects client retention in care.



(optional) Ask the adolescent co-trainer to comment on some of the reasons that ALHIV may not be retained in care and what he or she thinks health workers and health facilities can do to help retain clients over the long term.



### Make These Points

- 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 in care is to ensure that services are youth-friendly. Refer to *Appendix 2B: Checklist and Assessment Tool for Youth-Friendly HIV Care and Treatment Services* in Module 2 for a listing of the characteristics of youth-friendly services.
- Some suggestions to make services youth-friendly include: offering services at times when adolescents can attend (after school and on weekends); ensuring staff are friendly, non-judgmental, and respectful; and establishing appointment and tracking systems.
- A CAB (consumer/client/community advisory board) can provide further guidance to ensure that services meet the needs of adolescent clients. (Note that there is more discussion of CABs in Module 12.)
- Services that are youth-friendly increase the likelihood of client retention and also support perfect or near-perfect adherence to treatment.

## 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.\*
- 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.



**Trainer Instructions**  
Slide 29

**Step 5:** Allow 5 minutes for questions and answers on this session.

## Session 8.3

# Providing Adherence Preparation Support to ALHIV and Caregivers



**Total Session Time:** 105 minutes (1 hour, 45 minutes)



### Trainer Instructions

Slides 30-31

- Step 1:** Begin by reviewing the session objectives listed below.
- Step 2:** Ask participants if there are any questions before moving on.

### 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

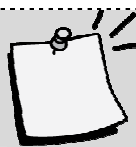


### Trainer Instructions

Slides 32-35

- Step 3:** Remind participants that some of their adolescent clients will have been on ART for many years and others will just be starting ART. In this session, we will focus on adolescent clients who are starting ART for the first time, and their caregivers.
- Ask participants to turn to the person seated next to them and assign each pair 1-2 of the questions below. Give the pairs about 5 minutes to discuss and then lead a large group discussion about all of the questions. Record responses on flip chart and fill in using the content below and in the slides.
- *What happens at your clinic now to prepare adolescent clients and caregivers to start ART?*
  - *What do you think works well? What are some of the challenges?*
  - *What are some considerations for younger adolescents in terms of adherence readiness and preparation?*
  - *What is a treatment buddy and how might a treatment buddy help an adolescent client?*
- Step 4:** Remind participants that, 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.

While it is important that health workers provide initial adherence preparation education and support, it is even more crucial that they provide ongoing adherence support to ALHIV and their caregivers over time and at every clinic visit.



### Make These Points

- Ideally, adherence preparation counseling should begin early during HIV care, but this should not be a reason to delay initiation of ART for most ALHIV.
- ART preparation usually includes group education sessions, individual counseling sessions, and an adherence readiness assessment.
- Each client should have AT LEAST one individual counseling session with a health worker (and/or other members of the multidisciplinary team, such as a Peer Educator or counselor) before starting ART. Young adolescents, when possible, should be accompanied during these sessions by a caregiver or another person who can provide them with support.
- Treatment buddies can be especially helpful for adolescent clients. A treatment buddy or treatment supporter is someone who is chosen by a client getting ready to start ART to provide him or her with ongoing adherence support.

## Adolescent-Friendly ART Adherence Preparation

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### 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.



#### Trainer Instructions

Slides 36-37

#### Step 5:

Provide an overview of any national adherence preparation guidelines and tools. Allow participants time to discuss the topics covered in addition to why each is important to adherence preparation.

Alternatively, ask for a volunteer participant familiar with national adherence preparation guidelines to lead this discussion.

#### Step 6:

Post 1-2 flip charts labeled “**ADHERENCE PREPARATION TOPICS**” on the wall. Give participants markers and ask them to write down which topics, based on their experience, they think are most important to cover during adherence preparation sessions with ALHIV and caregivers.

Once participants have recorded their responses, ask them to be seated and refer them to Table 8.1: “Key Topics for Adherence Preparation Education and Counseling.” Ask for participants to volunteer to read out the topic areas in the Table, comparing this list with the responses on the flip charts, and discuss why each topic is important. Ask if there are any additional topics that participants feel should be covered and record these on the flip chart as well.

Remind participants that it may be helpful to develop a checklist to ensure that adherence preparation sessions are consistent.





(optional) If willing and comfortable, ask the adolescent co-trainer to talk about his or her experiences starting ART (assuming that he or she started ART as an adolescent and not a baby). For example, the adolescent co-trainer could discuss the following:

- *Can you remember when you started ART? What kind of education and support did you and/or your caregivers receive at the clinic?*
- *What were your concerns about starting ART? Do you remember if your caregiver also had concerns?*
- *What was good about the adherence preparation you received? What could have been better?*
- *Do you have a treatment buddy? How does he or she help you?*



### **Make These Points**

- National adult and pediatric ART guidelines usually specify how many adherence preparation sessions are required as well as the content that should be covered during each session. Always follow national guidelines.
- It may be helpful to develop a checklist of adherence preparation topics to ensure that sessions are consistent and cover all of the necessary information.

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

<b>Key Topics to Discuss in Group Education and Individual Counseling Sessions with Clients Starting ART (and their Caregivers)</b>
<b>HIV Care and Treatment Basics</b>
<ul style="list-style-type: none"><li>• Understanding the diagnosis</li><li>• How HIV is transmitted and prevented</li><li>• How HIV affects the immune system</li><li>• The meaning of CD4 count</li><li>• Who needs ART</li><li>• Benefits of ART</li><li>• Importance of ongoing care and regular clinic visits</li><li>• Positive living</li><li>• HIV and sexual initiation, safer sex, dual protection, and prevention and treatment of STIs</li><li>• OI prophylaxis (especially CTX)</li><li>• TB prevention and treatment</li><li>• Importance of disclosure (own disclosure, disclosure to peers, sexual partners)</li><li>• Family testing and enrollment</li></ul>
<b>Adherence to Care and Treatment</b>
<ul style="list-style-type: none"><li>• Beliefs and attitudes about ART</li><li>• ART = lifetime commitment</li><li>• Importance of adherence to care plan and to treatment for own health and to prevent HIV transmission to sexual partners</li><li>• What happens when a person does not adhere</li><li>• Importance of social support for adherence, including having a treatment buddy and/or directly observed therapy (DOT)</li><li>• Understanding the treatment plan (explanation of each medicine, the dosing schedule, missed/late doses, adjustments according to school hours, etc.)</li><li>• How medicines are to be taken (and for young adolescents, how to measure and give medications, tips for children on swallowing pills)</li><li>• Preventing and managing side effects</li><li>• Previous adherence experiences (CTX, TB medicines, etc.), strategies, and challenges</li><li>• Adherence strategies, tips, and tools</li><li>• Problem-solving around adherence barriers, including the use of tools like medicine diaries, pill boxes, watches, cell phones, etc.</li><li>• How to make one's care and treatment plan part of one's everyday life and developing an individual adherence plan</li><li>• What to do if there is a problem or question</li><li>• Planning 2-week and subsequent follow-up visits</li><li>• Linkages and referral to support groups and community support services</li></ul>



### Trainer Instructions

Slides 38-40

#### Step 7:

Explain that when helping clients and caregivers prepare for ART, health workers should always address the ARE YOU COMMITTED? question and then the WHO, WHAT, WHEN, WHERE, and HOW of the medicines (see content below). Ask participants to discuss how answering these questions will help the client and caregiver come up with an individual adherence plan.

#### Step 8:

Refer participants to *Appendix 8A: Adherence Support Tree*, introducing the tool and explaining that health workers can use it to help clients and caregivers prepare for adherence to ART and to ask about adherence at follow-up appointments. Review the instructions for using the tree to help adolescent clients make an individualized adherence plan.

Ask participants to turn to the person seated next to them and to spend about 5 minutes practicing using the Adherence Support Tree. One person should play the role of the health worker and the other should play the role of an adolescent client. The health worker should use the Adherence Support Tree to discuss the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. After a few minutes, ask them to switch roles.

Debrief by asking participants:

- *What do you think of the Adherence Support Tree?*
- *How could the Adherence Support Tree be used in your clinic setting?*



### Make These Points

- When helping adolescent clients and caregivers prepare for ART, health workers should always address the ARE YOU COMMITTED? question and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines.
- The Adherence Support Tree in *Appendix 8A* can be a useful tool for health workers to discuss these questions and to make an individual adherence plan with adolescent clients.

## 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.



#### Trainer Instructions

Slides 41-44

#### Step 9:

Ask participants what system they currently use to assess clients' readiness to begin ART.

Explain that a standardized assessment tool can help health workers decide whether a client (and caregiver) is ready to start ART. Make the point, however, that assessment questions should NOT be used as a "test" or a reason to delay ART initiation. Instead, assessment questions should be used to identify areas where the client and caregiver may need additional support over time, once they have started ART.

Review each guide in *Appendix 8B: Adherence Preparation and Support Guides*, including the instructions. Ask participants:

- *How could this assessment be modified for adolescents of different ages?*
- *How do you think you could use these tools in your work/clinic?*

Tell participants that they will have a chance to practice using these guides in the next exercise.



### Make These Points

- A standardized assessment tool can help health workers determine client and caregiver readiness for ART and can help them work together to make an adherence plan. The assessment questions should be used to identify areas where the client and/or caregiver may need additional information and support. It should not be used as a ‘test’ that the client needs to pass before he or she can start ART.
- The Adherence Preparation and Support Guides in *Appendix 8B* can be useful tools for health workers to identify areas where clients and caregivers may need more adherence support and to assess their readiness to start ART.

## 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.

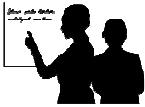


### Trainer Instructions

Slides 45-52

#### Step 10:

Lead participants through Exercise 1, which provides them with an opportunity to practice and discuss conducting adherence preparation sessions with adolescent clients and caregivers.

<b>Exercise 1: Developing an Adherence Plan: Trainer demonstration, case studies in small groups, and large group discussion</b>	
<b>Purpose</b>	To practice conducting adherence preparation counseling with adolescent clients and caregivers, including using the Adherence Support Tree ( <i>Appendix 8A</i> ) and the Adherence Preparation and Support Guides ( <i>Appendix 8B</i> )
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>• Review the case studies and make adjustments as needed.</li> <li>• Be prepared to explain how to use <i>Appendix 8A: Adherence Support Tree</i> and <i>Appendix 8B: Adherence Preparation and Support Guides</i>. If possible, make extra copies of these tools for each participant in advance.</li> <li>• If there are national guidelines on adherence preparation sessions and content, pass out a copy to each participant and be prepared to incorporate the guidelines into the discussion.</li> </ul>
<b>Introduction</b>	<p>Explain that, in this activity, we are going to explore how to educate, counsel, prepare, and assess the readiness of adolescent clients (and caregivers) who are preparing to start taking ART.</p> <p>Ask participants to review the case studies in their participant manuals. Refer participants to <i>Appendix 8A: Adherence Support Tree</i> and <i>Appendix 8B: Adherence Preparation and Support Guides</i>. Then refer participants to any national guidelines or checklists on adherence preparation that you have collected and photocopied in advance.</p>
	<p><b>Part 1: Trainer Demonstration and Role Play</b></p> <ol style="list-style-type: none"> <li>1. The trainer should start the activity by role playing the first case study below with 2 volunteer participants (or 1 volunteer participant and the adolescent co-trainer). The trainer should play the role of the health worker who is assisting the client to develop an adherence plan; 1 volunteer should play an adolescent who is about to start ART; and the other volunteer should play his or her caregiver. Ask the other participants to observe the counseling session and to ask questions at the end. This portion of the exercise should take approximately <u>20 minutes</u>.</li> <li>2. (optional) Encourage participation by the adolescent co-trainer. Ask the following questions to encourage his or her participation: <ul style="list-style-type: none"> <li>• <i>What did the health worker do to build trust and rapport with the client?</i></li> <li>• <i>What were the key ART readiness issues for the client? How did the health worker respond?</i></li> <li>• <i>Can you summarize the final adherence plan that was agreed upon for this client?</i></li> <li>• <i>Based on your own experience, is there anything else the health worker could have suggested or done to address the client's adherence challenges?</i></li> </ul> </li> </ol>

	<p><b>Part 2: Small Group Work</b></p> <p>3. Next, break participants into 4 small groups and assign each a case study (there are 5 case studies below, but the first will have been used in Part 1 of this exercise). Ask participants to discuss and respond to the questions at the end of their case study.</p> <p><b>Part 3: Large Group Discussion</b></p> <p>4. Bring the large group back together and ask each group to summarize its case study discussion. Ask the following questions to facilitate discussion and record responses on a flip chart (this portion of the exercise should take approximately 15 minutes):</p> <ul style="list-style-type: none"> <li>• <i>How did you decide on an adherence plan with the client or caregiver? What tools did you use? How would you measure the plan's success or outcome?</i></li> <li>• <i>Did you have any concerns about the client initiating ART? How would you address these concerns with the client and/or caregiver?</i></li> <li>• <i>What advice did you give to the client about adherence to care and medicines? The caregiver?</i></li> </ul> <p>5. If time allows, invite 1 or 2 of the groups to conduct a short role play in front of the large group.</p>
<b>Debriefing</b>	<ul style="list-style-type: none"> <li>• As health workers, one of our most important tasks is to provide adherence preparation counseling and support to our adolescent clients and their caregivers.</li> <li>• Group sessions are helpful for providing the content of adherence preparation, but individual sessions are required to explore and discuss clients' specific situations and to make an individual adherence plan with them and their caregivers.</li> <li>• Remember that when helping clients and caregivers develop an adherence plan, health workers should always address the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. Using the Adherence Support Tree in <i>Appendix 8A</i> can help with this.</li> <li>• Using standardized assessment tools (such as those in <i>Appendix 8B</i>) can help determine a client's and his or her caregiver's readiness for ART and can help health workers work with them to develop an adherence plan.</li> </ul>

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

### Case Study 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?*

### Key points for trainers: B\_\_\_ and her auntie

- Start by asking B\_\_\_ and her auntie what questions they have so far. Go over some of the key topics covered during the group sessions just to make sure they understood them (for example: *"I see your CD4 count is 350, can you tell me what a CD4 cell is?"*; *"I see you are on CTX, do you remember what CTX does?"*; *"We are going to start you on ART, can you tell me how you think ART will help you?"*; *"Why do you think excellent adherence is so important?"*). Emphasize the relationship between poor adherence and drug resistance.
- Next, start working with B\_\_\_ and her auntie to develop a personal adherence plan by asking the ARE YOU COMMITTED? question and then (assuming B\_\_\_ reassures you that she is planning to take her ART), ask the WHO, WHAT, WHEN, WHERE, and HOW questions. Use the Adherence Support Tree (*Appendix 8A*) to work through these questions.
- Administer the "Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART" (*Appendix 8B*) to B\_\_\_ and the "Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART" (*Appendix 8B*) to her auntie. Administer the guides to each separately, skipping any questions that were answered during the WHO, WHAT, WHEN, WHERE, and HOW discussion. In cases where their answers for parallel questions differ greatly, discuss with both of them together.
- Because B\_\_\_ is only 11, ensure that her auntie is ready to take an active role in assuring that B\_\_\_'s adherence is excellent.
- Record key points as you go along. Reassure B\_\_\_ and her auntie that starting ART is the right decision and that you are confident in B\_\_\_'s ability to adhere to her medicines with her auntie's help. As you close the discussion, summarize the key points (using your notes) and any next steps.

### 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?*



### Key points for trainers: S\_\_\_

- Start by asking S\_\_\_ what questions he has so far. Go over some of the key topics covered during the group sessions just to make sure he understood them (for example: “I see your CD4 count is 350, can you tell me what a CD4 cell is?”; “I see you are on CTX, do you remember what CTX does?”; “We’re going to start you on ART, can you tell me how you think ART will help you?”; “Why do you think excellent adherence is so important?”). Get him to do most of the talking and ensure he understands the relationship between poor adherence and drug resistance.
- Next, start working with S\_\_\_ to develop a personal adherence plan by asking the ARE YOU COMMITTED? question and then (assuming S\_\_\_ reassures you that he is planning to take his ART), ask the WHO, WHAT, WHEN, WHERE, and HOW questions. Use the Adherence Support Tree (*Appendix 8A*) to work through these questions.
- Pay special attention to his response to the WHO question. It’s quite likely that he won’t have anyone to help him remember to take his medications. This is OK — as long as you are satisfied that he has other ways of remembering.
- Also pay attention to his responses to the WHEN, WHERE, and HOW questions. Work with him to come up with a sustainable routine that works with his lifestyle. Apply any tricks he uses to adhere to CTX to his plan for adhering to ART.
  - For example, he might want to take his morning dose before he goes to work and his evening dose after or with dinner. Because he works a long day, this might mean that his evening dose is more than 12 hours after his morning dose and only 10 hours before the dose the next morning. Although he should ideally take his medicines every 12 hours, it is better to separate doses into a schedule that works for him and will help him adhere. Alternatively, he may want to take his morning dose at home before he leaves for work and then use a small pillbox to carry the rest of that day’s pills so he can take his evening dose while he is still at work.
- Make sure he knows what to do if he misses a dose.
- Reassure him that any 17-year-old responsible enough to hold down a job can certainly apply the same skills to taking medicines every day.
- Administer the “Adherence Preparation/Support Guide for Assessing Adolescents’ Readiness for ART” (*Appendix 8B*) to S\_\_\_ . Feel free to skip any questions that were answered during the WHO, WHAT, WHEN, WHERE, and HOW discussion.
- Record key points as you go along. Reassure S\_\_\_ that starting ART is the right decision and that you are confident in his ability to adhere to his medicines. As you close the discussion, summarize the key points (using your notes) and any next steps.

### 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?

### Key points for trainers: L\_\_\_ and her cousin

- Start by asking L\_\_\_ and her cousin what questions they have so far. Go over some of the key topics covered during the group sessions just to make sure they understood them (for example: *“I see your CD4 count is 350, can you tell me what a CD4 cell is?”*; *“I see you are on CTX, do you remember what CTX does?”*; *“We’re going to start you on ART, can you tell me how you think ART will help you?”*; *“Why do you think excellent adherence is so important?”*). Emphasize the relationship between poor adherence and drug resistance.
- Next, start working with L\_\_\_ and her cousin to develop a personal adherence plan by asking the ARE YOU COMMITTED? question and then (assuming L\_\_\_ reassures you that she is planning to take her ART), ask the WHO, WHAT, WHEN, WHERE, and HOW questions. Use the Adherence Support Tree (*Appendix 8A*) to work through these questions.
- Ask about disclosure. Obviously, L\_\_\_’s cousin knows that she has HIV, but how about her parents? Can her parents assist at all or do her medicines have to be hidden at all times?
- Administer the “Adherence Preparation/Support Guide for Assessing Adolescents’ Readiness for ART” (*Appendix 8B*) to L\_\_\_ and the “Adherence Preparation/Support Guide for Assessing Caregivers’ Readiness for ART” (*Appendix 8B*) to her cousin. Administer the guides to each separately, skipping any questions that were answered during the WHO, WHAT, WHEN, WHERE, and HOW discussion. In cases where their answers to parallel questions differ greatly, discuss with both of them together. Given that L\_\_\_ and her cousin do not live together, ask how they will ensure ongoing communication.
- Record key points as you go along. Reassure L\_\_\_ and her cousin that starting ART is the right decision and that you are confident in L\_\_\_’s ability to adhere to her medicines with her cousin’s help. As you close the discussion, summarize the key points (using your notes) and any next steps.

#### 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?*

### Key points for trainers: J\_\_\_ and her father

- Start by addressing J\_\_\_'s father's concern about ART. Explain what will happen to J\_\_\_ if she does not go on ART versus what happens to clients who do go on ART. Consider pairing the father with the parent of other ALHIV who are on ART so that he can hear about the benefits of ART from a peer. If there are local community or religious leaders who are vocal about the advantages of ART, ask that J\_\_\_'s father discuss the subject with them. Consider delaying initiation until the next visit if you think this might help.
- Next, ask J\_\_\_ and her father what (other) questions they have so far. Go over some of the key topics covered during the group sessions just to make sure they understood them (for example: *"I see your CD4 count is 350, can you tell me what a CD4 cell is?"*; *"I see you are on CTX, do you remember what CTX does?"*; *"We are going to start you on ART, can you tell me how you think ART will help you?"*; *"Why do you think excellent adherence is so important?"*). Emphasize the relationship between poor adherence and drug resistance.
- Then start working with J\_\_\_ and her father to develop a personal adherence plan by asking the ARE YOU COMMITTED? question and then (assuming J\_\_\_ reassures you that she is planning to take her ART), ask the WHO, WHAT, WHEN, WHERE, and HOW questions. Use the Adherence Support Tree (*Appendix 8A*) to work through these questions.
- When discussing WHO (*"Is there someone who can help you come to the clinic for appointments?"*), discuss the father's role. Enquire about the father's extensive work commitments and see how he and J\_\_\_ want to work around them. Ask if there is anyone else who can act as her treatment buddy when her father is absent? Does her older brother know she has HIV? If so, could he take on this role?
- Administer the "Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART" (*Appendix 8B*) to J\_\_\_ and the "Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART" (*Appendix 8B*) to her father. Administer the guides to each separately, skipping any questions that were answered during the WHO, WHAT, WHEN, WHERE, and HOW discussion. In cases where their answers to parallel questions differ greatly, discuss with both of them together.
- Record key points as you go along. Reassure J\_\_\_ and her father that starting ART is the right decision and that you are confident in J\_\_\_'s ability to adhere to her medicines. As you close the discussion, summarize the key points (using your notes) along with any next steps.

#### 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?*

### Key points for trainers: N\_\_\_

- Start by asking N\_\_\_ what questions he has so far. Go over some of the key topics covered during the group sessions to make sure he understood them (for example: “I see your CD4 count is 350, can you tell me what a CD4 cell is?”; “I see you are on CTX, do you remember what CTX does?”; “We’re going to start you on ART, can you tell me how you think ART will help you?”; “Why do you think excellent adherence is so important?”). Get him to do most of the talking and make sure he understands the relationship between poor adherence and drug resistance.
- Next, start working with N\_\_\_ to develop a personal adherence plan by asking the ARE YOU COMMITTED? question and then (assuming N\_\_\_ reassures you that he is planning to take his ART), ask the WHO, WHAT, WHEN, WHERE, and HOW questions. Use the Adherence Support Tree (*Appendix 8A*) to work through these questions.
- Pay special attention to his response to the WHO question. Now that you know his partner, A\_\_\_, is HIV-infected, ask if A\_\_\_ is on ART. If not, ensure A\_\_\_ is in care. If so, consider suggesting A\_\_\_ as a possible treatment buddy for N\_\_\_. Recommend that A\_\_\_ accompany him to his next visit. Consider postponing the remaining points of this counseling session until the next visit when A\_\_\_ can accompany him.
- Pay attention to his responses to the WHEN, WHERE, and HOW questions. Work with him to ensure that he can come up with a sustainable routine that works with his lifestyle. Apply any tricks he uses to adhere to CTX to his plan for adhering to ART. Apply lessons learned from missed doses of CTX to his plan for adhering to ART.
- Given N\_\_\_’s lack of commitment to school, listen carefully for statements suggesting that he’s not committed to his long-term health. Ensure that he knows that, by living positively, he can have a normal life. Discuss safer sex with N\_\_\_, give him condoms, and, if he doesn’t already know how, show him how to use them.
- Make sure he knows what to do if he misses a dose.
- Administer the “Adherence Preparation/Support Guide for Assessing Adolescents’ Readiness for ART” (*Appendix 8B*) to N\_\_\_. Feel free to skip questions that were already answered during the WHO, WHAT, WHEN, WHERE, and HOW discussion.
- Record key points as you go along. Reassure N\_\_\_ that this is the right decision and that you are confident in his ability to adhere to his medicines. As you close the discussion, summarize the key points (using your notes) along with any next steps.



#### Trainer Instructions

Slide 53

#### Step 11:

Allow 5 minutes for questions and answers on this session.

## Session 8.4

# Assessing Adherence and Providing Ongoing Adherence Support



**Total Session Time:** 80 minutes (1 hour, 20 minutes)



### Trainer Instructions

Slides 54-55

#### Step 1:

Begin by reviewing the session objectives listed below.

#### Step 2:

Ask participants if there are any questions before moving on.

## 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



### Trainer Instructions

Slides 56-60

#### Step 3:

Ask participants the following questions to facilitate discussion. Record responses on a flip chart.

- *How do you currently assess adherence with clients at your clinic? With caregivers? What works well? What is challenging?*
- *What questions would you ask clients and caregivers to assess adherence?*
- *What other methods (for example, pill count) would you use to assess adherence?*

Briefly review some of the methods used to assess adherence, using the content below and in the slides.



(optional) Ask the adolescent co-trainer the following questions to encourage participation:

- *What challenges have you, or adolescents you know, had with adherence? How do you think some of these challenges are different for adolescents than they are for adults?*
- *When/why is it most difficult to remember your medicines?*
- *How can health workers support ALHIV's adherence?*

**Step 4:**

Review *Appendix 8C: Adherence Assessment Guides* with participants and discuss how to conduct an adherence assessment. Note that there are 2 guides — 1 for adolescent clients and another for caregivers. If there are national guidelines and tools for adherence assessment, pass out copies to each participant and incorporate them into the discussion and exercise.

Ask participants:

- *Why might it be important to ask adolescent clients and caregivers about adherence separately?*
- *How could these assessments be modified for young versus older adolescents?*
- *How do you think you could use these tools in your work/clinic?*

Remind participants that they will be able to practice using these tools in the exercise that follows.

**Make These Points**

- Assessing adherence and providing adherence support to clients and caregivers are important tasks, but they can be challenging. There is no one particular way of assessing adherence. 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.
- It is important to conduct the adherence assessment in an individual counseling session to increase the likelihood of getting accurate responses and to provide an opportunity to offer individual support tailored to the adolescent's adherence needs. The Adherence Assessment Guides in *Appendix 8C* can be useful tools for health workers when asking clients and caregivers about adherence at follow-up visits.

## 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.
- 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

**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.

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.



**Trainer Instructions**  
Slides 61-63

**Step 5:** Discuss why it is important to provide ongoing adherence counseling and support to clients and caregivers. Ask the following questions to facilitate discussion:

- *Why is it important to provide ongoing adherence support?*
- *How do you think we can support long-term adherence to care among younger adolescents? Older adolescents? Caregivers?*

**Step 6:** Discuss what health workers should do when:

- A client seems to be adhering well to their care and treatment plan
- A client seems to be having adherence challenges

Fill in using the content below and in the slides.



### Make These Points

- Health workers can PREVENT adherence problems by providing individual counseling and support to help clients overcome barriers to adherence.
- Ongoing adherence support is especially important for adolescents. This is because their adherence to care and medications will not be static — meaning that it changes over time — especially for ALHIV who are going through different phases of life and different life situations.
- Peer education and support groups are valuable tools that can help adolescent clients with their adherence.
- Adherence support services should be ongoing rather than one-time events. The entire multidisciplinary team — not just counselors or Peer Educators — is responsible for providing these services.

## Providing Ongoing Adherence Support

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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.





### Trainer Instructions


Slides 64-70

#### Step 7:

Lead participants through Exercise 2, which provides an opportunity to practice conducting an adherence assessment with clients and caregivers (including using the Adherence Assessment Guides in *Appendix 8C*) and providing them with ongoing adherence support.

### Exercise 2: Assessing Adherence and Providing Support: Small group work, role play, and large group discussion

<b>Purpose</b>	To practice conducting adherence assessments with adolescent clients and caregivers and to practice providing ongoing adherence support
<b>Duration</b>	50 minutes
<b>Advance Preparation</b>	<ul style="list-style-type: none"> <li>Review the case studies and adapt if needed.</li> <li>Be prepared to adequately explain how to complete the adherence assessment tool in <i>Appendix 8C: Adherence Assessment Guides</i>.</li> <li>Make additional copies of <i>Appendix 8C</i></li> <li>If national adherence assessment guides/forms exist, be sure that each participant has copies and incorporate them into the exercise.</li> </ul>
<b>Introduction</b>	Explain that, during this activity, we are going to practice conducting adherence assessments with adolescent clients and caregivers, and also practice providing them with ongoing adherence support and counseling.
<b>Activities</b>	<p><b>Part 1: Role Play</b></p> <ol style="list-style-type: none"> <li>Break participants into 4 small groups. Ask participants to refer to <i>Appendix 8C: Adherence Assessment Guides</i> and pass out additional copies of the guides.</li> <li>Ask each of the small groups to choose people to play the part of the health worker, the client, and the caregiver.</li> <li>Assign each group 1 of the case studies. The participants playing the role of health workers from each group should NOT look at the case studies! Give the people playing the roles of the client and caregiver a couple of minutes to review the case study, including the background information.</li> <li>Ask the groups to role play their case study. The clients should start by introducing themselves to the health workers, reading aloud the 1<sup>st</sup> bullet point included in the case study. The clients and caregivers should keep any background information provided in mind during their conversation with the health worker.</li> <li>After the introduction, the health workers should take the lead, providing adherence counseling and support as discussed in this session. They should make sure to use the appropriate adherence assessment guides in <i>Appendix 8C</i>. Depending on the case study, they may want to meet with both the client and caregiver together and then with the client and caregiver individually. Finally, they may want to meet with both in order to resolve any important differences of opinion, to summarize key points, and to discuss the way forward.</li> </ol>

	<p>6. Participants who have not been given roles should act as observers, taking notes and advising those participating in the role play.</p> <p>7. During the role plays, trainers should circulate among the groups to answer questions and to ensure that participants are conducting the counseling sessions as expected (see “Key points for trainers” below).</p> <p><b>Part 2: Small Group Work</b></p> <p>8. After the role plays, ask participants to work together in their small groups to answer the following questions:</p> <p>A. <i>What are the client’s/caregiver’s main adherence challenges? What are some possible solutions?</i></p> <p>B. <i>What are some age-appropriate techniques a health worker could use to build the client’s/caregiver’s confidence and knowledge about adherence?</i></p> <p>C. <i>Are there any community-based services that might help the client? What suggestions or referrals would you make?</i></p> <p><b>Part 3: Large Group Discussion</b></p> <p>9. Bring participants back together. Have each small group summarize its case study and the answers to the 3 questions above. Also ask the additional question included at the end of the “Key points for trainers” following each case study below. Compare the process that each group went through with the “Key points for trainers.”</p> <p>10. After all 4 groups have reported, ask the following questions to facilitate discussion and record key points on a flip chart:</p> <ul style="list-style-type: none"> <li>• <i>What do you think will be the most challenging aspects of conducting adherence assessments with ALHIV and their caregivers at your clinic?</i></li> <li>• <i>What approaches should health workers take to make clients and caregivers feel comfortable giving honest answers about adherence?</i></li> </ul> <p>11. (optional) Encourage participation by the adolescent co-trainer, who should also participate in the small groups and role plays. Ask the following questions to encourage his or her input and participation:</p> <ul style="list-style-type: none"> <li>• <i>Is there anything else the health worker could suggest or discuss to address the client’s adherence needs?</i></li> </ul>
<p><b>Debriefing</b></p>	<ul style="list-style-type: none"> <li>• An adolescent client’s adherence needs change over time and as they age and develop. A client’s needs should be assessed and considered at every visit.</li> <li>• The Adherence Assessment Guides in <i>Appendix 8C</i> can be useful tools for health workers when asking clients and caregivers about adherence.</li> <li>• It is often helpful to ask clients and caregivers about adherence separately because they may have their own understandings and give different answers to questions.</li> <li>• It is important that health workers build a trusting relationship with adolescent clients so they feel comfortable being completely honest about their adherence support needs.</li> </ul>

- It is important not to judge clients (or caregivers) if they are non-adherent. Instead, we should try to understand why clients do not adhere and help them find ways to resume good adherence as soon as possible.

## Exercise 2: Assessing Adherence and Providing Support: Small group work, role play, and large group discussion

### 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.

### Key points for trainers: J\_\_\_ and his uncle

- During the **individual session with J\_\_\_'s uncle**, the health worker should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART” (*Appendix 8C*).
  - Tell J\_\_\_'s uncle that although frightening a person is one way to motivate him or her, it is rarely the most effective way. The health worker should tell J\_\_\_'s uncle that he or she will try other ways to encourage J\_\_\_ to adhere to his regimen instead (by discussing and addressing barriers, educating him, motivating him, etc).
- During the **individual session with J\_\_\_**, the health worker should:
  - Administer the “Adherence Assessment for Adolescents Taking ART” (*Appendix 8B*).
  - Use listening and learning skills to uncover the answer to **question “A”** above (*What are J\_\_\_'s main adherence challenges? What are some possible solutions?*). During the discussion, identify J\_\_\_'s strengths and praise him in order to build his confidence.
  - Ask J\_\_\_ in a non-confrontational manner about the claim that he is often out all night: “J\_\_\_, I understand that sometimes you stay out quite late, can you tell me your side of the story?” This may open the discussion around some of the underlying reasons for his poor adherence, such as his irregular schedule and excessive drinking.
  - Keep in mind J\_\_\_'s uncle's side of the story as J\_\_\_ responds to the questions about his adherence. If the stories differ, the health worker might want to mention (if he or she feels this will not be breaching the uncle's confidentiality), for

example: *“Your uncle worries about you because he loves you. He thinks that you might have thrown out your medicine. Is that true?”*

- Educate J\_\_\_ about the importance of adherence and the risks he takes by not adhering to his regimen (this will build J\_\_\_’s knowledge and also responds to **question “B”**).
- Find out what motivates J\_\_\_: What is important to him? Is it marriage and family, future career, or maybe he just wants to look good? Reassure J\_\_\_ that ART can help him achieve his life’s goals (this will build his confidence and also responds to **question “B”**).
- If J\_\_\_ states that he loves or respects his uncle’s family, the health worker may also say, *“Did you know that not taking care of yourself has been upsetting the people who love you?”*
- After meeting with J\_\_\_ and his uncle separately, the health worker may want to meet with them together to try to summarize the way forward, to discuss next steps, and to provide referrals (**question “C”**) to a Peer Educator, peer support groups, and any other appropriate services (substance abuse counseling?). The health worker can typically bring up any differing perspective during conversations with both the client and the caregiver but, in this case, it might cause too much conflict.
- **Discussion question for this case study: Ask the small group:**
  - *What did the health worker do to address differences between the 2 stories (J\_\_\_’s and his uncle’s)?*

#### 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?

#### Key points for trainers: N\_\_\_ and his mother

- During the **individual session with N\_\_\_’s mother**, the health worker should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART” (*Appendix 8C*).
  - Get a feel for the mother’s communication style, asking her why she thinks N\_\_\_ has suddenly become non-cooperative about taking his medicine. What has changed recently for N\_\_\_? What techniques has she been using to encourage N\_\_\_ to take his medicines? Does N\_\_\_ have any new friends? Has anyone made fun of him for taking medicines?
  - Confirm that N\_\_\_ does not know his HIV-status (disclosure)? Could knowing his

HIV-status help?

- During the **individual session with N\_\_\_**, the health worker should:
  - Administer the “Adherence Assessment for Adolescents Taking ART” (*Appendix 8C*).
  - Use listening and learning skills to uncover the answer to **question “A”** (*What are N\_\_\_’s main adherence challenges? What are some possible solutions?*) and to better understand what may have happened recently to explain why N\_\_\_ no longer wants to take his medicines. During the discussion, identify N\_\_\_’s strengths and praise him to build his confidence (**question “B”**).
  - Ask what N\_\_\_ knows about why he has to take medicine.
  - Educate N\_\_\_ about the importance of adherence and the risks he takes by not adhering to his regimen. Make sure this discussion is worded in a way that is respectful to N\_\_\_’s understanding of his diagnosis (this conversation will build N\_\_\_’s knowledge and also responds to **question “B”**).
  - Find out what motivates N\_\_\_: What is important to him? What does he want to be when he grows up? Reassure N\_\_\_ that ART can help him achieve his life’s goals (this will build his confidence and also responds to **question “B”**).
- After the health worker meets with N\_\_\_ and his mother separately, he or she might want to meet with them together to try to address any differences of opinion (if there were any), to discuss the plan agreed upon with N\_\_\_, to summarize next steps, and to provide referrals (**question “C”**) to a Peer Educator and peer support groups.
- **Discussion question for this case study: Ask the small group:**
  - *Did the issue of disclosure come up during your counseling session with either N\_\_\_ or his mother?*

### 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.

### Key points for trainers: P\_\_\_

- Note that, as P\_\_\_ has brought a friend with her (rather than a caregiver), it is unlikely that there is any compelling reason for the health worker to meet individually with her friend.
- During the **individual session with P\_\_\_**, the health worker should:
  - Administer the “Adherence Assessment for Adolescents Taking ART” (*Appendix 8C*).
  - Assess whether any of the drugs in P\_\_\_’s regimen are causing a metabolic disorder or lipodystrophy and, if so, whether they can be changed.

- Use listening and learning skills to uncover the answer to **question “A”** (*What are P\_\_\_’s main adherence challenges? What are some possible solutions?*), which seems to have more to do with body image and poor self-esteem than it does with P\_\_\_ actually feeling unwell.
  - Use listening and learning skills to address P\_\_\_’s key issue right now: low self-esteem. Praise her for what she has done well (for example, missing 3 out of 60 ART doses in the last month isn’t bad — it equals a 95% adherence rate). Encourage her to try new activities at school to build her self-confidence and to help her meet new people.
  - Educate P\_\_\_ about the importance of adherence and the risks she takes by not adhering to her regimen. Let her know that if she stops taking ART, she will lose weight and eventually start to look sickly (which is surely less appealing than looking a bit fat, right?). This conversation will build P\_\_\_’s knowledge and also responds to **question “B.”**
  - Discuss exercise as a way of losing excess weight, feeling better about one’s body image, and building self-confidence (this also responds to **question “B”**).
  - Find out what motivates P\_\_\_: What is important to P\_\_\_? What does she want to be when she grows up? What’s important to her now? Reassure P\_\_\_ that ART can help her achieve her life’s goals (this should build P\_\_\_’s confidence and it also responds to **question “B”**).
  - Provide referrals (**question “C”**) to a Peer Educator and peer support groups.
  - Ask P\_\_\_ if she would like to include her friend in the rest of the conversation. This will give the friend an opportunity to ask any questions she has. The health worker can also empower the friend with information on the importance of adherence (with P\_\_\_’s consent), so that she can support P\_\_\_’s decision to not go off ART.
- **Discussion question for this case study: Ask the small group:**
    - *Did you include P\_\_\_’s friend in any way? How could she be helpful?*

#### 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.

#### Key points for trainers: M\_\_\_ and her mother

- During the **individual session with M\_\_\_’s mother**, the health worker should:
  - Administer the “Adherence Assessment for Caregivers of Adolescents Taking ART” (*Appendix 8C*).
  - Praise M\_\_\_ for her excellent adherence and ask her mother how it is that M\_\_\_ can remember every single time.

- Inform M\_\_\_’s mother that the laboratory test results suggest that M\_\_\_’s health is declining. Can she help explain this? Is it possible that M\_\_\_ isn’t taking all of her medicines as directed?
- Try to validate the report of 100% adherence with pill counts and pharmacy refill records (if available).
- Let M\_\_\_’s mother know that it is OK to be honest, that health workers will try to help instead of judging her or M\_\_\_.
- During the **individual session with M\_\_\_**, the health worker should:
  - Administer the “Adherence Assessment for Adolescents Taking ART” (*Appendix 8C*).
  - Praise M\_\_\_ for what appears to be perfect adherence in order to build her confidence (**question “B”**).
  - Present her with the result of the pill counts and check on pharmacy refill records (if available).
  - Inform M\_\_\_ that the laboratory test results suggest that her health is declining. Can she help explain this? Use listening and learning skills to find out if it is possible that she is not taking all of her medicines as directed (this responds to **question “A”**).
  - Let M\_\_\_ know that it is OK to be honest, that health workers will try to help instead of judging her. Discuss the importance of excellent adherence and the risks people take by not adhering to their regimen (this conversation will build M\_\_\_’s knowledge and also responds to **question “B”**).
  - Ask M\_\_\_ about anything he or she learned during the individual session with her mother that needs validation.
  - Ask M\_\_\_ about any sexual partners and discuss safer sex, explaining that one of the risks of unsafe sex is that you can acquire a new strain of HIV that is resistant to the medications you are taking. Also tell her that she is less likely to pass HIV to her partner if she is adhering to her medicines. Is practicing safer sex a possibility for her?
- After the health worker meets with M\_\_\_ and her mother separately, he or she might want to meet with them together to try to address any differences of opinion (if there were any), to discuss the plan as agreed upon with M\_\_\_, to summarize next steps, and to provide referrals (**question “C”**) to a Peer Educator and peer support groups.
- **Discussion question for this case study: Ask the small group:**
  - *Do you think M\_\_\_ was really taking 100% of her medicines?*



### Trainer Instructions

Slide 71

#### Step 8:

Allow 5 minutes for questions and answers on this session.



### **Trainer Instructions**

Slides 72-74

**Step 9:**

Ask participants what they think the key points of the module are. What information will they take away from this module?

**Step 10:**

Summarize the key points of the module using participant feedback and the content below.

**Step 11:**

Ask if there are any questions or clarifications.





## 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<sup>1</sup>

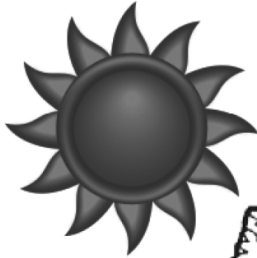
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### Instructions for the Adherence Support Tree:

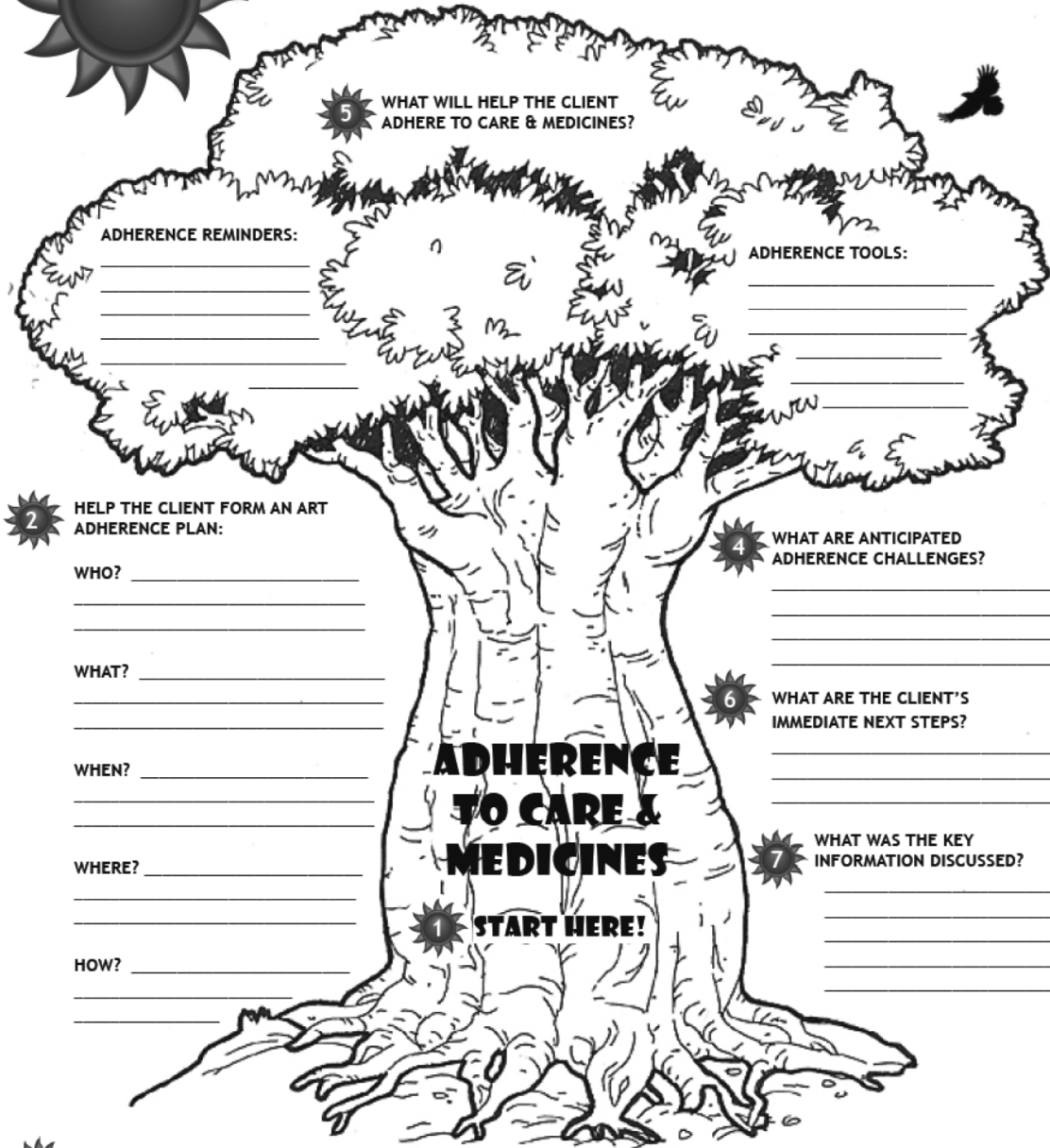
Each instruction below goes with a number on the Adherence Support Tree. The health worker should follow these instructions in order.

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?

\_\_\_\_\_  
 \_\_\_\_\_

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

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**3** WHAT SUPPORT DOES THE CLIENT HAVE?

FAMILY:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

PEERS:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

COMMUNITY:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Appendix 8B: Adherence Preparation and Support Guides

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### How to use these guides:

These adherence preparation and support guides were developed to assist a range of providers (trained 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. <i>If someone other than the caregiver:</i> 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

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### 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 <b>late</b> 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 <b>miss</b> 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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<sup>1</sup> 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.