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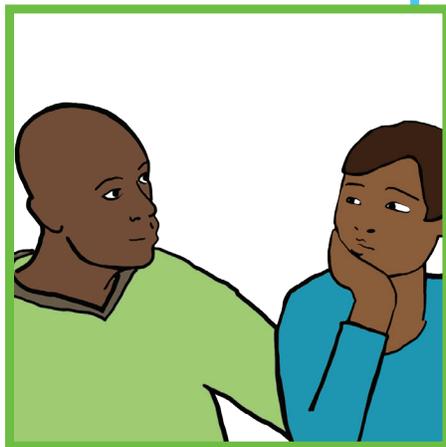
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U.S. President's Emergency Plan for AIDS Relief

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# TOOLKIT FOR TRANSITION OF CARE AND OTHER SERVICES FOR ADOLESCENTS LIVING WITH HIV

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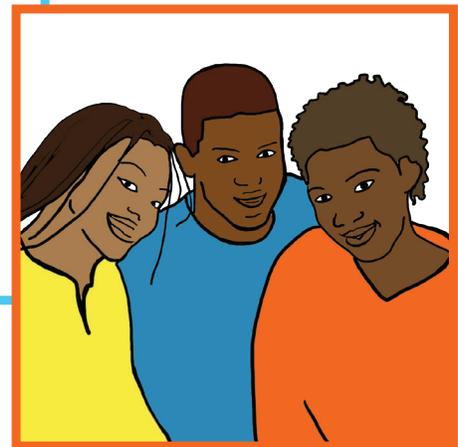
## TRAINING MANUAL



*Tools for Parents/Caregivers*



*Tools for Providers*



*Tools for Adolescents*

**AIDSTAR-One**  
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES

**JANUARY 2014**

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# **AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES PROJECT**

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A final note that focuses on the youth themselves, the authors want to express extreme gratitude to those adolescents living with HIV who have taken the time to share their experiences with us, provided guidance for the Toolkit and who have inspired many to continue this important work.

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# FOREWORD

As the number of vertically infected adolescents living with HIV (ALHIV) continues to grow, there is an increased need to support these individuals as they transition from pediatric to adult care. With the limited number of health care providers (HCPs) and community care providers (CCPs) throughout much of sub-Saharan Africa, it is likely that many adolescents will not experience a physical transition from one clinic to another; however, all ALHIV undergo a mental transition to adulthood, and during this time period self-care and self-management of HIV is key. Adolescence is a developmental phase between childhood and adulthood that is characterized by physical, psychological, and social changes at the individual level (World Health Organization [WHO] 2010). The WHO defines adolescence as the ages between 10 and 19, but many others consider adolescence to last until age 25. Transition is a “multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused health care system” (Reiss and Gibson 2002). Through provision of instruction and tools, the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* provides clear guidance to HCPs and CCPs, the adolescent, and his or her family/caregiver to promote a smooth transition. HCPs and CCPs using the Toolkit can work with the adolescent and his or her family/caregiver to develop a minimum package of services that are individually tailored to meet the needs of the adolescent in a developmentally appropriate manner. This Training Manual was created to assist HCPs and CCPs in effectively providing services to ALHIV through providing important technical guidance and information on how to use the Toolkit in practice.

A comprehensive package of materials has been created to address adolescent transition:

1. *Toolkit of Transition of Care and Other Services for Adolescents Living with HIV Training Manual*
2. *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*
3. *Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa Technical Brief*

By attending to the unique needs of the HIV-positive adolescent as they undergo the transition process, they will have their clinical and psychosocial needs met, attain greater self-management skills and as a result experience improved health outcomes as they progress toward adulthood.

# BEFORE YOU PRESENT THIS COURSE

## TRAINING CONTENT

This training is composed of content that prepares participants to use the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* while also providing background technical information and guidance to increase their knowledge about the special needs of ALHIV.

The three-day training consists of a series of sessions that provide important guidance for providers working with ALHIV. These sessions include: Toolkit Introduction, The Special Needs of Adolescents Living with HIV, Adolescent-Friendly Services, Effective Communication Strategies, and Working with the Family/Caregiver to Support the Adolescent Living with HIV. Correlating to each module of the Toolkit, there are 11 additional sessions which provide background technical information and guidance to review each tool within that module of the Toolkit so that users will be prepared to use the Toolkit in practice following the training.

## PLANNING CHECKLIST TO PREPARE FOR THE TRAINING

- Identify participants and send invitations which include information surrounding the intensity and time required to complete the training.
- Review all of the materials in this Training Manual, including the exercise within each session of the manual.
- Become familiar with the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*.
- Ensure sufficient materials have been procured for the training, including:
  - Flip charts/Markers
  - Markers
  - Name tags
  - Sufficient copies of the Toolkit for each participant
  - Sufficient copies of the handouts available in the back of this Training Manual.

# SUGGESTED COURSE SCHEDULE

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## Day 1:\*

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<b>Session 1: Introduction</b> .....	8:00—9:10
<b>Session 2: The Special Needs of ALHIV</b> .....	9:10—10:10
<b>Session 3: Toolkit Introduction</b> .....	10:10—11:10
<b>Session 4: Adolescent-Friendly Services</b> .....	11:10—12:25
LUNCH.....	12:25—1:30
<b>Session 5: Effective Communication Strategies Working with Adolescents</b> .....	1:30—2:45
<b>Session 6: Working with Families/Caregivers to Support the ALHIV</b> .....	2:45—4:00

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## Day 2:\*

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<b>Session 7: The Transition Process</b> .....	8:00—9:15
<b>Session 8: Psychosocial Development</b> .....	9:15—10:15
<b>Session 9: Mental Health Considerations</b> .....	10:15—11:15
<b>Session 10: Sexual &amp; Reproductive Health</b> .....	11:15—12:15
LUNCH.....	12:15—1:15
<b>Session 11: Protection</b> .....	1:15—2:15
<b>Session 12: Alcohol &amp; Substance Use</b> .....	2:15—3:15
<b>Session 13: Beneficial Disclosure</b> .....	3:15—4:45

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## Day 3:\*

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<b>Session 14: Loss, Grief, &amp; Bereavement</b> .....	8:00—9:15
<b>Session 15: Clinical Considerations</b> .....	9:15—10:30
<b>Session 16: Positive Living</b> .....	11:30—12:45
LUNCH.....	12:45—1:45
<b>Session 17: Building Community Linkages</b> .....	1:45—2:45
<b>Session 18: Putting the Toolkit into Practice</b> .....	2:45—4:35

\* Build in tea breaks as the schedule allows.

# GOAL & OBJECTIVES

## COURSE GOAL:

By the end of this training, participants will have the technical knowledge and skillset to provide individualized transition services and incorporate the relevant modules of the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* into routine health services.

## COURSE OBJECTIVES:

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

1. Describe characteristics of adolescent-friendly services
2. Communicate effectively with adolescents
3. Identify a minimum package of services for the individual adolescent client
4. Educate and strategize with the family/caregiver to support the adolescent client.
5. Describe the unique needs of adolescents living with HIV as they relate to each module within the Toolkit.
6. Use the Toolkit in daily practice to provide a minimum package of services for the HIV-positive adolescent.
7. Build the self-management capacity of the adolescent to work toward a successful transition of care.

# SESSION 1: INTRODUCTION

**Total Session Time: 1 hour and 10 minutes**

## OBJECTIVES:

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

1. Acquaint themselves with fellow participants and the trainers
2. Review the course goals, objectives, and schedule
3. Adopt group norms for the training.

## MATERIALS



- Flip chart stand, papers, and markers
- Name badges and stiff paper to create name tents
- Parking Lot
- Toolkits

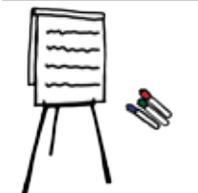
## HANDOUTS & TOOLS



### Activity 5:

- **Handout 1: Sample Pre- and Post-Test and Answer Key**

## FLIP CHARTS



### Activity 4:

- Proposed Group Norms

## ADVANCE PREPARATION



- Prepare an attendance sign-in sheet
- Invite a health official or guest speaker for opening remarks
- Make sure you have all materials, handouts, and flip charts needed
- Cut and place Icebreaker exercise papers in envelope

### Activity 5:

- Make sufficient copies of **Handout 1** in advance

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
	Speech from Health Official	Opening remarks	15 minutes
1	Welcome and Introduction of Trainers	Lecturette	5 minutes
2	Participant Icebreaker	Interactive exercise	10 minutes
3	Course Schedule, Goal, and Objectives	Lecturette, large group discussion	10 minutes
4	Group Norms and Use of the Parking Lot	Lecturette	10 minutes
5	Pre-Test	Test	20 minutes

# THE MORNING OF THE COURSE:

- » As participants arrive, welcome them and ask them to write their name on a name badge and on a sheet of stiff paper that is folded in half to make a “name tent.” They should write their names with a marker on both sides of the name tent so that anyone sitting behind them can also see their name. The name tents should be placed on the table in front of their chair.
- » Have participants sign the course registration sheet so that you will have a confirmed list of the people in the training. Depending on your system, you should advise participants to sign in each morning and afternoon on an attendance sheet so that they will receive their per diems.

## LEARNING ACTIVITIES

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### Activity 1: Welcome and Introduction of Trainers (~5 Minutes)

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- » After giving a few words of welcome, you should each introduce yourselves by giving the following information.
  - Name (name you would like to be called during the training)
  - Title (nurse, technical specialist, etc.)
  - Work site and/or organization
  - Years in public health, HIV work, or working with adolescent clients.
- » Explain that the participants will also be introduced with a participatory icebreaker.

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### Activity 2: Participant Icebreaker—Get to Know Your Colleagues (~10 Minutes)

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- » Explain to participants that one of the most important norms for the course is strong participation by everyone. Next, ask them to do an exercise with two purposes: to reinforce strong participation and to get to know one another to increase productivity in the course. Refer to the **“participant icebreaker”** on page 77 in this manual.
- » Follow these basic steps as you explain the icebreaker:
  1. Explain that this exercise should be fun. It has important purposes, but participants should have fun with this—it is not as technical as other parts of the course. (Note: Keep it light and lively. Get some humor into the start of the course!)
  2. Tell the participants you are passing around an envelope with pieces of paper in it. Without looking, they should select a piece of paper.
  3. Tell participants that each piece of paper contains a category. Tell the participants to choose something that fits in that category. Give an example: “My paper says ‘color’ so I would say I am yellow, because it reminds me of sunshine and I’m always in a good mood.” Give them approximately 1 minute to think about their answer.
  4. Ask them to present themselves to the group, say what category their piece of paper says, and what they identify with in that category and why.

5. Once each participant has introduced themselves, the trainers should also select a piece of paper from the envelope and introduce themselves in the same manner.

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### **Activity 3: Course Schedule, Goal, and Objectives (~10 Minutes)**

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- » Read the following to the participants:
  - What if somebody told you that there is a way to gradually build the self-management capacity of the adolescent living with HIV, helping them independently manage their care?
  - What if it helped to improve communication between the provider and the adolescent?
  - What if it also helped to support the family/caregiver of the adolescent?
  - What if it was also a way to prepare you as a health professional to transition adolescent clients to adult services making room for new clients?
  - What if it also helped to reduce HIV stigma among health and community providers?
  - What if it also helped to provide more comprehensive services for the adolescent?
  - What if it also helped to improve health and social outcomes of adolescent clients?
  - What if you could learn about this in only three days?
  - Would you be interested?
- » When the group responds with a loud “Yes,” tell them: *Well, you are in the right place!* In this course, you will learn important information about the special needs of adolescents living with HIV and how to apply the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* to improve the lives of the adolescent client—helping them build the skillset to transition to adult-focused care in a deliberate manner and equip them with information and tools to help them live healthy lives. This course combines learning and practical application of the Toolkit and sharing your experiences while also providing technical knowledge and resources to do all of these things.
- » Review the course schedule with them, and point out the following:
  - Daily schedule (emphasize beginning time)
  - Breaks for tea/coffee and lunch
  - Possible changes in the schedule depending on the needs of the group.
- » Tell participants that they will not have to take extensive notes, as the information presented during this course is also available in the Toolkit.
- » Next, review the **Goals & Objectives** on page 8 of this manual with participants. Give a few examples of some of the objectives. Ask them if they have any questions.

- » Explain that while participants may have already been working with adolescents living with HIV, this course will help them build their skillset and technical knowledge. Through application of the Toolkit, participants will build the self-management capacity of the adolescent so that they can move toward transition of care to adult-focused services.
- » If anybody wants to ask questions or find out more, tell them there will be lots of time for questions and discussion later.

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### **Activity 4: Group Norms and Use of the Parking Lot (~10 Minutes)**

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- » Introduce this activity by explaining that because participants will be working closely together for the next few days, it is important to agree on ways to act as a group to ensure their work will be successful. Explain that these behaviors are usually called “group norms.”
- » Post the group norms flip chart with the partial list of group norms prepared in advance. It should look like this:

**PROPOSED GROUP NORMS**

- Start on time and end on time
- Everyone participates, but nobody over-participates
- Always show respect for colleagues
- No side conversations
- Turn off mobile phones
- What else?

- » Explain that you have suggested five group norms on the flip chart based on agreement by participants in previous courses. Ask the participants if they agree with the proposed group norms on the flip chart.
- » Ask participants if there are ground rules that they want to add. As a ground rule is suggested, you should quickly check with everyone to see if they agree to it. If so, add it to the list.
- » Spend no more than a few minutes developing this list. A total of six to eight group norms is plenty. When it is complete, put it on the wall in a prominent place so that it can be referred to as needed. Trainers or participants may propose additional group norms later. The list should stay on the wall until the course ends.
- » Take a second to discuss the group norm of starting and ending on time. Show the timekeeper’s bell (or glass that you can tap loudly with a spoon) that you have probably already started to use. Explain that now one of the trainers is a timekeeper and that participants will also be recruited to serve as co-timekeepers. Tell them that sessions will not only start on time, but will also end on time. There is often a five-minute warning bell toward the end of a session; there may even be a one-minute bell. The same is true at the start and end of lunch and breaks. Explain that the trainers believe good timekeeping is very important, and you hope that the participants find it important too. Recruit a participant to serve as co-timekeeper for the day, making sure that he or she understands the duties, has access to a watch, and has studied the schedule for the day. Give him or her a bell or a glass to tap on.
- » Now take a regular sheet of flip chart paper and write “Parking Lot” across the top. Tell participants that this flip chart is called the “Parking Lot” because you “park” questions or items there when these questions are interesting or important, but they are not part of the session or the discussion that you are having at that moment.

- » Explain that sometimes you might write a question on the Parking Lot because you do not know the answer. Smile and admit that trainers do not know everything. You just write the question or item on the Parking Lot, and you can get back to it later. You will try to empty the Parking Lot by the end of the course or even the end of each day.
- » Close out this session by thanking the participants for a good start to the course and explaining that in the next session—**Session 2**—you will go into an overview of the special needs of adolescents living with HIV.

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## Activity 5: Pre-Test ~(20 Minutes)

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In order to measure changes in participants' knowledge during this short course, **Handout 1: Sample Pre- and Post-Test** is available. This activity is a quantitative assessment of participants' learning that measures changes in participants' knowledge before and after the course. There is also an answer sheet and guide for scoring the test.

The pre-test should be administered at the end of the introductory session and the post-test at the end of the closing session on the third day.

### INSTRUCTIONS:

- » Explain that you will be administering a pre- and post-test at the beginning and end of this course.
  - The results of the pre-test will help you tailor the course to the topics where participants have the most to learn, while spending less time on topics that they already know.
  - The results of the post-test will allow you to see how much the group has learned and how effective the course has been. This is important information for trainers, so they can improve the course in the future.
- » Tell participants that they do not need to write their names on the test. You will not be judging how well individual participants have done, but how well the group as a whole has done. However, if you want to compare results between pre- and post-tests, ask them to include their name or an exclusive number/word. An exclusive number/word is a number/word they will remember and will be able to include on their post-test, for comparative purposes.
- » Tell them that they have 15 minutes to take the test.
- » Ask participants not to talk to each other or to help each other, but to answer as best they can on their own. If they do not know the answer to some of the questions, that is not a problem, the course will address this gap. Instruct them not to spend a lot of time worrying about those questions; they should move on to the next question. Hopefully, by the end of the course they will know the answers to the questions that look difficult now.
- » Ask the people who finish first to sit quietly in their seats or to get up and stand quietly at the back of the room, so as not to disturb others who are still working.
- » Check if the instructions are clear and ask if anybody has any questions.
- » Let people know at half-time and again five minutes before time is up. When everybody is finished, collect the tests right away.
- » It is recommended to analyze the results of the pre-test as soon as possible in the workshop. That will allow you to devote more time to the topics where the group has the most to learn.

# SESSION 2: THE SPECIAL NEEDS OF ALHIV

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**Total Session Time: 1 hour**

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**OBJECTIVES:**

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

1. Understand the special needs of HIV-positive adolescents
2. Explain the unique differences between perinatally versus behaviorally infected adolescents
3. Explain potential differences in chronological versus developmental age in adolescents

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**MATERIALS**



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

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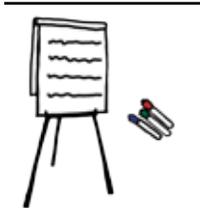
**HANDOUTS & TOOLS**



- Activity 1:**
- Toolkit *Tool 1.1.1: Stages of Psychosocial Development*

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**FLIP CHARTS**



- Activity 1:**
- Characteristics of Adolescence: Physical, Psychological, and Social
  - Special Needs of Adolescents Living with HIV
- Activity 2:**
- Perinatal versus Behavioral Infection: Characteristics and Needs

---

**ADVANCE PREPARATION**



- Activity 1 & 2:**
- Prepare flip charts (see examples below)

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**SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:**

No.	Learning Activity	Principal Training Method	Time
1	Special Needs of ALHIV	Group discussion and lecturette	30 minutes
2	Perinatal versus Behavioral Infection	Group discussion and lecturette	30 minutes

# LEARNING ACTIVITIES

## Activity 1: The Special Needs of Adolescents Living with HIV (~30 Minutes)

- » Begin by stating that in this session you will be reviewing the special needs of ALHIV.
- » The WHO defines adolescence as a developmental phase between childhood (under 10 years) and adulthood (over 19 years) characterized by physical, psychological and social changes at the individual level. There are however, various definitions of adolescence. Ask participants what definition they use at their sites.
- » Display a flip chart with five columns with the following labels in each column: physical, emotional, cognitive, family, and friends. Identify a participant to be a recorder and write down responses. Ask participants to identify characteristics of adolescents typically noted in their settings; classify their responses into each of the categories on the flip chart.

PHYSICAL	EMOTIONAL	COGNITIVE	FAMILY	FRIENDS

- » When the flip chart is relatively complete, refer to *Tool 1.1.1: Stages of Psychosocial Development* in the Toolkit on page 20 and review each category with participants. Explain that it is not uncommon for adolescents to carry out risk-taking behavior during this period that may result in drug and alcohol use, an early sexual debut, sexual experimentation, adolescent pregnancy, and/or having consecutive sexual partners. It is important to keep this in mind and to plan to address these behaviors throughout the transition process.
- » Ask participants what they would do if they had a 13-year-old client who they suspect to be sexually active or using drugs. After some discussion, explain that all adolescents develop at different rates and that an adolescent's chronologic age may not match what one would expect for them developmentally. Although 13 years old may be young to be sexually active or experiment with drugs, once it is clear that the adolescent is not being abused or forced to use drugs, the client should be treated based upon their developmental age versus their chronologic age.

Other unique considerations for ALHIV include potential pubertal delays (Arpadi 2005), developmental delays (Brown, Lourie, et al. 2000), or developmentally advanced behaviors (Tindyebwa, Kayita, et al. 2006). One should also not assume that just because a client is of a certain age, they are not participating in behaviors that are more advanced or delayed. Careful developmental assessments are an essential component of adolescent care, especially when considering an adolescent's readiness to take on greater self-management responsibilities working toward transition. We will talk more about this in the Psychosocial Development session.

- » Ask for a volunteer recorder and brainstorm together a list of the needs that are unique to adolescents living with HIV who they encounter in clinic. Encourage participants to consider their own adolescent clients and the topics that they generally encounter when working with them.
- » After a number of responses have been gathered, tell participants that there are many potential needs that any single adolescent may have—the role of the provider is to identify these needs and ensure that they are met. Adolescents living with HIV are more likely to have lost a parent, caregiver, or sibling to HIV (Andrews & Skinner et al. 2006; Petersen & Bhana et al. 2010). In addition, they are more likely to be reliant on a caregiver who is also sick (Prendergast & Tudor-William, et al. 2007). They must prepare for a future that includes long-term planning for HIV (WHO 2009). The development of healthy responses to psychosocial issues, stigma, adherence, disclosure, sexual initiation, and loss and bereavement are very important (Cluver, Gardner, et al. 2007; Menon, Glazebrook, et al. 2007; Miles, Edwards, et al. 2004; Petersen, Bhana, et al. 2010; Ross & Cataldo 2010; While, Fobes, et al. 2004). Responsibilities for self-care may be delayed due to HIV status (Ferrand, Munaiwa, et al. 2010) and the adolescent may experience pubertal or psychosocial delays (Arpadi 2005; Brown, Lourie, et al. 2000).

Remind providers that each adolescent is unique and that individual needs should be assessed to determine the most appropriate care and that these needs will likely change over time.

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## Activity 2: Perinatal Versus Behavioral Infection (~30 Minutes)

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It is important to consider that the needs of adolescents who were infected during infancy may be different than the needs of an adolescent who was recently infected. Ask participants to consider what these differences might be, taking into account that the perinatally infected adolescent has been living with HIV for a significantly longer period of time.

Keep in mind that adolescents who were perinatally infected may be more ill, have more complex medication regimens, experience developmental delays, and may have lost loved ones. Adolescents who were more recently infected may have more mistrust and less understanding of how to navigate the medical system, and may have less knowledge surrounding HIV. We will discuss this more in the clinical considerations module.

- » Ask participants to consider the following two cases and how their **characteristics** and **needs** may differ:
  - A 16 year old who was infected at birth and has known that he is HIV positive his entire life
  - A 16 year old who was infected by her boyfriend and received the diagnosis this year
- » Complete the flip chart that you have prepared according to the example below. Fill in the participant's responses, differentiating between the perinatally infected and the behaviorally infected adolescent by outlining unique characteristics of each population.

	PERINATALLY INFECTED	BEHAVIORALLY INFECTED
CHARACTERISTICS		
NEEDS		

- **Characteristics:** If participants have not brought up the following, note that the adolescent who was infected in infancy may have already been taking on some responsibility for self-care and have practice confronting issues such as disclosure, stigma, and adherence. However, they may be more ill and require a higher degree of clinical monitoring. The adolescent who was recently diagnosed may not be as clinically ill, but is just beginning to understand what it means to be diagnosed with HIV. Because of this they may not be prepared to take on the same responsibilities as the adolescent diagnosed in infancy; even though they may be healthier, they may not transition at the same speed.
- **Needs:** Note that all ALHIV have similar needs in regards to access to sexual and reproductive health (SRH), disclosure (to self and others), psychosocial support, stigma (internal and external), secondary prevention, access to HIV clinical services, access to prevention of mother-to-child transmission (PMTCT) services, access to ART, adherence support, and transition support. The timing at which these needs will arise will depend upon a number of factors including when the adolescent was infected.

Encourage participants to keep these principles in mind as they return to their work—this will help them to better meet the unique needs of the adolescent and allow them to more appropriately provide services that are specific to the adolescent as they grow and change over time!

# SESSION 3: TOOLKIT INTRODUCTION

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**Total Session Time: 1 hour**

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## OBJECTIVES:

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

1. Explain the general layout and format of the Toolkit
2. Take a tour of the Toolkit

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## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

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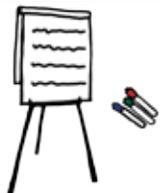
## HANDOUTS & TOOLS



- Activity 1:**
- Toolkit Pages 3–4, and 10–12
- Activity 2:**
- **Handout 2: Touring the Toolkit**

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## FLIP CHARTS



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## ADVANCE PREPARATION



- Activity 2:**
- Make sufficient copies of **Handout 2** in advance

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## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

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No.	Learning Activity	Principal Training Method	Time
1	Toolkit Introduction	Group discussion	30 minutes
2	Touring the Toolkit	Teamwork	30 minutes

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# LEARNING ACTIVITIES

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## Activity 1: Toolkit Introduction (~30 Minutes)

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- » Tell participants that they will now be reviewing the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*. They will become very familiar with it throughout this training and will soon be putting it into use when they return to their practice settings!
- » Do a walk-through of the Toolkit with participants. Tell the participants to turn to the Table of Contents on Pages 3 and 4 of the Toolkit. Here they can see the general organization of the Toolkit which includes introductory and instruction pages, transition specific information and tools, and 10 modules that respond to the health and social needs of adolescents living with HIV.
- » **Point out the following pages:**
  - **Page 7: How to Use the Toolkit.** The Toolkit provides a framework to promote self-care within the adolescent through the provision of tools and information for the health care provider/community care provider (HCP/CCP), the family/caregiver and the adolescent as the adolescent transitions to adult focused care.

The Toolkit also provides a framework for a minimum package of services for the adolescent based upon their individual needs. Ask participants to explain what a “minimum package of services” means. Explain that for the purposes of this Toolkit, it means that tools should **only** be utilized as they apply to the adolescent’s needs. This means that one should avoid using the Toolkit front to back, trying to use each module for a single adolescent, or overwhelming the client by using multiple modules at the same time.

- **Page 8: How the Toolkit is Organized.** The Toolkit is designed for three audiences, and tools are labeled accordingly.
  1. **HCP/CCP**
  2. **Family/Caregiver**
  3. **Adolescent**

To make it easier to distinguish the tools for each audience, the tools for the HCP/CCP are blue, the tools for the family/caregiver are green, and the tools for the adolescent are red.

It is anticipated that health and community providers will use the Toolkit during routine appointments with HIV-positive adolescent clients. Through interviews with the client, they will determine what their immediate needs are during that visit and use and distribute modules and tools within the Toolkit only as they apply to the adolescent’s immediate needs or for long-term transition planning.

Many of the tools are interactive in nature. The HCP/CCP should distribute the tool to the adolescent and/or family/caregiver, taking the opportunity to provide health education on the topic, and encouraging the adolescent and/or family/caregiver to complete the tool and use it on a continual basis as it is helpful.

The tools are numbered in a consistent manner and refer to the audience the tool targets. For example, Tool 7.3.5 is found in Module 7: Loss, Grief, and Bereavement, targets the adolescent audience (audience 3) and is the fifth tool in that module.

- **Page 9: Adapting the Toolkit.** As sub-Saharan Africa is a large and diverse area, the Toolkit has been written for a general African context. Prior to dissemination within a site, the Toolkit should be adapted to the local context. This

page provides considerations for adaptation. Once the Toolkit has been downloaded to a computer, a person who has been designated responsible for Toolkit adaptation may use this page as a guide to determine which components of the Toolkit require adaptation. We will return to this later in the training.

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## **Activity 2: Touring the Toolkit (~30 Minutes)**

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- » Tell participants that they will become further acquainted with the Toolkit through an activity. Tell participants to find a partner. Pass out **Handout 2: Touring the Toolkit**. Tell participants that they have approximately 15 minutes to respond to the questions. They should answer the questions by reading the introduction and instruction page and skimming through the various modules and tools available.
- » After 15 minutes have passed bring participants back together. Review each question on the handout and carry out a discussion surrounding each.
- » Respond to any questions and let the participants know that you are just getting started; they will have lots of time to become acquainted with the Toolkit throughout this training.

# SESSION 4: PROVIDING ADOLESCENT- FRIENDLY SERVICES

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**Total Session Time: 1 hour and 15 minutes**

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**OBJECTIVES:**

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

1. Understand if their clinic/organization provides adolescent-friendly services.
2. Identify specific actions (both supportive and clinically focused) they can take to make their clinic/organization more adolescent friendly.
3. Understand how the holistic nature of the Toolkit promotes adolescent-friendly services.

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**MATERIALS**



- Toolkits
- Flip chart stand, paper, and markers
- Parking Lot

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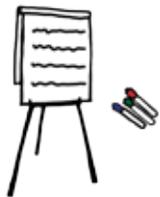
**HANDOUTS & TOOLS**



- Activity 1:**
- **Handout 3: Adolescent-Friendly Checklist**
- Activity 2:**
- Toolkit Pages 3-4

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**FLIP CHARTS**



- Activity 1**
- Flip chart with columns for AFS scores
- Activity 2**
- Flip chart with columns on barriers
  - Flip chart with columns on solutions

---

**ADVANCE PREPARATION**



- Activity 1**
- Make sufficient copies of **Handout 3** in advance
- Activity 1 & 2**
- Prepare flip charts (see examples below)

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**SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:**

No.	Learning Activity	Principal Training Method	Time
1	Adolescent-Friendly Services	Group discussion and activity checklist	60 minutes
2	Using the Toolkit to Provide Holistic Services	Group work	15 minutes

# LEARNING ACTIVITIES

## Activity 1: Adolescent-Friendly Services (~60 Minutes)

- » Begin by stating that in this session you will be exploring what it means to make the services that you provide adolescent friendly, and spend time discussing how services can effectively engage and retain ALHIV.

Adolescents living with HIV are young people, and like all young people they desire to love and be loved. The sexual and reproductive health needs of adolescents living with HIV are not so different from those of their HIV-negative counterparts. ALHIV need clinical services that can help them prevent unwanted pregnancies, have children safely, and prevent STIs. HIV-positive adolescents also need services that take into account where they are in their unique developmental stage so that their health and social needs are met. All adolescents—including ALHIV—have the right to access accurate information and comprehensive sexual health services (Baryamutumama & Baingana 2011).

- » Ask for a display of hands and ask the question “Are your services for adolescents living with HIV youth friendly?” Ask participants to identify characteristics at their clinic that makes them adolescent or youth friendly. Put their responses on the flip chart.
- » When the flip chart is relatively complete, pass out **Handout 3: Adolescent-Friendly Checklist**. Have them pair with someone from their clinic and rank themselves, explain the scoring system:

**2**= Criteria fully met

**1**= Criteria partially met

**0**= Criteria not met.

This is not a competition, but a way to understand more deeply what adolescent-friendly services (AFS) really means. Explain that the checklist includes both clinical and social support services, as an adolescent-friendly program has both elements.

- » Ask participants to complete the checklist, tally their clinical and supportive scores, then prepare a flip chart with three columns that are written as follows:

<b>YOUTH FRIENDLY</b> <b>34–36</b> <b>Clinical=24+</b> <b>Supportive=12+</b>	<b>PROVISIONALLY YOUTH FRIENDLY</b> <b>31–33</b> <b>Clinical=21–23</b> <b>Supportive=10+</b>	<b>SOME YOUTH-FRIENDLY SERVICES ROOM FOR GROWTH</b> <b>0–30</b> <b>Clinical=0–20</b> <b>Supportive=0–10</b>
<hr style="border: 0; border-top: 1px solid black; margin-bottom: 10px;"/>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 10px;"/>	<hr style="border: 0; border-top: 1px solid black; margin-bottom: 10px;"/>

- » Have the participants come up and put a check in the box that matches their facility score. Reinforce that in order to be adolescent-service friendly they must have BOTH clinical and supportive services, (or very strong linkages for both).The Toolkit reinforces this through focusing on the holistic needs of ALHIV by providing information and tools for health and community care providers—this message will be reinforced throughout this training as we review the Toolkit.
- » Examine the scores and ask participants what they observe in regards to AFS that are provided. Summarize the results, then display the following flip chart:

<b>BARRIERS</b>		
<b>PROVIDERS</b>	<b>FACILITIES</b>	<b>SERVICE DESIGN</b>

- » Ask participants to identify some barriers that exist at their facilities in the three categories listed on the flip chart. For example, many times the single most important barrier to care relates to providers' attitudes toward adolescents. This is particularly true during transition from childhood to adolescence. Give the participants time to brainstorm either as a larger group or in pairs. Then list their ideas on the flip chart. After the list is complete compare the notes below and make sure the key points are covered.

**Key Points:<sup>2</sup>**

- **Barriers for Providers may include:** 1) attitudes; 2) lack of respect; 3) lack of time available to spend with adolescents; 4) lack of training; 5) not comfortable with adolescents; 6) not comfortable talking about sex or reproductive health (RH).
- **Barriers for Facilities may include:** 1) location either too close to the adolescent's home or too far away; 2) lack of privacy; 3) no area set aside where young people can wait to be seen; 4) setting is too clinical, too adult, and/or welcoming only to women and not also to men.
- **Barriers for Services may include:** 1) cost, 2) crowded waiting rooms, 3) counseling spaces that do not afford privacy, 4) appointment times that do not accommodate adolescents' work and school schedules, 5) little or no accommodation for walk-in patients, and 6) limited supplies and options.

- » Ask the participants for a list of ways to overcome the barriers, noting that they should think in terms of small doable actions. Small doable actions cost little or no money, and a person can start doing them immediately.
- » Give the participants time to brainstorm either as a larger group or in pairs. Then list their ideas on the flip chart. After the list is complete compare the notes below and make sure the key points are covered.

---

<sup>2</sup>Moya 2002.

SOLUTIONS		
PROVIDERS	FACILITIES	SERVICE DESIGN

**Key Points:**

- **Solutions to Barriers for Providers may include:** 1) treat adolescents as respectfully as adults 2) don't judge their behavior 3) provide all staff with ongoing training in adolescent development; 4) encourage counselors to spend as much time as necessary with each adolescent client in order to address all of her/his concerns.
- **Solution to Barriers for Facilities may include:** 1) find out if public transportation is available, provide this information at places where adolescents gather; 2) set aside a separate space for adolescent services, or, if that is not possible, set aside special hours in the late afternoon, evenings and on weekends; 3) create an atmosphere that is welcoming, youthful, informal, and culturally appropriate for all adolescents accessing services.
- **Solutions to Barriers for Services Design may include:** 1) involve adolescents in designing and running services; 2) offer free or low cost services to them; 3) schedule appointments to shorten waiting time; 4) permit adolescents to walk in for services; 5) ensure that counseling spaces are private 6) maintain adequate contraceptive supplies, including condoms; 7) as possible, provide contraception to young women without requiring a pelvic examination and blood tests; 8) welcome young men, have trained male staff; 9) welcome clients' partners; 10) offer as many services as possible in a single location, refer when necessary; 11) provide culturally appropriate information in the language and at the comprehension level of the client; 12) inform adolescents about available services and assure them of confidentiality.

State that small actions can have an important impact on improving services for adolescents. You can do a lot with a little!

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## Activity 2: Using the Toolkit to Provide Holistic Services (~15 Minutes)

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- » Return to the Toolkit Table of Contents with participants. Note how the Toolkit provides 10 modules, some focused more on clinical needs and some on social support needs. Some modules are a mixture of both. Review the modules and have the participants raise one hand if the module focuses **only** on clinical needs, raise both hands if it is focused **only** on support needs, and stand up if the module focuses on both clinical and support needs. Use the table below for the most correct answers:

<b>MODULE</b>	<b>CLINIC ONLY</b>	<b>SUPPORT ONLY</b>	<b>BOTH</b>	<b>HOW TO TELL:</b>
<b>1. Psychosocial Development</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 3 audiences: CCP, HCP and Adolescent.
<b>2. Mental Health</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>3. Sexual &amp; Reproductive Health</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>4. Protection</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 3 audiences: CCP, HCP, and Adolescent.
<b>5. Alcohol &amp; Substance Use</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>6. Beneficial Disclosure</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>7. Loss, Grief, Bereavement</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>8. Clinical Considerations</b>	<b>X</b>			Checklists look at clinical needs. Tools are for 3 audiences: CCP, HCP, and Adolescent.
<b>9. Positive Living</b>		<b>X</b>		Checklists look at support needs. Tools are for 4 audiences: CCP, HCP, Adolescent, and Caregiver/Family.
<b>10. Linking Health and Community Services</b>			<b>X</b>	Checklists look at support and clinical needs. Tools are for 2 audiences: linking CCP and HCP.

- » Note the Toolkit reinforces holistic and comprehensive care in all the modules. Adopting the different modules of the Toolkit into your service provision will ensure that the services offered in your facility or organization are adolescent friendly.

# SESSION 5: EFFECTIVE COMMUNICATION STRATEGIES WORKING WITH ADOLESCENTS

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. List and practice the 7 key communication skills in family-centered care
2. Understand how to use the Toolkit to increase levels of communication with the adolescent and his/her family/caregiver

## MATERIALS



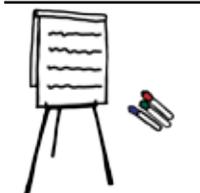
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 1:**
- **Handout 4: 7 Communication Skills Checklist**
- Activity 2:**
- **Handout 5: Toolkit Module Checklist**
  - Toolkit Pages 3–4

## FLIP CHARTS



- Activity 1**
- Flip chart papers (7 for all skills small group work)
- Activity 2**
- Flip chart with 7 skills listed

## ADVANCE PREPARATION



- Activity 1**
- Prepare flip chart with one skill listed on each sheet
  - Make sufficient copies of **Handout 4** in advance
- Activity 2**
- Prepare flip chart with all 7 skills listed on each sheet
  - Make sufficient copies of **Handout 5** in advance

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Communicating with Adolescents: 7 Skills	Small group work and role play	45 minutes
2	Communication through the Modules	Small group work and presentation	30 minutes

# LEARNING ACTIVITIES

## Activity 1: Communicating with Adolescents: 7 Skills to Master (~45 Minutes)

- » Begin by stating that in this session we will be exploring some techniques on how best to communicate with adolescents in building their skills to self-manage their diagnosis. Additionally we will talk about ways you can help model active listening and communication to parents and caregivers.
- » Building a relationship with ALHIV requires clear and effective communication between the provider and the adolescent. Throughout the transition process it will also be key to communicate with the parents and caregivers, and help them talk to their adolescent. Strong levels of communication between parents/caregivers and adolescents are a protective factor that leads to stronger adolescent sexual and reproductive health outcomes (Kajula et al. 2013 & Levetown 2008).
- » There are a number of factors that can affect how well the provider and parents/caregivers communicate with the adolescent. Factors such as attitudes toward adolescents, duration of relationship with the adolescent, gender, confidentiality, and the communication skills of the adolescent, the health provider, and the parent/caregiver can all lead to communication challenges. Many times adolescents can be reluctant to raise personal or sensitive issues or to ask questions that are related to their treatment adherence patterns (Beresford & Sloper 2003).
- » There are 7 basic skills that are commonly practiced by good communicators (ICAP 2011). Show the flip chart below to the participants

7 SKILLS	EXAMPLES
<b>Skill 1: Nonverbal communication</b>	
<b>Skill 2: Active listening</b>	
<b>Skill 3: Open-ended questions</b>	
<b>Skill 4: Reflect</b>	
<b>Skill 5: Empathize</b>	
<b>Skill 6: Don't judge</b>	
<b>Skill 7: Set goals</b>	

- » Break up the participants into groups of 7 and give them each a skill from the list above. Have them spend 5-10 minutes writing examples of each skill on a flip chart you provide. Tell them they must model one action from their examples to the entire group. After the time is up, pass out **Handout 4: 7 Communication Skills Checklist**.
- » Have each group act-out their selected skill and have the group guess what skill and example it is. Then have the entire group of participants review **Handout 4: 7 Communication Skills Checklist** and have each of the 7 groups compare the handout to their flip chart. Based on their comparisons, have a brief discussion regarding the knowledge emerging through their small group work.

- » End this activity by reinforcing how crucial good communication is to support an adolescents' transition. State again that communication throughout the transition process is key to successful transition, and modeling the 7 communication skills in sessions with parents/caregiver and the adolescent will improve communication. Working with the adolescent and his/her family reflects the Toolkit's focus on holistic care for adolescents living with HIV. Practicing the skills on the checklist in Handout 4 throughout the training and when you return to facility will help the ALHIV successfully transition toward managing their health.

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## **Activity 2: Communication through the Modules (~30 Minutes)**

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- » State again that communication throughout the transition process is key to a successful transition, and return to the Toolkit Table of Contents on pages 3 and 4. Pass out **Handout 5: Toolkit Module Checklist**. State that this handout lists each module and note how most modules focus on delivering information for providers, adolescents, and their family/caregiver to promote strong communication. Break the participants into groups of 5, have each review 2 modules and list which of the 7 communication skills could be used in each module. Give them 5-10 minutes to complete the activity.
- » After the time is up, have each group list which of the 7 communication skills can be used in each module (it is possible some modules will require all 7). Then have the entire group of participants review Handout 5, and have a brief discussion to add to the handout based on the knowledge emerging through their small group work.
- » Note that the Toolkit was structured to reinforce strong communication among providers, family/caregivers, and adolescents. In particular, there are several tools that specifically address positive communication including *Tool 9.1.1: Tips for Motivational Interviewing*, and *Tool 9.1.2: The Readiness to Change Rulers*. Participants will have more time to explore these tools in later sessions.
- » Throughout this training, it is important to think critically on how to apply the 7 communication skills in each Module. Strong communication will result a stronger transition to self-management of care for the adolescent.

# SESSION 6: WORKING WITH FAMILIES & CAREGIVERS TO SUPPORT THE ADOLESCENT LIVING WITH HIV

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Define family-centered care in the context of transition
2. Understand their positive and negative attitudes toward family-centered care
3. Understand the benefits of family-centered care

## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



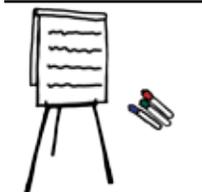
### Activity 1:

- **Handout 6: Family-Centered Care Values and Attitudes**

### Activity 2:

- Toolkit Module 10: Linking Health Facilities & Community Programs

## FLIP CHARTS



### Activity 2

- Flip chart with columns for Benefits of Family Care with 7 skills listed

## ADVANCE PREPARATION



### Activity 1

- Make sufficient copies of **Handout 6** in advance
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Family-Centered Care—What Is it? Attitudes	Lecturette and discussion	30 minutes
2	Family-Centered Care—Why Do it? Benefits	Group work	30 minutes
3	Transition Tools	Group work	15 minutes

# LEARNING ACTIVITIES

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## Activity 1: Family-Centered Care: What Is It? Attitudes (~30 Minutes)

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- » State that almost all adolescents living with HIV have family or caregivers. Whether these people are a family of origin or a family of choice is not as relevant as knowing that they are the people who may bring the adolescent into services, and who feed, clothe, and care for the adolescent as best they can. Many times the adolescent is not seen in this context, and they are portrayed as very vulnerable and often alone. Community and health care service providers should understand that adolescents living with HIV are connected to adults and other adolescents and children through family, kin, and clan networks. Being attached to a family is a global cultural norm and is required to promote optimal growth, learning, and socialization (Richter et al. 2009).

Family-centered care is key to a successful transition, as transitioning into adult HIV care is not a simple process; both individuals and families need to be adaptable. With clear planning and forethought, the process can create a sense of partnership between the adolescent, family members, and health/community care providers, and lead to stronger management of HIV over time. Studies show that when health care providers, clients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and client satisfaction increases (DeGennara & Zeitz 2009; Leeper et al. 2010; Rochat et al. 2011).

Family-centered care operates by working collaboratively with the families to strengthen their capacities, competencies, possibilities, visions, and hopes. This perspective acknowledges and strengthens individual and familial protective traits and does not ignore or downplay real problems (Sharer & Fullem 2012).

- » Transition requires collaboration, partnership, and flexibility—all core values of family-centered care (ICAP 2011). Ask participants about their personal attitudes and beliefs on family-centered care. Next, look at **Handout 6: Family-Centered Care Values and Attitudes**, and discuss what elements might be relevant for transition.
- » **Handout 6** has questions to help participants explore attitudes about adolescent and family involvement in their own health care. Discuss the questions in small groups for 5 minutes and reflect on how participants can improve the quality of services as they work with adolescents living with HIV and their families.
- » After 5 minutes, facilitate a discussion with participants to discuss their attitudes on working with families and adolescents. Once participants have shared, point out some similar attitudes that emerge. Point out that using a family- and adolescent-centered care model makes for the most successful transition.
- » Tell participants that the Toolkit promotes families' and adolescents' ability to self-manage their care throughout the transition process.

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## Activity 2: Family-Centered Care: Why Do It? Benefits (~30 Minutes)

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- » Tell participants that evidence shows that family-centered care can provide the best outcomes for the adolescent. Let's spend a little bit more time thinking about this in your context. Display the following flip chart:

BENEFITS		
BENEFITS FOR ME AND OTHER PROVIDERS	BENEFITS FOR ADOLESCENT AND FAMILY/CAREGIVER	BENEFITS FOR HEALTH FACILITIES OR COMMUNITY PROGRAMS

- » Ask participants to identify some benefits for themselves as the providers. For example, if more responsibility is taken by the adolescent or his/her caregiver/family, this can often decrease the workload of the provider. Give the participants time to brainstorm either as a larger group or in pairs. Then list their ideas on the flip chart. After the list is complete compare the notes below and make sure the key points are covered.

**Key Points:**

- **Benefits for Providers may include:** 1) better health outcomes; 2) more efficiency in their day; 3) more job satisfaction; 4) more opportunities for creative care models; 5) being inspired and more motivated at work; 6) decreased burden on staff—you don't have to have all the answers; 7) reassurance that education and information provided has been heard by multiple audiences to reinforce the message.
- **Benefits for Adolescent and Family/Caregiver may include:** 1) better health outcomes; 2) stronger understanding of self-management and their role in it; 3) strengthen the adolescents role in his/her self-care; 4) strengthen the transition planning process with the family/caregiver.
- **Benefits for Health Facilities and Community Programs may include:** 1) more cost-effective programs and services 2) strengthen the links between community and health services; 3) greater community involvement in the service delivery process.

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### Activity 3: Toolkit Family Care Tools (~15 Minutes)

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- » Tell participants that the Toolkit is designed to promote working with adolescents and their families to promote self-care. The entire Toolkit embraces the family care model—Module 10 specifically has a number of tools we can review now through a family-centered care lens.
- » Direct participants to page 98 of the Toolkit, *Module 10: Linking Health Facilities & Community Programs*. Families have a range of needs, and identifying where to meet these needs is a crucial role of all health and community care providers.
- » Direct participants to page 100 of the Toolkit, *Community-Based Organization/Health Facility Directory*, and review the directory available in the Toolkit. State that many people have this information inside their heads, but when it is on one sheet of paper with contact information it can lead to adolescents and their families accessing these services. Information is a key first step.

- » Direct participants to page 101 of the Toolkit, *Tool 10.1.2: Needs of Transitioning Adolescents Living with HIV*, and review the key points. Note that it is important to share this information with other organizations working with ALHIV in order to provide them with information on the needs of transitioning adolescents. Helping others understand the needs of adolescents and their families will promote family-centered care.
- » Direct participants to turn to page 102 of the Toolkit, *Tool 10.1.3: Home Visit Guidance*. Home visits are an excellent way to deliver family-centered care. This will allow for all providers to understand the strengths of the family and the adolescent. Home visits can lead to providers being able to provide holistic care that meets the physical, psychological, social, and spiritual needs of their clients.
- » Remind participants that all of the tools in the Toolkit promote family-centered care; adolescents and families must partner with providers to promote self-management. A true partnership will guarantee that the health and community services will be responsive to the needs and concerns of adolescents living with HIV. Family-centered care will lead to better outcomes and enhance efficiency and cost-effectiveness. They as providers will also discover a more gratifying, creative, and inspiring way to practice.

# SESSION 7: THE TRANSITION PROCESS

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Explain the process of transition
2. Describe fundamentals of developmental readiness for self-management
3. Use transition tools in practice with adolescent clients

## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



### Activity 1:

- Toolkit pages 10–16

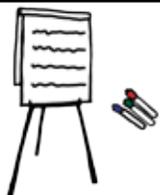
### Activity 2:

- **Handout 7: Developmentally Appropriate Transition**

### Activity 3:

- Toolkit pages 10–16

## FLIP CHARTS



### Activity 2

- Flip chart with columns for Benefits of Family Care Flip chart with 7 skills listed

## ADVANCE PREPARATION



### Activity 1

- Make sufficient copies of **Handout 7** in advance
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Developmental Readiness for Self-Management and Transition	Lecturette and discussion	15 minutes
2	Transition is a Long Time	Group activity	30 minutes
3	Transition Tools	Group work	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Developmental Readiness for Self-management and Transition (~15 Minutes)

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Approximately one-third of infants born to mothers living with HIV not on antiretroviral therapy (ART)—either for their own clinical care or for the prevention of mother-to-child transmission—will be infected during pregnancy, birth, or breastfeeding. Until recently, it was assumed few children infected during this period would live beyond their fifth birthday. Recent data has emerged to challenge this assumption because children infected via vertical routes are now entering adolescence in sub-Saharan Africa. Recent projections suggest that 36 percent are slow progressors and have a median survival age of 16 even without access to treatment (Ferrand et al. 2009).

Many children who acquire HIV during the perinatal period—and are subsequently on ART—are now expected to live a long healthy life. However, they live with a host of clinical and psychosocial care needs that most community support and health systems in sub-Saharan Africa are not equipped to address (Ferrand et al. 2010; Li et al. 2010; Petersen et al. 2010; Valenzuela et al. 2009). Transition can be both a mental and physical reality for all adolescents living with HIV, and services should promote self-care that includes adherence to ART and the adoption of appropriate individualized prevention strategies to help reduce further HIV transmission (The Lancet 2011).

- » Write the following definition on a flip chart and keep it posted throughout the day. "Transition is a multi-faceted, active process that attends to the medical, psychological, and educational or vocational needs of adolescents as they move from the child focused to the adult focused health care" (Reiss and Gibson 2002). The transition process is a positive one that increases the adolescent's autonomy, linkages with their community and retention, and HIV care and treatment programs.

Evidence shows that poorly planned transitions can result in harmful consequences such as treatment non-adherence and loss to follow-up in care and support services—both severely impacting the health of the adolescent and having social and educational repercussions (Ferrand et al. 2010; Gilliam et al. 2010; Machado, Succi, and Turato 2010).

- » Facilitate a discussion with participants to discuss how transition is currently handled within their facilities. Once participants have shared, point out the differences between facilities—or if there is no transition planning occurring—emphasize that transition planning is important to ensure that adolescents have the skills, knowledge and ability to self-manage their care prior to transitioning.
- » Emphasize again that transition is not based upon a specific age, but rather is based upon developmental readiness, maturity and willingness of the adolescent to take on increasing responsibility of self-care. Some young adolescents may be completely independent while other older adolescents still may be reliant upon their caregivers for many tasks. This is why it is imperative to assess the individual client's ability to take on new tasks and assign responsibilities accordingly in order to plan for the smoothest transition possible.
- » Have participants turn to page 21 of the Toolkit, *Tool 1.1.1: Self-Management Timeline*. Explain that the column on the left side depicts various topics that arise during adolescence. The row at the top of the page shows age ranges with the action that typically should be taken by the health or community care provider if the adolescent is progressing as expected through development. Refer to the sexual and reproductive health component. Explain that for the age range of 8-12, any questions should be answered honestly. For the age range of 13-16, the adolescent should be referred to sexual and reproductive health services, have or be referred for sexual health check-ups, and HIV prevention should be discussed. Encourage participants to review the timeline and ask for any questions (Jacob & Jearld 2007). Remind participants that if an

adolescent is more delayed or advanced than expected, they should defer to the action in the table that is appropriate to their actual developmental stage.

- » Tell participants that they will learn in this workshop and when utilizing the Toolkit, that it is very important to tailor the transition to meet the needs of the individual patient through becoming acquainted with them and understanding their psychosocial and clinical needs and background. This will also help facilitate a team approach and supportive environment for the adolescent learning new self-management tasks.

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## **Activity 2: Transition is a Long Time! Adolescents and Developmentally-Appropriate Transition (~30 Minutes)**

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The Toolkit provides modules on a number of other topics that may arise during the adolescent period. Adolescence is a long time, and can span a 10-year (or more) period. Throughout this period all adolescents (younger and older) need to feel safe and it is key that the tools in the Toolkit facilitate building trust. Earning the trust of both younger and older adolescents may require different strategies that we will explore at this time.

- » Adolescents are often lumped into groups, such as 10 to 19, or 15 to 24, but there are vast differences between adolescents of different ages and transition must not ignore those differences. Ask participants to examine their own experiences and think about how to work with adolescents in a way that is developmentally appropriate and that can reinforce positive behaviors at the onset of transition.
- » Ask participants to consider their own experiences of working with adolescents of different ages for a few minutes. Have each participant share an experience of working with a 10 to 12-year-old adolescent with the person sitting next to them. Then have participants share an experience of working with a 18-year-old adolescent with the person sitting next to them. What are some of the differences?
- » Then share two flip charts that look like this:

<b>NEEDS OF YOUNGER ADOLESCENTS</b>	<b>NEEDS OF OLDER ADOLESCENTS</b>

- » Break the group up into two groups, have one group list the needs of younger adolescents on the flip chart, and have the other group prepare the list for older adolescents. Then post both flip charts at the front of the room.

- » State or circle the needs that are the same using the same color pen or marker; there should be some similar needs between the two groups and also some differences. Make the point that all adolescents have some needs that are the same and note the diversity within and amongst the two groups!
- » Now let's look at **Handout 7: Developmentally Appropriate Transition**, and discuss some considerations for younger and older adolescents to facilitate transition. **Handout 7** has some key concepts, activities and considerations listed. Discuss these in the larger group and link them to what participants have written on the flip chart. Note this is new and emerging information and they are really the experts here, so congratulate them for coming up with new knowledge if the flip charts show new ideas!
- » Tell participants that the Toolkit promotes transition throughout adolescence which may require different skills to be learned at different times in the developmental stages of the adolescent.
- » Remind participants that the transition information and tools in the Toolkit should be used at minimum twice annually to assess the adolescent's capacity to self-manage their care, establish self-management goals that are developmentally appropriate, and determine readiness to transition.

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### **Activity 3: Transition Tools (~30 Minutes)**

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- » Tell participants that the Toolkit is designed to specifically address the process of transition through provision of tools and information. In addition, the Toolkit provides modules on a number of other topics that may arise during the adolescent period. Addressing these topics will help the adolescent to care for themselves and increasingly take on self-management of care. For this session, we will just be addressing the transition tools and checklists.
- » Direct participants to page 10 of the Toolkit, *The Transition Framework*. Explain that transition is an individualized process based upon the developmental readiness and individual needs of the adolescent client. Transition discussions and preparation should begin as early as possible in adolescents to allow ample time for the adolescent to emotionally and mentally prepare for transition.
- » Pediatric and adult health care providers, along with community care providers should work together to provide case management and prepare for transition. At health facilities where there are not separate pediatric and adult health care providers, a physical transition may not occur. However, the adolescent will still require "transition services" so that they build their skillset to independently self-manage their care as they move toward adulthood.
- » Direct participants to page 11 of the Toolkit, *Key Checklists to Use Throughout Transition*, and review each checklist available in the Toolkit.
- » Direct participants to page 12 of the Toolkit, *Checklist 1: Monitoring the Use of the Modules*. This tool will help the HCP/CCP keep track of which modules within the Toolkit they have used with the individual client. After tools and information from a module have been used within the Toolkit, the appropriate box may be checked in this tool. This will assist the HCP/CCP to determine which topics may be appropriate to address or review with the client as needed.
- » Direct participants to turn to page 13 of the Toolkit, *Checklist 2: Comprehensive Transition Checklist*. This checklist should be referred to a minimum of twice per year. The HCP/CCP and the adolescent should work closely to set self-management goals using this checklist. The far left column has self-management tasks for the adolescent to complete prior to transition. Next to the self-management task is the age in which it is expected that the adolescent should accomplish this task. To the right of the expected age column is a check box to keep track that this task has been discussed with the adolescent, and a date for the goal of expected completion of this behavior. To the right of this box is an additional box to mark if the goal was completed. If the goal was not completed, a "No" should be placed in this box with another goal made after further

support is provided. The HCP/CCP may keep this tool in the client record and add to the record each time new goals are established until the adolescent has accomplished each task in the checklist and is ready to transition.

- » Direct participants to turn to page 14 of the Toolkit, *Checklist 3: HCP/CCP Checklist*. This checklist provides a framework for the provider to follow as the adolescent is ready for transition. This includes:
  - The adolescent verbalizing that they are prepared to transition
  - The pediatric and adult provider meeting for a case management discussion for transition
  - The adolescent completing tasks within their checklist and responding correctly to questions within *Tool 9.1.3: HIV Knowledge Assessment Quiz*
  - The adolescent demonstrating adherence to medication and verbalizing changes in their health status
  - The adolescent having their psychosocial needs met through provision of CBO services and verbalizing plans for long-term care
- » Direct participants to turn page 15 of the Toolkit, *Checklist 4: Family/Caregiver Checklist*. This checklist should be given to the family/caregiver. It explains the transition process to the family/caregiver and explains tasks that the adolescent will need to self-manage prior to transition. In addition, tips are provided to the family/caregiver to assist them in supporting the adolescent throughout the transition process.
- » Direct participants to turn to page 16 of the Toolkit, *Checklist 5: Adolescent Checklist*. This checklist should be given to the adolescent. It provides the adolescent with the tasks that they must complete prior to transition. They can use this as a prompt throughout the transition process to encourage self-management goals.
- » Remind participants that the transition information and tools in the Toolkit should be used at minimum twice annually to assess the adolescent's capacity to self-manage their care, establish self-management goals, and determine readiness to transition.

# SESSION 8: PSYCHOSOCIAL DEVELOPMENT

**Total Session Time: 1 hour**

## OBJECTIVES:

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

1. Explain various psychosocial considerations for ALHIV
2. Identify potential psychosocial needs of ALHIV
3. Use psychosocial tools within the Toolkit

## MATERIALS



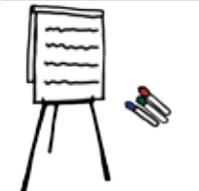
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 2:**
- Toolkit Module 1: Psychosocial Development

## FLIP CHARTS



- Activity 1**
- Internal and External Factors
- Activity 2**
- Tool review outline

## ADVANCE PREPARATION



- Activity 1 & 2**
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	The Psychosocial Needs of ALHIV	Discussion and lecturette	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: The Psychosocial Needs of ALHIV (~30 Minutes)

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- » Begin by stating that in this session you will be reviewing the psychosocial needs of adolescents living with HIV. Dramatic changes occur during adolescence including rapid physical development and further developments in personality and social skills. This can include a separation from the family/caregiver; further developing a sense of self and creating new relationships with peers (Hagan, Shaw, and Duncan 2008). No two adolescents are exactly alike—some are in school or working, some are already parents themselves or are taking care of their younger brothers and sisters. Some are already married, and some have been responsible for their own care while others are still completely reliant on their families/caregivers (Tindyebwa, Kayita, and Musoke, 2006). This diversity can lead to challenges, as the multiple needs of the adolescent can be difficult to address in a comprehensive manner, especially when considering that the adolescent is continually growing and evolving.

Psychosocial development is defined as the development of personality, social skills and attitudes from infancy to adulthood. Because adolescence is considered a period of rapid growth and changes—physically, psychologically and socially—each adolescent will have varying needs that will require considerations. Monitoring developmental milestones will assist to determine the adolescent's readiness to take on increasing responsibility for self-management of his or her health.

- » Ask participants to reflect on their own adolescent clients, and to identify factors that may influence their psychosocial development. When responses are given, write them on the flip chart and separate them into categories: Internal and External. If participants are slow to respond, provide examples including: 1) potential developmental delays which may interfere with the ability to care for one self, and 2) the health status of the adolescent's family/caregivers and their ability to provide support to the adolescent. Ask for more responses until a comprehensive list has been created

INTERNAL	EXTERNAL

- » Note that there are a variety of factors that may influence the psychosocial development of an adolescent. These may include internal factors such as developmental delays, and external factors that affect the personal growth and development of the adolescent, like socio-economic status (ie: the adolescent is malnourished, or has housing issues), loss of an important family member; or lack of access to school and educational opportunities. It is important to take into account all factors when assessing the psychosocial development of the adolescent.

Monitoring developmental milestones will assist in determining the adolescent's readiness to take on increasing responsibility for self-management of his or her health. ALHIV may experience a delayed onset of puberty, where the adolescent may appear smaller and younger; but is actually more cognitively mature (Arpadi 2005). Some ALHIV may also experience developmental

delays and learning problems, which may result in a slower than expected transition to self-management (Brown, Lourie, and Pao 2000). A careful assessment of cognitive development is key to providing appropriate psychosocial care and to determine what may be expected of the adolescent in managing his or her own care.

- » Explain to participants that this module of the Toolkit provides tools to help carry out a detailed psychosocial assessment to identify factors that will assist the adolescent with the transition process.
  - Involve the adolescent's family/caregiver wherever possible, as they likely play an important role in assisting the adolescent to manage his or her diagnosis. Speak with the adolescent and the family/caregiver together and ask questions about their general well-being. Be sure to note any concerns that the family/caregiver may have regarding the emotional and physical status of the adolescent, academic performance, ability to get along with other family members and peers, as well as any risk-taking behaviors and current self-management activities. Observe the interaction between the adolescent and the family/caregiver to determine their relationship and their ability to communicate with each other in a productive manner.
  - Also speak to the adolescent privately and screen for gender-based violence (GBV). Provide reassurance that the information that the adolescent shares is confidential and ask about SRH, substance and drug use, risk-taking behaviors, and any other concerns that the adolescent may not want to discuss in front of the family/caregiver. Provide referrals for psychosocial services within the community. Many ALHIV may not have family/caregiver support, further increasing their vulnerability during transition. Emphasize and encourage protective factors that are identified during the psychosocial assessment, and suggest new—and reinforce existing—positive coping strategies to address challenges that may support the adolescent during the transition process.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 5 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart below to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP, family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions and encourage participants to continually assess psychosocial development when identifying individual adolescent needs and capacity to take on greater self-management responsibility in the transition of care.

# SESSION 9: MENTAL HEALTH CONSIDERATIONS

**Total Session Time: 1 hour**

## OBJECTIVES:

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

1. Explain various mental health considerations for ALHIV
2. Identify approaches to identify and care for the mental health needs of ALHIV
3. Use mental health tools within the Toolkit

## MATERIALS



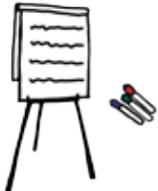
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 1:**
- **Handout 8: The HIV-Positive Adolescent Client and Mental Health**
- Activity 2:**
- Toolkit Module 2: Mental Health Considerations

## FLIP CHARTS



- Activity 2**
- Tool review outline

## ADVANCE PREPARATION



- Activity 1**
- Make sufficient copies of **Handout 8** in advance
- Activity 2**
- Prepare flip chart (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Mental Health Considerations	Discussion and lecturette	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Mental Health Considerations (~30 Minutes)

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In addition to the typical emotional changes that occur during adolescence, ALHIV must deal with stressors such as loss of loved ones, stigma and isolation, gender-based violence, sexual orientation, and the responsibility of taking care of oneself in the presence of a chronic illness. ALHIV are more likely to experience anxiety and depression, with symptoms generally emerging during adolescence. Adolescents who suffer from depression are more likely to be non-adherent to their medication and have other self-care issues (Brown, Lourie, and Pao 2000; Gonzalez et al. 2011). To minimize setbacks during the transition process, it is essential to screen for and treat mental health problems.

- » Ask participants to explain the difference between the term “psychosocial” which was referred to in the previous session and the term “mental health”. After a number of responses have been provided, explain that—according to the WHO—mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community. Further explain that mental health is heavily influenced by psychosocial factors which may include socio-economic status, gender discrimination, social exclusion, and access to education—among many others (2010b) aspects that were discussed in the previous session.
- » Tell participants that they will now take part in an activity that will help them to start thinking about the mental health needs of their adolescent clients and actions that they can take when mental health problems are suspected. Provide **Handout 8: The HIV Positive Adolescent Client & Mental Health**. Direct participants to work in groups of 2-3 to discuss and respond to each question on the hand out. After 10 minutes have passed, bring the group back together and lead a discussion on each question. Summarize the responses and tell participants that when mental health symptoms are suspected, the HCP/CCP should refer to the mental health screening assessments within the Toolkit. Emphasize that addressing the adolescent’s mental health is a critical component to help the adolescent learn to self-manage their care and progress toward adulthood in a healthy manner.
- » Ask participants to describe potential symptoms of a client experiencing depression. If not mentioned, share the following symptoms: social withdrawal, loss of appetite or increased appetite, difficulty sleeping or too much sleep, poor personal hygiene, and flat affect, among others.

It is important to routinely assess for depression. In particular, the period immediately after diagnosis of HIV poses the highest risk for attempted suicide. Ask the client directly if they are suicidal and if so, whether they have a plan to harm themselves; document these discussions. If it is suspected that he or she is thinking about suicide, provide an urgent (same day) referral for mental health counseling and involve the family/caregiver whenever possible (Thom 2009). If there are transportation issues, work with the family/caregiver to solve them.

- » Ask participants to describe potential symptoms of a client experiencing anxiety. If not mentioned, share the following symptoms: a lack of appetite, tremulousness, sweating, racing heart, difficulty breathing, headaches, difficulty falling asleep, restlessness, and difficulty concentrating (ICAP 2011).

In some instances, post-traumatic stress disorder (PTSD) symptoms are present in adolescents who have experienced or witnessed a traumatic, sudden, or distressing event. In some countries, PTSD is often referred to as continuous traumatic stress, as individuals are often subjected to ongoing traumatic or distressing situations. Some of these symptoms may include low mood, exaggerated startled response (very jumpy), emotional numbness, and agitation (feeling on edge). When emotional problems are suspected, referrals should be made to peer support groups and to lay counselors if trained mental health professionals are not available.

Health and community care providers should monitor for mental health symptoms at each visit, and also teach the symptoms of mental health problems to the adolescent and their family/caregiver so that they can also monitor the adolescent's mental health.

- » Encourage participants to become acquainted with the mental health counselors and other support services— such as peer and community support groups—who work with adolescents to engage all parties in an effort to create a therapeutic and supportive environment for a smooth transition.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Divide participants into 5 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess the adolescent's mental health status when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 10: SEXUAL & REPRODUCTIVE HEALTH

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Explain various aspects of adolescent sexual and reproductive health as they relate to HIV
2. Identify approaches to address sexual and reproductive health
3. Use sexual and reproductive health tools within the Toolkit

## MATERIALS



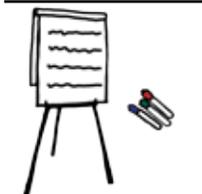
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 1:**
- **Handout 9: Identifying and Overcoming Barriers to Provision of ASRH Services**
- Activity 2:**
- Toolkit Module 3: Sexual & Reproductive Health

## FLIP CHARTS



- Activity 1:**
- Barriers to ASRH Service Provision and Methods to Overcome Them
- Activity 2:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 1**
- Make sufficient copies of **Handout 9** in advance
- Activity 1 & 2**
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Sexual & Reproductive Health	Discussion and lecturette	45 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Sexual & Reproductive Health (~45 Minutes)

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Adolescence is a period of self-discovery and exploration when sexual initiation usually occurs (Baryamutuma and Baingana 2011; Elkington et al. 2009). Like their HIV-negative peers, ALHIV have the right to a healthy sex life, and should be equipped with the skills to protect themselves and their partners. Sexual and reproductive health (SRH) services are a critical component of the transition of care (Obare, Birungi, & Kavuma 2011).

Some health and community providers may feel uncomfortable discussing sexual and reproductive health issues with their adolescent clients, especially when the client may have been known by the provider since infancy. However, discussing SRH with the adolescent client is critical to ensure that they are protecting themselves and their partner from HIV transmission and unwanted pregnancy, and also carrying out long-term planning for future children if desired.

- » Distribute **Handout 9: Identifying and Overcoming Barriers to Provision of ASRH Services**. Tell participants that the first step to overcoming barriers to provision of adolescent sexual and reproductive health (ASRH) services is to identify them. Have participants gather in groups of 2-3. Give them 10 minutes to discuss barriers to providing ASRH services and at least 1-2 methods to overcome the barrier. Remind them that ASRH services may include sex education, provision of condoms and other birth control, and identifying and addressing sexual abuse.
- » After 10 minutes, bring participants back together and select a group to present their barriers and the methods to overcome the barriers. List the barriers and methods to overcome them on a flip chart as they are listed. Allow for some discussion after the group has presented to determine if other groups have additional ideas for overcoming the barriers. Follow the discussion by allowing each group to present any barriers that have not yet been mentioned, until all barriers and methods to overcome them have been identified and addressed. Encourage participants to work to overcome ASRH service provision barriers keeping these methods in mind.

In order to build trust and open communication with the adolescent, speak with the adolescent privately and routinely about SRH. Tell the adolescent that sexual questions, thoughts, and desires are normal. Discuss issues of sexuality in a nonjudgmental, constructive manner. Be sensitive to diverse sexual orientations (Birungi 2007) and be careful how questions are phrased to the adolescent—do not assume that the adolescent identifies as heterosexual or only engages in sex with people of the opposite sex. Once the adolescent is comfortable discussing these topics, gently broach the topic of sexuality and simply ask the adolescent if they like girls or boys or both. Always provide reassurance that what they share will not be shared with anyone else. Work with families/caregivers to provide education and encourage them to provide guidance without violating the confidentiality of the adolescent.

ALHIV may engage in sexual risk-taking behavior as a coping mechanism to deal with recent disclosure, feelings of hopelessness, poor body image, or orphanhood (Operario et al. 2011). Engaging in sexual behavior as a means to gain peer acceptance may occur with all adolescents (Clum et al. 2009; Elkington et al. 2009; Wiener, Battles, and Wood 2007). Provide education on HIV transmission and prevention, abstinence, correct and consistent condom use, and where to obtain condoms. Build skills for ALHIV to build committed relationships, engage partners in open communication, and practice safer sexual practices.

Many youth living with HIV plan to have families of their own; provide education, family planning services, and referral to antenatal care for PMTCT to minimize transmission. (Baryamutuma & Baingana 2011). Educate on ART adherence and encourage dual protection—use of a hormonal and barrier method—to offer greater pregnancy and STI protection. For serodiscordant couples, viral load monitoring may help with timing conception attempts to minimize the risk of HIV transmission to the uninfected partner.

Routine STI screening is essential once the adolescent initiates sexual activity. Educate on STI transmission and prevention, and symptoms of STIs. Women living with HIV are particularly susceptible to human papillomavirus. Provide annual Papanicolaou tests to identify cervical abnormalities (Brogly et al. 2007). Where available, offer Gardasil and hepatitis B vaccines. For HIV-negative male partners, refer to voluntary male medical circumcision services to decrease the likelihood of HIV acquisition.

HIV-positive adolescents may be at risk for sexual abuse and violence, intimate partner violence, engaging in transactional sex, increasing the risk of unintended pregnancy, and STIs. Screen for these risks at each visit.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 7 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP, family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess the sexual and reproductive health needs of the adolescent when identifying the individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 11: PROTECTION

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**Total Session Time: 1 hour**

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## OBJECTIVES:

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

1. Explain various aspects of protection
2. Identify approaches to address protection issues among adolescent clients
3. Use protection tools within the Toolkit

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## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

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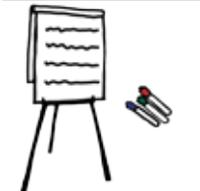
## HANDOUTS & TOOLS



- Activity 1:**
- Toolkit *Tool 4.1.1: Protective Services Checklist*
- Activity 2:**
- Toolkit *Module 4: Protection*

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## FLIP CHARTS



- Activity 1:**
- Recognizing Signs of Abuse and Neglect in Adolescent Clients
- Activity 2:**
- Tool review outline

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## ADVANCE PREPARATION



- Activity 1 & 2:**
- Prepare flip charts (see examples below)

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## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Protection and the Adolescent	Discussion and lecturette	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

## Activity 1: Protection and the Adolescent (~30 Minutes)

Many ALHIV have lost one or both parents to AIDS, or have a caregiver who is also living with HIV. Losing a parent to AIDS increases the chance a child will experience stigma, rejection, and a lack of love and care. Being an AIDS orphan or having a caregiver living with HIV is also associated with an increased likelihood of being emotionally or physically abused. Children made vulnerable by HIV are at greater risk of being neglected and exploited through forced labor or trafficking (Cluver et al. 2011).

People living with HIV are more likely to experience gender-based violence (GBV), which is violence directed at someone based on his or her sex, gender identity, or perceived adherence to gender norms. Gender-based violence may occur in different forms throughout the lifespan. For adolescents, this may include sexual abuse, trafficking, neglect, and domestic violence (Khan 2011).

- » Tell participants that as health and community care providers, it is their responsibility to be aware of potential abuse and neglect among clients. Creating an open and communicative environment may help the adolescent to report the abuse or neglect. However, some adolescents may be scared or nervous about their safety if they report the abuse or neglect. It is part of the health and community care providers job to be able to identify potential signs of abuse and neglect, even if the adolescent does not report it.
- » Ask for a volunteer recorder to write down participant responses on the flip chart. Tell participants that you will now brainstorm and make a list of various potential signs of abuse and neglect that they might identify in adolescent clients. Write down all responses until the list is fairly complete and summarize the responses. Refer to the table below to supplement the responses from participants.

SIGNS OF EMOTIONAL & PHYSICAL ABUSE	SIGNS OF SEXUAL ABUSE
<ul style="list-style-type: none"> <li>— Fear of parents/caregivers being contacted, going home or receiving medical advice</li> <li>— Flinching when touched</li> <li>— Refusal to discuss injury</li> <li>— Covering arms and legs</li> <li>— Over reaction to mistakes</li> <li>— Extremes of emotions</li> <li>— Self-mutilation</li> <li>— Unexplained or untreated injuries,</li> <li>— Injuries on unlikely or unusual parts of the body</li> <li>— Cigarette burns, bite, belt marks, or scalds,</li> <li>— Poor personal hygiene</li> <li>— Constantly hungry and tired</li> <li>— Inappropriate clothing or dress</li> <li>— Disheveled appearance</li> <li>— Lonely, no friends</li> <li>— Obviously underweight</li> <li>— No parental support or interest</li> <li>— Chronic yet unexplained health problems</li> <li>— Academic problems</li> </ul>	<ul style="list-style-type: none"> <li>— Pain, itching, bruising, or bleeding in the genital area</li> <li>— STIs</li> <li>— Early pregnancy in young women</li> <li>— Stomach pains</li> <li>— Discomfort when walking</li> <li>— Unexplained sources of money</li> <li>— Inappropriate sexual drawings/language/behavior;</li> <li>— Being withdrawn or in fear of one person</li> </ul>

(Footy4kids 2013.; East, Central and South African Health Community 2011).

These symptoms are not always necessarily the result of abuse. Talk to the adolescent about what is going on in his or her home, community, relationships and school (ICAP 2011).

Be sure to ask to speak to the adolescent privately, as the abuse could be from the family/caregiver/partner, and be sure to not rush the physical exam. In some cases the abuser may insist on accompanying the client to the appointment and may be hesitant to leave the client alone. You may ask to speak to the adolescent privately by telling the person who accompanied them that you ask to see all clients alone and that this is part of routine services provided.

Before you screen for abuse or violence, you must have strong supportive services available for the adolescent. These can be trained counselors and support services located on-site, or available via a clear and simple referral pathway to ensure the adolescent receives appropriate care if he or she discloses abuse.

- » *Tool 4.1.1: Protective Services Checklist* has been provided in the Toolkit on page 43 to guide referrals. Tell Participants that they should brainstorm together any protective services available within their community or district. Give them 10 minutes to complete the Protective Services Checklist to the best of their ability. After 10 minutes have passed, remind them that completing this checklist will be an important step to adapt the Toolkit and ensure its relevance to their setting.

Adolescents may be reluctant to betray family/caregivers or authority figures, or if they are married, their spouses, so provide reassurance about the confidential nature of your discussions and encourage the adolescent to talk when he or she is ready. However, tell the adolescent that you may have to bring in additional providers, such as those involved with law enforcement, as necessary.

Abuse may lead to mental health problems, promiscuous sexual behavior, or alcohol and substance use, so be vigilant for signs of abuse when screening for these.

Adolescents—especially female adolescents—may engage in transactional sex to help meet basic needs such as those for food, shelter, and school fees. Adolescents affected by HIV are at greater risk for engaging in transactional sex (Cluver et al. 2011). Talk to the adolescent about whether or not his or her basic needs are met and identify who helps see they are met. Discuss risks associated with transactional sex, and work with the adolescent and the family/caregiver to identify resources to help meet their needs. In the event of child abuse and/or neglect, legal action may be appropriate; be sure to check what laws exist in your country. Coordinate with social workers and law enforcement as needed to ensure protective action for the adolescent.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into three separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately ten minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately two minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess protection when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 12: ALCOHOL & SUBSTANCE USE

**Total Session Time: 1 hour**

## OBJECTIVES:

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

1. Explain alcohol and substance use issues among adolescents
2. Identify approaches to address alcohol and substance use among adolescent clients
3. Use alcohol and substance use tools within the Toolkit

## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



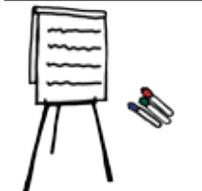
### Activity 1:

- **Handout 10: Values, Thoughts, and Perceptions Surrounding Adolescent Alcohol and Substance Use**

### Activity 2:

- Toolkit Module 5: Alcohol & Substance Use

## FLIP CHARTS



### Activity 2:

- Tool review outline

## ADVANCE PREPARATION



### Activity 1:

- Make sufficient copies of **Handout 10** in advance

### Activity 2

- Prepare flip chart (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Alcohol and Substance Use	Discussion and lecturette	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Alcohol and Substance Use (~30 Minutes)

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ALHIV may experiment with alcohol and other substances, just like their uninfected peers (Battles and Wiener 2002; Machado, Succi, and Turato 2010; Ryscavage et al. 2011). Some adolescents may view alcohol and substance use as a means of peer acceptance, especially if they feel behind for their age, are smaller or younger-appearing than their peers, or feel isolated in their peer group (Elkington et al. 2009). ALHIV may also use alcohol or other substances as a coping mechanism to deal with feelings of sadness or hopelessness around their diagnosis, especially after disclosure, or with parental illness (Clum et al. 2009; Hagan, Shaw, and Duncan 2008; Mellins et al. 2011).

If a parent, caregiver, or another member of the household uses alcohol or other substances, the adolescent is more likely to do so as well. It is important to talk to adolescents before a problematic pattern of behavior or dependency is established. Motivational interviewing is a technique that may help you talk to the adolescent and also discuss behavior change—remember the adolescent must be ready to discuss these issues.

- » As health and community care providers it is essential to feel comfortable approaching the topic of adolescent alcohol and substance use. It is not uncommon to experience hesitation or discomfort in approaching this topic with clients. It is helpful to first understand one's own thoughts and attitudes toward the topic prior to discussing it with the adolescent. Direct participants to turn to **Handout 10: Values, Thoughts, and Perceptions Surrounding Adolescent Alcohol and Substance Use**. Tell participants that they have 10 minutes to work with a partner to discuss and record their responses to the handout.
- » After 10 minutes have passed, lead a discussion surrounding participant responses to each question followed by a summary of responses for the activity. Emphasize that in order to provide a supportive and sharing environment, do not allow personal perceptions about drug and alcohol use interfere with communication. If the adolescent feels that they are able to share without judgement, they will be more likely to accurately communicate their behaviors, and the health and community provider will have an improved ability to respond and assist the adolescent!

Adolescents may feel some discomfort discussing alcohol and other substance use with parents or other caregivers present, so you may request to speak with the adolescent in private. Use of the substance abuse and alcohol screening tool within the Toolkit can help you to do this. Part of general psychosocial screening and mental health screening can include asking the adolescent if he or she has tried or is using alcohol or other substances, and reaffirming that your conversation will be kept confidential. Substance use may be a sign of—or coping mechanism for—mental illness or experiencing violence or abuse (Mellins et al. 2011; Williams et al. 2010).

Be sure to review the respiratory and other health consequences of smoking with adolescent clients. Ask the adolescent about alcohol, tobacco, and substance use in his or her peer group. Encourage a dialogue with the adolescent to discuss why he or she might want to experiment with alcohol or other substances, especially in the context of his or her peers and social settings.

It is important to work with family/caregivers to look for signs or symptoms of alcohol and other substance use, as they may only be noticed by those in daily contact with the adolescent. Potential indicators of alcohol or other substance use include changes in friends, missing school or church groups, negative changes in schoolwork, or increased secrecy about activities. The adolescent may also seek to borrow money more frequently.

Discussion of alcohol and substance use can be an opportunity to reinforce messages about safer sexual practices, especially around the risk of engaging in unsafe sex while under the influence of alcohol or other substances. Stress how alcohol and

substance use can increase higher-risk sexual practices—such as not using condoms—which can increase possible HIV or other STI transmission (Morojele et al. 2006). Another risk of alcohol or substance use is the potential for skipping antiretroviral medications. Inform the adolescent about the risks of non-adherence and what consistent non-adherence could mean for his or her long-term health outcomes.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 5 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions and encourage participants to continually assess alcohol and substance use when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 13: BENEFICIAL DISCLOSURE

**Total Session Time: 1 hour and 30 minutes**

## OBJECTIVES:

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

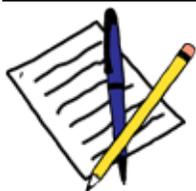
1. Explain issues surrounding beneficial disclosure among adolescents
2. Identify beneficial disclosure approaches for adolescents
3. Use beneficial disclosure tools within the Toolkit

## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 3:**
- Toolkit *Module 6: Beneficial Disclosure*

## FLIP CHARTS



- Activity 2:**
- Flipchart with who and why noted
- Activity 3:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 2 & 3**
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Beneficial Disclosure	Discussion and lecturette	30 minutes
2	Disclosure: Who and Why?	Group work and discussion	30 minutes
3	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Beneficial Disclosure (~30 Minutes)

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Disclosure is not a singular event, but a process that occurs over time. Beneficial disclosure can help buffer some of the uncertainty of a future with HIV infection, help alleviate feelings of anxiety and fear, and build trust between the adolescent and the family/caregiver or HCP/CCP. However, serious risks exist with each instance of disclosure (Battles and Wiener 2002). These risks must be considered by the adolescent, his or her family/caregiver, and the HCP/CCP.

Many perinatally infected children grow up unaware of their HIV status—family/caregivers and providers struggle to protect themselves and their children from the stigma and discrimination associated with HIV. Children in preadolescence often have increasing awareness of their illness and social values associated with HIV. By adolescence, most children have established cognitive capacities for understanding concepts of illness and health, including treatment progression (Ayres et al. 2006; WHO 2011).

Disclosure to children in adolescence is complicated by cognitive readiness, puberty, and emerging sexuality. Often, adolescence is the time when sexual relationships are initiated and people begin to plan for future families. Disclosing an HIV diagnosis should be done at a time appropriate to a child's needs and developmental stage, not their chronological age. Current WHO guidelines recommend disclosure to children of school age (i.e., before age 12) (WHO 2011).

As disclosure is a process and not a singular event, adolescence is a time to reinforce information already shared with the adolescent. The HCP/CCP should work together with families/caregivers to create a trusting and supportive environment for disclosure (Abadía-Barrero & Larusso 2006).

Disclosure is a time to revisit knowledge of HIV infection and transmission, and the social context of HIV. Adolescents may internalize some of the stigma surrounding HIV and experience feelings of hopelessness around their diagnosis. Reinforcing correct information about treatment, outcomes, and transmission is important during the process of disclosure. There are secondary issues of disclosure to consider as well. For perinatally infected adolescents, disclosure of their HIV status is also disclosure of their mother's status. For adolescents who acquired HIV through sexual risk or injecting drug use, HIV disclosure may also mean giving information that may lead to further stigmatization.

The circumstances of the adolescent's care in both the facility and the home should also be considered. With the families/caregivers, you should assess the adolescent's ability to process information about HIV and reinforce the psychosocial support system the adolescent has. Be honest and open with the adolescent, and encourage a dialogue to allow the adolescent to ask you any questions or voice any concerns he or she may have. You should also support families/caregivers to discuss the adolescent's illness with him or her over time.

Knowing about HIV infection and his or her status is an important part of active participation by the adolescent in his or her own care (Thorne et al. 2002). Together with his or her caregivers, you can assist the adolescent in increasingly making decisions about his or her own care. When and how to disclose to others is an important part of maturing and self-management of HIV. You should also support the adolescent in disclosing his or her status to others, another ongoing process.

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## Activity 2: Disclosure: Who and Why? (~30 Minutes)

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- » Tell participants that disclosure is a part of living with HIV, and many times, transition begins with learning they are positive either through disclosure or testing. Ask participants to share their experiences with disclosure and to think of the different

ways to help the adolescent and their family/caregiver approach disclosure in a beneficial manner. The ultimate goal of disclosure is to make the adolescent healthier and happier. So we need to keep that at the forefront throughout this session and throughout the process of helping to support disclosure in practice.

- » First facilitate a larger group brainstorm, disclosure to the child of his/her status is usually the first step in transition among those children infected perinatally. Let's assume the adolescent already knows his/her status: who do you think the adolescent and/or the family/caregiver may **want to** consider disclosing to? Ask them to speak from experience. Keep the adolescent needs and wants at the forefront—have disclosure always be guided by the needs the adolescent and his/her family.
- » Always keep in mind the key concepts of beneficence (doing the most good by the adolescent) and doing no harm (not damaging the adolescent and his/her family). Collect the “who” list on a flip chart that looks like this:

<b>BENEFICIAL DISCLOSURE: TO WHO?</b>	

- » After the list is relatively complete, fill out the second column with “Beneficial Disclosure: Why?” The flip chart should now look like this:

<b>BENEFICIAL DISCLOSURE: TO WHO?</b>	<b>BENEFICIAL DISCLOSURE: WHY?</b>

- » Again focus the participants to discuss beneficence (doing good by the adolescent) and doing no harm (not making life harder for the adolescent) for each “who” they stated (e.g., telling a friend as a “who,” then why the adolescent might benefit from peer support, or experience more discrimination from the peer). State each group under the “who” and explore why they may want to be disclosed to. Note how disclosure can be both harmful or helpful. The key in this session

is to reinforce how complex disclosure is and the tools in the Toolkit can help with that.

**Key Points: EVERYBODY has a role.**

- **Role of Providers:** HCP/CCPs can help adolescents understand the benefits of disclosure, and also practice how and when to disclose to selected family members and close friends. They can also help adolescents understand the importance of disclosure through counseling and peer support groups. HCPs/CCPs need to be aware that there is a risk when disclosing HIV status in an unsupportive setting, in particular for young women who may be at risk of domestic violence.
  - **Role of Adolescents:** Adolescents with perinatally acquired HIV are able to cope better if they were told about their HIV status at a young age. Involving ALHIV who have already successfully disclosed their status may be helpful in working through the challenges of beneficial disclosure with adolescents thinking about disclosing their HIV status.
  - **Role of Caregiver/Family:** Support from family or a guardian is particularly important for adolescents because they are still young, inexperienced, and may be close to their family. Additionally as the adolescent gets older he or she will continue to disengage from their family as they take on more of a role in transition and self-management. At all stages family and caregivers are key to include in the discussion about beneficial disclosure.
- » At the end of the session state that helping adolescents and families/caregivers with disclosure can be a difficult process, but if you keep the key principles of beneficence and doing no harm at the center you can help the adolescent and his/her family approach disclosure from a beneficial frame.

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### **Activity 3: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 5 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

#### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP, family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess beneficial disclosure when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 14: LOSS, GRIEF, & BEREAVEMENT

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Explain issues surrounding loss, grief, and bereavement for the adolescent client
2. Identify approaches to address loss, grief, and bereavement for adolescents
3. Use loss, grief, and bereavement tools within the Toolkit

## MATERIALS



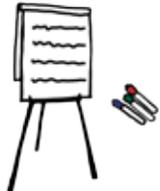
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 2:**
- **Handout 11: Basic Principles of Grief**
- Activity 3:**
- Toolkit Module 7: Loss, Grief, & Bereavement

## FLIP CHARTS



- Activity 2:**
- What is Grief?
- Activity 3:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 2**
- Make sufficient copies of **Handout 11** in advance
- Activity 2 & 3**
- Prepare flip chart (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Loss, Grief, and Bereavement	Discussion and lecturette	15 minutes
2	What is Grief?	Group activity	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Loss, Grief, and Bereavement (~15 Minutes)

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Talking about grief and bereavement is complicated, but it can be transformational for the adolescent. Let's review the key terms. **Bereavement** is the period of sadness after losing a loved one through death. **Grief** is the normal process of reacting to the loss of someone or something. People experiencing grief may assume mannerisms of the deceased, regress emotionally, repeat stories of their loved one, say nothing at all, show anger at others for no real reason, feel guilty for being angry at the deceased, exhibit mood changes over the slightest things, and have unexpected outbursts or crying. All of these behaviors are normal.

Many ALHIV have lost one or more family members or caregivers, which can result in potential depression, relationship problems with peers, post-traumatic stress disorder, and behavioral problems which may impact the transition process if left unresolved (Cluver et al. 2009).

In addition, adolescents may not feel that they are able to express their grief surrounding the loss of a loved one due to stigma surrounding HIV—resulting in a sense of shame surrounding the death and potentially worsening the mourning process (Brown, Lourie, and Pao 2000). Often, the grief experienced by ALHIV is multilayered and is referred to as “complicated grief.” This means that the adolescent might take a longer time to work through his or her issues related to grief and might even be vulnerable to other mental health conditions.

Complicated grief requires more intensive services. It is important to understand the referral process to best provide services for the adolescent. Complicated grief can include suicidal thoughts/actions, extreme aggressiveness, extreme withdrawal, phobias, extreme feelings of guilt, or preoccupation with the loss of the adolescent's loved one. If grief is complicated all of the traits may be exhibited and may interfere with normal functioning. If you suspect this, IMMEDIATELY refer this client for higher level mental health services.

When working with an adolescent who is experiencing acute grief, be sure to acknowledge it and monitor it throughout the transition process. Take note of the adolescent's emotional state and ensure that the adolescent has a strong support system as well as access to counseling services during this particularly vulnerable time for the adolescent (Ndiaye 2009).

Work with the adolescent and his or her family/caregiver to build upon existing strengths during the grieving process. To address anticipatory grief in response to an impending death of an ill family member, work with the ill family member to help him or her express his or her feelings of love and care to the adolescent. Encourage open communication regarding the loss within the household to support the grieving process (Demmer and Rothschild 2011).

- » Adolescents will understand and respond to grief differently based on their stage of development, their personality, their existing support system, and other losses that they have experienced (Ndiaye 2009). Ask participants how a grieving adolescent may appear. Routinely monitoring for grief symptoms is essential. If not mentioned, list sadness, poor appetite, weight loss, difficulty sleeping, crying, guilt, rage, numbness, disorganized thoughts, and a sudden increase in maturity as signs of grief. Keep in mind that these symptoms vary between individuals (Burns et al. 2009).

Provide an open environment where the adolescent can discuss his or her experiences in an unrushed manner and be sensitive to the adolescent's needs as this will help him or her to express any feelings of grief.

Additional ways to provide support include allowing the adolescent to grieve at his or her own pace, encouraging routine behavior such as school attendance or work, encouraging involvement of other family/caregivers wherever possible, identifying

positive role models outside of the home, encouraging the adolescent to be proactive in finding help to address his or her loss, and encouraging independent decision making and healthy friendships (Ndiaye 2009).

Be sure to refer ALHIV who display grief symptoms for counseling as well as to peer support groups to reinforce their resilience and to provide support throughout the grieving process.

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## Activity 2: What is Grief? (~30 Minutes)

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- » Tell participants that they will now be participating in an activity to better understand grief. Write 3 words on the flip chart:

NATURAL	UNIQUE	ONGOING

- » State, "Grief is Natural, Grief is Unique, Grief is Ongoing." Ask the group for an example from each column based on their experiences with adolescents. Then deliver **Handout 11: Basic Principles of Grief**.
- » Facilitate a discussion that reinforces the key points in Handout 11.
- » Ask for examples on how best to support the adolescents, some are listed and collect more. Additionally ask where you would refer the adolescent if you suspect complicated grief. This information should be included in the health and social services directory which is available in the Toolkit.
- » Ask for remaining questions and encourage participants to always keep those 3 principles at the forefront (Grief is Natural, Grief is Unique, Grief is Ongoing) when working with adolescents who have experienced loss.

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## Activity 3: Review of Tools (~30 Minutes)

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 5 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess grief and bereavement when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 15: CLINICAL CONSIDERATIONS

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Explain various clinical considerations ALHIV
2. Identify clinical approaches for working with ALHIV
3. Use clinical considerations tools within the Toolkit

## MATERIALS



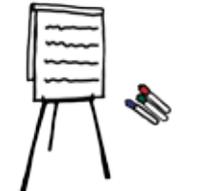
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 2:**
- Toolkit *Module 8: Clinical Considerations*

## FLIP CHARTS



- Activity 2:**
- Adolescent clinical considerations
- Activity 3:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 2 & 3**
- Prepare flip charts (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Clinical Considerations	Discussion and lecturette	30 minutes
2	Review of Tools	Group activity	45 minutes

# LEARNING ACTIVITIES

## Activity 1: Clinical Considerations (~30 Minutes)

» It is important to understand potential differences between perinatally and behaviorally exposed adolescents. Review the differences between these populations using the table provided below.

**FIGURE 2<sup>2</sup> DIFFERENCES BETWEEN ADOLESCENTS BY TRANSMISSION ROUTES**

PERINATALLY INFECTED	BEHAVIORALLY INFECTED
More likely to be in advanced stages of HIV	Earlier stages of HIV
More likely to have opportunistic infections (OI)	Fewer OIs
More likely to not be on first line drugs and in need of complex ART regimens	Less likely to need ART and resistance to ART less likely
More obstacles to achieving self-management and autonomy	Less likely to experience obstacles to achieving self-management and autonomy
More likely to have physical and developmental delays	Less likely to have physical and developmental delays
Higher risks of complications during pregnancy	Lower risks of complications during pregnancy
Higher mortality rates	Long-term chronic disease outlook
May not know their HIV status, though they may have been in treatment	May experience more adherence challenges
More likely to have experienced multiples losses related to HIV (parents, siblings, etc.)	More likely to have denial and fear of HIV
More secrecy regarding disclosure	More likely to be misinformed about HIV
Struggling with issues of sexuality and sexual identity	May distrust clinical facilities
May have heightened concerns about pregnancy and starting families	Lack of belief in clinical treatment to prevent vertical HIV transmission
More likely to have support from family/caregiver and health provider	More likely to lack familial, clinical, and social supports
Likely to have dealt with grief and bereavement due to loss of parent or other family member to HIV	

(Sharer and Fullem 2012)

Remember that there are many ALHIV who have not yet been tested and do not know their status. It is imperative to incorporate HIV testing as a routine component of clinical visits.

<sup>2</sup> Adapted from Gipson & Garcia 2009.

- » It is also important to remember the unique clinical considerations of the adolescent which may be different than the type of services that one would provide an adult client. Tell participants that they will now make a list of clinical considerations that are unique to adolescents. This may also include social aspects of dealing with HIV that may impact the adolescent's clinical status. Give participants approximately five minutes to brainstorm a short list of unique clinical considerations.
- » After 5 minutes, ask for a volunteer to record responses on a flip chart. Ask for input from participants. Continue the activity until the list is relatively complete. Review all of the items listed, and if the following considerations have not been mentioned, be sure to include them: adherence issues, stigma among peers, medication management while in school/working/involved in athletics/and community groups, and grasping the concept of self-care while still living with family/caregiver and gaining increased autonomy.

For those clients who are not yet on ART, the decision to begin ART is an important one and should include discussions between the HCP, the adolescent, the family/caregiver, and an adherence counselor. All adolescents with a CD4 count  $\leq$  350 or WHO Stage 3 or 4 should begin ART (see *Tool 8.1.5: Antiretroviral Therapy Guide*; in addition, see *Tool 8.1.9: Tanner's Staging Guides*). ART prescription should be clearly understood so that it is correctly prescribed. Educate the adolescent and his or her family/caregiver on medications including reasons for taking the medication, dosage, schedule, potential side effects, when to contact the HCP, and the importance of adherence. This information will increase the adolescent's ability to self-manage his or her care during the transition process.

Prior to beginning ART, assess ART readiness and prepare the adolescent through providing adherence counseling. Carry out a treatment adherence assessment at each visit. Poor adherence can lead to treatment resistance, resulting in limited treatment options. Poor adherence can also increase the likelihood of OIs, increased viral load, and the likelihood of death (National Institutes of Health 2001). Barriers to treatment adherence for the adolescent include depression, a high pill burden, advanced HIV status, alcohol use, dropping out of school, lack of access to transportation, and side effects of the medications (Nachega et al. 2009). Many adolescents fear the stigma that they may encounter when procuring their medications. Stock-outs of medications at your facility may also play a factor in poor adherence.

Using the tools within the Toolkit will help to assess for adherence readiness, assess adherence once the adolescent has started ART, and to help the adolescent keep track of their medications, through the *Tool 8.3.10: Medication Adherence Diary* and the adolescent *Tool 8.2.11: Medication Worksheet*.

In order to properly plan for transition, it is imperative to document all clinical findings in a clear and legible manner so that once the adolescent has transitioned, the documentation that you provide to the new HCP is complete and accurate. Be sure to follow your workplace HIV guidelines.

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## **Activity 2: Review of Tools (~45 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 12 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess clinical considerations when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 16: POSITIVE LIVING

**Total Session Time: 1 hour and 15 minutes**

## OBJECTIVES:

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

1. Explain various positive living considerations for ALHIV
2. Identify positive living approaches for working with ALHIV
3. Use positive living tools within the Toolkit

## MATERIALS



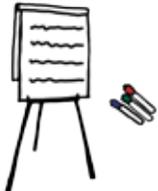
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 2**
- Toolkit *Tool: 9.1.2: The Readiness to Change Ruler*
- Activity 3:**
- Toolkit *Module 9: Positive Living*

## FLIP CHARTS



- Activity 3:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 3**
- Prepare flip chart (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Positive Living	Discussion and lecturette	15 minutes
2	Using a Readiness Ruler	Individual work and discussion	30 minutes
3	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Positive Living (~15 Minutes)

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Providing care that incorporates Positive Living will build the capacity of ALHIV to develop interpersonal skills, decision-making and critical-thinking skills, and coping and self-management skills (ICAP 2011). Positive Living promotes emotional, physical, and spiritual health as well as living responsibly. It is a topic that should be discussed and encouraged at each visit (ICAP 2011). Through provision of health education for Positive Living, the HCP/CCP and the family/caregiver can work together to help the adolescent develop skills to live a healthy life, and establish the foundation for a smooth transition.

Use of motivational interviewing techniques can also energize the adolescent to make decisions that lead to a positive lifestyle (Suarez and Mullins 2008). In addition, utilization of *Tool 9.1.2: The Readiness to Change Ruler* can help to assess the adolescent's readiness to change a specific behavior. It can also be used repeatedly over the course of transition to mark progress and identify new areas to address. ALHIV will inevitably deal with stigma—which may include violence surrounding their HIV status—this can have a significant impact on their quality of life. Help the adolescent to identify sources of stigma in his or her life. Once sources of stigma have been identified, assist them in completing a stigma action plan.

Be sure to discuss anticipated issues with the family/caregiver. Provide education on encouraging Positive Living for the adolescent as well as for themselves.

You will play a key role in connecting and referring the adolescent to community services offered by CBOs and faith-based organizations (FBOs). Keep in mind the benefits of peer support groups, which can guide adolescents to support each other and help develop a skill set that may decrease their sense of isolation due to their HIV status. If there are no community or peer support groups present in your area, work with health facility administrators and community organizations to develop an adolescent peer support group. We will talk more about this in the next session!

Providing health education to the adolescent and his or her family/caregiver is an essential component of the transition process. Through providing the adolescent with information surrounding his or her health and encouraging self-management of care, the adolescent will be more empowered to take on increasing responsibility through the transition process.

Always keep in mind available services in the community to which you can refer the adolescent and his or her family. This may include education support and food support in addition to support for social services. Promote an environment that actively involves the adolescent in his or her care. By maintaining a dialogue between you, the adolescent and the family/caregiver, you can encourage healthy decision making during each stage of adolescence.

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## Activity 2: Using a Readiness Ruler (~30 Minutes)

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- » Tell participants that they will now be practicing using a readiness ruler to facilitate behavior change. Readiness rulers can help build motivation for change and can be quickly drawn on a piece of paper, making them easy to use in practice. These are standard tools in the motivational interviewing technique mentioned earlier. Often the readiness ruler is used to discuss behavior change related to alcohol and substance use, but it can also be used as a behavior change tool to encourage positive living.
- » Refer the participants to *Tool 9.1.2: The Readiness to Change Ruler* in the Toolkit. Note that the rulers are focused on importance and confidence. These are two key concepts in behavior change. Tell participants that we will now put this into practice by applying the ruler to apply this to our own lives. Ask participants to think about a specific change they are

considering. Then ask “On this ruler from 0 to 10, how important is it to you to make this change?” 0 is the least important and 10 is the most important. Next ask participants to look at the second ruler and ask “On a scale of 1 to 10, how confident am I that I could make this change if I wanted to?” 0 is the least confident and 10 is the most confident.

- » Tell participants that the ruler can help in talking about positive living with the adolescent. Many adolescents will respond readily to a direct question such as, How important is it to you to take your medication daily right now? or How confident are you that you can your medication daily right now? This approach may be too abstract for younger adolescents who respond better to visual pictures. If this is the case, importance and confidence rulers, are excellent tools to use as visual aids. Ask the adolescent to point to a number on the scale that indicates how important (or how confident) he or she feels about making a specific behavior change.
- » Ask participants for a volunteer who is willing to share their desired behavior change with the larger group. Then facilitate the process with the volunteer. The focus of your conversation with the volunteer will depend on the rating levels for importance and confidence. Look at the ruler and ask for them to give a number to both importance and confidence. If one number is distinctly lower than the other, focus on the lower number first. If importance is low—or if both importance and confidence levels are about the same—focus on importance. If both are very low, explore the volunteers feelings about talking about the behavior. If both are high (8-10) explore what is preventing the volunteer from changing that behavior. For example, If you are a 5, why are you a 5 and not a 3? Or if you are a 5, what needs to happen for you to go to a 7? How could I assist you in getting to a 7?
- » Ask the participants if they have ever used a technique like this and if it is helpful. The readiness ruler can be used to help motivate an adolescent to make positive choices and change behaviors, and may be useful to use many times throughout the transition. It is particularly relevant to positive living, but can be applied to all modules in the Toolkit.
- » Summarize the discussion and ask for remaining questions. Encourage participants to use the readiness ruler as it reinforces the adolescent’s actions and capacity to take on greater self-management responsibility in moving toward transition of care.

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### **Activity 3: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 10 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

#### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions. Encourage participants to continually assess positive living when identifying individual needs and the adolescent's capacity to take on greater self-management responsibility in moving toward transition of care.

# SESSION 17: BUILDING COMMUNITY LINKAGES

**Total Session Time: 1 hour**

## OBJECTIVES:

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

1. Explain the role of community linkages for the transitioning adolescent
2. Identify approaches for building linkages in the community to support ALHIV
3. Use community linkages tools within the Toolkit

## MATERIALS



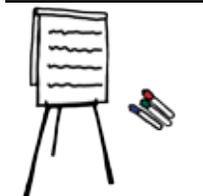
- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

## HANDOUTS & TOOLS



- Activity 2**
- Toolkit *Tool: 10.1.1: Community Based Organization/Health Facility Directory*
- Activity 3:**
- Toolkit *Module 10: Linking Health Facilities & Community Programs*

## FLIP CHARTS



- Activity 2:**
- Tool review outline

## ADVANCE PREPARATION



- Activity 2**
- Prepare flip chart (see examples below)

## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Building Community Linkages	Discussion and Lecturette	30 minutes
2	Review of Tools	Group activity	30 minutes

# LEARNING ACTIVITIES

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## Activity 1: Building Community Linkages (~30 Minutes)

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Linking health facility services and services offered by CBOs to enhance the care of adolescents is especially important when considering transition. These linkages can provide continual health and social services, and provide the adolescent with a broad spectrum of care while remaining a constant source of support throughout the transition process. Health facilities and CBOs should create strong linkages early in the transition process and routinely work together.

It is important to understand the clinical and community services that are available in your area so that you can provide the adolescent and his or her family/caregiver with a comprehensive package of services to provide the best quality of care possible. Examples of services that may be offered include ALHIV peer support groups, family support groups, food support, home-based care, income-generating activities, adherence support, educational and vocational support, transportation to clinic appointments, legal advice, spiritual advice, and a number of other services (ICAP 2011).

As HCPs and CCPs for ALHIV, it is your job to work with your facility to identify and forge linkages between organizations in your area. This can be done by making appointments with other organizations, meeting with them, understanding the services they offer, and discussing how to facilitate the referral process between your facilities. A two-way referral system is important as there may be a CBO offering services to adolescents who are in need of HIV testing or know their status and are not yet in care. In addition, there may be health facilities that only provide clinical services and will need the assistance of programs that are offered within the community.

WHO guidance for creating a referral network calls for a formalized system of referrals in which all organizations within the network agree on referral procedures. When establishing the referral network, all health and social organizations should meet to establish a formal relationship to clarify which services will be offered by each organization, identify a referral point-person at each organization, and establish formal referral protocols (WHO 2008).

Best practices also include identifying a lead organization to coordinate and track referrals within the network, and the use of case managers (including people living with HIV) to ensure that clients receive all of the appropriate social services and are following through with their referrals (Thurman et al. 2010; WHO 2008). Additional best practices include maintaining an up-to-date contact list of all services within the network, and creating a system to record, track, and monitor referral completion. Creating a standardized referral form used throughout the network which includes key client information and allows for a feedback loop of communication among organizations is also important (WHO 2008; Stuart and Harkins 2005). Providers should also be trained to clearly explain to clients why the referral is being made, and provide written and oral instructions on how to complete the referral. Any obstacles to the client completing the referral should be identified and addressed (WHO 2008).

Create a CBO/health facility directory as you carry out a tour of the services in your area. You may also take advantage of this opportunity to provide education to staff at other facilities surrounding the services that you offer and the needs of ALHIV. This directory will have to be updated routinely to ensure it is current.

- » Tell participants that they will now start to take this into practice. They will be taking a few minutes today to get started on the CBO/health facility directory. Direct participants to join in groups by site. Have them turn to page 100 of the Toolkit to *Tool 10.1.1: Community Based Organization/Health Facility Directory*. Tell them that they have approximately 10 minutes to discuss among themselves other health facilities and organizations within the community that may be helpful to support transitioning adolescents. Have participants fill out the directory to the best of their ability, and encourage them to complete this list once they return to their sites.

- » After 10 minutes have passed, reiterate to participants that they may not be aware of many of the services that are offered within their communities. Health care facilities and CBOs often do not routinely communicate or coordinate services. To overcome this challenge, recommend that participants create a forum for organizations in their community to meet on a routine basis in an effort to coordinate and enhance available package of services, facilitate strong linkages, and coordinate a referral system. Be sure to include a wide variety of organizations that offer child protection services, faith and spiritual support, vocational and educational support, and health and social services. During these meetings, you may provide education to the other members of the forum on the special needs of ALHIV during the transition process. It is also through this forum that unmet needs within the community can be identified and strategies developed to provide a coordinated package of services for the adolescent and his or her family/caregiver.

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## **Activity 2: Review of Tools (~30 Minutes)**

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- » Tell participants that they will now be participating in an activity to review the tools that are available within this module of the Toolkit.
- » Divide participants into 4 separate groups. Once the groups have been identified, assign each group a tool to review within this module. Once each group has been assigned a tool, tell participants that they have approximately 10 minutes to review their tool and present it to the larger group.
- » When preparing their brief presentation (approximately 2 minutes in duration), the groups should refer to the outline on the flip chart to provide information to the larger group.

### **TOOL PRESENTATION**

- Intended audience for the tool (HCP/CCP , family/caregiver, or adolescent)
- Name of the tool
- How the tool can be used during or after a client encounter
- What type of information this will gather
- How the tool can be used to provide information/education/facilitate transition

- » After the presentations are complete, ask for remaining questions and encourage participants to continually assess the SRH health needs when identifying the individual adolescent's needs and capacity to take on greater self-management responsibility to move toward transition of care.

# SESSION 18: PUTTING THE TOOLKIT INTO PRACTICE

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**Total Session Time: 1 hour and 50 minutes**

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## OBJECTIVES:

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

1. Review the dos and do nots of Toolkit utilization
2. Use the Toolkit correctly through a case study approach

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## MATERIALS



- Toolkits
- Flip chart stand, papers, and markers
- Parking Lot

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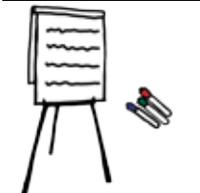
## HANDOUTS & TOOLS



- Activity 2**
- **Case Study Series (pages 92–111)**

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## FLIP CHARTS



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## ADVANCE PREPARATION



- Activity 2**
- Make sufficient copies of the **Case Studies** in advance
- Activity 3**
- Make sufficient copies of the **Post-Test** in advance

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## SUMMARY OF LEARNING ACTIVITIES IN THIS SESSION:

No.	Learning Activity	Principal Training Method	Time
1	Dos and Do Nots of Toolkit Utilization	Lecturette and discussion	20 minutes
2	Case Study Practice	Group work and discussion	70 minutes
3	Post-Test	Test	20 minutes

# LEARNING ACTIVITIES

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## Activity 1: Dos and Do Nots of Toolkit Utilization (~20 Minutes)

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- » Tell participants that they are now experts on providing HIV services for adolescent clients. They will soon be returning to their sites to provide services and to put the Toolkit into action.
- » They should remember that the Toolkit provides a framework to promote self-care. *The Key Checklists to Use Throughout Transition* (found on pages 12-16) provide a framework for transition to self-care and should be reviewed on a semiannual basis to set and review self-management goals and determine if the adolescent is on track. As you use *The Key Checklists*, please note that male and female adolescent clients may experience transition differently and may have different strengths and barriers associated with health care.

Furthermore, the Toolkit provides a framework for a minimum package of services. The modules should be used only as they are needed. Some adolescents will utilize several modules throughout the transition period while others may only require minimal resources from the Toolkit. The provider should only utilize the Toolkit as it is relevant to the adolescent and his or her family/caregiver.

### Users should avoid:

- Using the Toolkit in order from front to back
- Attempting to use every module within the Toolkit if it does not immediately meet the needs of the adolescent and the family/caregiver
- Using multiple modules of the Toolkit at one time; this may overwhelm the adolescent and the family/caregiver

### Users should remember to:

- Identify and respond to the chief complaint: Determine the biggest concern of the adolescent and the family/caregiver during the visit, then review and use the appropriate module and tools accordingly.
- Provide anticipatory guidance: Anticipate upcoming topics that you suspect the client may encounter (such as sexual activity, a family loss) and review and use the appropriate module and tools accordingly.
- Reinforce confidentiality: Routinely reassure the adolescent that his or her visits to your organization and any information disclosed to you is considered private. The only exception is if the adolescent shares that he or she intends to harm himself or someone else, in which case you will access services to help the adolescent get the additional support needed.
- Adapt the Toolkit to your specific context and setting before using it. Remember to follow the adaptation guidance that is provided on page 9 of the Toolkit.

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## Activity 2: Case Study Practice (~70 Minutes)

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- » As a final activity for this training, the participants will now be carrying out a series of case studies to put their new knowledge into practice, including how they will address the varying needs of HIV positive adolescent clients and how they will use the Toolkit to address these needs.
- » Tell the participants that they will now be dividing into small groups to practice using the Toolkit. Start at one end of the

room and have participants count off 1-10 so that there are 10 separate small groups that are relatively equal in size. Once participants have joined their small group, hand out a different blank case study to each group. Notify them that they have approximately 15 minutes to review the case study and to decide how they will use the Toolkit to approach the adolescent visit in the case study. They should respond to each of the questions in the case study. Remind them to consider all of the information they have learned throughout this training and adhere to the principles of Toolkit utilization previously discussed in this session.

- » After 15 minutes have passed, bring the groups back together. Allow each group to present their case study to all participants and share how they would use the Toolkit to meet the client's needs. After each presentation, facilitate a discussion with participants to determine if they agree or disagree with the group's approach to using the Toolkit, and determine if there are any further suggestions for usage. Refer to the Case Study Key for the Facilitator that is available for each case study to facilitate further discussion.
- » After all of the groups have presented, review with participants again that the Toolkit should be used as it meets the immediate needs of the adolescent client and as it helps to establish self-management goals as they progress toward transition.
- » Congratulate the participants on their excellent participation throughout this training, tell them that you are confident that they will put the information that they learned during this training to good use to improve the process of transition for ALHIV so that they move toward adult focused care in a healthy and thoughtful manner!

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### **Activity 3: Post-Test (~20 minutes)**

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In order to compare the participants' knowledge increase throughout the training, it will be important to take a post-test.

- » Tell participants that you will finish up the training by completing a post-training assessment in order to better understand how well they have learned the information provided during the training.
- » Hand out the post-test and give participants approximately 20 minutes to finish it. Have them follow the same identification system that you chose with the pre-test.
- » When the post-tests are complete, they may hand them over to you as the facilitator for you to compare with the pre-test scores and determine which elements of the training will need to be reinforced once the participants have returned to their sites.
- » Thank the participants for their excellent participation and wish them well as they return to their sites!

# HANDOUTS & TOOLS

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## **Icebreaker:**

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*Get to Know Your Colleagues*

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## **Handouts:**

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*Handout 1: Sample Pre- and Post-Tests and Answer Key*

*Handout 2: Touring the Toolkit*

*Handout 3: Adolescent-Friendly Checklist*

*Handout 4: 7 Communication Skills Checklist*

*Handout 5: Toolkit Module Checklist*

*Handout 6: Family-centered care Values*

*Handout 7: Developmentally Appropriate Transition*

*Handout 8: Mental Health Needs of ALHIV*

*Handout 9: Identifying & Overcoming Barriers to Adolescent Sexual & Reproductive Health*

*Handout 10: Values, Thoughts, and Perceptions Surrounding Alcohol & Substance*

*Handout 11: Basic Principles of Grief*

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## **Case Studies:**

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*Case Study 1: “A Lot of Responsibilities” and Answer Key*

*Case Study 2: “Sudden Behavior Changes” and Answer Key*

*Case Study 3: “Tempers Flaring” and Answer Key*

*Case Study 4: “When to Disclose” and Answer Key*

*Case Study 5: “New Relationship?” and Answer Key*

*Case Study 6: “Reluctant to Leave” and Answer Key*

*Case Study 7: “Coping with Grief” and Answer Key*

*Case Study 8: “A New Girlfriend” and Answer Key*

*Case Study 9: “New Caregiver” and Answer Key*

*Case Study 10: “Ready to Transition” and Answer Key*

# ICEBREAKER: GET TO KNOW YOUR COLLEAGUES

Cut along the dotted lines, fold each piece of paper in half, place all papers in a large envelope to pass around among participants (they will each draw one out).

<b>ANIMAL</b>	<b>ANIMAL</b>	<b>ANIMAL</b>
<b>FOOD</b>	<b>FOOD</b>	<b>FOOD</b>
<b>BEVERAGE</b>	<b>BEVERAGE</b>	<b>BEVERAGE</b>
<b>COLOR</b>	<b>COLOR</b>	<b>COLOR</b>
<b>SONG</b>	<b>SONG</b>	<b>SONG</b>
<b>FAMOUS PERSON</b>	<b>FAMOUS PERSON</b>	<b>FAMOUS PERSON</b>
<b>ANIMAL</b>	<b>ANIMAL</b>	<b>ANIMAL</b>
<b>FOOD</b>	<b>FOOD</b>	<b>FOOD</b>
<b>BEVERAGE</b>	<b>BEVERAGE</b>	<b>BEVERAGE</b>
<b>COLOR</b>	<b>COLOR</b>	<b>COLOR</b>
<b>SONG</b>	<b>SONG</b>	<b>SONG</b>

# HANDOUT 1: SAMPLE PRE AND POST TEST

1. For the purposes of this workshop, 'clinical transition' can be defined as:
  - a. physical changes that occur during puberty
  - b. the process of changing from pediatric to adult care
  - c. the process of switching medication regimes
  - d. when an adolescent switches from living with a parent to a different caregiver
2. Perinatally exposed adolescents:
  - a. are less likely to be ill than behaviorally exposed adolescents
  - b. are more likely to have issues distrusting the health system
  - c. are more likely to have developmental delays and be more ill than behaviorally exposed adolescents
  - d. have lower mortality rates than behaviorally exposed adolescents
3. Transition is based upon:
  - a. physical development, emotional maturity and the adolescent's health status
  - b. only the adolescent's health status
  - c. only the adolescent's age
  - d. the grade in school that the adolescent is in
4. You should begin to prepare for transition with the adolescent:
  - a. when they reach age 15
  - b. early in adolescence to provide time for preparation and planning
  - c. only if the adolescent asks about it
  - d. later in adolescence because some of the topics might not be appropriate for younger adolescents
5. Transition should include:
  - a. attending to the medical and psychosocial needs of the adolescent as they move from pediatric to adult care
  - b. disclosure to all individuals in the adolescent's life
  - c. making sure that the adolescent is financially independent prior to transition
  - d. a signed legal contract between the adolescent and both the adult and pediatric health providers
6. Often medication adherence \_\_\_\_\_ when the adolescent reaches age 14-16.
  - a. increases
  - b. decreases
7. How often should the *Comprehensive Transition Checklist* be referred to (at a minimum)?
  - a. it is necessary only if the adolescent is not on track
  - b. two times per year
  - c. every two years
  - d. only at the beginning and end of adolescence

- 8. The Modules in the Toolkit:**
- should only be utilized in order (starting with Module 1 and ending with Module 12)
  - should be utilized as needed to support the health or community care provider, the adolescent and the family/caregiver throughout the transition process
  - should only be utilized if the adolescent asks specifically for them
  - should ALL be utilized prior to transition
- 9. Susie, a 16 year old, is considering disclosing to her boyfriend. She asks you for additional support. From which Modules of the Toolkit should you consider providing supplemental tools and information over her next few visits?**
- beneficial disclosure
  - positive living
  - sexual and reproductive health
  - all of the above
- 10. A 17 year old is a client well known to you. Together you have been making significant progress toward a smooth transition. Prior to this appointment his mother pulls you aside and shares that she is concerned that Paul has come home intoxicated a couple of times recently. She is also concerned that he has not been taking his medications routinely. Over the next few visits, you should consider utilizing the following modules within the Toolkit:**
- only the *Alcohol & Substance Use* module
  - you should not utilize the Toolkit until you are sure that Paul has an alcohol problem
  - the *Alcohol & Substance Use* module in addition to any other relevant modules that will support the adolescent and their family/caregiver
  - you should try to use as many modules as you have time for during this appointment

# HANDOUT 1: SAMPLE PRE AND POST TEST ANSWER KEY

1. For the purposes of this workshop, 'clinical transition' can be defined as:
  - a. physical changes that occur during puberty
  - b. *the process of changing from pediatric to adult care***
  - c. the process of switching medication regimes
  - d. when an adolescent switches from living with a parent to a different caregiver
2. Perinatally exposed adolescents:
  - a. are less likely to be ill than behaviorally exposed adolescents
  - b. are more likely to have issues distrusting the health system
  - c. *are more likely to have developmental delays and be more ill than behaviorally exposed adolescents***
  - d. have lower mortality rates than behaviorally exposed adolescents
3. Transition is based upon:
  - a. *physical development, emotional maturity and the adolescent's health status***
  - b. only the adolescent's health status
  - c. only the adolescent's age
  - d. the grade in school that the adolescent is in
4. You should begin to prepare for transition with the adolescent:
  - a. when they reach age 15
  - b. *early in adolescence to provide time for preparation and planning***
  - c. only if the adolescent asks about it
  - d. later in adolescence because some of the topics might not be appropriate for younger adolescents
5. Transition should include:
  - a. *attending to the medical and psychosocial needs of the adolescent as they move from pediatric to adult care***
  - b. disclosure to all individuals in the adolescent's life
  - c. making sure that the adolescent is financially independent prior to transition
  - d. a signed legal contract between the adolescent and both the adult and pediatric health providers
6. Often medication adherence \_\_\_\_\_ when the adolescent reaches age 14-16.
  - a. *increases***
  - b. decreases
7. How often should the *Comprehensive Transition Checklist* be referred to (at a minimum)?
  - a. it is necessary only if the adolescent is not on track
  - b. *two times per year***

- c. every two years
  - d. only at the beginning and end of adolescence
8. **The Modules in the Toolkit:**
- a. should only be utilized in order (starting with Module 1 and ending with Module 12)
  - b. should be utilized as needed to support the health or community care provider, the adolescent and the family/caregiver throughout the transition process**
  - c. should only be utilized if the adolescent asks specifically for them
  - d. should ALL be utilized prior to transition
9. **Susie, a 16 year old, is considering disclosing to her boyfriend. She asks you for additional support. From which Modules of the Toolkit should you consider providing supplemental tools and information over her next few visits?**
- a. beneficial disclosure
  - b. positive living
  - c. sexual and reproductive health
  - d. all of the above**
10. **A 17 year old is a client well known to you. Together you have been making significant progress toward a smooth transition. Prior to this appointment his mother pulls you aside and shares that she is concerned that Paul has come home intoxicated a couple of times recently. She is also concerned that he has not been taking his medications routinely. Over the next few visits, you should consider utilizing the following modules within the Toolkit:**
- a. only the *Alcohol & Substance Use* module
  - b. you should not utilize the Toolkit until you are sure that Paul has an alcohol problem
  - c. the *Alcohol & Substance Use* module in addition to any other relevant modules that will support the adolescent and their family/caregiver**
  - d. you should try to use as many modules as you have time for during this appointment

# HANDOUT 2: TOURING THE TOOLKIT

1. When using the Toolkit, what are three actions to AVOID and four actions to DO?
2. Describe how the tools are numbered within the Toolkit.
3. When adapting the Toolkit for your setting, which considerations should you take into account when adapting Module 4?
4. Describe Checklist 3: HCP/CCP Checklist. When and how should they be used?
5. Describe the different tools available in Module 5. Who are they for?

# HANDOUT 3: ADOLESCENT-FRIENDLY CHECKLIST

CLINICAL SERVICES	INDICATORS	SCORE 2=yes; 1=partial; 0=no	RECOMMEN- DATIONS & ACTIONS
<b>1. Convenient open hours</b>	In addition to being open during the day, services are available at least 6 hours during the periods of late afternoon (2 – 5 p.m.), evenings (5 – 7 p.m.) and weekends per week.		
<b>2. Privacy is ensured</b>	Visual and auditory privacy is ensured in consultation rooms with adequate enclosures. There are no non-essential interruptions or intrusions.		
<b>3. Competent staff</b>	Staff are able to communicate well with adolescents, competently deliver HIV and RH services, discuss protection options (including dual protection) and answer client questions.		
<b>4. Respect for youth clients</b>	Clinic staff (receptionist, counselor, provider, and pharmacist) treat youth clients with respect and courtesy and allow clients time to ask questions.		
<b>5. Minimum package of services</b>	The following services are offered on-site: <ul style="list-style-type: none"> <li>— information and counseling on sexuality, safe sex, and reproductive health</li> <li>— contraceptive and protective method provision</li> <li>— STI diagnosis and management</li> <li>— HIV counseling (and referral for testing and care)</li> <li>— pregnancy testing and antenatal and postnatal care</li> <li>— counseling on sexual violence and abuse (and referral for needed services)</li> <li>— post abortion care (PAC) counseling and contraception.</li> <li>— The minimum package may vary depending on the type of facility and the services offered at that level of facility as mandated by the MOH.</li> </ul>		
<b>6. Sufficient supply of commodities &amp; drugs</b>	Commodities and drugs are actually available and they have not expired.		
<b>7. Range of FP methods offered</b>	Many of the following FP methods are offered: condoms, OCs, injectables, Norplant, emergency contraception.		
<b>8. Emphasis on dual protection/ condoms</b>	Protection against pregnancy and STI/HIV is mentioned with each client regardless of presenting conditions, and condoms are easily obtained.		
<b>9. Referrals available</b>	A system for referring clients is in place, including referrals to youth-friendly services addressing sexual abuse/violence treatment, PAC (treatment of complications), VCT.		
<b>10. Young adolescents (12-15) are served</b>	Young adolescents (between 12-15 years old), who are in need of protection, testing or care, are not refused services because of age.		
<b>11. Confidentiality is ensured</b>	Facility assures client confidentiality regarding both the consultation(s) and medical records.		
<b>12. Waiting time not excessive</b>	Young people can be seen within one hour of arrival or one-half hour of appointment time and internal referrals are done in an expedited manner.		
<b>13. Affordable Fees</b>	The cost of the service is free to adolescents, or at a level not comprising a barrier to access.		
<b>14. Separate space and/or hours</b>	Waiting areas and consultation rooms are separated from those of other clients, or YFS are provided at special hours, affording greater confidentiality.		

# HANDOUT 4: 7 COMMUNICATION SKILLS CHECKLIST

MODULE	HOW TO TELL:
<b>1. Nonverbal communication</b>	<p>Convey nonverbal messages through gestures, gazes, posture, and facial expressions. Show you care about what is said.</p> <ul style="list-style-type: none"> <li>— Face the person, smile, and make eye contact.</li> <li>— Place your hands in your lap, nod, and lean forward toward the speaker.</li> <li>— Do not look at your phone, watch, or anything other than the client.</li> <li>— Minimize writing or taking notes during the session.</li> </ul>
<b>2. Active listening</b>	<p>Demonstrate you are listening to the client.</p> <ul style="list-style-type: none"> <li>— Use gestures that show interest (nod and smile). Use encouraging responses (such as “yes,” and “okay”).</li> <li>— Clarify to prevent misunderstanding.</li> <li>— Summarize to review key points at any time during the session.</li> </ul>
<b>3. Open-ended questions</b>	<p>This encourages the client to talk openly and in a way that leads to further discussion. They help clients explain their feelings and concerns. An example of an open-ended question is: “How did that make you feel?”</p> <ul style="list-style-type: none"> <li>— Use questions beginning with words like “how,” “what,” “when,” “where,” or “why.”</li> </ul>
<b>4. Reflect</b>	<p>Paraphrase or repeat back what a client has said. Reflecting says it in a slightly different manner. An example is if an adolescent says: “I am scared someone at school will find out I am HIV positive” you could say, “It sounds like you are nervous about others knowing your status. Let’s talk about that some more.”</p> <p>Use phrases like:</p> <ul style="list-style-type: none"> <li>— “You seem to feel that _____ because _____.”</li> <li>— “So I sense that you feel _____ because _____.”</li> <li>— “I’m hearing that when _____ happened, you didn’t know what to do.”</li> </ul>
<b>5. Empathize</b>	<p>Empathy is when one person is able to begin to comprehend (or understand) what another person is feeling. Empathy does not involve pity (feeling sorry for another) or sympathy (feeling the same as another). Showing empathy can help encourage clients to discuss issues further. For example, if a client says, “I just can’t tell my boyfriend that I have HIV!” the health worker could respond by saying, “It sounds like you might be afraid of your boyfriend’s reaction.”</p> <ul style="list-style-type: none"> <li>— Use empathy in response to emotional statements.</li> <li>— Identify and articulate the emotions behind a client’s statement and show an understanding of how the client feels by naming the emotion he or she has expressed.</li> <li>— Avoid sympathy.</li> <li>— Other (specify)</li> </ul>
<b>6. Don’t judge</b>	<p>Judging words are words such as: right, wrong, well, badly, good, enough, and properly. Don’t ask questions that lead the client to respond in a certain way because they are scared to disappoint you.</p> <ul style="list-style-type: none"> <li>— Avoid judging words such as “bad,” “proper,” “right,” “wrong,” etc.</li> <li>— Use words that build confidence and give support—praise what a client is doing right).</li> </ul>
<b>7. Set goals</b>	<p>At the end of every meeting with the adolescent develop an action plan and to summarize the session.</p> <ul style="list-style-type: none"> <li>— Work with the adolescent to come up with realistic “next steps.”</li> <li>— Summarize the main points of the counseling session.</li> <li>— Set a next appointment date.</li> <li>— Discuss and make needed referrals.</li> </ul>

# HANDOUT 5: TOOLKIT MODULE CHECKLIST

MODULE	CCP/HCP (PROVIDER)	ADOLESCENT	FAMILY/ CAREGIVER	HOW TO PROMOTE BETTER COMMUNICATION (List which of the 7 Skills would be best to use in each module)
1. Psychosocial Development	X	X		
2. Mental Health	X	X	X	
3. Sexual & Reproductive Health	X	X	X	
4. Protection	X	X		
5. Alcohol & Substance Use	X	X	X	
6. Beneficial Disclosure	X	X	X	
7. Loss, Grief, & Bereavement	X	X	X	
8. Clinical Considerations	X	X		
9. Positive Living	X	X	X	
10. Linking Health & Community Services	X			

# HANDOUT 6: FAMILY-CENTERED CARE VALUES

## **What are your attitudes about partnering with adolescents and their families?**

*Use these questions to explore your attitudes about patient and family involvement in their own health care. Please discuss in small groups and reflect on how you can improve the quality of your services as you work with adolescents living with HIV and their families.*

### **Answer and discuss the following questions:**

#### **Individual: In each health or community service interaction:**

- Do I believe that adolescents and family members bring unique perspectives and expertise to the clinical relationship?
- Do I encourage adolescents and families to speak freely?
- Do I listen respectfully to the opinions of adolescents and family members?
- Do I encourage adolescents and family members to participate in decision-making about their care?
- Do I encourage adolescents and family members to be active partners in assuring the safety and quality of their own care?

#### **Organizational: Within your health or community organization:**

- Do I consistently let my colleagues know that I value the insights of adolescents and families?
- Do I believe that adolescents and families can play an important role in improving the quality of services within my organization?
- Do I believe in the importance of adolescents and family participation in planning and decision-making at the program and policy level?
- Do I believe that adolescents and families bring a perspective to a project that no one else can provide?
- Do I believe that the perspectives and opinions of adolescents, families, and providers are all equally valid in making decisions about their care?

# HANDOUT 7: DEVELOPMENTALLY APPROPRIATE TRANSITION

KEY CONCEPT	CONSIDERATIONS FOR YOUNGER ADOLESCENTS	CONSIDERATIONS FOR OLDER ADOLESCENTS
<b>BUILD TRUST</b>	Younger adolescents need time to feel safe and to build trust. Try starting the session by doing something together, like playing a game.	Ask older adolescents about the things that are important to them: hobbies, friends, sports, fashion, cars/motorbikes, music, family, boy/girlfriends, etc.
<b>ALLOW FOR TIME</b>	They need some time to observe you! Do not expect them to instantly begin talking. Allow plenty of time and be patient.	Get to know older adolescents to establish trust.
<b>CREATE A SAFE SPACE</b>	They may feel scared and they may fear being judged. They may feel anxious or embarrassed when asking for help	Try to understand the perspective of adolescent clients. Keep in mind that their life experiences are still relatively limited. Provide advice from the perspective that they have not yet had the opportunity to appreciate or know what you are explaining to them, rather than scolding them for their lack of knowledge. Never criticize them or say something they may interpret as criticism.
<b>ACCEPT DIVERSITY</b>	Allow for age to be just a number, and understand that one person's 12 might be another person's 18. Allow for a range of emotions, experiences, and development.	Do not assume that any one adolescent has the same interests or issues as other adolescents you have met. Adolescent clients may pride themselves on having the confidence to be different.
<b>SIMPLE MESSAGES</b>	Explain things in simple terms.	Keep messages simple and clear, if the older adolescent wants more information on certain areas like sexual and reproductive health, provide him/her with that information.
<b>AGE-RELEVANT</b>	Younger adolescents understand concrete things that they can touch and see. Drawing, demonstrations, or visual aids can be used to make information more concrete. Carry crayons or pencils to draw with.	Never assume that they are not yet sexually active. Also never assume that they are sexually active. The best way to know for sure is to build trust and rapport with adolescent clients so they feel comfortable sharing this type of information with you.
<b>LISTEN</b>	Just because an adolescent is not asking questions does not mean that he or she is not thinking about what is being said.	Allow the time needed for the adolescent to ask questions.
<b>PATIENCE</b>	Allow for silence. Do not force adolescents to share. Positively reinforce their efforts to express themselves.	
<b>ATTITUDE</b>	If a youth is rude or aggressive, remember that this behavior may not be directed at you. He or she may be feeling angry with adults in general for treating him or her badly or for letting him or her down. Be patient and don't take it personally.	

**In summary, never make assumptions, and always remain nonjudgmental.**

# HANDOUT 8: MENTAL HEALTH NEEDS OF ALHIV

1. What are common mental health problems that you see among HIV positive adolescent clients at your site?
2. What signs/symptoms might the client have that would lead you to believe that they are experiencing a mental health problem?
3. Why may an ALHIV be at an increased risk for experiencing depression?
4. What are some periods during the course of HIV when the adolescent may want to talk to someone more deeply about his or her feelings? Do you have this service available at your site? If not, where could you refer an adolescent for these services?



# HANDOUT 10:VALUES,THOUGHTS,AND PERCEPTIONS SURROUNDING ALCOHOL & SUBSTANCE ABUSE

1. Harmful alcohol and substance use is...
2. Discussing alcohol and substance use with adolescents is ...
3. The connection between harmful alcohol and substance use and HIV is...
4. Adolescents with harmful alcohol or substance use are generally considered...
5. Some of the traditional/cultural beliefs in this community around alcohol and substance use are....
6. It is important to address harmful alcohol and substance use in adolescents because...

# HANDOUT 11: BASIC PRINCIPLES OF GRIEF

## GRIEF IS...

<p><b>NATURAL</b></p>	<p>Grief is a natural reaction to death and other losses. However, grieving does not feel natural because it may be difficult to control the emotions, thoughts, or physical feelings associated with a death and loss. The sense of being out of control that is often a part of grief may overwhelm or frighten some adolescents. Remember that grieving is normal and healthy, but may be an experience adolescents resist and reject. Helping adolescents accept the reality that they are grieving allows them to do work and progress in their grief journey.</p>
<p><b>UNIQUE</b></p>	<p>Grieving is a different experience for each person. Adolescents grieve for different lengths of time and express a wide spectrum of emotions. Grief is best understood as a process in which bodily sensations, emotions, thoughts, and behaviors surface in response to the death, its circumstances, the past relationship with the deceased and the realization of the future without the person. For example, sadness and crying may be an expression of grief for one adolescent, while another may respond with humor and laughter.</p> <p>There is no “right” or “wrong” way to grieve. Coping with a death does not follow a simple pattern or set of rules.</p> <p>The way adolescents grieve differs according to personality and the particular relationship they had with the deceased. Adolescents typically react in different ways to the death of a parent, sibling, grandparent, child, or friend. For many peer relationships are primary.</p>
<p><b>ONGOING</b></p>	<p>Grief never ends, but it does change in character and intensity. Many grieverers have compared their grief to the constantly shifting tides of the ocean—ranging from calm, low tides to raging high tides that change with the seasons and the years.</p>
<p><b>WAYS TO SUPPORT THE ADOLESCENT</b></p>	<ul style="list-style-type: none"> <li>— Follow the basic principles outlined above.</li> <li>— Listen to the adolescent in a compassionate way.</li> <li>— Make time for emoting support, or refer for emotional support services (peer support, group support, etc.)</li> <li>— Ensure confidentiality.</li> <li>— Understand the referral process for complicated grief.</li> </ul>

# CASE STUDY I: “A LOT OF RESPONSIBILITIES”

Mary, a 16 year old who adheres to ART, was perinatally infected with HIV and lives in a child-headed household. She takes care of her younger brother and sister who are also HIV positive as both her mother and father passed away recently. You have been in the process of discussing and setting self-management goals to transition Mary from pediatric care to the adult clinic for three years. She has routinely been meeting self-management goals, attending regular appointments and typically has no complaints. Today she comes in with a list of vague reports of physical complaints. You think that there may be something else going on.

How will you approach your appointment with Mary today?

Which Toolkit Module will be most helpful in your visit with Mary today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Mary is transitioning as expected? Why or why not?

What other facility-based services are available to her that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY I: “A LOT OF RESPONSIBILITIES”

## ANSWER KEY

### How will you approach your appointment with Mary today?

Establishing trust will be a key component, consider carrying out a psychosocial assessment today. Providing an open and nonjudgmental environment where Mary can share her feelings is essential. It will be important to determine if Mary is experiencing a headache due to an organic cause or if this is due to emotional distress. Consider that some of her anxiety may be surrounding the stress of transition in addition to her home situation.

### Which Toolkit Module will be most helpful in your visit with Mary today?

*Module 2: Mental Health; Module 7: Loss, Grief, & Bereavement; and Module 1: Psychosocial Development* depending on individual provider's judgment.

### Which additional Modules and Tools might you consider utilizing?

Any number of modules and tools may be chosen for Mary based upon your findings. Utilize your judgment to supplement the care provided to Mary today.

- *Checklist 2: Comprehensive Transition Checklist* to monitor her progress
- *Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent*
- *Tool 7.1.1: Grief Assessment Discussion Guide, Tool 7.1.2: A Guide to Grief Counseling, Tool 7.3.6: My Grief Journal*
- *Tool 9.3.9: HIV Peer Support Groups, Tool 9.3.10: My Positive Living Journal*
- *Tool 2.1.1: The Mental Health Symptom Screener, Tool: Your Emotional Health, Tool 2.3.5: My Emotional Health Journal*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Mary is transitioning as expected? Why or why not?

Mary may be progressing well through the transition process as she is adherent to ART and has clearly taken on a fair amount of responsibility in taking care of her younger siblings. Consider that Mary's headache complaints may be psychosomatic and related to increasing self-care responsibilities due to the transition process.

### What other facility-based services are available to her that may help?

It will be important to consider the results from the grief assessment scale and your conversation with Mary to determine if she will benefit from additional counseling. Consider an in-house referral for counseling support if it exists.

### What other community-based services are available to her that may help?

Consider referring Mary to counseling if your facility does not offer it. Consider additional un-met needs that should be addressed such as nutritional support, peer support and programs that offer support to child-headed households.

### What will you consider doing at her next appointment and how soon will you want to see her back?

Follow up either by telephone or in person within one week to determine if her physical and/or emotional symptoms have dissipated and if issues that came to light during the last visit are improving. If not, determine next steps and additional needs to help resolve them and make sure that she continues on track toward transition. Consider holding off on further transition planning until her home situation stabilizes and she has developed increased coping skills.

# CASE STUDY 2: “SUDDEN BEHAVIOR CHANGES”

Maureen is a 13 year old HIV positive perinatally infected adolescent. She has been attending visits at your clinic since she was very young and as a result has been able to openly discuss her HIV status and ask clinic staff questions relating to her health. She has always been adherent to her medications, performed well in school and has a supportive and loving relationship with her family. At this visit Maureen’s mother tells you that Maureen has been fighting with her parents and that she is not eating or sleeping well. She also has run away from home a couple of times recently. The mother worries that Maureen is not adhering to treatment as well.

How will you approach your appointment with Maureen today?

Which Toolkit Module will be most helpful in your visit with Maureen today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Maureen is transitioning as expected? Why or why not?

What other facility-based services are available to her that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY 2: “SUDDEN BEHAVIOR CHANGES” ANSWER KEY

## How will you approach your appointment with Maureen today?

Establishing trust will be a key component, consider doing a psychosocial assessment. Initiate the visit with Maureen and her mother together to observe their interactions and to understand the situation. Request to have some time with Maureen alone to share information that she may not feel able to share in front of her mother. Approach her in a patient, nonjudgmental manner; reassure privacy unless you find that she is in danger.

## Which Toolkit Module will be most helpful in your visit with Maureen today?

Depending on the individual provider’s judgment, you may consider utilizing *Module 1: Psychosocial Development*, *Module 9: Positive Living*, or *Module 2: Mental Health Considerations*.

## Which additional Modules and Tools might you consider utilizing?

Depending upon the outcome of your interview, consider including:

- *Tool 1.1.1: Stages of Psychosocial Development Tool*, *Tool 1.1.3: Psychosocial Assessment Tool for the Interview with the Family/Caregiver*, *Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent*, *Tool 4.1.2: Gender-based Violence & Abuse Screening Tool for the Adolescent Interview*
- *Tool 5.1.1: The Substance Abuse Symptom Screener*, *Tool 2.1.1: The Mental Health Symptom Screener*
- *Tool 9.2.4: Positive Living Tips*, *Tool 9.3.10: My Positive Living Journal*
- *Tool 8.1.8: Adherence Assessment Tool*, *Tool 8.3.10: Medication Adherence Diary*
- *Tool 2.1.1: The Mental Health Symptom Screener*, *Tool 2.2.3: Your Adolescent’s Emotional Health*, *Tool 2.3.4: Your Emotional Health*, *Tool 2.3.5: My Emotional Health Journal*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

## According to the Comprehensive Transition Checklist, do you think that Maureen is transitioning as expected? Why or why not?

Maureen is not currently engaging in positive living behaviors as expected for someone of her age. Re-assess her current situation; connect her—and her family as appropriate—to services within the community. Encourage and educate Maureen on topics surrounding positive living and re-establish self-management goals to get her back on track toward transition.

## What other facility-based services are available to her that may help?

Consider an in-house referral for adherence counseling support if it exists.

## What other community-based services are available to her that may help?

Depending upon the outcome of the conversation, consider referring Maureen and her family for counseling and other psychosocial services within the community.

## What will you consider doing at her next appointment and how soon will you want to see her back?

Follow up with both Maureen and her mother to make sure that the situation and Maureen’s adherence is improving within two weeks. At that time, you should also determine if she has followed through on any referrals and reinforce education and information provided in the last appointment. Continue to monitor her progress toward transition.

# CASE STUDY 3: “TEMPERS FLARING”

Joseph, a 14-year-old adolescent, was recently tested and diagnosed with HIV after years of being chronically malnourished and treated for various illnesses throughout his childhood. It is likely he was perinatally infected with HIV and he arrives with his aunt as both his mother and father have passed. The aunt is a new caregiver who started accompanying Joseph to routine check-ups after he was told of his HIV-positive diagnosis. Joseph has received HIV education, asks questions and verbalizes understanding the illness and how to engage in basic self-management behaviors. Joseph's aunt states that he is easily angered and often fights with her children. She expresses that she is having a difficult time dealing with him. Joseph tells you privately that he does not like living with his aunt because she gives her own children more food and better clothing and is not as nice to him as she is to them..

How will you approach your appointment with Joseph today?

Which Toolkit Module will be most helpful in your visit with Joseph today?

Which additional Modules and Tools in the might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Joseph is transitioning as expected? Why or why not?

What other facility-based services are available to him that may help?

What other community-based services are available to him that may help?

What will you consider doing at his next appointment and how soon will you want to see him back?

# CASE STUDY 3: “TEMPERS FLARING”

## ANSWER KEY

### How will you approach your appointment with Joseph today?

Establishing trust will be a key component; consider carrying out a psychosocial assessment today. This should include noting Joseph’s physical appearance and if there is a weight loss trend present. Speak with Joseph’s aunt to help understand his living situation and any deficits that there may be in terms of household resources.

### Which Toolkit Module will be most helpful in your visit with Joseph today?

Depending on the individual provider’s judgment, you may consider utilizing *Module 1: Psychosocial Development*, *Module 9: Positive Living*, or *Module 7: Loss, Grief & Bereavement*.

### Which additional Modules and Tools in the might you consider utilizing?

Depending on the findings from the interview any of the below components should be considered:

- *Tool 1.1.1: Stages of Psychosocial Development Tool*, *Tool 1.1.3: Psychosocial Assessment Tool for the Interview with the Family Caregiver*, *Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent*
- *Tool 7.1.1: Grief Assessment Discussion Guide*, *Tool 7.1.2: A Guide to Grief Counseling*, *Tool 7.2.3: Helping your Adolescent to Grieve*, *Tool 7.3.6: My Grief Journal*
- *Tool 4.1.2: Gender Based Violence and Abuse Screening Tool for the Adolescent Interview*
- *Tool 9.2.4: Positive Living Tips*, *Tool 9.3.9: HIV Peer Support Groups*, *Tool 9.3.10: My Positive Living Journal*, *Tool 9.2.6: Food for Health: Nutrition Tips*, *Tool 9.3.7: Food for Health: Nutrition Tips*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Joseph is transitioning as expected? Why or why not?

Because Joseph was recently diagnosed, he is likely at the very beginning of the transition process. Based upon his age, he is behind the expected behaviors, but this is not unusual considering that he just recently learned of this HIV status. After helping to address his immediate concern which is his living situation, work with Joseph to provide education and meeting self-management goals.

### What other facility-based services are available to him that may help?

Refer Joseph to in-house services such as adherence support if he has started ART, and any peer support groups, if they are available within your facility.

### What other community-based services are available to him that may help?

Consider connecting his caregiver to support services within the community, including food support programs. It will also be important to connect Joseph to psychosocial support services and an HIV peer support group.

### What will you consider doing at his next appointment and how soon will you want to see him back?

Because Joseph has been ill and is just recently learning of his HIV status, follow up within the next month to make sure that Joseph’s nutritional status is stable. Check on the living situation to determine if it is improving with assistance from community resources and work on progress toward transition.

# CASE STUDY 4: “WHEN TO DISCLOSE”

Elsa is a 17 year old behaviorally infected adolescent who was diagnosed 6 months ago. Based upon her clinic guidelines, she is expected to transition to adult care shortly. She lives with her parents, who are not yet aware of her status. For this reason Elsa has been completely independent in attending appointments. She is not on medication. She has been healthy since she has been in your care and has been doing an excellent job of engaging in positive living decisions and meeting established self-management goals. She continues to date her boyfriend of 2 years who is not yet aware that she is HIV positive; Elsa does not know if he is monogamous.

How will you approach your appointment with Elsa today?

Which Toolkit Module will be most helpful in your visit with Elsa today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Elsa is transitioning as expected? Why or why not?

What other facility-based services are available to her that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY 4: “WHEN TO DISCLOSE”

## ANSWER KEY

### How will you approach your appointment with Elsa today?

Establishing trust will be a key component, consider carrying out a psychosocial assessment today. It is important to establish rapport and a nonjudgmental approach to ensure that Elsa feels comfortable sharing information regarding SRH and disclosure. Because Elsa was recently diagnosed but is an older adolescent, it will also be important to begin discussing transition early in the process. It will be your job to build her confidence and skill-set to participate in discussions with her boyfriend surrounding use of protection and monogamy.

### Which Toolkit Module will be most helpful in your visit with Elsa today?

Depending on the individual provider’s judgment, you may consider utilizing *Module 6: Beneficial Disclosure*, *Module 3: Sexual & Reproductive Health*, or *Module 9: Positive Living*.

### Which additional Modules and Tools might you consider utilizing?

Based upon your initial interview, consider utilizing:

- *Checklist 2: Comprehensive Transition Checklist*
- *Tool 3.1.1: Sexual & Reproductive Health Assessment Tool for the Adolescent Interview*, *Tool 3.1.2: Family Planning & Pregnancy Counseling Guide for the Health Care Provider*, *Tool 3.3.7: My Sexual & Reproductive Health Journal*
- *Tool 6.1.2: Disclosure Discussion Guide*, *Tool 6.3.5: My Disclosure Journal*
- *Tool 8.1.2: Key Steps at the Baseline Visit*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Elsa is transitioning as expected? Why or why not?

Elsa is progressing remarkably well for someone who was recently diagnosed as she is independently managing her care because her parents are not aware of her status. Consider providing information surrounding HIV and sexually transmitted infections, disclosure and pregnancy.

### What other facility-based services are available to her that may help?

Refer Elsa to in-house psychosocial, disclosure and sexual and reproductive health services if they exist.

### What other community-based services are available to her that may help?

Connect Elsa to services that may not exist at your facility including sexual and reproductive health, disclosure, and psychosocial support. Referral to peer support will also be helpful to her.

### What will you consider doing at her next appointment and how soon will you want to see her back?

Follow up on Elsa’s conversations with her boyfriend within one month, if she has not yet disclosed or had conversations surrounding protection and monogamy, reinforce and remind her of her strengths and ability to navigate these discussions. You may choose to return to the beneficial disclosure and SRH modules as needed.

# CASE STUDY 5: “NEW RELATIONSHIP?”

Stephen is a 15 year old perinatally infected adolescent who has been in your care since he was very young. You have been working on the transition process with him for three years. He is very knowledgeable surrounding his health, routinely participates in a peer support program within the community, and approaches health facility staff with any changes in his health status. He seems very shy during his clinic appointment today and finally at the end of the appointment tells you that he noticed that he has some strange bumps on his penis. When you ask Stephen if he is sexually active he looks embarrassed and stares at the floor.

How will you approach your appointment with Stephen today?

Which Toolkit Module will be most helpful in your visit with Stephen today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Stephen is transitioning as expected? Why or why not?

What other facility-based services are available to him that may help?

What other community-based services are available to him that may help?

What will you consider doing at his next appointment and how soon will you want to see him back?

# CASE STUDY 5: “NEW RELATIONSHIP?”

## ANSWER KEY

### How will you approach your appointment with Stephen today?

Establishing trust will be a key component; consider carrying out a psychosocial assessment today. Even though Stephen waited until the end of the appointment today to share his concerns with you, it is important to address the issue during this visit if possible. Carry out a full SRH assessment with Stephen and a physical exam if you are his health care provider. Reassure Stephen that genital warts are not an uncommon phenomenon, especially among those with HIV and that often times they disappear on their own. Approach the conversation in a respectful and nonjudgmental manner so that Stephen will feel comfortable reporting any other developments in future appointments. If you are a community care provider, be sure to connect Stephen to health care services. If possible, have a same-sex provider do the physical examination.

### Which Toolkit Module will be most helpful in your visit with Stephen today?

*Module 3: Sexual & Reproductive Health*

### Which additional Modules and Tools might you consider utilizing?

You may consider utilizing the following components:

- *Tool 3.1.1: Sexual & Reproductive Health Assessment Tool for the Adolescent Interview, Tool 3.1.3: Sexually Transmitted Infections Screening Tool, Tool 3.3.7: My Sexual & Reproductive Health Journal*
- *Tool 9.2.4: Positive Living Tips, Tool 9.3.9: HIV Peer Support Groups, Tool 9.3.10: My Positive Living Journal,*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Stephen is transitioning as expected? Why or why not?

Stephen is progressing well which is evidenced by his knowledge surrounding HIV, his participation in a peer support program within a community program, as well as his ability to approach health facility staff with changes in his health status.

### What other facility-based services are available to him that may help?

Connect him to SRH services at your facility, if they exist.

### What other community-based services are available to him that may help?

Consider connecting Stephen to Community-Based programs that specifically carry out work in SRH.

### What will you consider doing at his next appointment and how soon will you want to see him back?

See Stephen as advised by the treatment method utilized for the genital warts. Approach this topic in the next appointment after you have discussed all of the other routine topics so that Stephen has ample time to feel comfortable in his surroundings. Also discuss beneficial disclosure and condom use.

# CASE STUDY 6: “RELUCTANT TO LEAVE”

Jessica is an 18 year old perinatally infected adolescent who has been in your care since she was very young. She lives with a sister; is clinically stable, adherent to her medications and is completely responsible for her own medical care. You have been discussing transition with Jessica for several years. Because you have been Jessica’s provider for so long, she has been hesitant to transition to adult care. However, she has accomplished all of the tasks within her Comprehensive Transition Checklist and scored 100% on the HIV Knowledge Assessment. You believe that she is ready to transition to adult care.

How will you approach your appointment with Jessica today?

Which Toolkit component will be most helpful in your visit with Jessica today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Jessica is transitioning as expected? Why or why not?

What other facility-based services are available to her that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY 6: “RELUCTANT TO LEAVE”

## ANSWER KEY

### How will you approach your appointment with Jessica today?

Establishing trust will be a key component; consider carrying out a psychosocial assessment today. Be sure to take opportunities to encourage, provide education and support her to take responsibility for self-care. Speak openly about the expectations for transition and her readiness to do so. Clearly explain the transition process will consist of a visit that the two of you will make together to the adult provider, followed by her independently making visits to the adult provider thereafter. Reassure her that you have communicated her clinical information to the adult provider who is fully equipped to take over her care and that you are confident in her self-management abilities. Encourage continued use of community-based programs as she transitions.

### Which Toolkit component will be most helpful in your visit with Jessica today?

Based upon the provider’s judgment, the *Key Checklists to Use Throughout Transition* will most likely be the main component of the Toolkit referred to in this visit.

### Which additional Modules and Tools might you consider utilizing?

Based upon your conversation today, utilize these components:

- *Checklist 2: Adolescent Checklist*
- *Tool 8.1.1: Adolescent Clinical Transition Document*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Jessica is transitioning as expected? Why or why not?

She is ready to transition.

### What other facility-based services are available to her that may help?

A full review of Jessica’s psychosocial situation and needs can be done through reviewing notes within the Toolkit. Identify gaps that can be solved through referring Jessica to community services that are available.

### What other community-based services are available to her that may help?

Be sure to provide any referrals to community organizations that may assist her during this process prior to transition and encourage continuation of community-based services as she grows older.

### What will you consider doing at her next appointment and how soon will you want to see her back?

Attend Jessica’s first appointment with her adult provider to provide additional support within a short period of time to keep up the momentum for transition. Remind Jessica know that thereafter she will be responsible for attending the appointments independently.

# CASE STUDY 7: “COPING WITH GRIEF”

Joanna is a 15-year-old perinatally infected HIV-positive adolescent who lost both of her parents to HIV about two years ago. She lives with a caregiver, but takes primary responsibility for her younger brother and works after school. Due to her increasing responsibility at home, she has fallen behind and has not been meeting the established self-management goals that you have been regularly setting together. She has been engaging in positive living behaviors, but is hesitant to join a peer support group, is not able to verbalize side effects of her medications, and does not know when to call a doctor or access emergency services. She tells you that she is having problems coping with attending school, working and taking care of her brother. She is having problems sleeping, a loss of appetite, and has been having panic episodes for about six months.

How will you approach your appointment with Joanna today?

Which Toolkit component will be most helpful in your visit with Joanna today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Joanna is transitioning as expected? Why or why not?

What other facility-based services are available to her that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY 7: “COPING WITH GRIEF”

## ANSWER KEY

### How will you approach your appointment with Joanna today?

Establishing trust will be a key component; consider carrying out a psychosocial assessment. Recognize and commend Joanna for all of the responsibilities that she has taken on. Reassure her that it is not uncommon to experience feelings of panic. Provide an environment where Joanna can openly share what she is experiencing. Carry out a full psychosocial and mental health assessment to assist you in deciding your next actions.

### Which Toolkit component will be most helpful in your visit with Joanna today?

Based upon the provider’s judgment and mental health considerations, the *Loss, Grief & Bereavement* or *Psychosocial* Modules should be utilized.

### Which additional Modules and Tools might you consider utilizing?

Based upon your initial findings, consider utilizing the following components:

- *Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent*
- *Tool 7.1.1: Grief Assessment Discussion Guide, Tool 7.1.2: A Guide to Grief Counseling, Tool 7.2.3: Helping your Adolescent to Grieve, Tool 7.3.6: My Grief Journal*
- *Tool 9.3.9: HIV Peer Support Groups, Tool 9.3.10: My Positive Living Journal, Tool 9.3.7: Food for Health: Nutrition Tips*
- *Tool 2.1.1: The Mental Health Symptom Screener, Tool 2.2.3: Your Adolescent’s Emotional Health, Tool 2.3.4: Your Emotional health, Tool 2.3.5: My Emotional Health Journal*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Joanna is transitioning as expected? Why or why not?

She is not meeting expected self-management goals for her age, but she has met those expected for the ages of 11-14.

Consider that some of her anxiety may be due to increasing self-responsibility during transition. Consider slowing down some of the self-management goals until her anxiety has stabilized.

### What other facility-based services are available to her that may help?

Once you have carried out a full symptom assessment, consider referring Joanna to a mental health specialist.

### What other community-based services are available to her that may help?

Refer Joanna to a mental health specialist within the community if one does not exist at the facility. Also consider a referral to a peer support group.

### What will you consider doing at her next appointment, and how soon will you want to see her back?

Provide emotional support for Joanna at each opportunity. Follow up on panic symptoms within a week and determine if she followed through on the mental health referral. Revisit the Mental Health Tips and provide additional education surrounding managing anxiety symptoms.

# CASE STUDY 8: “A NEW GIRLFRIEND”

Jacob is a 16 year old HIV-positive boy who has been reaching most of his benchmarks and working toward transition. He is comfortable approaching community and health facility staff with questions, is able to verbalize when he has changes in his health status, and is able to list side effects of his medications. He is in a relationship with his first girlfriend and has not told her that he is HIV positive. He also has not told of any of his friends about his status. Because of his choice to not disclose, he has not been attending a peer support group for fear of unintentional disclosure. He expresses today that he feels like he might want to tell his girlfriend and maybe his best friend, but is not sure how to go about it. He asks for support in this area.

How will you approach your appointment with Jacob today?

Which Toolkit Module will be most helpful in your visit with Jacob today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Jacob is transitioning as expected? Why or why not?

What other facility-based services are available to him that may help?

What other community-based services are available to him that may help?

What will you consider doing at his next appointment and how soon will you want to see him back?

# CASE STUDY 8: “A NEW GIRLFRIEND”

## ANSWER KEY

### How will you approach your appointment with Jacob today?

Establishing trust will be a key component, consider carrying out a psychosocial assessment today. Congratulate Jacob on reaching this decision. Navigate a discussion surrounding what has brought him to this decision and why he has chosen to disclose to these particular people. Be sure to address SRH, as this may be an upcoming topic for Jacob.

### Which Toolkit Module will be most helpful in your visit with Jacob today?

Based upon the provider’s judgment, *Module 6: Beneficial Disclosure*.

### Which additional Modules and Tools might you consider utilizing?

Based upon your initial discussion, consider the following components:

- *Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent, Tool 3.3.7: My Sexual & Reproductive Health Journal*
- *Tool 6.1.2: Disclosure Discussion Guide, Tool 6.2.3: Discussion Guide: Disclosure, Tool 6.3.5: My Disclosure Journal*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Jacob is transitioning as expected? Why or why not?

Jacob is meeting established benchmarks in the Comprehensive Checklist including discussing HIV with community and health facility staff, verbalizing changes in health status and listing side effects of his medications. However, he has not met the benchmark of attending a peer support group due to his fear of unintentional disclosure.

### What other facility-based services are available to him that may help?

Consider connecting Jacob to organizations in your facility that deal specifically with disclosure and adolescent SRH. Also consider an HIV Peer Support Group.

### What other community-based services are available to him that may help?

Consider connecting Jacob to organizations in your facility that deal specifically with disclosure and adolescent SRH. Also consider an HIV Peer Support Group.

### What will you consider doing at his next appointment, and how soon will you want to see him back?

Follow up with Jacob per local guidelines. At the next visit, Inquire as to the outcome of disclosure, reinforce lessons, and provide support as needed. Continue with discussions surrounding sexual activity and protection. Ensure that he is reaching benchmarks for transition.

# CASE STUDY 9: “NEW CAREGIVER”

Sarah is a perinatally infected 11 year old who is recently orphaned because of the loss of her mother. Sarah has moved in with her neighbor, Nancy who is now her caregiver. This is your first visit with Sarah since she has moved in with Nancy. Prior to her mother’s passing, Sarah was able to openly discuss her experience of feeling stigmatized within the community due to her mother’s illness, and also expressed grief surrounding her impending loss; you were also beginning to provide basic education surrounding HIV, medication, and healthy living to Sarah. At this visit, you notice that Nancy appears impatient and angry toward Sarah. During the physical exam you notice that Sarah has lost a considerable amount of weight since her last visit. In addition you also notice a bruise that is shaped like a handprint on her arm.

How will you approach your appointment with Sarah today?

Which Toolkit Module will be most helpful in your visit with Sarah today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Sarah is transitioning as expected? Why or why not?

What other facility-based services are available to them that may help?

What other community-based services are available to her that may help?

What will you consider doing at her next appointment and how soon will you want to see her back?

# CASE STUDY 9: “NEW CAREGIVER”

## ANSWER KEY

### How will you approach your appointment with Sarah today?

Establishing trust will be a key component, consider carrying out a psychosocial assessment today. Allow Nancy to participate in the initial part of the interview with Sarah. Let Nancy know that routinely you like to speak with clients alone and that she will be asked to step out of the room after you have had the opportunity to speak as a group. Observe how Nancy and Sarah interact to determine if it is as expected. When Nancy has left the room, let Sarah know that anything she shares is private unless you find out she is in danger, in which case you will need to get additional assistance to help her. Provide an open and comfortable environment for Sarah to share information.

### Which Toolkit Module will be most helpful in your visit with Sarah today?

Based upon the provider’s judgment, modules to consider include *Module 4: Protection* and *Module 1: Psychosocial Development*.

### Which additional Modules and Tools might you consider utilizing?

Based upon the initial discussion, consider utilizing:

- *Tool 1.1.: Psychosocial Assessment Tool for the Interview with the Family/Caregiver, Tool 1.1.4: Psychosocial Assessment Tool for the Interview with the Adolescent*
- *Tool 4.1.2: Gender Based Violence and Abuse Screening Tool for the Adolescent Interview, Tool 4.3.3: My Safety Journal*
- *Tool 9.2.5: Self-Care Guide*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Sarah is transitioning as expected? Why or why not?

Sarah is transitioning as expected as evidenced by her ability to discuss experienced stigma and grief. She is just beginning to learn about HIV, medication, and positive living.

### What other facility-based services are available to them that may help?

If the weight loss is due to a knowledge deficit surrounding nutrition requirements, refer both Nancy and Sarah to a nutritionist.

### What other community-based services are available to her that may help?

If you determine that Sarah is a victim of child abuse, you are obligated to report this to child protection authorities in your area. Be sure to connect both Nancy and Sarah to additional psychosocial support in your area. If you have determined that Nancy and Sarah are experiencing household food insecurity connect them to a food assistance program.

### What will you consider doing at her next appointment and how soon will you want to see her back?

If you determine that Sarah is not a victim of child abuse and that there is another explanation for the bruise, be sure to see her on a more frequent basis and carry out routine assessments to monitor for further evidence of injuries. If you suspect that Sarah is a victim of child abuse, contact the local child protection authorities immediately. See Sarah within two weeks to make sure that her household situation is improving.

# CASE STUDY 10: “READY TO TRANSITION”

Matthew is a clinically stable 16 year old who has been in your care for about 2 months after testing positive for HIV during a youth HTC drive. He is not on ART. From previous discussions you know that he is performing well at school and has a couple of good friends to whom he has disclosed. He comes in today with his father for a routine visit and has no new issues. You are thinking about introducing the transition process today.

How will you approach your appointment with Matthew today?

Which Toolkit component will be most helpful in your visit with Matthew today?

Which additional Modules and Tools might you consider utilizing?

According to the Comprehensive Transition Checklist, do you think that Matthew is transitioning as expected? Why or why not?

What other facility-based services are available to him that may help?

What other community-based services are available to him that may help?

What will you consider doing at his next appointment and how soon will you want to see him back?

# CASE STUDY 10: “READY TO TRANSITION”

## ANSWER KEY

### How will you approach your appointment with Matthew today?

Establishing trust will be a key component, consider carrying out a psychosocial assessment today. Prior to the appointment, check the Individualized Checklist to determine which components should be addressed during this visit. After you have carried out your initial discussion with Matthew and his father, broach the topic of transition by explaining the process. Discuss *Checklist 2: The Comprehensive Transition Checklist*, *Checklist 4: Family/Caregiver Checklist*, and *Checklist 5: Adolescent Checklist*. Provide education and begin to establish self-management goals

### Which Toolkit component will be most helpful in your visit with Matthew today?

Based upon the provider’s judgment, *Module 8: Clinical Considerations*.

### Which additional Modules and Tools might you consider utilizing?

Based upon your discussion, consider utilizing the following components:

- *Checklist 2: The Comprehensive Transition Checklist*, *Checklist 3: HCP/CCP Checklist*, *Checklist 4: Family/Caregiver Checklist*, and *Checklist 5: Adolescent Checklist*
- *Tool 8.1.3: Key Steps for Adolescents Not on ART*
- *Tool 10.3.4: Guide to Health & Social Resources*

Remember to only utilize the tools that are most relevant to the client and the family/caregiver and to not overwhelm the client by providing many tools during a visit.

### According to the Comprehensive Transition Checklist, do you think that Matthew is transitioning as expected? Why or why not?

Because Matthew was diagnosed within the last two months, he is at the very beginning of the transition process. As evidenced by his good school performance and the fact that he has already disclosed to a few friends and his dad, developmentally he is likely able to take on increasing self-care tasks and will be able to set self-management goals to work toward transition.

### What other facility-based services are available to him that may help?

Consider connecting Matthew to a peer support group if you have one at your facility.

### What other community-based services are available to him that may help?

Consider connecting Matthew to psychosocial services in the community from which he may benefit as needs arise.

### What will you consider doing at his next appointment, and how soon will you want to see him back?

Ask Matthew to return within one month and revisit the Comprehensive Transition Checklist at routine intervals to determine if self-management goals are met. Where goals are not met, provide further education, direction and support to Matthew and his family and re-establish goals. Check to make sure that Matthew follows through on referrals. Continue with assessments and tools as needs arise.

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