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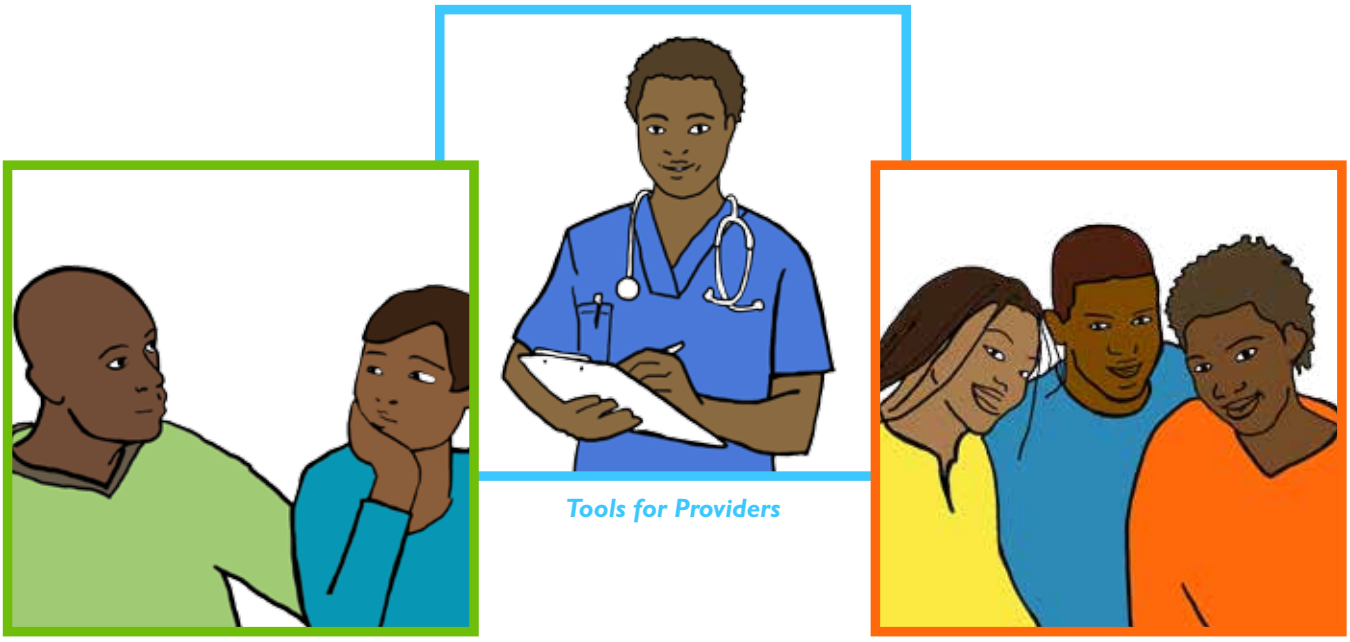
TOOLKIT FOR TRANSITION OF CARE AND OTHER SERVICES FOR ADOLESCENTS LIVING WITH HIV



Tools for Providers

Tools for Parents/Caregivers

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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TABLE OF CONTENTS

ACRONYMS

3TC	lamivudine
ABC	abacavir
ALHIV	adolescents living with HIV
ART	antiretroviral therapy
AZT	zidovudine
BAI	Beck Anxiety Inventory
BDI-II	Beck Depression Inventory Second Edition
CBO	community-based organization
CCP	community care provider
CES-D	Center for Epidemiological Studies Depression Scale
CHS	Columbia Health Screen
d4T	stavudine
EFV	efavirenz
FBO	faith-based organization
GBV	gender-based violence
HADS	Hospital Anxiety and Depression Scale
HCP	health care provider
ICAP	International Center for AIDS Care and Treatment Programs
NNRTI	non-nucleoside reverse transcriptase inhibitor
NRTI	nucleoside reverse transcriptase inhibitor
NVP	nevirapine
OI	opportunistic infection
PCL	PTSD Checklist
PHQ-9	Patient Health Questionnaire
PTSD	post-traumatic stress disorder
SRH	sexual and reproductive health
STI	sexually transmitted infection

INTRODUCTION

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 and community care providers 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 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 select tools created, the *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* provides clear guidance to community care providers (CCPs) and health care providers (HCPs), the adolescent, and his or her family/caregiver to promote a smooth transition for the adolescent. The Toolkit is useful for both perinatally exposed adolescents as well as behaviorally exposed adolescents. It is anticipated that this Toolkit will be used in tandem with the Technical Brief, *Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa*, which provides a framework for transition and outlines essential care, support, and treatment services to best meet the multiple unique needs of this population. CCPs and HCPs who use this Toolkit can work with the adolescent and his or her family/caregiver to develop a package of services that are individually tailored to meet the needs of the adolescent in a developmentally appropriate manner.

Among children known to be living with HIV, the transition process should begin in preadolescence with a transition plan developed and reviewed—at minimum—annually. Included in this Toolkit is information and tools that CCPs and HCPs can use to develop a minimum package of services for their clients that includes psychosocial support; mental health; sexual and reproductive health (SRH); protection; alcohol and substance use; beneficial disclosure; loss, grief, and bereavement; positive living; clinical considerations; and linking health facilities and community programs. Utilization of these components will provide for a more holistic and smooth transition process. The *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV* allows the adolescent and the family/caregiver to participate and guide the transition process based upon the adolescent's readiness. In addition, it allows the HCP/CCP to support the adolescent during the transition process to maximize resiliency, minimize risk factors, and promote positive personal growth.

HOW TO USE THE TOOLKIT

This Toolkit is a guide that assists both HCPs and CCPs to tailor a package of services for ALHIV. HCPs and CCPs are the primary users of the Toolkit, and they should use the Toolkit and distribute content/tools as appropriate to the adolescent and the family/caregiver.

THE TOOLKIT PROVIDES:

1. **A framework to promote self-care:** The Key Checklists (found on pages 12 to 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 to 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.

2. **A framework for a minimum package of services:** Utilize the modules within the Toolkit 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.

AVOID:

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

DO:

- **Identify and respond to the chief complaint:** Determine one to two of the biggest concerns of the adolescent and the family/caregiver during the visit and review and use the appropriate module(s) 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 unless the adolescent shares that he or she intends to harm him- or herself or someone else, in which case you will access services to help the adolescent get the additional support needed.
- **Adapt to your context and setting:** See page 9 for adaptation guidance.

HOW THE TOOLKIT IS ORGANIZED

WHO IS THE TARGET AUDIENCE?

Each module contains a title page with a directory of tools available within the module. After the title page there is a summary page to provide guidance and information for the HCP/CCP. Following the summary page are tools available for three audiences which are numbered accordingly:

1. Audience 1. **The HCP/CCP** may use any of the tools to enhance their own practice. Health facilities and community-based organizations (CBOs) should keep in mind that modules outlining services they do not currently offer is a reminder that bidirectional referrals are an important component of care.

2. Audience 2. **The family/caregiver** should receive tools and information from the HCP and CCP as a means to better understand how to support the adolescent during the transition process. Caregivers may be neighbors, friends, partners, or spouses, and should be known by the provider as the primary point of contact for the adolescent.

3. Audience 3. **The adolescent** should receive tools and information from the HCP and CCP to assist with navigating the transition process. Several of the tools intended for the adolescent require a participatory approach; in these cases, the HCP or CCP should review these tools with the adolescent and utilize them as a means to provide and reinforce health education opportunities.

HOW ARE THE MODULES AND TOOLS NUMBERED?

The tools are numbered in a consistent manner and refer to the audience of the tool targets. For example, Tool 7.3.6 is found in *Module 7: Loss, Grief, & Bereavement*, targets the adolescent (audience 3), and is the sixth tool in that module.

In order to further distinguish tools for each of the three audiences the following color coding applies throughout the Toolkit:

1 HCP/CCP Tools

2 Family Caregiver Tools

3 Adolescent Tools

ADAPTING THE TOOLKIT

This Toolkit has been written for the general context of Africa; as this is a large and diverse region, adaptation of the Toolkit is encouraged prior to use. Once the Toolkit is received within a facility, an on-site administrator should adapt the Toolkit to ensure cultural and contextual appropriateness. Components of the Toolkit may also need to be adapted for low literacy audiences.

THE FOLLOWING MODULES MAY REQUIRE ADAPTING:

- ***Module 1: Psychosocial Development:*** Ensure that the psychosocial development outlined is culturally appropriate and within the range of expected behaviors for each age group.

- ***Module 2: Mental Health Considerations:*** Review the mental health screening tools to determine if they are culturally relevant and include correct symptomatology.

- ***Module 3: Sexual & Reproductive Health:*** Ensure that this module reinforces helpful traditional practices, reflects the services available in your area, and meets the needs of your population. Check components that include assessment and information on lesbian, gay, and transgender populations to ensure that they are culturally appropriate and do not promote harmful attitudes and behaviors to the client.

- ***Module 4: Protection:*** Review the screening tools to determine if they are culturally relevant, follow local laws, and match the local context and resources available. Many countries may have referral protocols for abuse. Check with child protection stakeholders to learn what you are legally required to do and the appropriate legal response when abuse or neglect is suspected.

- ***Module 5: Alcohol & Substance Use:*** Review this to determine if you should add a specific drug or drug name that is commonly used among adolescents at your setting.

- ***Module 6: Beneficial Disclosure:*** Consider adapting this component to consider specific considerations for disclosure in your cultural context.

- ***Module 7: Loss, Grief, & Bereavement:*** There is a wide variance in how different cultures express emotions; review all tools to determine appropriate adaptations to improve contextual relevance.

- ***Module 8: Clinical Considerations:*** The medication regimen according to WHO guidelines is included within the Toolkit; adapt this to the guidelines and standards that are used within your facility. If guidelines are updated, the Toolkit should also be updated to include the most recent guidelines.

- ***Module 9: Positive Living:*** Review the nutrition tool to determine if the foods discussed are appropriate to your cultural setting and adapt as appropriate.

- ***Module 10: Linking Health Facilities and Community Programs:*** Cross-referrals and linkages are an essential component of transition. This component of the Toolkit will require adapting in every setting so as to include information about available services in the community. Appoint a person responsible for collecting and documenting this information; keep it updated on a semiannual basis, and routinely distribute it to clients and families/caregivers.

THE TRANSITION FRAMEWORK

Transition to self-care should be an individualized and client-centered approach based on the physical development, emotional maturity, and health status of the client. Self-care is defined as taking greater responsibility for tasks such as taking medication as scheduled, attending appointments, filling prescriptions, filling out medical paperwork, and making appointments independently. It is important to remember that,—while each adolescent is different,—the ability to take on these tasks will likely require a period of several years. Transition should build upon the strengths of the client's home and community support systems (International Center for AIDS Care and Treatment Programs [ICAP] 2011). Disclosure is a prerequisite to self-care; if the adolescent does not yet know his or her status, assist the family/caregiver with disclosure prior to beginning transition. By beginning the transition discussion with the adolescent early in their adolescence, the HCP and CCP can tailor health education to the adolescent's changing needs, connect the adolescent and his or her family/caregiver to various community and health services, and continually discuss and assess the adolescent's ability to self-manage his or her care. Beginning transition discussions early can assist the adolescent to be more emotionally and mentally prepared to manage his or her own care, to move from pediatrics to adult care, and to build stronger support systems that will help the adolescent remain engaged in his/her health care over the long term. For those adolescents recently diagnosed with HIV, transition planning should occur shortly after diagnosis. As the period immediately surrounding an HIV diagnosis is often overwhelming, these adolescents may progress more slowly toward self-management; therefore, it will be important to present transition topics as appropriate for each adolescent.

Pediatric and adult care providers and CCPs should all work together to build a cooperative relationship that will foster easy communication before and throughout the transition process. These relationships will allow for information exchange on the unique needs of adolescents, create an avenue for case management during transition, and enhance the ability to follow-up if challenges emerge during the transition process. CBOs play an important role in the transition process as they are able to address gaps in services that the client may experience and serve as a constant presence from the beginning of the transition process to far beyond the point that transition has occurred.

It should be noted that in many settings there is no separate pediatric and adult provider; care is given by the same providers to all populations. In these cases, the HCP/CCP should continue to focus on setting self-management goals with the client to increase the client's knowledge and ability to take care of him- or herself over time. The client should also be linked to additional community-based resources as his or her needs change to enhance the quality of care he or she receives.

KEY CHECKLISTS TO USE THROUGHOUT TRANSITION

As adolescents begin the journey to self-management, they may or may not make a physical transition from a pediatric to an adult facility. Regardless of the actual location of services, all adolescents must undergo a mental transition that requires them to move toward medical autonomy and self-care. This Toolkit provides some key checklists to better manage this transition for ALHIV.

1 HCP/CCP Checklists:

- ***Monitoring the Use of the Modules (Checklist 1)***
  This checklist should be utilized throughout adolescence to track which modules in this Toolkit have been introduced. It can help ensure that these components are reviewed as needed to increase the adolescent's and the family/caregiver skill set and knowledge base.

- ***Comprehensive Transition Checklist (Checklist 2)***
  This checklist provides a format for the provider to establish goals for self-management tasks with the adolescent as they progress towards transition of care. Transition is dependent upon the adolescent's knowledge surrounding HIV, preventive health behaviors, ability to manage psychosocial issues, and achievement of self-management goals. It will be helpful to provide updated copies to the adolescent and the family/caregiver as new self-management goals are established. Encourage the adolescent and his or her family/caregiver to use the comprehensive transition checklist to reinforce goal-setting at home.

- ***HCP/CCP Transition Readiness Checklist (Checklist 3)***
  This checklist provides prompts and links to critical tools within this Toolkit that can assist the provider in assessing if the adolescent is transition ready. See the key tools referenced in this checklist to assess if the adolescent client is transition-ready.

2 Family/Caregiver Checklist:

- ***Family/Caregiver Checklist (Checklist 4)***
  This checklist provides information to the family/caregiver on how to support the transitioning adolescent and should be provided to the family/caregiver at the beginning of the transition process.

3 Adolescent Checklist:

- ***Adolescent Checklist (Checklist 5)***
  This checklist assists the adolescent in thinking about his or her self-care tasks. The adolescent should be able to accomplish all of these tasks prior to transition.

MONITORING THE USE OF THE MODULES

It is important to keep track of the various transition topics that you have discussed with the adolescent and his or her family/caregiver. To ensure that each relevant component is addressed, mark the appropriate box and the age at which the component was addressed. Review this checklist at each visit to prompt you as to which topics may require addressing or reinforcing.

Client Name: _____

TOOLKIT COMPONENT	**≤ 10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**
Key Checklists: comprehensive transition checklist, provider checklist, family checklist, adolescent checklist (should be utilized semi-annually)										
Module 1: Psychosocial Development										
Module 2: Mental Health Considerations										
Module 3: Sexual & Reproductive Health										
Module 4: Protection										
Module 5: Alcohol & Substance Abuse										
Module 6: Beneficial Disclosure										
Module 7: Loss, Grief, & Bereavement										
Module 8: Clinical Considerations										
Module 9: Positive Living										
Module 10: Linking Health Facilities & Community Programs										

COMPREHENSIVE TRANSITION CHECKLIST

The provider should use this checklist to establish self-management goals with adolescent and the family/caregiver. The column on the left describes the expected self-management task; the next column describes the age range in which the task is expected to take place. Discuss each task with the client and set realistic goals together as age appropriate. Document if the goal was completed and re-establish goals where additional support is needed. Refer to this sheet to routinely establish new goals and monitor progress of previously established goals. Transition should be considered when the adolescent has successfully carried out all tasks in the checklist.

SELF-MANAGEMENT TASK	EXPECTED AGE RANGE FOR TASK (Years of Age)*	DISCUSSED (√)	GOAL FOR TASK (Month & Year)	GOAL REACHED? (Y/N)
Interacts with providers; asks questions.	Below 11			
Explains knowledge about HIV.	Below 11			
Identifies symptoms of grief and a person they can speak with when grieving.	Below 11			
Describes stigma and its effects.	Below 11			
Makes healthy diet and exercise decisions.	Below 11			
Explains what HIV is.	11 - 14			
Explains what CD4 cells are.	11 - 14			
Explains what a viral load is.	11 - 14			
Explains names/dosages of medications correctly each time there is a medication change.	11 - 14			
Discusses pros/cons of contraception options.	11 - 14			
Explains STIs including transmission and prevention.	11 - 14			
Explains meaning of HIV diagnosis for pregnancy.	11 - 14			
Abstains from drugs that have not been prescribed, alcohol, and cigarettes.	11 - 14			
Independently gives medical history.	11 - 14			
Explains reasons for disclosure and disclosure methods.	11 - 14			
Attends first peer support group.	11 - 14			
Describes side effects of medications.	15 - 24			
Verbalizes when and how to call doctor and emergency care.	15 - 24			
Identifies members of the health care team, roles, and how to contact them.	15 - 24			
Lists community services for ALHIV and accesses them independently	15 - 24			
Fills prescriptions and refills them independently.	15 - 24			
Takes medication independently and is adherent to medications.	15 - 24			
Makes and attends appointments independently.	15 - 24			
Sets up transportation for appointments independently.	15 - 24			

Adapted from Bartlett et al. (2011)

HEALTH CARE PROVIDER/COMMUNITY CARE PROVIDER TRANSITION READINESS CHECKLIST

Transition may be a vulnerable period for the adolescent due to the fact that he or she may not have a lot of experience managing his or her own health care. It is important to work with adolescent clients to encourage them to routinely attend their appointments, adhere to their medications, identify and access additional sources of support such as other community-based services, and abstain from drugs and alcohol that may negatively impact their health. Some adolescents may be resistant to leave the comfort of their pediatric provider and may continue to seek out their pediatric HCP after transition has occurred. In these cases, it is best for the pediatric HCP to consider speaking with the adult HCP and defer to their plan of care.

The adolescent has met the requirements for transition when he or she has completed all goals within Checklist 2: *Comprehensive Transition Checklist* and has voiced readiness to transition. Make sure that the adolescent has met these qualifications prior to transition. See the following list, which highlights the tools relevant for the pediatric and adult HCPs to help evaluate if the adolescent is transition-ready:

- ☐ The adolescent agrees that he or she is prepared to transition.
- ☐ The adult HCP has spoken with the pediatric HCP about the client, and the pediatric HCP has provided a copy of the adolescent's medical record or the *Adolescent Clinical Transition Document* (Tool 8.1.1).
- ☐ The adolescent completes all of the tasks on *Adolescent Checklist* (Checklist 5) without requiring reminders.
- ☐ The adolescent is able to correctly respond to all questions in the *HIV Knowledge Assessment* (Tool 9.1.3)
- ☐ The adolescent remains adherent to his or her medication (Tool 8.1.7 and Tool 8.3.11).
- ☐ The adolescent is able to communicate any changes in health status and verbalizes when to access health services in case of emergency (Tool 8.3.12).
- ☐ Psychosocial needs have been addressed or are being addressed currently by services at CBOs (Tool 10.1.1 and Tool 10.2.4/10.3.4).
- ☐ The adolescent verbalizes long-term goals and plans for long-term survival (Tool 9.3.10)

Bartlett et al., 2011

FAMILY/CAREGIVER CHECKLIST

Transition, the process of moving towards self-care, can be a challenging time for the adolescent as he or she must cope with typical challenges that teenagers encounter in addition to learning how to manage HIV. It can also be a challenging time for the family/caregiver as they give up control and the right to decision making as the adolescent becomes more autonomous. The adolescent's health and community providers will be encouraging the adolescent to take on greater responsibility for his or her own health. Use the following checklist to make sure that the adolescent is on track for transition and that you, as the family/caregiver, are supporting the adolescent to take greater responsibility for their health.

THE ADOLESCENT WILL LEARN TO PERFORM THE FOLLOWING TASKS:

- ☐ **Fill prescriptions, obtain refills from the pharmacy, and take medications independently**
- ☐ **Make their own appointments to see their health and community care providers and attend appointments on a routine basis**
- ☐ **Arrange transportation to go to their appointments**
- ☐ **Keep a calendar of when they have health care and other appointments**
- ☐ **Access other social services within the community and at the health facility**

TIPS FOR THE FAMILY/CAREGIVER:

- Bring the adolescent with you initially to fill their medication prescriptions. Encourage the adolescent to ask for the prescriptions. When the adolescent appears confident in requesting these items, encourage him or her to go independently and follow-up to make sure he or she fulfilled the task until you are sure that the adolescent can do this without reminders.
- Encourage the adolescent to utilize the *Medication Worksheet* that the health or community provider will provide to help the adolescent remember important information about his or her medicine. Also encourage utilization of the *Medication Adherence Diary* to help monitor if they are taking their medication as prescribed.
- Attend health care appointments with the adolescent to help him or her plan the transition process. You can also provide information at the appointment about how things are going at home as the adolescent takes on greater responsibility for his or her health. As the adolescent becomes more responsible, encourage him or her to make health appointments independently.
- Teach the adolescent how to utilize transportation to attend appointments. Go with the adolescent until you feel that he or she is able to use transportation independently and safely.
- Talk with health and community providers to identify other community organizations that provide supportive services to the adolescent and encourage the adolescent to access these services.
- Communicate with the adolescent throughout the transition process to determine where the challenges are and how they can best be addressed.
- Encourage and reward the adolescent's increasing independence.

Adolescent Checklist

Transition is an important period in your life. As you become increasingly independent, it is important to make sure that you continue to take good care of yourself and follow through on the tasks that keep you healthy! Changing health care providers and taking care of yourself can be a big change, and you should speak with your health and community care providers as well as your family/caregiver to make sure that you are prepared beforehand. In order to have the smoothest transition possible, make sure that you are able to carry out all of the tasks in the following checklist before you transition. If you have any questions, make sure to talk to your health and community care providers!

- ☐ I can explain what HIV is and how to take care of myself, and my health and community care providers have answered all of my health related questions.
- ☐ I have had all of my questions answered about my own sexual and reproductive health.
- ☐ If I am taking medications, I am able to take them every day at the same time, and I do not require anyone to remind me to take it. If I do forget to take a pill, I understand what I am supposed to do.
- ☐ I refill my medication prescriptions on my own, and I do not need to be reminded to do it.
- ☐ I make and attend all of my appointments with my health and community care providers and I do not need to be reminded to do it.
- ☐ I have available transportation that I can independently use to bring me to my health care and other appointments and to the pharmacy.
- ☐ I know what to do if I am not feeling well and when I should contact my health care provider.
- ☐ I have built connections with community based organizations who will continue to support me throughout the transition process.
- ☐ I have verbalized to my current health care provider that I am prepared to transition.

Adapted from Jacob and Jearld, 2007

ADDITIONAL TOOLS & RESOURCES

For those HCPs and CCPs and program designers who are seeking to carry out comprehensive HIV programs for ALHIV in resource-limited settings, the following resources are available for reference.

- **Adherence Curriculum. Baylor International Pediatric AIDS Initiative.**
  The Adherence Curriculum is a two-session training curriculum for healthcare providers to provide education and support to parents and caregivers who care for adolescents who are on ARV treatment. The curriculum has been adapted for international use.
  www.bipai.org/Adherence-Curriculum/

- **Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers. ICAP.**
  A comprehensive training curriculum that equips multi-disciplinary health teams to provide adolescent friendly services as they move towards transition. The training package includes a Trainer's Manual and a Participant's Manual.
  http://icap.columbia.edu/resources/detail/adolescent-hiv-care-and-treatment

- **Teen Talk: A Guide for Positive Living. AIDSTAR-One.**
  A question and answer guide for HIV positive adolescents, addressing topics including ARVs, adherence, friendship, nutrition, exercise, reproductive health, positive prevention, multiple concurrent partnerships, safe male circumcision, prevention of mother to child transmission, emotions and disclosure.
  http://www.aidstarone.com/focus_areas/treatment/resources/pediatric_disclosure_materials/teen_talk

- **Transitioning Care and Other Services for Adolescents Living with HIV: Technical Brief. AIDSTAR-One.**
  This technical brief provides guidance for program managers and policymakers in order to develop services for ALHIV and their families/caregivers as they transition toward HIV self-management and adult clinical care. Highlighting key principles and recommendations, this brief offers guidance to countries and programs on how to provide the multidisciplinary care, support, and treatment services these adolescents need.
  http://www.aidstar-one.com/focus_areas/care_and_support/resources/technical_briefs/alhiv_transitions

- **Resources for the Clinical Management of Children and Adolescents Who Have Experienced Sexual Violence. AIDSTAR-One.**
  These technical considerations and accompanying job aids serve as a guide for medical providers to address and respond to the unique needs and rights of children and adolescents who have experienced sexual violence and exploitation.
  http://www.aidstar-one.com/focus_areas/gender/resources/prc_technical_considerations

MODULE 1: PSYCHOSOCIAL DEVELOPMENT

Module 1: Summary

1 HCP/CCP Tools:

- ***Stages of Psychosocial Development Tool (Tool 1.1.1)***
  This tool aids to assess the adolescent's developmental stage. An additional table is provided to document and track psychosocial development over time.

- ***Self-Management Timeline (Tool 1.1.2)***
  This may be used as a resource to determine expected behavior for the adolescent to take on self-management responsibility.

- ***Psychosocial Assessment Tool for the Interview with the Family/Caregiver (Tool 1.1.3)***
  This tool may be used to assess the living situation through interviewing the adolescent and their family/caregiver together.

- ***Psychosocial Assessment Tool for the Interview with the Adolescent (Tool 1.1.4)***
  This tool may be used assess the current psychosocial status through a private interview.

3 Adolescent Tools:

- ***My Psychosocial Development Journal (Tool 1.3.5)***
  This journal may be given to the adolescent to help him or her identify strengths and explore challenges.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 1.3.5 can be found in Module 1, targets the adolescent (audience 3), and is the fifth tool in this module.

MODULE 1: PSYCHOSOCIAL DEVELOPMENT

Dramatic changes occur during adolescence including rapid physical development and further developments in personality and social skills including 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.

Monitoring developmental milestones will assist to determine the adolescent's readiness to take on increasing responsibility for self-management of his or her health (see Tool 1.1.2: *Self-Management Timeline*). ALHIV may experience a delayed onset of puberty, where the he or she may appear smaller and younger, but is actually more cognitively mature than he or she appears (Arpadi 2005). Some ALHIV may also experience developmental delays and learning problems, which 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 to manage his or her own care. Tool 1.1.1 provides information surrounding the stages of psychosocial development to assess transition readiness.

Carry out a detailed psychosocial assessment to identify factors that will assist the adolescent with the transition process (see Tool 2.2.3 and Tool 2.3.4 for psychosocial assessments for the family/caregiver and for the adolescent). 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 by asking questions about their general well-being and noting any concerns that they may have regarding their emotional and physical status, 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), which is included in ***Module 4: Protection*** (see Tool 4.1.2: *Gender-Based Violence & Abuse Screening Tool for the Adolescent Interview*). Provide reassurance that the information that he or she 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 (see ***Module 10*** for further information about creating linkages between CBOs and health facilities). Many ALHIV may not have family/caregiver support, further increasing their vulnerability during transition (see Tool 1.3.5 for an adolescent psychosocial journal that provides the adolescent with an opportunity to document his or her experiences.) 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 transition process.

STAGES OF PSYCHOSOCIAL DEVELOPMENT

Adolescents progress at different rates through the psychosocial stages of development. Careful assessments should be carried out routinely to determine his or her readiness to take on self-management tasks. Use the information below to assess which stage the adolescent is currently in and document your assessment in the table that follows to track the adolescent's psychosocial development over time, as well as his or her readiness to transition. If the client is not developing as expected, determine potential issues by carrying out a psychosocial assessment found in Tool 1.1.3 and Tool 1.1.4 of this module to aid in determining next steps.

AREA OF DEVELOPMENT	EARLY: 10-13	MIDDLE: 14-16	LATE: ≥ 17
Physical *	Pubertal changes.	End of pubertal changes.	Sense of responsibility for one's health.
Emotional	Wide mood swings, intense feelings, low impulse control, role exploration.	Sense of invulnerability, risk-taking behaviour.	Increasing sense of vulnerability, able to consider others and suppress ones needs, less risk taking.
Cognitive	Concrete thinking, little ability to anticipate long-term consequences of their actions, literal interpretation of ideas.	Able to conceptualize abstract ideas such as love, justice, truth, and spirituality.	Formal operational thought, able to understand and set limits, understands thoughts and feelings of others.
Relation to family	Estranged, need for privacy.	Peak of parental conflict, rejection of parental values.	Improved communication, accepts parental values.
Peers	Increased importance and intensity of same-sex relationships.	Peak of conformity, increase in relationships with opposite sex.	Peers decrease in importance, mutually supportive, mature and intimate relationships.

**See Tool 8.1.9 for Tanner's Staging Guides*

DATE OF VISIT	STAGE OF DEVELOPMENT (EARLY, MIDDLE, LATE)	APPROPRIATE TO AGE (YES/NO)	NOTES

Adapted from Tindyebwa, Kayita, and Musoke 2006

SELF-MANAGEMENT TIMELINE

Provided in the following table is a self-management timeline that describes when and how to address various topics based on the stage of development and the adolescent's expected ability to self-manage his or her care. This may be used as a loose guide; remember that the adolescent may be developing more slowly or more rapidly than expected. Self-management guidance should be based on your psychosocial assessment and reflect the capabilities of the health system.

	Between 8–13 Years: "Envisioning a Future"	Between 14–16 Years: "Working Toward Responsibility"	Age 17 and Greater: "Capacity to Transition"
PERSONAL GROWTH AND ENVIRONMENTAL SUPPORT: ENCOURAGING HEALTHY DECISIONS			
Psychosocial support	Link to relevant support and peer groups.	Link to relevant support and peer groups and programs.	Link to relevant support and peer groups and programs; support mentorship of younger positive adolescents.
Sexual and reproductive health, positive health and prevention	Answer any questions that emerge truthfully and honestly.	Link to adolescent-friendly reproductive health clinics; review sexual issues and safe sex practices; refer to regular sexual health checkups; discuss HIV prevention methods.	Continue sexuality conversations; encourage questions about HIV, pregnancy, and sexuality; refer for regular sexual health checkups; discuss HIV prevention methods; link to PMTCT services if pregnant.
Protection	Discuss self-esteem, healthy family environments, and rights to attend school and to feel safe; determine disclosure status; support disclosure where appropriate.	Discuss the links between transactional and coerced sex, violence, and poor health outcomes; link to support groups to continue education; determine disclosure status; support the family/caregiver and adolescent with disclosure if it has not yet occurred; support the adolescent in disclosure to peers and partners where appropriate.	Discuss the links between transactional and coerced sex, violence, and poor health outcomes; link to life skills training and labor opportunities; support the adolescent in disclosure to peers and partners where appropriate.
Substance use	Discuss substance use and how it can impact health and lead to poor medication adherence and retention in care.	Discuss the links between sexually risky behaviors, substance abuse, and poor health outcomes; assess if using substances and what triggers use.	Discuss the links between sexually risky behaviors and substance abuse, and poor health outcomes; assess if using substances and triggers use.
Future planning	Initiate conversation about future goals (work, school, etc.).	Promote peer education opportunities; connect ALHIV with relevant nongovernmental organizations.	Connect ALHIV to job training, vocational training, and continued education opportunities.
CLINICAL SUPPORT: PROVIDING OR FACILITATING REFERRALS FOR NEEDED SERVICES			
Self-care	Support caregivers to disclose to the adolescent if not already done; talk to the child to start mapping out of the transition timeline after disclosure.	Build a schedule with the adolescent to strengthen adherence to treatment and retention in support programs; discuss and address transportation barriers and other issues that hinder adherence to ART.	Reinforce responsibility in taking medications and keeping appointments.
Clinical management	Begin to explain medications and reinforce adherence messages for those already on ART; talk about issues; link to counseling for any mental health issues.	Talk to the adolescent about diagnosis, medications, and adherence; talk to the adolescent about how to seek clinical care for symptoms or emergencies; link to counseling for any mental health issues.	Review clinical history with the adolescent; help identify appropriate adult providers/clinics; solicit questions about care, treatment, and potential future changes in treatment; link to counseling for any mental health issues.

Adapted from Gipson and Garcia 2009, Hodgson et al. 2011, Jacob and Jearld 2007, Reiss, Gibson, and Walker 2005

PSYCHOSOCIAL ASSESSMENT TOOL FOR THE INTERVIEW WITH THE FAMILY/CAREGIVER

Interview the family/caregiver together with the adolescent in the room for a discussion surrounding psychosocial issues and readiness for self-management of clinical care. Interview findings may be used to identify gaps, create referrals for psychosocial services and to recognize modules within this toolkit that will assist the adolescent and the family/caregiver.

QUESTION	NOTES
How are things since you learned about your adolescent's HIV status? What are the biggest challenges?	
Who lives at home and who cares for the adolescent? What responsibilities does the adolescent have for taking care of him or herself and others members of the family?	
Are you the parent or caregiver of the adolescent? Do you know your own HIV status? If you are the caregiver, how is the adolescent adapting to living in your household? *Refer the family/caregiver to counseling and testing as needed.*	
Do you think that he or she confides in you when needed? Is there anything that you would like to speak to the adolescent about such as sex or drug and alcohol use, but find it difficult to do?	
How would you describe the mood of the adolescent on most days? Is he or she generally happy or sad?	
How is the adolescent performing at school or work? Is he or she able to attend most days?	
Do you think that the adolescent is ready to take on more responsibility for self-management of his or her illness? What do you think that the adolescent is prepared to take charge of independently?	
What factors are present that will make transition to self-management of clinical care more difficult for the adolescent? What are some ways to overcome these barriers?	
What factors are present that will help make a smooth transition to self-management of clinical care for the adolescent? Do you think that the adolescent is ready and willing to take on more responsibility?	
What other questions or concerns would you like to discuss today?	

Adapted from ICAP 2011

PSYCHOSOCIAL ASSESSMENT TOOL FOR THE INTERVIEW WITH THE ADOLESCENT

Interview the adolescent privately to maximize sharing of information. Reassure the adolescent that the information he or she shares will remain confidential. Use interview findings to identify gaps, create referrals to respond to gaps, as well as to recognize additional modules within this toolkit that will assist the adolescent and the family/caregiver.

QUESTION	NOTES
Who are you living with and how long have you lived with them? Do you get along well with them? Is anyone else in the house HIV positive? Do you help to take care of them?	
Who do you feel close to? Who can you go to for emotional support	
Do you go to school or work outside the home?	
How often in the last week have you used cigarettes, alcohol, or other drugs?	
Have you disclosed your HIV status? If yes, to whom? If you haven't disclosed to anyone, why not?	
Do you belong to a community/religious organization or support group that gives you the support you need?	
Have you experienced negative attitudes or treatment because of your HIV status or for other reasons? Has anyone caused you harm in the past (for example hurt you physically or unwanted sexual encounters)?	
How is your mood now? Do you feel sad or depressed? What changes have you noticed in your mood?	
Do you have financial support? Who do you go to when you need help with financial support?	
Other than coming to the HIV clinic, do you go to any other clinical or traditional healers for health services?	
Are you having sex? Are you using a family planning method? What is it? Do you use condoms?	
How do you remember to take your medications daily? How do you remember to return to the clinic for appointments? Who helps you with this?	
What other questions or concern do you want to discuss today	

Adapted from ICAP 2011

My Psychosocial Development Journal

Keeping a journal can help you think about your development as you gain increasing independence and take on greater responsibility for yourself.

The accomplishments that I am most proud of . . .

My greatest strengths are . . .

Some things that I would like to accomplish are . . .

Some things about me that I would like to work on are . . .

What do I want to talk about only with my healthcare provider?

What do I want to talk about only with my family?

What do I want to talk about only with my peers/friends?

What do I want to talk about only with my teacher or another adult?

What do I want to keep to myself and not share with anyone?

Adapted from Robinson et al. 2006

MODULE 2: MENTAL HEALTH CONSIDERATIONS

Module 2: Summary

1 HCP/CCP Tools

- ***The Mental Health Symptom Screener (Tool 2.1.1)***
  This tool can be utilized to assess for depression and anxiety in the adolescent.

- ***Additional Mental Health Screens (Tool 2.1.2)***
  This list provides a collection of mental health screening tools to consider.

2 Family/Caregiver Tools

- ***Your Adolescent's Emotional Health (Tool 2.2.3)***
  This information sheet can be provided to the family/caregiver so that they are aware of depression and anxiety signs and symptoms to monitor in the adolescent.

3 Adolescent Tools

- ***Your Emotional Health (Tool 2.3.4)***
  This information sheet can be provided to the adolescent so that he or she may self-monitor for signs and symptoms of depression and anxiety.

- ***My Emotional Health Journal (Tool 2.3.5)***
  This tool should be utilized by the adolescent to explore his or her own thoughts around his or her emotional health. The adolescent should be told this is for private journaling, and the adolescent can share it with others only if he or she wants to.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 2.3.5 can be found in Module 2, targets the adolescent (audience 3), and is the fifth tool in this module.

MODULE 2: MENTAL HEALTH CONSIDERATIONS

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.

Routinely assess for signs and symptoms of mental health problems such as flat affect, dramatic changes in appearance and self-care patterns, irritability, behavioral problems, difficulty concentrating, sleeping difficulties, decreased socialization with peers and others, and reports of poor school performance (Thom 2007). 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 you suspect that he or she is thinking about suicide, provide an urgent referral for mental health counseling and involve the family/caregiver whenever possible (Thom 2009). Discuss depression symptoms and its potential effects with the adolescent and his or her family/caregiver. Provide the adolescent and the family/caregiver with Tool 2.2.3: *Your Adolescent's Emotional Health*, and Tool 2.3.4: *Your Emotional Health*. Know the mental health counselors and other supportive services, such as peer and community support groups, who work with adolescents in your area, and work with them to engage all parties to create a therapeutic and supportive environment for a smooth transition. In addition, see the counseling tip sheet in Tool 7.1.2 in ***Module 7: Loss, Grief, & Bereavement*** for further information.

Anxiety signs and symptoms include a lack of appetite, tremulousness, sweating, racing heart, difficulty breathing, headaches, difficulty falling asleep, restlessness, and difficulty concentrating (ICAP 2011). Tool 2.1.1: *The Mental Health Symptom Screener* and Tool 5.1.2: *Alcohol & Substance Use Counseling Guide* may help to identify mental health and substance use issues which can be used as a prompt for counseling referrals. These referrals could be to peer support groups and to lay counselors if trained mental health professionals are not available. Tool 2.1.2: *Additional Mental Health Screens* provides additional screening options to consider when integrating mental health services. 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).

Additionally, you may want to refer to ***Module 4: Protection*** (see Tool 4.1.2: *Gender-Based Violence & Abuse Screening Tool for the Adolescent Interview*). Note that before you screen for abuse or violence, you must ensure strong supportive services are available for the adolescents (see Module 4 for more information). Provide the adolescent with Tool 2.3.5: *My Emotional Health Journal*.

THE MENTAL HEALTH SYMPTOM SCREENER

Note to provider: This screen may be useful to combine with Tool 5.1.1: The Substance Abuse Symptom Screener, depending on the adolescent.

The adolescent might not always be able to answer the questions as they are posed on the screening tool, so you might therefore need to ask the questions in other ways or in an indirect manner.

TOPIC	QUESTION	YES	NO
Medications	During the past 12 months, were you ever on medication/antidepressants for depression or nerve problems? (Provider note: Antidepressants/medication for mental health may be uncommon in most settings.)		
Major Depression	During the past 12 months, was there ever a time when you felt sad, angry, or depressed for 2 weeks or more in a row?		
	During the past 12 months, was there ever a time lasting 2 weeks or more when you lost interest in most things like hobbies, work, or activities that usually give you pleasure?		
Generalized Anxiety Disorder	During the past 12 months, did you ever have a period lasting 1 month or longer when most of the time you felt worried and anxious?		
Panic Disorder	During the past 12 months, did you have a spell or an attack when all of a sudden you felt frightened, anxious, or very uneasy when most people would not be afraid or anxious?		
	During the past 12 months, did you ever have a spell or an attack when for no reason your heart suddenly started to race, you felt faint, or you could not catch your breath? (If respondent volunteers "only when having a heart attack or due to physical causes," mark "No.")		

Client should be considered positive for symptoms of mental illness if he or she responded yes to any question. Refer to a mental health professional.

If a mental health professional is not available, refer the adolescent to the most qualified health or community care provider. This may include lay counselors, peer support groups, spiritual caregivers, or other sources of support that exist in your community.

Date: _____

Positive screen: **Yes** **No**

Action taken (education provided; referral for alcohol/substance use counseling, etc.):

ADDITIONAL MENTAL HEALTH SCREENS

The following is a list of potential mental health screening tools that have been used among young people, and the tools may be useful in your facility or organization. Some are free to use, and some have costs associated with them. In some cases, the cost to use may be waived. It is important to check if any mental health screens have been validated in your country. Link with mental health professionals in your country to see what is most appropriate for your setting; they may be able to provide the necessary tools and support for your program.

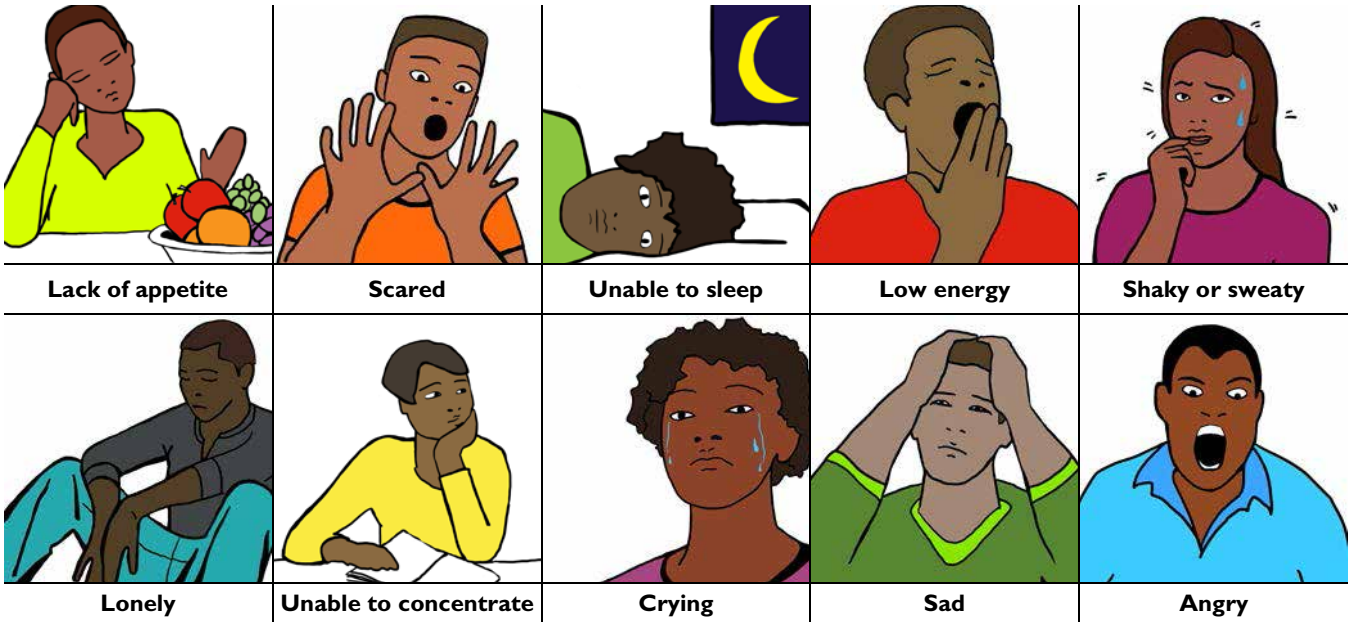
TOOL	BASIC INFORMATION
CES-D	– Brief 20-item self-report scale focused on depression – Widely used – Free and available at: http://idacc.healthbase.info/questionnaires.html.
PHQ-9	– Depression only – Nine questions and takes approximately two minutes to complete and score in most cases – Free of charge – Not available in a range of languages – Available at www.cqaimh.org/pdf/tool_phq9.pdf.
HADS	– Assesses both anxiety and depression, and the overall score gives one of four severity categories – Longer and takes more time to complete compared to PHQ-9 – Used in multiple countries with reliable and valid results – Cost associated with use – See www.ehow.com/how_5069944_use-hospital-anxiety-depression-scale.html and Herrmann (1997) for more information.
BDI-II and BAI	– Use of both to screen for anxiety and depression – Longer and take more time to complete compared to PHQ-9 and HADS – Used in multiple countries with reliable and valid results – Cost associated with use – Available in a range of languages – See www.ehow.com/how_5642339_interpret-beck-depression-inventory.html and www.ehow.com/how_5078582_score-beck-anxiety-scale.html for more information.
CHS	– Brief self-report 14-item questionnaire; takes approximately 10 minutes to complete – Designed for youth aged 11 to 18 in the United States – Comprehensive: includes depression, anxiety, suicide risk behaviors (i.e., suicide ideation and attempts), alcohol and drug use, and general health problems – Not validated outside the Unites States – Availability and more information can be found at http://www.channelingreality.com/un/education/CHS.pdf.
PCL	– Brief self-report 17-item scale – Is available in different languages and has been used internationally – Availability and free to use, with credit given to the developers, available at http://idacc.healthbase.info/questionnaires.html.

YOUR ADOLESCENT'S EMOTIONAL HEALTH

Adolescents who are emotionally healthy are more likely to take better care of their physical health. The stress of dealing with HIV can lead to emotional health problems like anxiety and depression. Depression is when an individual feels sad, helpless, hopeless, or worthless. Anxiety is when an individual feels worried, nervous, and fearful.

WHAT TO LOOK FOR:

Look for the following symptoms with the adolescent. Some of these feelings are a normal part of adolescence, but talk to your teen and their health or community care provider if they begin to occur regularly or more often.



Other symptoms to look for include: low self-esteem, irrational fears or worries, nightmares, or withdrawing from friends.

WHAT YOU CAN DO:

Monitor your adolescent for symptoms and speak with your adolescent and their health and community care provider. They can offer emotional health tips and connect you to a trained counselor who can help. They may also provide connections to a community support and/or peer support group.

MORE TIPS FOR HELPING YOUR ADOLESCENT:

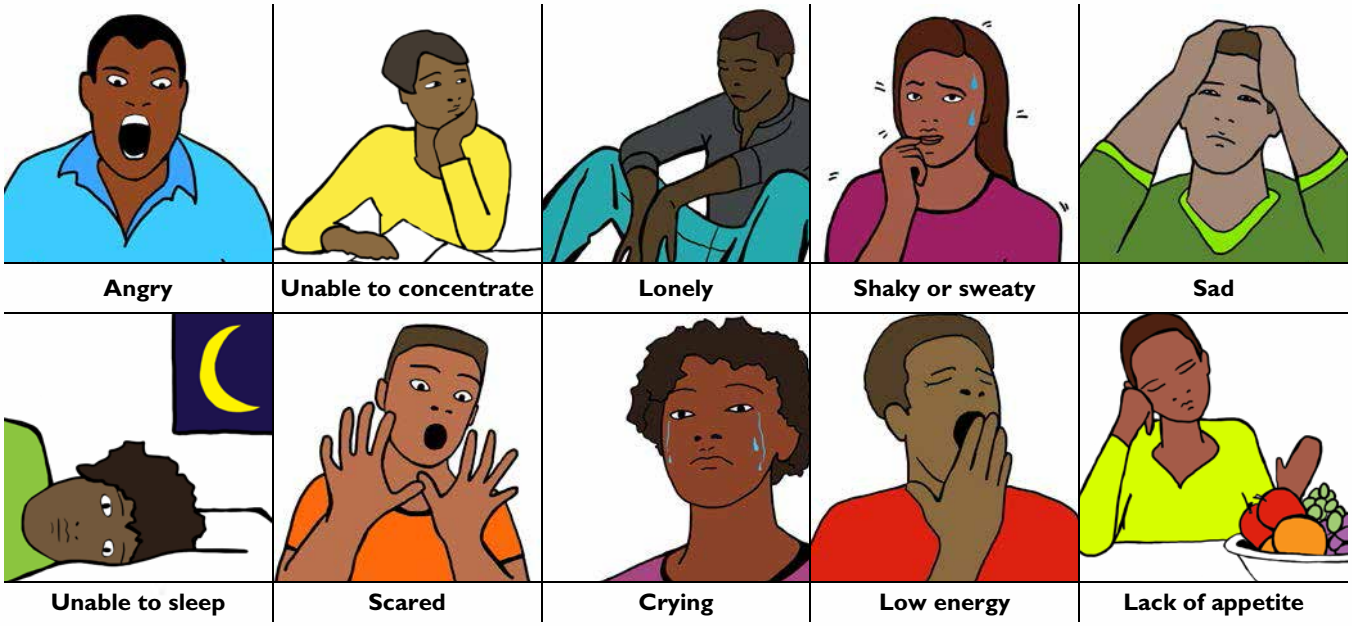
Offer Support	Let your adolescent know that you are there for him or her completely. Do not ask a lot of questions. Express that you are willing to provide whatever support he or she needs.
Be Gentle But Persistent	Do not give up if your adolescent shuts you out at first. Talking about emotional health can be very difficult. Be respectful of his or her comfort level while expressing your concern and willingness to listen.
Listen Without Criticizing	Do not criticize or pass judgment once your adolescent begins to talk. The important thing is that your child is talking. Avoid offering advice that is not asked for.
Validate Their Feelings	Do not try to talk them out of their feelings, even if their feelings or concerns appear silly or irrational to you. Simply acknowledge the pain and sadness they are feeling.

Your Emotional Health

When you are emotionally healthy, you are able to take better care of your physical health. Dealing with HIV is stressful, and anxiety and depression are common emotional health problems. Depression is when you feel very sad, helpless, hopeless, or worthless. Anxiety is when you feel worried, nervous, and fearful.

What to look for:

If you start to notice any of the following symptoms and if they occur regularly or begin to occur more frequently, speak to your family/caregiver about it and notify your health and community care provider, if appropriate.



Angry	Unable to concentrate	Lonely	Shaky or sweaty	Sad
Unable to sleep	**Scared**	**Crying**	**Low energy**	**Lack of appetite**

What you can do:

It is important to let your family/caregiver and healthcare provider know if you experience any of these symptoms. They can connect you to a trained counselor who can help treat these symptoms. They can also help to connect you to a community support and/or peer support group where you can work with others to improve your emotional health.

More tips to help improve your emotional health:

Find support	You are not alone! Talk to someone you trust: a parent, caregiver, friend, spiritual advisor, or health/community provider, or anyone else you feel comfortable sharing your feelings with.
Write your thoughts	Writing can help you to understand your emotions and gain perspective on what you are thinking (ask your health or community provider for a journal to write down your feelings.). Try writing at least one good thing that happens to you every day.
Relax your mind	Find a quiet place, sit down, close your eyes, and listen to your breathing. This can help you focus and feel more calm. Music, art, and walking may also help to calm your mind.
Get involved in spiritual activities	Becoming involved in spiritual activities, such as a church, mosque, or other events, may increase your sense of hope and provide more meaning in your life.
Rest	Getting enough rest will help you feel better. Make sure you are getting 7-9 hours of sleep.
Help others	Helping others can increase your social network, improve your self-esteem, and give you a sense of purpose and achievement.
Exercise	Exercise can improve your mood and sleep, and increases your energy and strength.

My Emotional Health Journal

I feel happiest when . . .

Some things that make me feel sad or anxious are . . .

Some things that I can do to help myself feel better when I am feeling sad or anxious . . .

Some people who I can trust to talk to about my emotions are . . .

What do I want to talk about only with my healthcare provider?

What do I want to talk about only with my family?

What do I want to talk about only with my peers/friends?

What do I want to keep to myself and not share with anyone?

Other thoughts on my mind . . .

Adapted from Robinson et al. 2006

MODULE 3: SEXUAL & REPRODUCTIVE HEALTH

Module 3: Summary

1 HCP/CCP Tools

- ***Sexual & Reproductive Health Assessment Tool for the Adolescent Interview (Tool 3.1.1)***
  This tool can aid in assessing the SRH needs and hopes of the adolescent.

- ***Family Planning & Pregnancy Counseling Guide for the Health Care Provider (Tool 3.1.2)***
  This tool should be utilized as a resource to guide SRH decisions and can be adapted to fit the family planning methods available in different contexts/settings.

- ***Sexually Transmitted Infections Screening Tool for the Health Care Provider (Tool 3.1.3)***
  This tool should be utilized by the HCP to assess the need for testing for STIs.

2 Family/Caregiver Tools

- ***Discussion Guide: Sex & Relationships (Tool 3.2.4)***
  This tool can guide family/caregivers in how to talk to their adolescent about sex and relationships; it can be adapted to fit to different contexts/settings.

3 Adolescent Tools

- ***Sexually Transmitted Infection Fact Sheet (Tool 3.3.5)***
  This fact sheet should be shared with the adolescent to give him or her more information on STIs and their prevention.

- ***Pregnancy & Prevention of Mother-to-Child Transmission Fact Sheet (Tool 3.3.6)***
  This fact sheet should be shared with the adolescent to give him or her more information on adolescent pregnancy and prevention of mother-to-child transmission of HIV.

- ***My Sexual & Reproductive Health Journal (Tool 3.3.7)***
  This tool should be utilized by the adolescent to explore his or her own future hopes and sexuality. The adolescent should be told this is for private journaling, and it can be shared with others only if the adolescent wants to.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 3.3.5 can be found in Module 3, targets the adolescent (audience 3), and is the fifth tool in this module.

MODULE 3: SEXUAL & REPRODUCTIVE HEALTH

Adolescence is a period of self-discovery and exploration where sexual initiation usually occurs (Baryamutuma and Baingana 2011; Elkington et al. 2009). Like their HIV-uninfected 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, and Kavuma 2011). Speak with the adolescent privately and routinely about SRH to build trust and open communication. 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). Work with families/caregivers to provide education and encourage them to provide guidance without violating the confidentiality of the adolescent (see Tool 3.1.1 for an SRH assessment tool and Tool 3.2.4 for a family/caregiver discussion guide on sex and sexuality).

ALHIV may engage in sexual risk-taking behavior as a coping mechanism to deal with a 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 safe sexual. Tool 3.3.7: *My Sexual & Reproductive Journal Adolescent Journal* allows ALHIV to explore their feelings and thoughts on sex and sexuality.

Many youth living with HIV plan to have families of their own; provide education, family planning and referral to antenatal care for PMTCT to minimize transmission. (Baryamutuma and Baingana 2011). Educate on ART adherence and encourage dual protection; use of a hormonal and barrier method; to offer greater pregnancy and STI protection (see Tool 3.3.5: *Sexually Transmitted Infection Fact Sheet*). For sero-discordant couples, viral load monitoring may help with timing conception attempts to minimize the risk of HIV transmission to the uninfected partner (see Tool 3.1.2: *Family Planning & Pregnancy Counseling Guide for the Health Care Provider* and Tool 3.3.6: *Pregnancy & Prevention of Mother-to-Child Transmission Fact Sheet*).

Routine STI screening is essential once the adolescent initiates sexual activity. Educate on STI transmission and prevention, and symptoms of STIs. See Tool 3.1.3: *Sexually Transmitted Infection Screening Tool for the Health Care Provider.* 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.

ALHIV may be at risk for sexual abuse and violence, intimate partner violence, and engaging in transactional sex, increasing the risk of unintended pregnancy, and STIs. Screen for these risks at each visit (see ***Module 4: Protection***, which provides tools to help you screen and refer for services related to GBV and abuse).

SEXUAL & REPRODUCTIVE HEALTH ASSESSMENT TOOL FOR THE ADOLESCENT INTERVIEW

Date: _____

Carry out this assessment with the adolescent privately to maximize sharing of information. Discussion topics are written in *italics*. Reassure the adolescent that the information shared will remain confidential. Use responses to these questions as opportunities to provide sexual education as the need arises.

QUESTIONS AND DISCUSSION TOPICS	NOTES
Have you been noticing any changes in your body? *Explain physical changes of puberty and what can be expected.*	
Have you had any romantic or sexual feelings toward anyone? *Discuss sexuality, healthy relationships, and communication.*	
What does sex mean to you? Are you sexually active? What sexual activities have you tried? Have you possibly transmitted HIV through sexual activity to any partners? *Explain different types of sexual activities and their relative risk for STIs and pregnancy.*	
Do you have a partner/boyfriend/girlfriend? Do you tell your partner(s) that you are living with HIV? *Discuss disclosure to partners.*	
If you are having sex, are you using condoms? Are you comfortable talking to your partner about condoms? Are they easy for you to obtain? *Review correct and consistent condom use. Discuss where condoms may be obtained and how to negotiate their use.*	
Do you drink alcohol or use drugs (not your medicines) when you have sex? How do you think this affects your decisions? *Discuss potential increased risks with alcohol and unsafe sex.*	
Has anyone ever forced you to have sex or do something sexual that you did not want to do? *Screen for sexual abuse using tools found in Module 4: Protection.*	
Tell me what you know about STIs. *Screen for exposure and link to testing services as appropriate using Tool 3.1.3: "Sexually Transmitted Infection Screening Tool for Health Care Providers."*	
Tell me about what you know about family planning. *Discuss family planning options and access to family planning methods. Link to family planning services as appropriate.*	
Would you like to have children one day? *Reinforce that it is okay and their right, discuss family planning options, and link to prevention of mother-to-child transmission services as appropriate. Remind the adolescent of the importance of adherence during pregnancy and breastfeeding.*	
What other questions would you like to discuss today?	

Adapted from ICAP 2011

FAMILY PLANNING & PREGNANCY COUNSELING GUIDE

Date: _____

Carry out this assessment with the adolescent privately to maximize sharing of information. Discussion topics are written in italics. Reassure the adolescent that information shared will remain confidential. If the adolescent is married, consider inviting his/her partner to be present as appropriate and participate in the discussion. Use responses to these questions as opportunities to provide health education as the need arises.

QUESTIONS AND DISCUSSION TOPICS	NOTES
Have you thought about having children one day? *Explain the basics of mother-to-child transmission.*	
What do you think is a good age to start a family? *Discuss the physical (health) risks of adolescent pregnancy.*	
What family planning methods to control the timing of pregnancy have you heard of? *Provide overview of family planning methods and options.*	
Have you used any of these family planning methods? Tell me about your experience with them. Were they easy to use? Did you experience any side effects? *Review alternative options, if so desired and feasible.*	
Have you heard anything about side effects of family planning methods? Tell me about what you have heard. *Explain the side effects of hormonal contraception and what interactions they might have with other medications.*	
Do you know if your partner is also HIV-positive? *Review the importance of secondary prevention and also the risk of HIV transmission via unprotected sex.*	
Tell me what you know about reducing risk of transmission between you and your partner when trying to conceive. *Explain the safest times (high CD4 count, undetectable viral load, adherent to medications, etc.) to try for conception.*	
Do you know what your HIV infection might mean for a pregnancy and the baby? *Discuss the potential effects of HIV infection on pregnancy and the potential effects of pregnancy on HIV infection. Review Tool 3.3.6: Pregnancy and Prevention of Mother-to-Child Transmission Fact Sheet for Adolescents.*	
What do you know about prevention of mother-to-child transmission services? Let's talk about reducing the risk of transmitting HIV to your baby. *Link to prevention of mother-to-child transmission services as appropriate.*	
Tell me about the support systems you would have to raise a child. *Discuss the psychological, social, and economic risks of early parenthood.*	
What other questions would you like to discuss today?	

Adapted from ICAP 2011

SEXUALLY TRANSMITTED INFECTIONS SCREENING TOOL

Perform appropriate physical exams and order diagnostic laboratory tests and treatments as often as the adolescent requires. Screen for Gender Based Violence (see Tool 4.1.2).

QUESTIONS FOR ADOLESCENT WOMEN	NOTES
Have you had fluids or other discharge from your vagina that is not normal for you? It could be a different color, amount, or smell.	
Does it hurt when you urinate (pee)?	
Have you noticed any sores or bumps around your vagina or anus?	
Do you have any pain in your lower abdomen (belly)?	
Does it hurt when you have sex?	
Do you have any other questions or concerns you would like to discuss today?	

Additional notes:

QUESTIONS FOR ADOLESCENT MEN	NOTES
Have you had fluids or other discharge from your penis?	
Does it hurt when you urinate (pee)?	
Have you noticed any sores or bumps around your penis or anus?	
Do you have any other questions or concerns you would like to discuss today?	

Additional notes:

Date: _____

Laboratory testing (mark all that apply for this visit):

- Gonorrhea/chlamydia
- Herpes
- Syphilis
- Human papilloma virus/Papanicolaou smear
- Hepatitis B
- Other

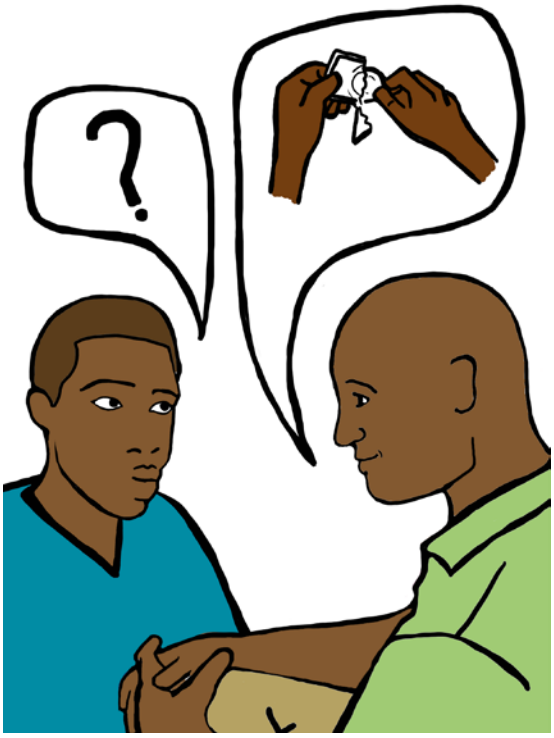
Test results:

Action taken (medication/education, partner testing, etc.):

Adapted from ICAP 2011

DISCUSSION GUIDE: SEX & RELATIONSHIPS

Talking about sex and sexuality is important to help prevent teen pregnancy and the spreading of HIV and other sexual infections. Talking to your adolescent about sex and sexuality will not make him or her more likely to have sex, and not talking to him or her can increase the risk of HIV and teen pregnancy. Youth want to hear about sex from their parents and caregivers and have ongoing discussions about sex, sexuality, life, and relationships. Take the opportunity to spend time with your adolescent and build an open, honest, and trusting relationship where the adolescent feels open to sharing their thoughts feelings and questions with you!



KEY POINTS INCLUDE:

- **Understand your own values** about sex and sexuality. Identify what you think is important to discuss. Be prepared for questions that challenge your values.
- **Relax** so that your adolescent will feel comfortable. Despite the fact that you and your adolescent might initially feel uncomfortable discussing sex, he or she does want to hear from you.
- **Share appropriate information** considering his or her age and maturity level.
- **Express that you care.** Let your adolescent know that you do not want anything bad to happen to him or her and that he or she shouldn't feel pressured to have sex until he or she is ready.

- **Ask questions:**
  - What the adolescent thinks about relationships and sex and what a healthy relationship is?
  - When might a relationship include sexual activity? What are reasons to wait?
  - What does safe sex means to the adolescent? Does he or she know how to use a male and/or female condom and where to get them? Does he or she feel confident talking to his or her partner about using condoms?
- **Carry out a discussion and share information:**
  - Discuss different types of sexual activities, risks of each for spreading sexual infections or the risk of pregnancy, and how to lower risks.
  - Discuss how to recognize an unhealthy relationships, sexual pressure, and intimate partner violence.
  - Discuss the risks of having sex while using alcohol or other drugs.
- **Ask for information and support** from your adolescent's health or community care provider to help prepare you for discussing sex and sexuality with your adolescent.

Sexually Transmitted Infection Fact Sheet

What is a sexually transmitted infection (STI)?

- An STI—or a sexually transmitted disease (STD)—is an infection spread between people through sexual contact.
- STIs include gonorrhea, chlaymydia, syphilis, changroid, herpes, HIV human papilloma virus (HPV) and hepatitis B.
- STIs can also be spread by people sharing needles, a blood transfusion, or from mother to baby during pregnancy or birth.
- If left untreated, STIs can increase a person's risk for other infections, lead to infertility, or certain types of cancers.
- A pregnant mother with certain STIs is at risk for having her baby early, losing the baby, or giving birth to a baby with health problems.
- Infection with STIs may also increase the risk of spreading HIV to sexual partners.

How can I tell if I have a sexually transmitted infection (STI)?

- Symptoms of an STI can include fluid, sores or bumps on your vagina or penis, swelling or pain in your stomach or groin, or a burning feeling when you pee or have sex.
- Some STIs do not have any symptoms at all, so it is important to get tested regularly if you are sexually active or sharing needles.
- Your healthcare provider can give you an examination and laboratory tests to test for STIs.

How are sexually transmitted infections (STIs) treated?

- STIs caused by bacteria are treated with antibiotics. If they are treated early, they can often be cured completely.
- If you are treated for an STI with an antibiotic, it is important that your partner receive treatment as well.
- STIs caused by viruses cannot be cured but can be treated with medicines to help control their symptoms.
- It is very important to treat an STI early; if you are sexually active, make sure you are getting tested regularly.
- Talk to your health or community care provider about helping you notify your partners.

How can I prevent sexually transmitted infections (STIs)?

- Abstaining from any kind of sexual activity—oral, vaginal, or anal sex—is the only way to prevent an STI.
- If you choose to be sexually active, make sure you and your partner get tested first.
- To prevent spreading STIs, use a male condom (made of latex or polyurethane)—or a female condom (made of polyurethane)—correctly each and every time you have sex.
- Vaccines exist to prevent certain STIs, such as human papilloma virus (HPV) and hepatitis B. Ask your healthcare or community care provider about these vaccines.
- Voluntary male medical circumcision may protect a man from acquiring certain STIs, including HIV.

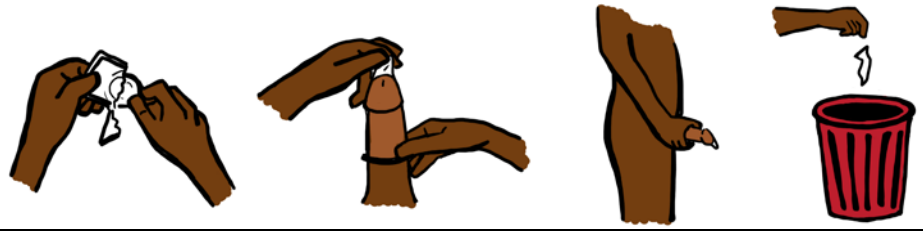
How do I use a condom?

- Refer to the illustrations below, and ask your healthcare or community care provider to show you how to use a condom.
- Practice placing a condom in your vagina or on your penis.

Where can I get condoms?

- Ask your health or community care provider. You can buy condoms and they and may be free at your clinic.

Male Condom



Female Condom

Adapted from WHO 2011, FHI360 1998

Pregnancy & Prevention of Mother-to-Child Transmission Fact Sheet

What pregnancy might mean for me (the mother):

- Many young women who become pregnant have to leave school and have few work opportunities.
- A young unmarried woman is more likely to have an unplanned pregnancy than an older woman.
- Adolescents are more likely than older women to have complications during pregnancy and childbirth including blood and bleeding problems, malaria, sexually transmitted infections (STIs), and mental disorders.
- Adolescent mothers may not know the signs of pregnancy complications.
- Younger women are more likely to have unsafe abortions than older women, and the possible complications are worse for adolescent women.
- Adolescent mothers are more likely to die during childbirth than mothers over 20 years of age.
- Young mothers may not have the education, livelihood skills, and information about how to prevent further pregnancies.

What pregnancy might mean for me (the father):

- Younger men who become fathers—especially in their teens—have fewer work and school opportunities.
- Many young men are not prepared to provide the social and economic support a family needs.
- A young father may not be able to have the relationship he would like with his child, especially if the pregnancy occurs outside of a marriage.
- The effects of early fatherhood may not be as obvious as those of young motherhood, but can become more noticeable as the young man ages.

What pregnancy might mean for my baby:

- Stillbirths and death in the first month of the baby's life are more common among babies whose mothers are under the age of 20.
- Babies born to adolescent mothers are more likely to be born premature, of low birth weight, or with breathing problems.

What pregnancy might mean if I have HIV:

. . .if I have a baby will it have HIV?

- Not necessarily. Even if without antiretroviral medication, less than half of babies born to HIV-positive mothers will get HIV.

. . . what can I do to prevent transmitting HIV to my baby?

- Take all your medicines as you have been told during the pregnancy and while breastfeeding, if that is the infant feeding option you choose.
- Talk to your healthcare provider about having your baby in a health care facility or with a trained birth attendant if you have the baby at home.
- Talk to your healthcare provider and your family about feeding your baby. Breastfeeding is the best option for the baby, but it carries a risk of spreading the virus to your baby, which is why medications are provided to you and/or your baby.
- Stay healthy by eating nutritious foods, getting plenty of sleep, and exercising.

. . . what can I do to make sure I do not have a baby until I am ready?

- Your healthcare provider can help you select a family planning method that will help you control when you become pregnant.

United Nations Children's Fund (2010), United Nations Population Fund (2009), and WHO (2008)

My Sexual & Reproductive Health Journal

What does having a partner/boyfriend/girlfriend mean to me?

What does sex mean to me?

What does sexuality mean to me? What about sexual orientation?

Do I have questions or concerns about sex or sexuality? Who can I talk to about them?

If I plan to have sex, do I know how to use a male or female condom? Where do I get them?
Do I feel comfortable talking to my partner about using condoms?

How do I tell my partner about my HIV status? When?

Have I ever told a partner before about my HIV status? What was it like?
What might I do differently next time?

Do I want to have children one day?

What can I do to make sure I do not get pregnant or my partner does not get pregnant until we are ready?

Adapted from Robinson et al. 2006

MODULE 4: PROTECTION

Module 4: Summary

1 HCP/CCP Tools

- ***Protective Services Checklist (Tool 4.1.1)***
  This allows the HCP to ensure a range of protective services are available in the community. Use in conjunction with the tools found in Module 10: Linking Health Facilities and Community Programs.

- ***Gender-Based Violence & Abuse Screening Tool for the Adolescent Interview (Tool 4.1.2)***
  This allows the health provider to screen for abuse and GBV.

3 Adolescent Tools

- ***My Safety Journal (Tool 4.3.3)***
  This journal can be provided to the adolescent to allow him or her to process experiences around abuse and prepare for articulating the experience to providers.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 4.3.3 can be found in Module 4, targets the adolescent (audience 3), and is the third tool in this module.

MODULE 4: PROTECTION

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; U.S. President's Emergency Plan for AIDS Relief 2006). People living with HIV are more likely to experience gender based violence (GBV)—violence directed at someone based on his or her sex, gender identity, or perceived adherence to gender norms. For adolescents, this may include sexual abuse, trafficking, neglect, and domestic violence (Khan 2011). Tool 4.1.1 provides the *Protective Services Checklist* for HCPs and CCPs to use with the adolescent.

Look for signs of abuse, including physical marks (e.g., bruises, cuts, and burns), symptoms of STIs or early pregnancy in young adolescents, chronic yet unexplained health problems, changes in behavior or mood, and academic problems (East, Central, and Southern African Health Community 2011). As these are not necessarily indications of abuse, talk to the adolescent about what is going on in his or her home, community, and school (ICAP 2011). You may ask to speak to the adolescent privately, as the abuse could be from the family/caregiver and be sure to not rush the physical exam (see Tool 4.1.2: *Gender-Based Violence & Abuse Screening Tool for the Adolescent Interview*). 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 that the adolescent receives appropriate care if he or she discloses abuse. 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. It is important to tell the adolescent that you may have to bring in additional providers—such as those involved with law enforcement—as necessary (see Tool 4.3.3: *My Safety Journal*). 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 (see Tool 3.1.1: *Sexual & Reproductive Health Assessment Tool for the Adolescent Interview*, Tool 5.1.2: *Alcohol & Substance Counseling Guide*, Tool 2.1.1: *Mental Health Symptom Screener*, and Tool 5.1.1: *The Substance Abuse Symptom Screener*).

Adolescents, especially female adolescents, may engage in transactional sex to help them meet their 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 (see ***Module 10: Linking Health Facilities and Community Programs***).

PROTECTIVE SERVICES CHECKLIST

Complete these checklists with information Tool 10.1.1: *Community Based Organization & Health Facility Directory*, found in Module 10 to have a list of comprehensive Protective Services and Collaborating Services.

PROTECTIVE SERVICE/ACTIVITY	AVAILABLE IN THE FACILITY/COMMUNITY? WHERE?
Birth registration and identification (documentation)	
Assistance in inheritance claims	
Gender based violence and abuse protection	
Emotional and/or psychological abuse protection	
Temporary or permanent home placement for abused children	
Support services for caregivers (stress management, resource management)	

COLLABORATING AGENCY/PROGRAM	POINT PERSON FOR REFERRAL
Emergency health care	
Mental health services	
Gender based violence and abuse services	
Schools/education	
Alcohol/substance use treatment	
Police/law enforcement	
Legal representation	
Residential services	

Adapted from U.S. President's Emergency Plan for AIDS Relief 2006

GENDER-BASED VIOLENCE & ABUSE SCREENING TOOL FOR THE ADOLESCENT INTERVIEW

Carry out this assessment with the adolescent privately to maximize sharing of information. Reassure the adolescent that the information shared will remain confidential. It is recommended that the files have names removed and replaced with unique numbers and placed in a locked location. It is critical to ensure that follow-up services and support are available before screening for abuse and violence. An immediate referral should be made if abuse and/or GBV are identified. If abuse is identified, have a trusted adult accompany the adolescent to the appropriate service provider once referred. Ensure that the adolescent completed the referral. Schedule follow-up appointments for the following week, and then one, two, three, and six months after. Perform physical exams to identify the signs of abuse and order diagnostic tests (e.g., for STIs or pregnancy) as appropriate. You may find it works well to use this assessment tool in conjunction with Tool 2.1.1: *The Mental Health Symptom Screener*, and Tool 5.1.1: *The Substance Abuse Symptom Screener*.

QUESTIONS AND DISCUSSION TOPICS	NOTES/ACTIONS
Do you feel safe at home? Tell me about why or why not.	
Do you feel safe at school? In your community? Tell me why or why not.	
Does anyone scream or yell at you, or talk down to you? *Ask who does this and when it occurs.*	
Does anyone threaten you with physical violence? *Ask who does this and when it occurs.*	
Have you ever been physically hurt by someone important to you? What happened?	
Has anyone ever touched you sexually against your will? When did it first occur? Is it still happening?	
Have you ever spoken to anyone about this abuse or reported it? What happened?	
Has anyone ever pressured you to have sex or made you do something else you did not want to? Has anyone been violent with you during sex?	
Have you ever taken alcohol or drugs to feel better about what happened or try to forget what happened?	
Have you ever tried to hurt yourself to cope with what happened?	
Is there anything else you would like to talk about today?	

Additional notes and follow-up actions:

Adapted from Family Health International 2011, Rabin, Jennings, and Campbell 2009

My Safety Journal

Do I feel safe at home? Why/why not?

Do I feel safe at school and In my community? Why/why not?

Has anyone ever hit, slapped, kicked, or burned me? Who can I talk to about that?

Has anyone ever pressured me to have sex or made me do something else I did not want to?
Has anyone been violent with me during sex? Who can I talk to about that?

Do I get enough food to eat, and do I have clothes to wear, a place to sleep, and things I need for
Do I have to do anything, like have sex with someone, to make sure I get these things?

What do I want to talk about only with my healthcare or community care provider?

What do I want to talk about only with my family?

What do I want to talk about only with my peers/friends?

What do I want to keep to myself and not share with anyone?

Adapted from Robinson et al. 2006

MODULE 5: ALCOHOL & SUBSTANCE USE

Module 5: Summary

1 HCP/CCP Tools

- ***The Substance Abuse Symptom Screener (Tool 5.1.1)***
  This tool can help to assess for alcohol and substance abuse. This will help you determine if the adolescent is at risk for has alcohol and substance use issues.

- ***Alcohol & Substance Use Counseling Guide for Health Care Providers (Tool 5.1.2)***
  This tool can help the provider talk to the adolescent about alcohol use and other substances.

2 Family/Caregiver Tools

- ***Discussion Guide: Alcohol & Substance Use (Tool 5.2.3)***
  This tool can guide families/caregivers in how to talk to their adolescent about alcohol and substance use.

3 Adolescent Tools

- ***My Alcohol & Substance Use Journal (Tool 5.3.4)***
  This tool should be utilized by the adolescent to explore his or her own thoughts around alcohol and substance use. The adolescent should be told this is for private journaling, and the adolescent can share it with others only if he or she wants to.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 5.2.3 is found in Module 5, targets the family/caregiver (audience 2), and is the third tool in this module.

MODULE 5: ALCOHOL & SUBSTANCE USE

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 other member of the household uses alcohol or other substances, the adolescent is more likely to use him or herself. It is important to talk to adolescents before a problematic pattern of behavior or dependency is established (see Tool 5.1.2: *Alcohol & Substance Counseling Guide*). 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 (see Tool 9.1.1: *Tips for Adolescent Motivational Interviewing* and Tool 9.1.2: *The Readiness to Change Ruler*).

As with sexual activity, adolescents may not feel comfortable discussing alcohol and other substance use with parents or other caregivers present, so you may request to speak with the adolescent in private. 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, reaffirming that your conversation will be kept confidential. Substance use may be a sign—or coping mechanism— of mental illness or experiencing violence or abuse (Mellins et al. 2011; Williams et al. 2010) (see Tool 5.1.1: *The Substance Use Symptom Screener,* Tool 2.1.2: *Additional Mental Health Screens,* and Tool 4.1.2: *Gender-Based Violence & Abuse Screening Tool for the Adolescent Interview*). Review the respiratory and other health consequences of smoking. 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 (see Tool 5.3.4: *My Alcohol & Substance Use Journal*.)

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 (see Tool 5.2.3: *Discussion Guide: Alcohol & Substance Abuse*).

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 (see Tool 8.1.7: *Adherence Assessment Tool*).

THE SUBSTANCE ABUSE SYSTEM SCREENER

Explain to the adolescent that you are going to ask a series of questions about alcohol and substance use in the past year. The adolescent should answer as best he or she can remember. Review what you mean by "nonprescription drugs," as this could include pills like painkillers but also inhalants such as glue, paint, and gasoline.

1. How often do you have a drink containing alcohol? (Alcoholic drinks include one beer, one glass of wine, or a mixed drink of hard liquor.	**2.** How many drinks do you have on a typical day when you are drinking?	**3.** How often do you have four or more drinks on one occasion?	**Sum of questions 1—3 =**
0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	0—One or two drinks 1—Three or four drinks 2—Five or six drinks 3—Seven to nine drinks 4—10 or more drinks	0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	Client positive for substance use if sum is ≥ 5.

4. In the past year, how often did you use nonprescription drugs to get high or change the way you feel?	**5.** In the past year, how often did you use drugs prescribed to you or to someone else to get high or change the way you feel?	**Sum of questions 4—5 =**
0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	Client is considered positive for substance use if the sum is ≥ 3.

6. In the last year, how often did you drink or use drugs more than you meant to?	**7.** How often did you feel you wanted or needed to cut down on your drinking or drug use in the last year, and not been able to?	**Sum of questions 6—7 =**
0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	0—Never 1—Monthly or less 2—Two to four times a month 3—Two to three times a week 4—Four or more times a week	Client positive for substance use if the sum is ≥ 1.

Refer the client for substance abuse counseling if substance abuse symptoms are present.

Date: _____

Do the client's scores indicated that there may be problematic drug and/or alcohol use: yes no

Action taken (education provided; referral for alcohol/substance use counseling, etc.):

HIV Resource Group 2011

ALCOHOL & SUBSTANCE ABUSE COUNSELING GUIDE

Engage the adolescent in a private conversation about his or her alcohol and/or substance use. Tool 9.1.1: *Tips for Adolescent Motivational Interviewing* and Tool 9.1.2: *The Readiness to Change Ruler* can help guide how to talk to the adolescent and provide some key techniques to promote behavior change.

KEY POINTS INCLUDE THE FOLLOWING:

- Begin by stressing the importance of the adolescent and his or her health to you. The information the adolescent shares with you may remain confidential, but it might be important to include the family in the discussion as well.
- Stress that you do not want anything bad to happen to the adolescent or those around him or her.
- Be prepared to refer the adolescent for counseling to deal with depression, experiences of gender based violence, trauma, or other mental health issues that may lead to drinking and substance use. Have a list of possible referrals ready to share with the adolescent (see ***Module 10: Linking Health Facilities & Community Programs***).
- Ask if the adolescent is using a drug. If yes, which one(s)? Alcohol? How often?
- Ask who the adolescent uses with. Where does the use happen?
- Ask why the adolescent uses. Is he or she using alcohol or other substances to cope with his or her feelings, such as feelings of sadness or hopelessness? Was there a particular event that triggered use?
- Ask what you can do to help him or her not use alcohol or other drugs.
- Ask who the adolescent can talk to at home about drinking or using drugs, and who he or she can talk to about what leads to alcohol and or drug use.
- Discuss the potential negative consequences of alcohol and/or drug use, including physical injury, lack of adherence to medication, and unsafe sex.
- Remember you may need to have this conversation more than once.
- Refer the adolescent for treatment as necessary for dependency. If this is not available, discuss treatment options within the family/caregiver and/or community context such as spiritual and peer support.

Adapted from ICAP (2011) and National Youth Anti-Drug Media Campaign (n.d.)

ALCOHOL & SUBSTANCE ABUSE

Engage your adolescent in a conversation about alcohol and/or substance use. Approach the adolescent in an open and caring manner that encourages the adolescent to share their experiences openly. Remember that talking about alcohol and substance use should be an on-going conversation that you have with your adolescent to help him or her make healthy choices!

KEY POINTS INCLUDE:

- **Begin by expressing the importance of the adolescent** to you and the family.
- **Express caring** by telling the adolescent that you do not want anything bad to happen to him or her or those around him or her.
- **Establish and/or review the rules** of the family/home regarding alcohol and drugs.
- **Ask:**
  - If the adolescent is using a drug or substances. If yes, which one(s)? Alcohol? How often?
  - Who the adolescent uses with. Where does the use happen?
  - Ask why the adolescent uses. Is he or she using alcohol or other substances to cope with feelings of sadness or hopelessness? Did something happen, like an event that led the adolescent to use?
- **Discuss:**
  - Potential dangerous effects of alcohol and/or drug use, including physical injury, effects on medication adherence, and unsafe sex.
  - Different ways to resist pressure from friends to use alcohol and or drugs.
  - Healthy choices that the adolescent can make instead of using alcohol and drugs.
- **Express support.** Remind the adolescent you are there to support him or her. Ask what you can do to help him or her not use alcohol or drugs.
- **Be prepared to seek professional help** if you think that the adolescent may need support to quite the alcohol and/or drug use. Ask the adolescent's health and community care provider to help you find treatment for the adolescent. If professional help is not available, discuss treatment options with the adolescent including religious support, peer support groups, community support programs and school programs.

Adapted from the National Youth Anti-Drug Media Campaign (n.d.)

My Alcohol & Substance Use Journal

Have I ever wanted to try alcohol? Why did I want to try it?

When have I had a drink? Who was with me, and where were we?

How much do I drink? Have I ever drank until I cannot remember or throw up?

What do I do when I am drinking that I would not do sober? Do I do anything that could put my health at risk?

Once I start drinking, is it easy for me to stop?

Have I ever wanted to try drugs? Why did I want to try them? Which drugs?

What happens when I take drugs? Do I do anything that could put my health at risk?

Do I lie about drinking or using drugs? Who do I lie to? Why?

Do I feel I have to drink or take drugs to feel better or to help with my life situation?

Who can I talk to if I think I, or someone I know has a drinking or drug problem?

Adapted from Robinson et al. 2006

MODULE 6: BENEFICIAL DISCLOSURE

Module 6: Summary

1 HCP/CCP Tools

- ***Stepwise Disclosure (Tool 6.1.1)***
  This tool should be utilized by HCPs and families/caregivers to work toward beneficial and developmentally appropriate disclosure.

- ***Disclosure Discussion Guide (Tool 6.1.2)***
  This tool can help the provider discuss the complexities associated with disclosure to both the adolescent and the family/caregiver.

2 Family/Caregiver Tools

- ***Discussion Guide: Disclosure (Tool 6.2.3)***
  This tool can guide families/caregivers in how to talk about disclosure with the adolescent.

3 Adolescent Tools

- ***Disclosing Your Status (Tool 6.3.4)***
  This tool should be utilized by the adolescent to plan for disclosing his or her HIV status to others. The adolescent should be told that when to disclose and to whom is completely up to him or her.

- ***My Disclosure Journal (Tool 6.3.5)***
  This tool should be utilized by the adolescent to explore his or her own thoughts around disclosure. The adolescent should be told this is for private journaling, and the adolescent can share it with others only if he or she wants to.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 6.2.3 can be found in Module 6, targets the family/caregiver (audience 2), and is the third tool in this module.

MODULE 6: BENEFICIAL DISCLOSURE

Disclosure is not a singular event, but a process. 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; 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. Many perinatally infected children grow up unaware of their HIV status as 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 2011a). 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 his or her chronological age (see Tool 1.1.3: *Psychosocial Assessment Tool for the Interview with the Family/Caregiver*, and Tool 6.1.1: *Stepwise Disclosure*). Current WHO guidelines recommend disclosure to children of school age (i.e., before age 12) (WHO 2011a). 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 and 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 (see ***Module 9: Positive Living*** for more information on stigma).

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 (see Tool 6.1.2: *Disclosure Discussion Guide*, and Tool 6.2.3: *Discussion Guide: Disclosure*).

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 (see Tool 6.3.4: *Disclosing Your Status* and Tool 6.3.5: *My Disclosure Journal*).

STEPWISE DISCLOSURE

To help the family/caregiver disclose the adolescent's HIV status to them in a manner that is developmentally appropriate, the following outlines a stepwise process of disclosure. If disclosure has not been initiated by adolescence, begin as early as possible. With all adolescents, the points may be revisited.

EARLY STEPS	**Make sure he or she knows:** – To stay healthy he or she must take the medicines. – When to take his or her medicines. – How to take his or her medicines. – The name of his or her medicines.	Remember to be encouraging and give positive messages.
NEXT STEPS	**Make sure he or she knows:** – Medicines make him or her healthy by increasing the strength in the body. – As his or her body gets stronger, health problems decrease. – As long as his or her body is strong, he or she can do whatever he or she wants in life.	Remember to stress the future and positive messages. Remind the child or adolescent that he or she is not the only one; there are others like them.
FINAL STEPS	**Make sure he or she knows:** – His or her body can become weak because of the virus. – The proper terms CD4 cells and HIV. – To tell the truth to minimize misconceptions. How the virus is transmitted (for older teenagers, talk about safer sex in a clear and direct manner).	Remember to be open to questions and answer all truthfully.

Sharer and Fullem 2012, presentation from Paediatric KITSO, Botswana-Baylor Children's Clinical Center of Excellence, Botswana MOH, and UNICEF 2011

DISCLOSURE DISCUSSION GUIDE

Your role is to support the family/caregiver in disclosing the adolescent's HIV status to him or her. Engage the family/caregiver in a conversation about the adolescent's HIV status, and make a disclosure plan that is appropriate to the adolescent's development stage. Disclosure is a process, which may be partial at first, providing the adolescent with some information on his or her illness, and then moving to full disclosure, informing the adolescent about his or her HIV infection, treatment, prevention, and all symptoms, as the adolescent is ready. Seek support and advice from colleagues and other older adolescents living with HIV who may have more or different experience with supporting the disclosure process. This is an emotional and often on-going process, so see Tool 9.2.5: *Self-Care Guide*.

PROVIDING SUPPORT TO THE FAMILY/CAREGIVER:

Keep in mind the barriers the family/caregivers may face when disclosing the HIV status to the adolescent, including discomfort discussing the adolescent's HIV status, feelings of guilt for transmitting the virus to the adolescent, fear of double disclosure (parent's status and child's status), causing psychological harm, concern the adolescent will not understand what the information means, being unsure of how to answer the adolescent's questions, and fear of stigma and discrimination. Be ready to help the family/caregiver through these concerns. Connect the family/caregiver to support groups in the community. Use the following questions to guide your discussion with the family/caregiver:

- What are your own fears?
- How do you feel about the adolescent's health? Do you have any questions about his or her health?
- What are the most important messages you want to convey to the adolescent?
- How do you feel about disclosing, and when do you think disclosure should take place?
- What do you think will be the easiest thing to talk about during the disclosure process? What will be the adolescent's easiest questions to answer?
- What will be the most difficult thing to talk about during the disclosure process for you?
- What will be the adolescent's most difficult questions to answer?
- Tell me about the kinds of support you and your adolescent will have during and after disclosure?
- What is your plan for disclosure? Where will it happen? Who will be there? Who will talk?
- What support do you and other family members need for this process?

FOR THE ADOLESCENT:

Support the adolescent in asking the family/caregiver questions he or she may have and help reinforce the messages from the family/caregiver. Possible questions include the following:

- Do you have any questions about the information disclosed to you?
- What questions do you have about what this means for your health care and the medicines you are taking?
- What are your plans to stay healthy? Tell me about your plan for positive living (see Module 9: Positive Living).
- What are some of the benefit and risks of disclosing your status to other people?
- To whom do you plan to disclose? Why?
- To whom do you *not* want to disclose to? Why?
- What support do you need in this process?

Adapted from ICAP 2011

DISCUSSION GUIDE: DISCLOSURE

Telling the adolescent about his or her HIV status can be difficult for many parents and caregivers. You are not alone!

If you need support, discuss a plan with the adolescent's health care and community providers to help to share information to the adolescent about his or her HIV status.

You do not need to try to share everything at once, so choose information you think the adolescent is ready to hear, and answer his or her questions.

Engage the adolescent in a conversation about his or her HIV status. Remember you should plan to have this conversation multiple times, allowing the adolescent to understand the information and ask you questions.

Disclosure to the adolescent can be difficult as it may raise questions about the parents' HIV status as well. While these may be difficult and emotional questions to respond to, disclosure to the adolescent is still important, so plan how you will answer these questions if they come up.

KEY POINTS INCLUDE:

- Begin by telling the adolescent you want to help him or her stay healthy.
- Give the adolescent information about his or her illness, and explain the importance of taking medications and seeing the healthcare provider regularly.
- If the adolescent is ready, tell them about HIV, how it can be spread, and if appropriate, how he or she got the virus.
- Remind the adolescent that he or she is normal and did not do anything wrong to get HIV. HIV is what he/she has, not who he/she is.
- Ask the adolescent if he or she has any questions. Answer his or her questions the best that you can. If you do not know the answers, make an appointment with the adolescent's health care provider so he or she can help you to answer the adolescent's questions together.
- Stress that the adolescent plays an important part in his or her own health care.
- When the adolescent is ready, review a plan for how the adolescent can adhere to his or her medications and how they can take greater responsibility for managing their health.

REMEMBER:

- You can ask the adolescent's health care provider if he or she will help you to disclose to the adolescent together, especially if you need help answering the adolescent's questions about HIV.
- You should plan on having this conversation more than once with the adolescent. Each time you have the conversation, you can share more information with the adolescent and review information about his or her illness.
- It may be helpful to go with the adolescent to support groups if he or she wants, or let him or her attend with peers. Introduce the adolescent to a peer group as soon as he or she is ready.

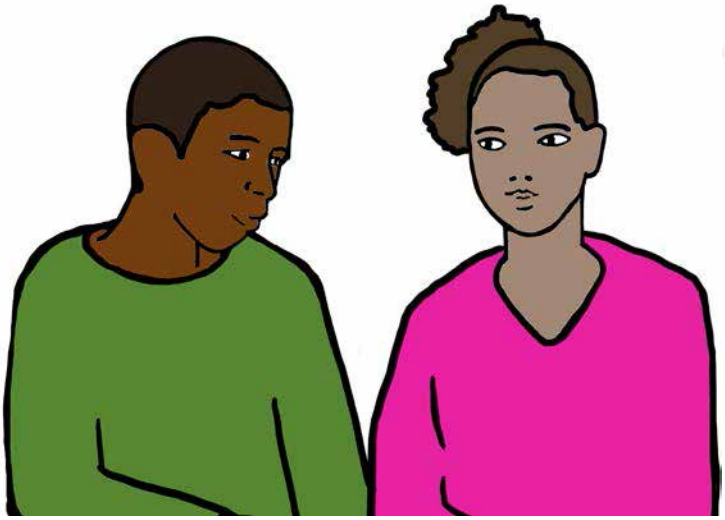
Adapted from ICAP 2011

Disclosing Your HIV Status

Deciding to disclose one's HIV status is a decision faced by everyone living with HIV. Disclosure is not a one-time event; it is a lifelong process. It is up to you to decide with whom you want to share your status, how much of your story you want to tell, and when to tell them. When you are ready to disclose, remember that you are not alone. There are people who can support you.

Why Should I Tell Someone I am Living with HIV?

Telling people you care about and who care about you can help them to support you and your health. It may remove the stress of keeping a secret, boost your self-esteem, and lead to healthier relationships, especially with your sexual partners and reduce the risk of spreading HIV.



Who Should I Tell?

Before telling someone, ask yourself if that person is important enough in your life to know your status and be trusted to keep your confidence. It is important that he or she is nonjudgmental and is going to be supportive of you. Remember, you do not have to tell everyone your entire story all at once.

If you are in a romantic relationship, you may choose to tell the person early in the relationship or wait to see how serious the relationship becomes. Disclosing your status to your sexual partner can help you both make decisions to protect each other. If you and your partner want to have a baby, disclosing your status is also important to prevent the transmission of HIV to your children.

How Should I Tell Them?

Be sure you feel ready to tell the person you trust. It is okay to feel nervous, embarrassed, or even scared. Give yourself time to figure out when and where to tell them. Pick a place where you feel comfortable and have privacy. Stick to the facts about HIV. By educating yourself beforehand, you can be ready to answer their questions, and know where you can both seek additional support.

What Happens Next?

Everyone will react differently, but no matter what their response is, be proud of your decision! You are strong and a warrior! There are some risks associated with disclosure like abandonment and violence. If you are afraid of how someone may react, or if someone has hurt or threatened you, talk to your healthcare or community care provider about protective services and/or support groups available to you. If you choose to disclose to a person who may become violent, disclose in the presence of someone else, such as your healthcare provider or someone else you trust who knows your status.

Where Can I Get Help?

It is important to remember you are not alone. There are people who can help support you at your clinic and in your community. Your health or community care provider can link you to a peer support group. Talking to other young people who have gone through this process will help you with your own disclosure.

Adapted from aids.gov 2009, AIDSmeds 2010, Project Inform 2011, Teen Talk 2007, Teen Talk/Botswana 2011, the Well Project 2010

My Disclosure Journal

Who knows my HIV status?

Why do I want to tell someone about my HIV status? Who do I want to tell?

Why would I want to keep my HIV status private, to myself? Who do I not want to know?

What would I say if someone asked me about my HIV status?

How would I tell someone I have HIV?

Have I ever told anyone about my HIV status? What happened? What would I do differently next time?

What do I want to talk about only with my healthcare provider?

What do I want to talk about only with my family?

What do I want to talk about only with my peers/friends?

What do I want to keep to myself and not share with anyone?

Adapted from Robinson et al. 2006

MODULE 7:
LOSS, GRIEF, AND BEREAVEMENT

Module 7: Summary

1 HCP/CCP Tools

- ***A Grief Assessment Discussion Guide (Tool 7.1.1)***
  This provides open-ended questions allowing the HCP/CCP to routinely monitor the adolescent's grieving symptoms over time.

- ***A Guide to Counseling (Tool 7.1.2)***
  This allows the HCP/CCP to review effective counseling techniques and outlines behaviors and language to avoid.

2 Family/Caregiver Tools

- ***Helping Your Adolescent to Grieve (Tool 7.2.3)***
  This tip sheet should be provided the family/caregiver to aid them in supporting the adolescent as he or she experiences the grieving process.

- ***A Guided Memory Book (Tool 7.2.4)***
  This tool can be utilized by the ill family member to provide his or her loved ones with information about his or her life and family prior to passing. Provide a memory book for each ill family member or encourage them to utilize it collectively.

3 Adolescent Tools

- ***My Grief Journal (Tool 7.3.5)***
  This guided journal can be provided to the adolescent who is experiencing a loss as a means to express his or her grief.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 7.2.3 can be found in Module 7, targets the family/caregiver (audience 2), and is the third tool in this module.

MODULE 7: LOSS, GRIEF, AND BEREAVEMENT

Many ALHIV have lost one or more family members or caregivers. This can result in potential depression, relationship problems with peers, PTSD, and behavioral problems, which may impact the transition process if left unresolved (Cluver et al. 2009). Because of the stigma surrounding HIV, adolescents may not feel that they are able to express their grief from losing a loved one—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 may even be vulnerable to other mental health conditions (see ***Module 2: Mental Health Considerations*** for more resources).

When working with the adolescent who is experiencing complicated grief, be sure to acknowledge it and monitor it throughout the transition process by taking note of the adolescent's emotional state. It is important that the adolescent has a strong support system as well as access to counseling services, especially when the grief is acute—a particularly vulnerable time for the adolescent (Ndiaye 2009) (see Tool 7.1.2: *A Guide to Counseling* for further counseling support). Work with the adolescent and his or her family/caregiver to build upon existing strengths during the grieving process (see Tool 7.2.3: *Helping Your Adolescent to Grieve*). 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 (see Tool 7.2.4: *A Guided Memory Book*). 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, culture, and other losses that they have experienced (Ndiaye 2009). Routinely monitor for grief symptoms, which may include sadness, poor appetite, weight loss, difficulty sleeping, crying, guilt, rage, numbness, disorganized thoughts, and a sudden increase in maturity. Keep in mind that these symptoms vary between individuals (Burns et al. 2009) (see ***Tool 7.1.1:*** *A Grief Assessment Discussion Guide*).

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 feelings of grief (see Tool 7.3.5: My Grief Journal). 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.

A GRIEF ASSESSMENT DISCUSSION GUIDE

It is very important to talk to the adolescent about changes in his or her life. When a loss occurs, assessing grieving symptoms will be important to help you understand how the adolescent is adjusting to the loss. However, it should be kept in mind that when you ask these questions the adolescent may experience the grief more profoundly, and therefore be mindful of the risk of re-traumatization when assessing grief symptoms.

Allow the adolescent to guide discussions about any grief that he or she may be experiencing. In addition, before you use this guide, be sure to have a strong referral system in place to support the adolescent. Based upon the results of this discussion, refer the adolescent to a trained counselor if you determine that the adolescent will benefit from additional emotional assistance or explore other community support options (see Tool 10.1.1: *Community-Based Organization/Health Facility Directory* for referral information for emotional health counselors in your area; also, refer to Tool 7.1.2: *A Guide to Counseling* for counseling tips).

Please note the following questions should be asked after a strong level of trust has been established with the adolescent. Asking questions in non-direct and non-confrontational ways may facilitate the adolescent to respond more openly. The questions might need to be asked in different ways or reworded to obtain the required information from the adolescent.

GRIEF ASSESSMENT QUESTIONS:

- How often do you think about the death of your loved one(s)?
- Do you ever feel angry when you think about the death(s)?
- Is it still hard for you to believe your loved one(s) is (are) really dead (or gone)?
- How has your faith in God since the death of your loved one(s)?
- Have you have lost confidence in people since the death of your loved one(s)?
- Since the death of your loved one, do you ever feel like life is meaningless?

Client referred: **Yes** **No**

Date referred: _____

Referred to: _____

Brown et al. 2009, Boris & Brown 2008

A GUIDE TO COUNSELING

Grieving can be a life-long process. Counseling may be something that you have not been formally trained in, but it will inevitably be a component of your work with adolescents. Counseling will help the adolescent share, express, and better understand how he or she is feeling. Be sure to adjust your counseling style to the needs of the client. Be sure to monitor and adapt your tone of voice, posture, and eye contact based upon the individual adolescent needs. Check in with the adolescent and ask how he or she feels during the counseling session so that you can adapt your style to best meet his or her needs.

EFFECTIVE COUNSELING METHODS INCLUDE THE FOLLOWING:

- Listen without judgment.
- Respect the adolescent's right to determine his or her own grief process.
- Provide examples through story telling about similar real-life situations.
- Use indirect questions and ask open-ended questions.
- Speak about nonthreatening topics before approaching potentially sensitive or uncomfortable topics.
- Provide additional resources where the adolescent can talk about his or her feelings and provide linkages for involvement in peer support groups.
- Establish a supportive relationship with the adolescent and listen carefully when he or she shares information.
- Help the adolescent to identify their own personal strengths and to develop self-confidence and a positive attitude.
- Keep an open mind in trusting the client's decisions and feelings.
- Remember that the adolescent may also benefit from additional religious and spiritual support and referrals.
- Normalize the adolescent's feelings—reassure them that it is a normal, appropriate reaction to loss

AVOID:

- Solving the adolescent's problems, making decisions for him or her and telling him or her what to do.
- Blaming, judging, and preaching.
- Making promises if they cannot be kept.
- Forcing your own values and beliefs onto the adolescent.
- Providing information that is incorrect.
- Rushing the adolescent through the grieving process.

Adapted from ICAP 2011

HELPING YOUR ADOLESCENT TO GRIEVE

Many adolescents have other family members and friends who are also HIV-positive. It is important to talk to the adolescent when they are going to lose a loved one and to speak openly about the loved one, once they have died. While families/caregivers may not want to express sadness in front of the adolescent, it is important for the family/caregiver to talk about the loss in a manner that also makes the adolescent feel that he or she can express their emotions openly. The following tips may help you support the adolescent through the grieving process.

PREPARING FOR THE LOSS

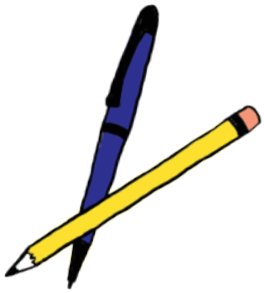
- Answer the adolescent's questions honestly about their ill loved one.
- Identify the adolescent's support systems early in the process and encourage regular communication with those support systems. Support systems may include friends, teachers, neighbors, or other family members.
- Talk about changes early. If the adolescent will experience a change in living situation or a change within his or her role in the family—such as caring for their siblings—talk about this early in the process to help prepare the adolescent.
- Make a memory book together with the adolescent to help him or her remember the loved one. Your adolescent's health or community care provider can provide you with a memory book for you to complete.
- Encourage the adolescent to express his or her emotions and needs surrounding the death such as speaking with the loved one prior to his or her passing, and helping to plan and attend the funeral.

ONCE THE LOSS HAS OCCURRED

- Understand that each person expresses and experiences grief differently.
- Understand your own grief and establish healthy coping mechanisms, like talking about the loved one who died, attending a support group, and taking good care of yourself.
- Return to daily living activities as soon as possible to provide the adolescent with their regular routine including eating meals together.
- Tell the adolescent's teachers about the loss so that the teacher can make sure the adolescent is adjusting in a healthy manner and be sensitive to his or her needs, if he or she is in school.
- Provide reassurance to the adolescent that despite the loss of the loved one, he or she will still be cared for and that the family will remain together whenever possible.
- Encourage positive living choices whenever possible. This includes finding healthy ways to manage stress, eating well, exercising, and meetings with friends and other loved ones. Ask the adolescent's health and community providers to provide additional information on positive living.
- Encourage the adolescent to participate in activities that he or she enjoys such as sports and other fun events.
- Speak with the adolescent's health and community care provider about connecting with counseling services to further assist in managing the adolescent's grief. You may also consider contacting other community resources for additional support.

Ndiaye 2009, Adapted from Pomeroy, Parish, and Garcia 2011

A GUIDED MEMORY BOOK



Many families/caregivers who are living with HIV worry that they will pass away before their children become adults. These important people have much wisdom to share with their families. Creating a memory book can give families/caregivers the opportunity to share information with their children in a way that will last long after they are gone. Memory books are also special for the children as they will forever have a reminder of their loved one as they grow older.

The following pages contain a blank memory book where the family/caregiver can consider the guided questions and provide information as they wish. If the family/caregiver is unable to write, he or she can draw in the spaces or have a community health worker or a neighbor assist in writing down the information that is to be shared.

MY MEMORY BOOK

This book is for:

I am making this book because:

My family background and history:

What my children were like when they were young:

What I hope my children will be like when they grow up; what qualities and values they will possess:

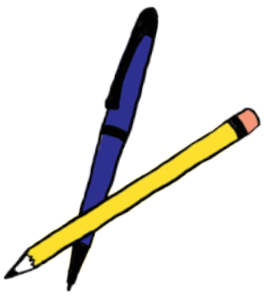
Notes for each person in the family:

Our family health history:

Inheritance information:

Other information that I want to share:

Space for photos or drawings of him or her, the home, and children:



Adapted from Colton et al. 2006, Morgan et al. 2007

My Grief Journal

Losing a loved one is one of the most difficult things you will face in life. It is normal to feel sad, but it is important to remember that you will feel better in time. It may help to share your feelings with your family and friends, your health or community care provider, or a teacher. Use these pages to express yourself and help you remember and celebrate the life of your loved one.

The person who I lost:

What he or she means to me:

Where there is love there is no darkness.

(Burundi)

What he or she looked like:

My favorite thing about him or her:

The depth of a person's life is more important that its length.

(East Africa)

My favorite memory of him or her:

A loved one has no faults.

(East Africa)

What I learned from him or her:

How will I honor him or her and carry on their memory?

There is one who loves you after seeing you and there is one who loves you unseen.

(East Africa)

Things that I can do that make me feel better when I am missing him or her:

What do I want to share with my healthcare provider about how I am feeling?

We live life forwards but it can only be understood backwards.

(East Africa)

What do I want to share with my family, friends, about how I am feeling?

What do I want to keep to myself and not share with anyone?

That which you love, you make last long.

(Uganda)

Adapted from Robinson et al. (2006). Quotes are from African Wedding Traditions (n.d.)

MODULE 8:
CLINICAL CONSIDERATIONS

Module 8: Summary

1 HCP/CCP Tools

- ***Adolescent Clinical Transition Document (Tool 8.1.1)***
  This tool should be completed by the pediatric HCP and given to the adult HCP upon transition.
- ***Key Steps at the Baseline Visit (Tool 8.1.2)***
  This checklist outlines key steps that should take place on the first visit.
- ***Key Steps for Adolescents not on Antiretroviral Therapy (Tool 8.1.3)***
  This checklist outlines key steps that should be taken routinely for adolescents not yet on ART.
- ***Key Steps for Follow-up Visits & Clients on Antiretroviral Therapy (Tool 8.1.4)***
  This checklist outlines key steps that should be taken for adolescents on ART who have routine follow-up visits.
- ***Antiretroviral Therapy Guide (Tool 8.1.5)***
  This tool is an ART prescription guide for pre-pubertal and post-pubertal adolescents.
- ***Adherence Support Prior to Treatment Discussion Guide (Tool 8.1.6)***
  This tool may be used to determine the adolescents' and/or family/caregiver ART preparedness.
- ***Adherence Readiness Assessment Quiz (Tool 8.1.7)***
  Provide this quiz to the adolescent prior to ART prescription to determine adherence readiness.
- ***Adherence Assessment Tool (Tool 8.1.8)***
  This tool should be utilized to assess adolescents' medication adherence.
- ***Tanner's Staging Guide (Tool 8.1.9)***
  This tool provides puberty staging information for girls and boys.

3 Adolescent Tools

- ***Medication Adherence Diary (Tool 8.3.10)***
  This tool should be completed by the adolescent to record their medications; they should be encouraged to bring this diary to clinic visits as an additional adherence assessment tool.
- ***Medications Worksheet (Tool 8.3.11)***
  This tool should be utilized to by the adolescent to help keep track of his or her medicines.
- ***My Clinical Considerations Journal (Tool 8.3.12)***
  This tool may be used by the adolescent to explore his or her own thoughts around-—and adherence to-—medication.

Note: The tools within this module are directed for the HCP; however, the CCP may use them a reference to facilitate the referral process for adolescents within their programs. The tools are numbered in a consistent manner throughout the modules. Tool 8.3.12 can be found in Module 8, targets the adolescent (audience 3), and is the twelfth tool in this module

MODULE 8: CLINICAL CONSIDERATIONS

It is important to understand potential differences between perinatally and behaviorally exposed adolescents. Perinatally exposed adolescents are more likely to be experiencing advanced stages of HIV including presence of opportunistic infections (OIs), physical and developmental delays, higher risks of pregnancy complications, complex medication regimes, and higher mortality rates. In contrast, adolescents who are behaviorally infected tend to be in the earlier stages of disease, have fewer OIs, are less likely to be on ART, are less likely to have physical and developmental delays, and have a lower risk of pregnancy complications. However, they may experience more adherence challenges when on ART and have a greater distrust of clinical facilities (Gipson and Garcia 2009). 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.

For those clients who are not yet on ART, the decision to begin ART is an important one and should include discussions between you, the adolescent, the family/caregiver, and an adherence counselor. All adolescents with a CD4 count ≤ 350 or WHO Stage 3 or 4 should begin ART (see Tool 8.1.5: *Antiretroviral Therapy Guide*, and Tool 8.1.9 for *Tanner's Staging Guides* to guide you in prescription of ART). ART prescription should be clearly understood so that you can correctly prescribe and educate the adolescent and his or her family/caregiver. Health education includes a description of the medication regime, potential side effects of the medications, how they help to fight the HIV virus, and the risks associated with poor adherence. This information will increase the adolescent's ability to self-manage his or her care as he or she undergoes the transition process (see Tool 8.1.2: *Key Steps at the Baseline Visit,* Tool 8.1.3: *Key Steps for Adolescents not on Antiretroviral Therapy,* and Tool 8.1.4: *Key Steps for Follow-up Visits and Clients on Antiretroviral Therapy* for information on caring for the adolescent at baseline, pre-ART, and on ART).

Prior to beginning ART, assess ART readiness and prepare the adolescent through providing adherence counseling (see Tool 8.1.6: *Adherence Support Prior to Treatment*). 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 result in an increase of OIs, increased viral load, and 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 (see Tool 8.1.7: *Adherence Readiness Assessment Quiz*, Tool 8.1.8: *Adherence Assessment Tool*, Tool 8.3.10: *Medication Adherence Diary*, and Tool 8.3.11: *Medications Worksheet*; in addition, see Tool 8.3.12: *My Clinical Considerations Journal*).

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 (see Tool 8.1.1 for a clinical transition document that should be provided to the receiving clinician). Be sure to follow your workplace HIV guidelines.

ADOLESCENT CLINICAL TRANSITION DOCUMENT

Name:		Telephone number:	
Date of Birth:		Address:	
Sex:			

Emergency Contact Name:	
Emergency Contact Address:	

Date and Age of Diagnosis:	Current Medication Regimen:
	Past Medication Regimen (and reason for switch):
Past Medical History:	Past Psychosocial History:
Date of First CD4 Count:	Date of Last CD4 Count:
First CD4 Count:	Last CD4 Count:
Date of First Viral Load:	Date of Last Viral Load:
First Viral Load:	Last Viral Load:

Additional Notes:

KEY STEPS AT THE BASELINE VISIT

This tool may provide important cues for providing adolescent HIV services, but does not replace the clinical care records at your facility. Utilize this checklist to prompt you to carry out and record important tasks for the baseline visit.

- ☐ Confirm HIV status
- ☐ Take a complete medical and social history including prenatal, birth, and family history. Enquire about disclosure to the adolescent (if perinatally exposed) or disclosure to others.
- ☐ Identify co-occuring medical conditions (Hepatitis B or C, OIs, TB, pregnancy).
- ☐ Conduct a physical examination including Tanner Staging, STI screening if sexually active, skin exam and scoliosis examination.
- ☐ Prevent, diagnose, and treat OIs and other concomitant conditions, including TB, diarrhea, malaria and pregnancy.
- ☐ Assess growth and nutrition (weight, height) as appropriate for age and sex.
- ☐ Review immunization status.
- ☐ Conduct a psychosocial assessment (see Tool 1.1.3 and Tool 1.1.4)
- ☐ Assess WHO clinical stage. If not on ART, determine if the adolescent meets the clinical criteria for ART initiation. If on ART, determine if any new stage 3 or 4 events have occurred.
- ☐ For those eligible for ART by clinical criteria (WHO Stage 3 or 4), consider preparation for ART initiation.
- ☐ Schedule indicated laboratory results.
- ☐ Discuss findings with client.
- ☐ Schedule next visit.

Adapted from ICAP 2011

KEY STEPS FOR ADOLESCENTS NOT ON ANTIRETROVIRAL THERAPY

This tool may provide important cues for providing adolescent HIV services, but does not replace the clinical care records at your facility. Utilize this checklist to prompt you to carry out and record important tasks for follow-up visits for adolescent clients not on ART.

- ☐ Assess growth and nutrition (weight, height) as appropriate for age and sex.
- ☐ Assess development and neurodevelopment as appropriate for age and sex.
- ☐ Conduct a physical examination including Tanner Staging, STI screening if sexually active, skin exam and scoliosis examination.
- ☐ Prevent, diagnose, and treat opportunistic infections and other concomitant conditions, including TB, diarrhea, malaria and pregnancy.
- ☐ Review concomitant medications, consider drug interactions and make dose adjustments as needed. Include any traditional medicines that the adolescent may be taking.
- ☐ If on Cotrimoxazole, provide a refill, monitor adherence and address the adolescent's and family/caregiver's understanding of and adherence to the therapy.
- ☐ Assess WHO clinical stage.
- ☐ Review clinical and laboratory findings from recent visits and consider ART and cotrimoxazole elibility. If eligible, initiate adherence preparation.
- ☐ Conduct psychosocial assessment (see Tool 1.1.3 and Tool 1.1.4)
- ☐ Discuss positive living including nutritional counseling, and positive prevention.
- ☐ Provide sexual and reproductive health information, screening, diagnosis, treatment, counseling and supplies.
- ☐ Carry out mental health screening and refer for gender based violence care if needed.
- ☐ Provide additional support for adolescent clients who are switching providers or transitioning into adult care.
- ☐ Schedule laboratory tests.
- ☐ Discuss findings with client.
- ☐ Schedule next visit.

Adapted from ICAP 2011

KEY STEPS FOR FOLLOW-UP VISITS & CLIENTS ON ANTIRETROVIRAL THERAPY

This tool may provide important cues for providing adolescent HIV services, but does not replace the clinical care records at your facility. Utilize this checklist to prompt you to carry out and record important tasks for follow-up visits for adolescent clients on ART.

- ☐ Assess growth and nutrition (weight, height) as appropriate for age and sex.
- ☐ Assess development and neurodevelopment as appropriate for age and sex.
- ☐ Conduct a physical examination including Tanner Staging, STI screening if sexually active, skin exam and scoliosis examination.
- ☐ Prevent, diagnose, and treat OIs and other concomitant conditions, including TB, diarrhea, malaria and pregnancy.
- ☐ Review concomitant medications, consider drug interactions and make dose adjustments as needed. Include any traditional medicines that the adolescent may be taking.
- ☐ Provide refills for ART and cotrimoxazole, monitor adherence and address the adolescent's and/or family's/caregiver's understanding of and adherence to therapy.
- ☐ Assess WHO clinical stage. Determine if any new Stage 3 or 4 events have occurred since ART was initiated.
- ☐ Conduct psychosocial assessment (see Tool 1.1.3 and Tool 1.1.4)
- ☐ Discuss positive living including nutritional counseling, and positive prevention.
- ☐ Provide SRH information, screening, diagnosis, treatment, counseling and supplies.
- ☐ Carry out mental health screening and refer for gender based violence care if needed.
- ☐ Provide additional support for adolescent clients who are switching providers or transitioning into adult care.
- ☐ Schedule laboratory tests.
- ☐ Discuss findings with client.
- ☐ Schedule next visit.

Adapted from ICAP 2011

ANTIRETROVIRAL THERAPY GUIDE

Adolescents who have not yet begun puberty or who are in the beginning stages are in Tanner's Pubertal Stages I, II, and III (see Tool 8.1.9 and Tool 8.1.10) and will require a different ART regime than those who are in Tanner's Stages IV and V, who are treated under the ART guidelines for adults. Check these regimens against your national guidelines prior to prescription. Utilize national guidelines if they differ from these regimens.

REGIMENS FOR PREPUBERTAL ADOLESCENTS (TANNERS SCALE I, II, III)

	NRTI Backbone	NNRTI Component
Preferred first line	AZT + 3TC +	NVP or EFV[1,2]
Alternative first line[3]	ABC + 3TC +	NVP or EFV[1,2]
Second alternative first line[4]	d4T + 3TC +	NVP or EFV[1,2]

[1]The preferred regimen for adolescents with tuberculosis is EFV, the 2 NRTI backbone.

[2]The use of EFV should be avoided in adolescent girls due to the fact that it may cause fetal harm in the first trimester of pregnancy. If possible, adolescent girls taking EFV should be switched to a NVP-based or other regimen or counseled on and provided with a contraceptive method.

[3]Use the alternative first-line regimen only if there are contraindications to AZT (e.g., severe anemia < 8 g/dL; or neutropenia < 500 cells/mm^3) or AZT availability cannot be assured.

[4]Due to its unfavorable toxicity profile and its selection for unfavorable resistance patterns, use of d4T should be minimized; therefore d4T/3TC should only be used as a last resort for initiating infants on ART if the use of AZT or ABC is contraindicated or cannot be assured.

REGIMENS FOR POSTPUBERTAL ADOLESCENTS (TANNERS SCALE III, IV)

	NRTI Backbone	NNRTI Component
Preferred first line	TDF + FTC +	NVP[1] or EFV[2]
Alternative first line[3]	ABC + 3TC +	NVP or EFV[2]
Second alternative first line[4]	AZT[5] +3TC+	LPV/r

[1]Avoid use of NVP for either of the following groups of patients: (a) women who have had exposure to sdNVP without tail coverage with 7 days of AZT + 3TC within the last 12 months 9 (for PMTCT). Instead do not use an Efavirenz containing regimen, instead use LPV/r. If unsure whether the tail coverage for sdNVP was provided, then use LPV/r. (b) Patients with CD4 > 250.

[2]The use of EFV should be avoided in women due to the fact that it may cause fetal harm in the first trimester of pregnancy. If possible, women taking EFV should be switched to a NVP-based or other regimen or counseled on and provided with a contraceptive method.

[3]TDF has been associated with renal toxicity: if CrCl<50mL/min, initiate therapy with ABC/3TC (the alternative first-line regimen).

[4]This is the preferred second-line regimen for patients failing TDF-based first-line regimen. Other possible NRTI backbones for second-line regimen are d4T+3TC+LPV/r, but as d4T is associated with long-term toxicity, it should be used only if AZT cannot be tolerated.

[5]AZT is not recommended in patients with Hgb< 10. Delay ART until anemia is treated or use alternative NRTI combination (some of the alternatives are listed in note 4).

** See Acronym List for guide to ARVs referred to in above chart.*

ADHERENCE SUPPORT PRIOR TO TREATMENT

It is important to prepare both the adolescent and the family/caregiver for ART adherence prior to beginning treatment. This should consist of education and counseling that takes place over, at minimum, three sessions with the adolescent. At least one session should also occur with the adolescent and the family/caregiver.

CHECKLIST OF EDUCATION AND COUNSELING TOPICS:

- ☐ Disclosure status
- ☐ Daily habits, adolescent's thoughts toward health and medicine use
- ☐ Thoughts of family/caregiver toward medicine use
- ☐ Family/caregiver preparation in supporting the adolescent with adherence
- ☐ Potential barriers to treatment adherence
- ☐ Risk of others discovering HIV status, handling stigma associated with treatment
- ☐ Purpose of medicine and how it works
- ☐ Importance of treatment adherence and risks associated with poor adherence
- ☐ Medication names, what each looks like, routes, possible side effects, and management of side effects
- ☐ Plan for medication schedule once treatment begins
- ☐ What to do if forget to take a pill or have run out of medicine

ADHERENCE TIPS:

- Prior to beginning treatment, allow the adolescent to practice adherence by using practice "pills" such as vitamins or candies using a pill box.
- Identify a family member/caregiver with the adolescent who can provide medication reminders.
- Identify a medication schedule through using cues such as meals or tooth brushing, and encourage placing of medications where the adolescent will see them during regular activities.
- Plan for use of adherence reminders including alarm clock, cell phone alarm, etc.
- Explain use of adherence diary in Tool 8.3.10.
- Assist the adolescent to fill out *My Medication Worksheet* in Tool 8.3.11 once education has been provided.

Adapted from Bosteels and Goetghbuer 2008

ADHERENCE READINESS QUIZ

The following quiz can help to determine if the adolescent is prepared to start and adhere to their medications. Ask the adolescent how ready they feel if they were to start taking HIV medications today. Have the adolescent read each of the following statements, and on a scale of 1 to 5, rate how ready they feel today to make the following changes (circle a number from 1 to 5 for each item). Tell the adolescent to tell you how he or she is honestly feeling (not what they think you want to hear). See the following scale to assist you with your responses:

1 = Not at all ready 2 = Mildly ready 3 = Moderately ready 4 = Quite ready 5 = Extremely ready

IF YOU WERE GOING TO START TAKING HIV PILLS TODAY, HOW READY WOULD YOU BE TO:					
1. Make the necessary changes in your diet (i.e., eat at regular times, take pills with certain foods)	1	2	3	4	5
2. Accept the idea of taking these HIV pills for a long time (e.g., years)	1	2	3	4	5
3. Change your work, school, or home schedule to help you take your HIV pills (e.g., take a lunch break)	1	2	3	4	5
4. Deal with bringing your HIV pills to social activities (e.g., sporting events, friend's house)	1	2	3	4	5
5. Take many pills (e.g., more than 10) several times a day, at specific times	1	2	3	4	5
6. Ask for support from friends or family to help you remember to take your HIV pills	1	2	3	4	5
7. Live less spontaneously because you have to take your HIV pills at specific times (e.g., having to go home first to take your pills before going out)	1	2	3	4	5
8. Wear a watch or carry a beeper to remind you to take your HIV pills	1	2	3	4	5
9. Have a regular bedtime and morning wake-up time so as not to forget to take your HIV pills	1	2	3	4	5
10. Continue taking your HIV pills, even if you experience unpleasant side effects (e.g., vomiting, diarrhea, change in body shape)	1	2	3	4	5

SCORING

After the survey has been completed, add the numbers together for each response and divide by 10. Scores of 31.50 and greater indicate that the adolescent is adherent ready. Scores below this cutoff indicate that further exploration is required to address concerns, ambivalence, and knowledge gaps.

Total score: _____

Adherent ready: (circle one) Yes No

Balfour et al. 2007

ADHERENCE ASSESSMENT TOOL

To determine the adolescent's medication adherence since the last visit, ask the following questions and document your findings. Use this assessment as a guide to adherence education opportunities.

Date: _____

Total pills missed: _____

QUESTIONS	NOTES
How have you been feeling since the last visit?	
Have you experienced any changes in your household work? If yes, what are they?	
Have you experienced any changes at school? If yes, what are they? Are you attending regularly? How are your grades? Any problems with teachers or	
How has your mood been? Have you felt sad or depressed?	
Have any of these factors impacted your daily routine?.	
Have you been utilizing your Medication Adherence Diary?	
Is there anyone at home who helps you remember to take your medication? How often do they remind you?	
What time to you take your medications every day?	
Since our last visit have you taken any doses that were at different hours of the day, if yes, why?	
In the past week have you missed any doses? If yes, what happened?	
In the past month have you missed any doses? If yes, what happened?	
Since our last visit have you missed any doses? If yes, what happened?	
If yes, can you describe what happened?	
Which days did this occur?	
If this happens again, what can you do to help you remember to take your medication?	
Have you noticed any side effects from the medications? If so, what are they and did they contribute to you not taking the medication?	
Do you have any questions about your medications?	

Adapted from ICAP 2011, and Jacob and Jearld 2007

TANNER'S STAGING GUIDE

Refer to the Tanner's Guide for Pubertal Staging of Boys and Girls to routinely assess pubertal development. This tool may also be utilized to assist with ART prescription (see Tool 8.1.5).

GIRLS

STAGE	BREAST GROWTH	PUBIC HAIR GROWTH	OTHER CHANGES	AGE RANGE
I	Preadolescent	None	Preadolescent	0-15
II	Breast budding, areolar hyperplasia with a small amount of breast tissue	Long, downy pubic hair near the labia, often appearing with breast budding or several	Peak growth velocity often occurs after stage II	8 or 8½–15
III	Further enlargement of breast tissue and areola, with no separation of their contours	Increase in amount of pigmentation of hair	Menarche occurs in 25% of girls late in stage III	10-15
IV	Separation of contour; areola and nipple form secondary mound above breast tissue	Adult in type but not distribution	Menarche occurs in most girls in stage IV, 1–3 years after breast budding	10-17
V	Large breast with single contour	Adult in distribution	Menarche occurs in 10% of girls in stage V	12½–18

BOYS

STAGE	TESTES GROWTH	PENIS GROWTH	PUBIC HAIR GROWTH	OTHER CHANGES	AGE RANGE
I	Preadolescent testes ≤ 2.5cm	Preadolescent	None	Preadolescent	0-15
II	Enlargement of testes; pigmentation of scrotal sac	Minimal or no enlargement	Long, downy hair, often appearing several months after testicular growth; variable with pattern noted with pubarche	-	10-15
III	Further enlargement	Significant enlargement, especially in diameter	Increase in amount; curling	-	10½–16½
IV	Further enlargement	Further enlargement, especially in diameter	Adult in type but not in distribution	Axillary hair and some facial hair develop	Varies (12–17)
V	Adult in size	Adult in size	Adult in distribution	Body hair continues to grow and muscles continue to increase in size for several months to years; 20% of boys reach peak growth velocity	13–18

Tindyebwa, Kayita, and Musoke 2006

Medication Adherence Diary

Place this Medication Adherence Diary next to your medications and record each dose on this sheet. Bring this to your appointments to discuss your medication adherence with your provider.

Medication Name	Date	Time Taken

Medication Name	Date	Time Taken

Medication Worksheet

Fill in this table with your health or community care provider. Keep this sheet handy to help you remember important information about your medication.

Medication	What do I Take It For?	Do I Have any Reaction(s) or Side Effects?	When do I Take It? And How Often?	How Will I Remember to Take It?	Additional Notes

I should contact my health care provider immediately if:

My health care provider's contact information is:

Adapted from Robinson et al. 2006

My Clinical Considerations Journal

Ways that I can keep myself healthy include . . .

The people who encourage and help me to take care of myself are . . .

When I have questions about my health, I can talk to . . .

When I feel ill, I will take the following actions . . .

Some actions that I can take to help me remember my medicine are . . .

What do I want to talk about only with my healthcare and community care providers?

What do I want to talk about only with my family?

What do I want to talk about only with my peers/friends?

What do I want to keep to myself and not share with anyone?

Adapted from Robinson et al. 2006

MODULE 9: POSITIVE LIVING

Module 9: Summary

1 HCP/CCP Tools

- ***Tips for Adolescent Motivational Interviewing (Tool 9.1.1)***
  This tip sheet should be used by the HCP/CCP when trying to facilitate positive change with the adolescent.

- ***The Readiness to Change Ruler (Tool 9.1.2)***
  This assessment helps to determine the adolescent's readiness to change a specific behavior.

- ***HIV Knowledge Assessment (Tool 9.1.3)***
  This quiz can test the adolescent's HIV knowledge and also be used as a teaching tool to review important information prior to transition. The answer key can be found on the following page.

2 Family/Caregiver Tools

- ***Positive Living Tips (Tool 9.2.4)***
  This tip sheet provides information for the family/caregiver on assisting the adolescent in living positively.

- ***Self-Care Guide (Tool 9.2.5)***
  Provide this tool to the family/caregiver to discuss strategies to maintain their own well-being.

- ***Food for Health: Nutrition Tips (Tool 9.2.6)***
  Provide this tool to the family/caregiver to encourage nutritious eating at home.

3 Adolescent Tools

- ***Food for Health: Nutrition Tips (Tool 9.3.7)***
  Provide this tool to the adolescent to supplement health education for improved nutrition.

- ***Stigma Action Plan (Tool 9.3.8)***
  Share this stigma action plan with the adolescent to identify sources of stigma, and to create action plans to address stigma.

- ***HIV Peer Support Groups (Tool 9.3.9)***
  This tool provides information to the adolescent on the benefits of joining or starting an HIV peer support group.

- ***My Positive Living Journal (Tool 9.3.10)***
  This comprehensive guided journal and workbook should be distributed to the adolescent to encourage positive living.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 9.2.5 can be found in Module 9, targets the family/caregiver (audience 2), and is the fifth tool in this module.

MODULE 9: POSITIVE LIVING

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 and living responsibly, and 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 life 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) (see Tool 9.1.1: *Tips for Adolescent Motivational Interviewing)*. In addition, utilization of the readiness ruler tool can help to assess the adolescent's readiness to change a specific behavior (see Tool 9.1.2: *The Readiness to Change Ruler*). ALHIV will inevitably deal with stigma, which may include violence surrounding their HIV status, which 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 to utilize the stigma action plan in Tool 9.3.8. Be sure to discuss anticipated issues with the family/caregiver and to accordingly provide education to them on encouraging Positive Living for the adolescent (see Tool 9.2.4: *Positive Living Tips*) as well as for themselves (see Tool 9.2.5: *Self-Care Guide*).

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 to develop a skill set for Positive Living and may decrease their sense of isolation due to their HIV status. If there are no community and peer support groups present in your area, work with health facility administrators and community organizations to develop an adolescent peer support group (see Tool 9.3.9: *HIV Peer Support Groups*).

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. Tool 9.1.3: *HIV Knowledge Assessment* is a tool for the provider to assess the adolescent's knowledge level. This tool should be used as a platform to provide health education. Nutrition tips for the family/caregiver and the adolescent are also provided in Tool 9.2.6 and Tool 9.3.7.

Always keep in mind available services in the community to which you can refer the adolescent and his or her family, including education support, food support, as well as support for social services. Promoting an environment that actively involves the adolescent in his or her care—which includes dialogue between you, the adolescent, and the family/caregiver—can encourage healthy decision making during each stage of adolescence. See Tool 9.3.10 for a complete Positive Living journal where the adolescent can document his or her thoughts and feelings as well as plan for the future.

TIPS FOR ADOLESCENT MOTIVATIONAL INTERVIEWING

WHAT IS MOTIVATIONAL INTERVIEWING?

In motivational interviewing the adolescent client is considered to be the expert and is responsible for his or her own healthy decision making, strengthening the adolescent's motivation to make healthy lifestyle choices. This collaborative process, which empowers the adolescent and encourages independent decision making, identifies the adolescent's values and motivation for positive change.

WHAT TOPICS ARE USEFUL FOR MOTIVATIONAL INTERVIEWING?

Adherence, Alcohol use, Drug use, Sexual decision making, Motivation for education, Diet and exercise.

TIPS FOR MOTIVATIONAL INTERVIEWING (OARS)

- **Open-ended questions:** Ask questions that require the adolescent to respond with a thoughtful response. An example is: "Tell me about how you have been since our last visit." Avoid questions that can be answered by a yes/no response.
- **Affirmations:** Provide genuine and positive feedback to the adolescent that emphasizes his or her strengths to build the relationship and increase the adolescent's confidence in his or her ability to make a positive change. An example is: "That was very clever of you to make plans with a friend who participates in healthy behaviors; this is a great first step!"
- **Reflections:** Actively listen in order to understand the adolescent's perspective on an issue and repeat or paraphrase the statement back to the adolescent to ensure that there is mutual understanding of what is being said and to let the adolescent know that you are actively listening. An example is: "So, if understand what you are saying, you are having a difficult time saying no when your friends offer you alcohol?"
- **Summaries:** Use a summary statement at the end of the appointment to emphasize specific items that were discussed. Summary statements help to ensure a mutual understanding. An example of a summary statement is: "To recap our conversation, you believe that you are.

HOW DO I INCORPORATE MOTIVATIONAL INTERVIEWING INTO DAILY PRACTICE

- Create a sharing environment by reassuring the adolescent that all discussions are confidential.
- Explore the adolescent's values and how his or her goals align with his or her value system.
- Encourage the adolescent to look forward in his or her life.
- Strengthen confidence at every opportunity to increase the adolescent's self-efficacy.
- Involve parents when appropriate and with the adolescent's permission.
- Set goals and establish a plan together based on the adolescent's readiness for change

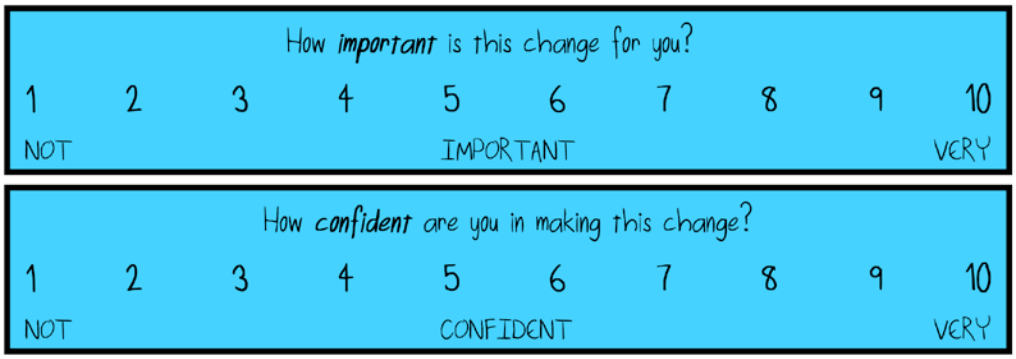
WHAT SHOULD I AVOID?

- Avoid arguing with and trying to persuade the adolescent as a means to create a positive change.
- Do not assume the role that you are the expert; this is an interactive process.
- Do not criticize, make the adolescent feel ashamed, or blame the adolescent for any poor choices.
- Do not make the adolescent feel rushed; he or she needs to know that you are actively listening and that he or she is important.

Miller 2011, Suarez and Mullens 2008, Miller 2002

THE READINESS TO CHANGE RULER

The Readiness to Change Ruler is a quick assessment of a client's readiness to change a behavior like harmful alcohol or drug use. The rulers examine desire and motivation to change from the client's perspective on a continuum between "not important" and "very important." Once the client has identified where he or she is on these rulers, use the questions below to further discuss the client's readiness to change.



	IMPORTANCE	CONFIDENCE
If the mark is a low number (1-4)	– If it is not important to change, how will you know when it is time to change? – What would be the benefits if you did consider changing?	– What prevents you from changing? – What could you do to increase your ability to change?
If the mark is in the middle (5-6)	– Why did you put your mark here? – What are the benefits that you are experiencing as you try to change? – What are the barriers to changing? – How can you overcome these barriers?	– Why did you put your mark here? – What actions might you take to try to change? – When you made other changes in your life, how did you do it? – What are the barriers to changing? – How can you overcome these barriers?
If the mark is on a higher number (7-10)	– What will be different for you when you reach your goal? – What people, places, or things do you still need to consult/go to, or what things do you still need to do to maintain your behavior?	– What will be different for you when you reach your goal? – What people, places, or things do you still need to consult/go to, or what things do you still need to do to maintain your behavior?
If the client has taken a serious step to make a change	– What made you decide to take this step? – What has helped you to be successful in taking this step? – What else will help? – What is your next step?	– What made you decide to take this step? – What has helped you to be successful in taking this step? – What else will help? – What is your next step?
If the client has had a relapse	– What worked for a while? – What did you learn from the experience? – How will this help you give it another try?	– What worked for a while? – What did you learn from the experience? – How will this help you give it another try?

Zimmerman, Olsen, and Bosworth 2000

HIV KNOWLEDGE ASSESSMENT

Assess your client's knowledge surrounding HIV by providing the following statements and request a true/false response. The adolescent should be able to respond correctly to all statements prior to transition. After the adolescent has taken the assessment, review the answer key on the following page with the adolescent to identify where additional information is needed.

STATEMENTS	TRUE	FALSE	DON'T KNOW
HIV and AIDS are the same thing.			
HIV is a virus that attacks a person's immune system.			
The cells of the immune system that fight infection are called "CD4 cells."			
The amount of HIV in a person's blood is called viral load.			
There is a cure for HIV.			
You can tell a person has HIV by looking at him/her.			
People with HIV may feel healthy for years, even if they are not on treatment.			
A person with HIV will stay healthy if their CD4 cells are high and their viral load is low.			
Even though a person with HIV may feel healthy, the virus can still be damaging his or her immune system.			
If my sexual partner is HIV-negative, we have to use a condom.			
If my sexual partner is also positive, we don't have to a use condom.			
If I am pregnant, my baby will be born with HIV.			
People with AIDS may get sick easily, lose weight, and have yeast infections, pneumonia, and low CD4 cells.			
If I take my medicine, I don't have to use condoms when I have sex.			
It is okay to miss doses of medication.			
I should call the doctor/nurse/pharmacist before I stop my medication.			
If I miss doses of medicine, the virus can become resistant and the medicine won't work.			
I should see the doctor and check my CD4 cells regularly.			
If my viral load is "undetectable," it is less likely that I will transmit HIV and less likely that I will get sick.			

Jacob and Jeard 2007

HIV KNOWLEDGE ASSESSMENT KEY: (F = FALSE, T = TRUE)

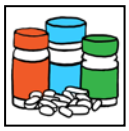
STATEMENTS	ANSWER AND EXPLANATION
HIV and AIDS are the same thing.	**F** HIV is the virus that causes AIDS.
HIV is a virus that attacks a person's immune system.	**T** HIV attacks a person's immune system, including the CD4 cells, resulting in higher susceptibility to illness.
Immune system cells that fight infection are called "CD4 cells."	**T** CD4 cells help the body fight infection.
The amount of HIV in a person's blood is called viral load.	**T** The amount of HIV in the body is measured through a laboratory test called the viral load.
There is a cure for HIV.	**F** While treatment is available to control HIV, there is no cure.
You can tell a person has HIV by looking at him/her.	**F** There is no way to tell that a person has HIV by their appearance.
People with HIV may feel healthy for years, even if they are not on treatment.	**T** The course of HIV varies for each person, but many people with HIV can feel healthy for a long time.
A person with HIV will stay healthy if their CD4 cells are high and their viral load is low.	**T** A person is more likely to stay healthy if their immune system is strong and they have less HIV in their body.
Even though a person with HIV may feel healthy, the virus can still be damaging his or her immune system.	**T** Even though a person may not feel ill, when present the HIV virus can cause damage to the immune system.
If my sexual partner is HIV-negative, we have to use a condom	**T** In order to prevent transmission of HIV, condoms must be worn with every sexual act. If the couple determines that they would like to become pregnant, they should discuss and plan with their HCP.
If my sexual partner is also positive, we don't have to a use condom.	**F** Condoms must be worn with each sexual act to prevent "re-infection," which may result in a risk of acquiring a strain of HIV that is resistant to certain types of HIV medications.
If I am pregnant, my baby will be born with HIV.	**F** HIV transmission to a baby may be prevented by the mother taking medication during pregnancy and labor, and by giving medication to the baby postpartum.
People with AIDS may get sick easy, lose weight, and have yeast infections, pneumonia, and low CD4 cells.	**T** People with AIDS are very susceptible to illness and become ill easily due to a low CD4 cell count.
If I take my medicine, I don't have to use condoms when I have sex.	**F** Even though HIV medication can decrease the HIV viral load, HIV can still be transmitted and condoms should be worn. If one wishes to have sex without condoms, one should speak with their HCP to check viral load to determine likelihood of transmission.
It is okay to miss doses of medication.	**F** In order to stay healthy and prevent resistance to HIV medication, no doses should be missed.
I should call the doctor/nurse/pharmacist before I stop my medication.	**T** The HCP should be notified before medications are stopped.
If I miss doses of medicine, the virus can become resistant and the medicine won't work.	**T** Missing doses of HIV medication increases the risk of the virus becoming resistant.
I should see the doctor and check my CD4 cells regularly.	**T** Regular visits to the HCP to check CD4 cells are an important part of routine care for HIV.
If my viral load is "undetectable," it is less likely that I will transmit HIV and less likely that I will get sick.	**T** When the viral load is "undetectable," there is a very small amount of HIV in the body, making it less likely that one will transmit HIV and more likely that one will stay healthy.

Jacob and Jearld 2007

POSITIVE LIVING TIPS

For adolescents living with HIV, Positive Living includes keeping the mind, body, and spirit healthy while also choosing to protect others by preventing new infections. Despite the adolescent's increasing independence, the adolescent will continue to need your love, support, and care. You, as the family/caregiver, play an important role in the adolescent's ability to live positively with HIV. The following is a list of tips for encouraging Positive Living for your adolescent.

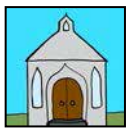
Health care: Your adolescent should become increasingly independent making and attending healthcare appointments. Work together with the adolescent and his or her health care provider to discuss the adolescent's health, your concerns, and your thoughts on his or her readiness to take greater responsibility for his or her health care.



Medication adherence: It is important that the adolescent takes their medication every day at the same time. Allow the adolescent to take greater responsibility while still monitoring to ensure that the medications are taken.

Staying active and socially engaged: Encourage the adolescent meet with friends and to participate in a peer support group for adolescents living with HIV. Regular exercise can also help the adolescent deal with stress, increase his or her appetite, and build strength.

School or work attendance: Encourage school attendance—it increases the adolescent's future opportunities and helps build knowledge, confidence, and decision-making skills. If he or she has a job, encourage continued working to provide purpose and social opportunities.



Spiritual practices: Set an example for the adolescent by continuing to attend religious services or through incorporating spiritual practices into your everyday life.

Rest: Make sure that the adolescent is getting enough sleep and that he or she has a regular sleep schedule. Getting rest is a very important part of staying healthy.

Personal hygiene: Provide a clean example and monitor regular bathing and hand washing, especially after toileting, touching body fluids, and before preparing foods. If she is menstruating, teach her to change sanitary pads or cloths and dispose of them into a latrine or burn them.

Nutrition and food hygiene: Make sure that the adolescent is eating healthy food. Provide a good example by teaching him or her to cook healthy meals and by eating foods that are prepared in a clean manner. Ask the adolescent's healthcare provider for more information on nutrition.

Sexual health: While talking to the adolescent about sex is not always easy, it is very important. Begin talking about sex early so that as the adolescent gets older, he or she feels comfortable talking with you about sex. Ask the adolescent's health care provider for more information about sexual health.

Drug and alcohol use: Provide the adolescent with a strong sense of self-confidence to help him or her avoid peer pressure to use drugs and alcohol. Be a good example by not using drugs and alcohol at home and discuss their potential effect on healthy decision-making.

Source: ICAP 2011, Ramsden and Vawda 2007

SELF-CARE GUIDE

Caring for an adolescent living with HIV can be stressful for the family/caregiver. It is a lot of work to make sure that the adolescent is taking proper care of themself while also caring for the rest of your family, and taking care of your own needs and responsibilities. It is important that you take the time to take good care of yourself so that you can continue to take good care of your family!

SELF-CARE INCLUDES:

- **Prioritize health and wellness for yourself.** Make sure that you are eating healthy, exercising regularly, and getting enough rest.
- **Ask for help when you need it.** Let others know when you need help; identify a support system and ask for help from them when you need it.
- **Identify support within the community.** Ask for the information that you need to take care of yourself and your family. Identify sources within the community including health and community care providers, community members, friends, and spiritual and religious leaders who can help equip you with the information that you need to stay healthy.
- **Encourage and teach the adolescent to take responsibility.** Emphasize to your adolescent that they will gradually take greater responsibility for their own care so that someday they will be able to independently manage their health.
- **Have realistic expectations of the adolescent.** Assign responsibilities that are manageable to the adolescent. This will help in the gradual transition of self-management responsibilities to your adolescent.
- **Assign clear responsibilities.** Make sure to outline clear roles and responsibilities between yourself, the adolescent, and his or her health and community care providers. Routinely communicate to ensure that they are carried out.
- **Seek regular emotional support.** Support may come from your support systems including religious and spiritual leaders. Check with health and community providers to determine if there is a support group for people affected by HIV in your community.
- **Acknowledge your feelings.** This may include feelings of fear, powerlessness, and anger. Make sure to ask for support from other adults when you need it—do not make the adolescent feel responsible for your emotional well-being.
- **Take time out for yourself.** Routinely build in time for yourself for recreation and relaxation.

Adapted from Family Health International (2009)

FOOD FOR HEALTH: NUTRITION TIPS

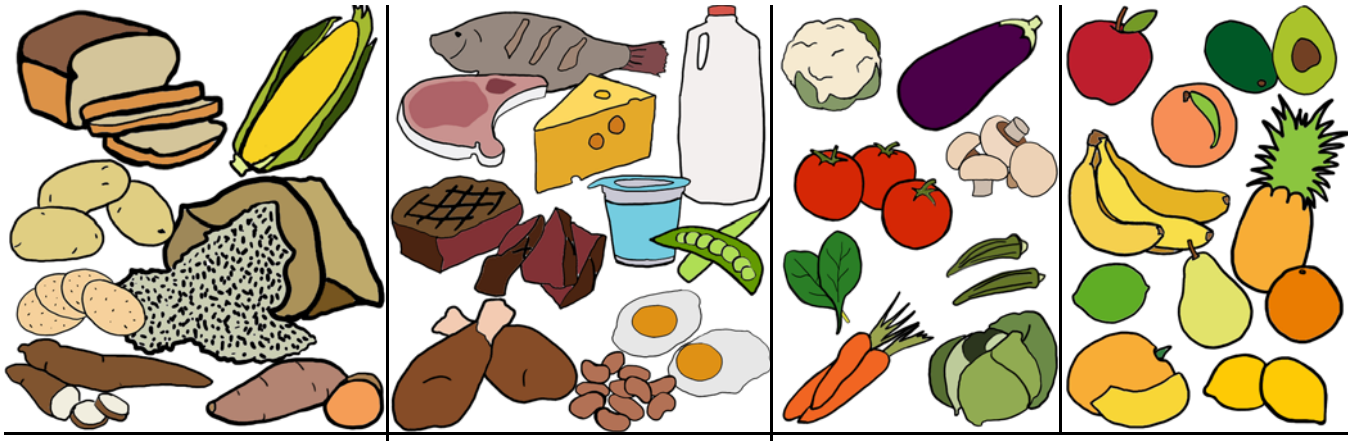
WHY IS NUTRITION IMPORTANT?

Providing healthy foods at home is a very important part of helping your adolescent stay healthy and manage his or her HIV. HIV increases the body's need for healthy foods. When the adolescent eats healthy foods, he or she is strengthening the body to fight off opportunistic infections and to slow down the course of HIV.

HOW CAN I HELP MY ADOLESCENT TO EAT HEALTHY?

- Provide a good example. Eat a variety of healthy foods that are freshly prepared at home.
- Try to provide foods that give energy such as breads and grains, and foods that have protein such as animal products and peas, beans, and nuts. Also, provide plenty of fresh fruits and vegetables.
- Discourage eating junk foods such as soda pop, sugary foods, or potato chips. Make sure that these foods are not available at home. Provide oils and fats in moderate amounts.
- Teach the adolescent healthy recipes. Have him or her participate in preparation of healthy meals for the family.
- Talk to the adolescent about the importance of a healthy diet as a part of their routine HIV care.
- Make sure that the adolescent receives sufficient amounts of food every day. It is best if he or she eats small regular meals throughout the day.
- If you do not have enough food, talk to the adolescent's health and community care provider to help you identify organizations in your community that can assist you.

EXAMPLES OF ENERGY GIVING, BODY BUILDING, AND PROTECTIVE FOODS:



Energy Giving Foods (Starches)	Body Building Foods (Protein and Dairy)	Protective Foods (Fruits and Vegetables)

WHAT ARE SOME TIPS FOR PREPARING FOOD SAFELY?

- Always wash hands before handling any food.
- Wash all surfaces well before cooking.
- Wash fruits and vegetables well before eating.
- When eating meat, make sure that it is fully cooked.
- Store foods in a cool place, and do not eat foods that have been sitting out for long periods.

Source: ICAP 2011

Food for Health: Nutrition Tips

Why is Nutrition Important?

Eating healthy is a very important part of taking care of yourself and managing your health. HIV increases your body's need for good food. When you eat healthy you are helping your body stay strong which means you are less likely to experience opportunistic infections and more likely to slow down the course of HIV!

What Foods Should I Avoid?

Soda pop, potato chips and candy snacks area quick and easy and might taste good, but are considered "junk foods" for a reason. They have little or no health value. When choosing what to eat, make sure to pick fresh foods that are not packaged.

How Do I Choose Healthy Foods?

- Make sure that you eat a variety of foods from all food groups. Try to eat foods that give you energy such as breads and grains. Also eat foods that have protein, such as animal products like meat and fish. If you are unable to eat meat, try to eat plant proteins like beans, peas, and other nuts.
- Make sure to eat plenty of fresh fruits and vegetables.
- Eat foods that contain fat and oils in moderation.
- Eat sweets sparingly.

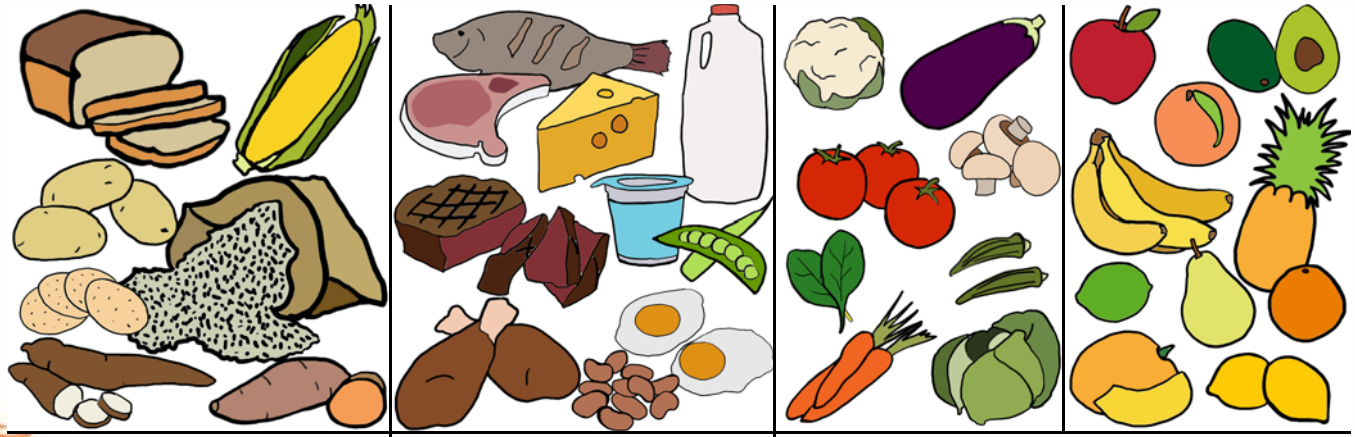
What are Some Other Tips for Good Nutrition?

- Eat small meals often & stick to a schedule every day when you eat. If you are busy during the day, carry a healthy snack with you.
- Take a multivitamin every day.
- Make sure that you are weighed at every health visit to make sure that you maintain a healthy weight.
- Ask your health or community provider about nutritional counseling services and programs for adolescents who need food assistance in your community.

What are Some Tips for Preparing Food Safely?

- Always wash hands before handling any food.
- Wash all surfaces well before cooking.
- Wash fruits and vegetables well before eating.
- When eating meat, make sure that it is fully cooked.
- Store foods in a cool place and do not eat foods that have been sitting out for prolonged periods.

Examples of Energy Giving, Body Building, and Protective Foods:



Energy Giving Foods (Starches)	Body Building Foods (Protein and Dairy)	Protective Foods (Fruits and Vegetables)

Source: ICAP 2011

Stigma Action Plan

It is important to understand the stigma that you experience and begin to think about ways that you can address it. The following is an action plan to help you. Consider all of the sources of stigma that you experience in your life and think about steps that you can take to deal with it in a healthy way. Share this with your provider, your counselor, or a loved one so that they can support you in acting on your action plan.

	Problem	Action Step	Resources Needed	By Whom	By When
Example Problem	I feel lonely since being diagnosed with HIV	Tell my best friend to let her know how I am feeling.	None.	I will talk with him or her.	After school tomorrow.
		Make an appointment to speak with a counselor.	A counselor that works at the clinic or in a community organization.	I will make the appointment, and I will tell my caregiver that I am going to do it so that they will encourage me to follow through.	I will do this the next time I have an appointment at the clinic.
		Join a peer support group.	Access to a peer support group.	When I ask about the counselor, I will ask for information about peer support groups.	I will do this the next time I have an appointment at the clinic.
Problem #1					
Problem #2					

Adapted from The Policy Project n.d.

Peer Support Groups

An HIV peer support group is a group that is made up of adolescents living with HIV who come together to talk about their experiences and provide emotional and social support to each other.

Why Should I Join a Peer Support Group?

Living with an HIV diagnosis can be very lonely, and you may feel like you are the only adolescent living with HIV. A peer support group provides a setting for you to share your thoughts, feelings, and experiences about living with HIV in a safe and confidential setting. Research shows that people who attend HIV support groups report less stress, greater self-confidence, and an improvement in their overall health. Peer support groups help empower adolescents to take charge of their health, give them a greater sense of confidence, build healthy relationships, and to make healthy living choices.

What Can I Expect from a Peer Support Group?

A trained counselor who has experience in this area will lead the group in talking about issues that are important in your life. You will be given the opportunity to speak with the counselor and your peers about your experiences and feelings about living with HIV. You will also be able to listen to your peers who are having similar experiences, so that you can learn from each other, provide support for each other, and encourage each other to make healthy decisions.

How Can I Find a Peer Support Group?

Speak with your provider or counselor about HIV support groups for adolescents in your area. You may also want to speak with various community organizations that work with adolescents living with HIV in your area.

What if there is no Peer Support Group Where I Live?

If there is no peer support group for adolescents in your area, then you can start one! Let your provider know, and he or she can work with you to identify a peer group leader, other adolescents interested in joining, as well as additional logistics.

This is a great opportunity to be a leader, to meet other adolescents who are having similar experiences as you, and to take charge of your health!

Funck-Brentano et al. 2005

My Positive Living Journal

Support System

Who supports you in your life? They could be family members, friends, nurses, doctors, counselors, or someone else.

Name:

Relationship:

Why I trust this person:

Ways this person helps me:

Ways I help this person:

Name:

Relationship:

Why I trust this person:

Ways this person helps me:

Ways I help this person:

Name:

Relationship:

Why I trust this person:

Ways this person helps me:

Ways I help this person:

Name:

Relationship:

Why I trust this person:

Ways this person helps me:

Ways I help this person:

Health

What do I do to stay healthy? Do I exercise, eat healthy, and get enough sleep?

How do I feel about my body? Do I feel over- or underweight?

Am I having difficulty in school or work?

Am I getting along with other people?

Do I do things that put my health at risk (i.e., drugs, alcohol, unprotected sex)?

Do I ever take substances, such as drugs and alcohol, to help deal with my life situation?

When do I feel sad? Do I have thoughts of low self-esteem or hopelessness?

What do I do to make myself feel better when I am feeling down?

What do I do to stay healthy? Do I exercise, eat healthy, and get enough sleep?

Stigma

Have I ever experienced stigma?

Where and why did I experience it?

What are my feelings about this experience?

What are actions I can take to reduce stigma?

Do I feel comfortable talking about stigma to someone? Who would this be? What will I say?

My Goals

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

How can I accomplish this?

Goal:

How can I accomplish this?

How will I overcome potential challenges?

Who can help me and how?

When do I want to accomplish this?

How can I accomplish this?

Goal:

How can I accomplish this?

How will I overcome potential challenges?

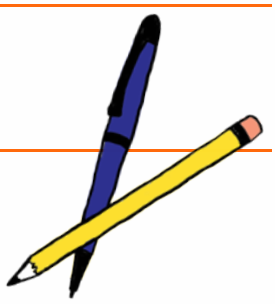
Who can help me and how?

When do I want to accomplish this?

How can I accomplish this?

Accomplishments

	How Can I Get This Done?	When Can I Get This Done?	Date Completed
Finish school			
Find a job			
Get job training			
Take my medicine without reminding			
Refill my medicines at the pharmacy			
Make appointments			



Adapted from: Robinson et al. 2006

MODULE 10: LINKING HEALTH FACILITIES & COMMUNITY PROGRAMS

Module 10: Summary

1 HCP/CCP Tools

- ***Community-Based Organization/Health Facility Directory (Tool 10.1.1)***
  The CBO/health facility directory provides a template to fill in when gathering information about programs for ALHIV in your region; include information for your facility as well. When all of the information has been gathered, this directory should be distributed among all facilities in your community to facilitate bidirectional referrals and linkages. You should incorporate routine use of this directory into your services to make referrals for ALHIV and their families/caregivers.

- ***Needs of Transitioning Adolescents Living with HIV (Tool 10.1.2)***
  This information sheet should be distributed to other organizations who work with ALHIV to provide them with information surrounding the needs of transitioning adolescents so that they can adapt their services and support referrals to other organizations accordingly. This information sheet can be distributed during your visits to organizations within your community or during the community-based forum meetings.

- ***Home Visit Guidance (Tool 10.1.3)***
  Home visits can provide an opportunity to get a more complete picture of the adolescent's life. Providers will be more able to provide holistic care that meets the physical, psychological, social, and spiritual needs of their clients.

2 Family/Caregiver and Adolescent Tool

- ***Guide to Health & Social Resources (Tools 10.2.4)***
  This guide can be filled out based on the information that you have entered into the directory. This guide should be filled out by yourself or a program administrator and distributed to families/caregivers. Encourage family/caregiver to access these services during the transition process.

3 Family/Caregiver and Adolescent Tool

- ***Guide to Health & Social Resources (Tools10.3.4)***
  This guide can be filled out based on the information that you have entered into the directory. This guide should be filled out by yourself or a program administrator and distributed to adolescents. Encourage the adolescent to access these services during the transition process.

Note: The tools are numbered in a consistent manner throughout the modules. For example, Tool 10.3.4 can be found in Module 10, targets the family/caregiver (audience 2) and adolescent (audience 3), and is the fourth tool in this module.

MODULE 10: LINKING HEALTH FACILITIES & COMMUNITY PROGRAMS

Linking health facility services and services offered by community based organizations (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 to 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). In this Toolkit, CBOs also include faith based organizations (FBOs); remember the meaningful impact and numerous resources that FBOs in your area have to offer adolescents.

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 through 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 CBOs 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. Create a CBO/health facility directory as you carry out a tour of the services in your area (see Tool 10.1.1 for a template to fill out when making visits). You may also take advantage of this opportunity to provide education to staff at the other facilities surrounding the services that you offer and on the needs of the ALHIV as you carry out these visits. Additionally, you may want to do a home visit with the adolescent. Home visits can provide an opportunity to get a more complete picture of the adolescent's life (see Tool 10.1.3 for a guidance sheet for home visits).

You may not be aware of many of the services that are offered within your community; health care facilities and CBOs often do not routinely communicate or coordinate services. To overcome this challenge, create a forum for organizations in your community to meet on a routine basis to coordinate and enhance the available package of services within the community, and to facilitate strong linkages and a coordinated referral system. Be sure to include a wide variety of organizations that offer child protection services, faith and spiritual support, and vocational and education support, in addition to 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 (see Tool 10.1.2: *Needs of Transitioning Adolescents Living with HIV* for a supplementary guide to present to CBOs). 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 (see Tool 10.2.4 and Tool 10.3.4 for a guide for adolescents and their families/caregivers that you can fill out and use to provide information surrounding services available within your community).

COMMUNITY-BASED ORGANIZATION/HEALTH FACILITY DIRECTORY

CBO OR HEALTH FACILITY NAME	TYPES OF SERVICES PROVIDED	CONTACT PERSON	TELEPHONE NUMBER & ADDRESS OF ORGANIZATION	HOURS/DAYS OF OPERATION

NEEDS OF TRANSITIONING ADOLESCENTS LIVING WITH HIV

Adolescents living with HIV require extra support from organizations that provide social services when they are transitioning to self-care. You, as a service provider in the community, have the opportunity to provide stability and to be a continuous presence throughout this vulnerable period in the adolescent's life. Work closely with other health and community care providers, the adolescent, and his or her family/caregiver to identify and respond to the unique needs of each adolescent. This sheet provides important information about the needs of adolescents living with HIV.

- **Psychosocial development:** Assessment of psychosocial development is important as it provides information on the adolescent's ability to take on increasing responsibility of his or her health. It is important to assess the adolescent's strengths support system at home and in the community.
- **Mental health support:** Adolescents may suffer from anxiety and depression or other mental health conditions. Monitor adolescents for emotional health issues that may arise and provide emotional health counseling and referrals.
- **Sexual and reproductive health:** Discussing sexual and reproductive health with the adolescent can help to prepare him or her for current and future sexual activity. Providing the adolescent with information surrounding contraception, pregnancy planning, STIs, and protecting and disclosing to partners is essential.
- **Protection:** Health and community care providers should identify issues such as neglect, abuse, gender-based violence, and exploitation; take steps to protect their adolescent clients when issues arise.
- **Drugs and alcohol:** Educate adolescents surrounding the risks of drugs and alcohol. When drug and alcohol use is suspected, screen for use and provide counseling or a counseling referral.
- **Disclosure:** Support the adolescent and his or her family/caregiver during the disclosure process. This is a difficult and vulnerable period for all involved; provide education for various disclosure strategies and a safe place to practice.
- **Loss, grief, and bereavement:** Many adolescents living with HIV have suffered one or many losses of loved ones due to the illness of other family members. Screen adolescents who receive services at your organization for loss. Provide or refer for counseling services and encourage support group attendance.
- **HIV testing, adherence support, and clinical referrals:** Encourage adolescents who do not know their status to get tested. Create an open dialogue through speaking about HIV with every adolescent who accesses services in your facility.
- **Positive living:** Take opportunities to provide health education surrounding nutrition, exercise, the importance of staying in care, creating and setting positive education and work goals, and other factors that contribute to a positive lifestyle for the adolescent.

HOME VISIT GUIDANCE

WHY DO A HOME VISIT?

Home visits can provide an opportunity to gain a greater understanding of the adolescent's life and provide holistic services that meet the client's physical, psychological, social and spiritual needs. In the home, health and community care providers can observe environmental factors that affect health, social and psychological influences, and relationships between family members. Providers can also see first-hand how well the adolescent can perform self-care tasks at home.

WHO TO VISIT AT HOME?

It is not cost-effective to provide home visits for all adolescents; in general, priority should be given to those who are most vulnerable, most disadvantaged, and in high-risk groups. These groups will vary from place to place and may include adolescents living with HIV who:

- Are living in child-headed households or on their own
- Recently lost someone close to them
- Have limited financial resources
- Have missed clinical care appointments
- Are at risk for substance use
- Have been diagnosed with co-morbid conditions
- Are pregnant, have recently given birth or are mothers with small children

HOW TO DO A HOME VISIT?

Pre-visit/planning stage:

- Determine and prioritize which clients need a visit according to the agreed criteria.
- Review clients' records, goals of care, and reasons for the home visit.
- Schedule the visit with clients and/or family members.
- Bring any supplies, toolkit modules and tools, or other educational materials for clients and their family/caregiver.
- Review safety considerations, such as the timing of the visit and assessment of the environment.

The visit:

- Introduce yourself to the client and family/caregivers. Initiate a brief discussion to establish rapport; start with the positive (e.g., "I can see you really care for your family, you keep your home so clean").
- Review plans for the visit with the client.
- Determine the expectation of the client regarding home visits.
- Conduct an assessment of the environment, client, medication, nutrition, functional abilities and limitations, psychosocial, and spiritual issues. Many of the items in this Toolkit can provide you with the proper assessment tools based on the client's needs.

Evaluating the visit:

- Evaluate the effectiveness of the interventions based on the response both during the visit and at subsequent visits.

Documentation:

- Document the visit in the confidential adolescent file.
- Record actions taken, response of client, and outcomes of intervention.
- Record both objective data (health worker–based) as well as subjective data (client-based).

Termination:

- Discuss that there may only be one home visit; and if more home visits are planned, termination must be discussed at the first visit as home visits are time-limited.
- At the final visit, review goal attainment with the client/family and make recommendations and referrals as appropriate for continued care issues.

Adapted from WHO 2004

GUIDE TO HEALTH & SOCIAL RESOURCES

SERVICE TYPE	NAME OF ORGANIZATION	DESCRIPTION OF SERVICES	TELEPHONE NUMBER & ADDRESS OF ORGANIZATION	HOURS/DAYS OF OPERATION

Guide to Health & Social Resources

Service Type	Name of Organization	Description of Services	Telephone Number & Address of Organization	Hours/Days of Operation

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ALIGN GRAPHIC DESIGN

AIDSTAR-One
AIDS SUPPORT AND TECHNICAL ASSISTANCE RESOURCES