ANECCA
Healthy women, children and Adolescents

POCKET GUIDE

ON COUNSELLING AND PSYCHOSOCIAL CARE FOR CHILDREN AND ADOLESCENTS LIVING WITH AND AFFECTED BY HIV IN AFRICA

By the African Network for the Care of Children Affected by HIV/AIDS – ANECCA

October 2018

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USAID FROM THE AMERICAN PEOPLE

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

AIDSFree Strengthening High Impact Interventions for an AIDS-free Generation

ANECCA

The African Network for the Care of Children Affected by HIV/AIDS (ANECCA) is a non-profit pan-African network of clinicians and social scientists with a mission to improve access to quality and comprehensive HIV prevention, care, treatment, and support services for children, integrated within the broader maternal and child health framework. The network works with experts in paediatric and adolescent HIV care to provide technical assistance to improve access and quality of services for children and adolescents living with HIV.

AIDSFree

The Strengthening High Impact Interventions for an AIDS-free Generation (AIDSFree) Project is a five-year cooperative agreement funded by the U.S. President's Emergency Plan for AIDS Relief with the United States Agency for International Development under Cooperative Agreement AID-OAA-A-14-00046. AIDSFree is implemented by JSI Research & Training Institute, Inc. with partners Abt Associates Inc., Elizabeth Glaser Pediatric AIDS Foundation, EnCompass LLC, IMA World Health, the International HIV/AIDS Alliance, Jhpiego Corporation, and PATH. AIDSFree supports and advances implementation of the U.S. President's Emergency Plan for AIDS Relief by providing capacity development and technical support to USAID missions, host-country governments, and HIV implementers at local, regional, and national levels.

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Cover Photo

An older sister cares for her younger sibling in a small fishing village of Rakai, Uganda, thought to be the epicenter of the AIDS pandemic. There are an estimated one million orphans in Uganda, resulting in many child-headed households like this one.

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Note on cover photo: use of a person's image in this publication is not meant to indicate or imply the person's HIV status.

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Appreciation goes to the writers of this Pocket Guide and the Handbook who volunteered their time to put together these excellent resources aimed at contributing to the well-being of children and adolescents affected by HIV in Africa. ANECCA is a pan-African network of clinicians and social scientists committed to improving the quality of lives of children and adolescents on the continent, and members who continue to identify and respond to gaps in service provision with evidence-based and culturally appropriate interventions.

Many of the contributors to this Pocket Guide are part of committees that write their respective national guidelines and documents. Therefore, some of the content here may be similar to content contained in some national documents; in particular, the contributions from national HIV programmes of Kenya, Malawi, and Uganda, are very much appreciated.

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The handbook is available at the ANECCA website www.anecca.org

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ACRONYMS

ADHD	attention deficit hyperactivity disorder
AIDSFree	Strengthening High Impact Interventions for an AIDS-free Generation (AIDSFree)
ALHIV	adolescent(s) living with HIV
ANECCA	African Network for the Care of Children Affected by HIV/AIDS
ANC	antenatal care
ART	antiretroviral treatment
CLHIV	child(ren) living with HIV
DBS	dried blood spot
DOT	directly observed therapy
ECP	emergency contraception pill
EID	early infant diagnosis
GATHER	Greet, Ask, Tell, Help, Explain and Demonstrate, Return [approach]
HBHTC	home-based HIV testing and counselling
HCP	health care provider
HEEADSSS	Home-Education/Employment-Eating-Activities-Drugs-Sexuality-Suicide/ Depression-Safety
HTC	HIV testing and counselling
HTS	HIV testing services
LTFU	lost to follow-up
M&E	monitoring and evaluation
MEMS	Medication Event Monitoring System
NRTI	nucleotide reverse-transcriptase inhibitors
OI	opportunistic infection
OVC	orphans and vulnerable children
PEP	post-exposure prophylaxis
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PHDP	positive health, dignity, and prevention
PrEP	pre-exposure prophylaxis
PI	protease inhibitor
PITC	provider-initiated testing and counselling
PMTCT	prevention of mother-to-child transmission
PSS	psychosocial support
SMART	specific, measurable, achievable, realistic, and time-bound
SRH	sexual and reproductive health
STI	sexually transmitted infection
SUSTAIN	Strengthening Uganda's Systems for Treating AIDS Nationally
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VMMC	voluntary male medical circumcision
WHO	World Health Organization

PURPOSE OF THE POCKET GUIDE

The African Network for the Care of Children Affected by AIDS (ANECCA) developed this Pocket Guide as a companion to the comprehensive *Handbook on Counselling and Psychosocial Care for Children and Adolescents Affected by HIV*; the Pocket Guide is a condensed version of the Handbook and is organised for on-the-job use. Like the Handbook, the Pocket Guide includes information on HIV clinical care; growth and development; mental health; child protection; counselling and communication; disclosure; loss, grief, and bereavement; adherence; sexual and reproductive health; transition of care; support systems; and monitoring and evaluation of psychosocial services. The information provided in this Pocket Guide aims to serve as a convenient clinical resource to equip health care providers (HCPs) with knowledge and skills that will help them to maximise resiliency, minimise risk factors, and promote positive personal growth among the children and adolescents they care for who are living with and affected by HIV.

HOW TO USE THE POCKET GUIDE

This Pocket Guide is directed at HCPs who care for child and adolescent clients. It contains practical resources that HCPs can quickly access during clinical encounters. When using this Pocket Guide in combination with the Handbook, HCPs will be better informed to understand and provide comprehensive and holistic care for these populations. The Pocket Guide's 13 chapters cover all major aspects of clinical and psychosocial care for children and adolescents living with and affected by HIV. Using a *child/adolescent*-centred perspective the Pocket Guide aims to engage the child/adolescent and the *family/caregiver* in every discussion and every decision. Information in each chapter is informed by the latest guidance from the World Health Organization (WHO 2018) and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR 2017). Each chapter provides a summary of practical approaches for HCPs to use to provide non-judgemental, context-specific and, where required, confidential medical and psychosocial services to best meet the specific needs of children and adolescents and help them improve their ability to cope and manage their diagnosis and well-being.

Each chapter uses the same format:

1. Introduction
2. General overview
3. Algorithms, scales, tools, and summary tables useful for holistic care
4. Links to additional resources

HCP may only need to select certain chapters in this Pocket Guide, depending on the client's needs, in order to quickly reference relevant clinical and psychosocial topics and use the available resources to provide integrated, child/adolescent-centred care. Where relevant, mention is made of other chapters that also contain information on a particular topic. For more in-depth information on each topic, HCPs should refer to the Handbook.

CHAPTER 1: KEY CONCEPTS IN PSYCHOSOCIAL SUPPORT

INTRODUCTION

Psychosocial support (PSS) **responds to the emotional, psychological, social, and spiritual needs and wishes** of the individual within the context of their family, friends, neighbours, and associations with others. Counselling (see ***Chapter 6***) is one form of PSS. Given the unique needs of children and adolescents living with HIV (CLHIV/ALHIV), as well as those affected by HIV, providing individualised psychosocial care and support as part of routine care is critical because:

- HIV affects physical, psychological, social, and spiritual elements of a child or adolescent's life, as well as those of their caregivers, and health care systems in low-resource settings often have difficulty helping clients to avoid or sufficiently address these challenges. (also addressed in Chapters 6, 12, 13)
- HIV can result in a chain of psychosocial issues, such as stigma, leading to non-disclosure and poor adherence to treatment, which leads to reduced viral suppression and disease progression (Mutumba et al. 2016). (Chapters 2, 3, 4, 7, 9, 11)
- Children affected by HIV may also experience the death of a parent, resulting in the loss of their basic needs (food, shelter, health care) (Sherr et al. 2014). The resulting orphanhood is associated with several vulnerabilities including: poor engagement in health care, poor school performance or school dropout, loss of income/employment, housing instability, mental health problems, and risk-taking behaviour (WHO n.d.). (Chapters 4, 5, 8, 10, 12)
- A child's or adolescent's relationships, with their caregivers and others in their community, can influence their physical health and also increase their ability to manage their own HIV, or cope with the illness of a HIV-positive family member (WHO 2013). (Chapters 8, 11, 12, 13)
- PSS can help children and adolescents make informed decisions to cope with HIV, deal effectively with stigma and discrimination, and address other social- and health-related vulnerabilities associated with HIV, leading to an enhanced quality of life (Mavhu et al. 2013). (All chapters)

APPROACH TO PSYCHOSOCIAL SUPPORT

PSS is a multi-step process that should begin with a thorough assessment, always building on the premise that they are children first. When providing services, meeting the basic needs of children and adolescents should be prioritised, while also providing (or linking to) specialised services based upon individual needs.

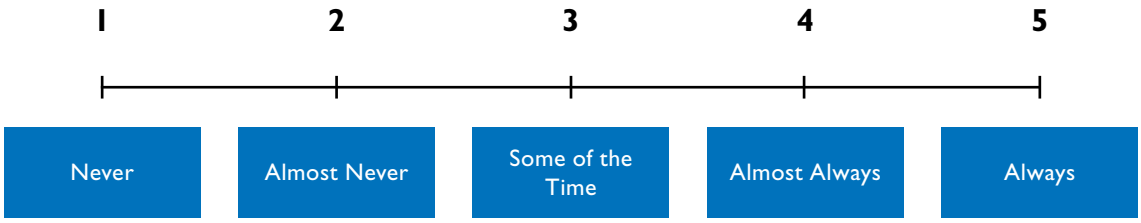
Below are tools that are commonly used to conduct a psychosocial assessment. **Figure 1.1** can help HCP to assess the presence and quality of social support available for children and adolescents.

CHILD AND ADOLESCENT SOCIAL SUPPORT SCALE

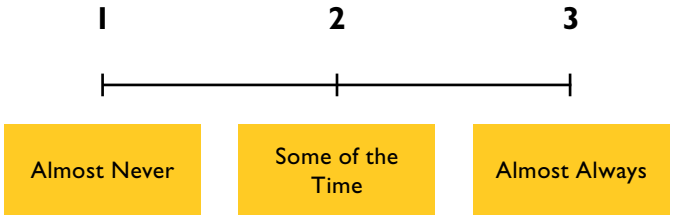
Below is a way to assess the level of social support a child/adolescent receives in order to identify the gaps in his/her needs so that they can be addressed either through routine service provision or via appropriate referrals and linkages to available services The focus is on parent/caregiver support as well as other support (as identified by the child/adolescent). This adapted scale examines two things: **how often** the child/adolescent receives the support, and **how important** that support is to the child/adolescent.

Figure 1.1. Scales to Assess Frequency and Importance of Social Support Received by Children/Adolescents

When asking the questions below on type of support received, using the following scale to determine how often the child/adolescent receives this type of support (adapted from Lowenthal et al. 2014):



When ranking how important the type of support received is, use the following choices:



Questions on type of support received:

1. My caregiver or parent(s) shows me they are proud of me.
2. My caregiver or parent(s) understands me.
3. My caregiver or parent(s) listens to me when I need to talk.
4. My caregiver or parent(s) gives me ideas when I don't know what to do.
5. My caregiver or parent(s) gives me good advice.
6. My caregiver or parent(s) helps me solve problems by giving me good information.

7. My caregiver or parent(s) tells me I did a good job when I do something well.
8. My caregiver or parent(s) nicely tells me when I make mistakes.
9. My caregiver or parent(s) rewards me when I've done something well.
10. My caregiver or parent(s) takes time to help me decide things.
11. My caregiver or parent(s) gets me many of the things I need.

Then ask the child/adolescent:

12. Is there anyone else in your life who helps you as much as your caregiver or parent(s)? (yes or no)

If yes, repeat the scale above and replace "caregiver or parent(s)" with the child's answer. Enter description of person, not name. (For example, "maternal aunt.")

The Home-Education/Employment-Eating-Activities-Drugs-Sexuality-Suicide/Depression-Safety tool (HEEADSSS) in **Table 1.1** may also be used to assess various aspects of an adolescent's life to help HCPs obtain a comprehensive history on the adolescent's psychosocial circumstances to make appropriate care decisions (Smith and McGuinness 2017).

Table 1.1. Adolescent Psychosocial Assessment: The Adapted HEEADSSS Tool[1]

COMPONENT	AREA OF ASSESSMENT *(TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMISE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCPS).*	NOTES
Home Situation/ Family	» Who do you live with? Where do you live? » Do you share a room or have your own room? » How would you describe your relationships with the people who you live with? » What do your parent/caretaker and relatives do for a living? Have they ever been institutionalised or incarcerated? Have you moved homes recently? Have you ever run away from home? » Are their new people in your home environment? Who are they? » Who in your house or family can you talk to about your HIV status? Have you personally disclosed your HIV status to anyone at home or in your family? If yes, to whom? If not, what are the reasons? Is there someone that you would like to disclose to and would like help disclosing to?	

1 Home, Education/Employment, Eating/Nutrition, Activities, Drugs, Depression, Sexuality, Suicidality, and Safety

COMPONENT	AREA OF ASSESSMENT *(TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMISE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCPS).*	NOTES
Education, Employment	» Are you currently in school? If yes, what grade are you in? (Any repeated years or failed classes?) » What are your favourite subjects? Least favourite subjects? How were your grades in these subjects? » Have there been any significant changes to your school performance since our last visit? School/grade performance—any recent changes? Any past dramatic changes? » Were there any years you repeated or classes you failed? » Have you ever been suspended or terminated from school? » If not currently in school: What was the highest grade you completed? What were your favourite/least favourite subjects? Do you wish to go back to school? » If not currently in school: Are you currently working? Suspension, termination, dropping out? » Tell me what your plans are for the future. What kind of education and work do you see yourself doing in the future? » What are your future education/employment plans? » Any current or past employment? » Relations with teachers, employers—school, work attendance?	
Eating/Nutrition	» How many times a day do you eat a meal? (Do you usually have something in the morning? What do you usually eat? How about lunch? How about dinner? » How many times a week do you skip a meal? What is the main reason you skip a meal? (No money to buy food? Busy schedule?) » Do you have access to clean running water to drink?	

COMPONENT	AREA OF ASSESSMENT *(TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMISE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCPS).*	NOTES
Activities	» What do you like to do when you are: • On your own, with peers (what do you do for fun? where? when?) • With family? » Do you enjoy any particular sports—regular exercise? » Religious attendance, clubs, projects? » Hobbies—other activities? » Reading for fun—what? » TV—how much weekly—favourite shows? » Favourite music? » Do you ride motorbikes or bicycles? Do you have a safety helmet that you use? » Do you have a car? Do you use seatbelts when you drive? » Have you ever been in trouble with the police or the law? History of arrests—acting out—crime?	
Drugs/Tobacco/ Alcohol	» Do you smoke cigarettes (tobacco)? » Do you have any friends who have ever smoked, sniffed, injected, or taken anything by mouth to get high? How about you? How about your family members? (include tobacco and alcohol) » Amounts, frequency, patterns of use/abuse, and car use while intoxicated? » Source—how did you pay for the substance?	
Sexuality	» Do you like boys, girls, both, or neither? » Have you had sex? If yes, did you use a condom? (normalise) » How many sexual partners have you had in your life? » Do you masturbate? (normalise) » Have you ever been pregnant? Have you ever had an abortion? » Do you know what a sexually transmitted infection is? How do you prevent acquiring and transmitting a sexually transmitted infection? » Do you use contraception? How often? Are you comfortable with your current sexual activity, enjoyment/ pleasure obtained?	

COMPONENT	AREA OF ASSESSMENT *(TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMISE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCPS).*	NOTES
Suicide/ Depression	» Do you have any problems sleeping? If yes, do you have problems falling asleep, early/frequent waking or greatly increased sleep or increasing fatigue? » Have you experienced: • Appetite/eating behaviour changes • Feelings of 'boredom' • Emotional outbursts and highly impulsive behaviour • History of withdrawal/isolation • Hopeless/helpless feelings • History of past suicide attempts, depression, psychological • History of suicide attempts in family or peers • History of recurrent serious 'accidents' • Psychosomatic symptomology • Suicidal ideation (including significant current and past losses) • Decreased affect at the interview, avoidance of eye contact—depression posturing » Have you thought of harming yourself or others?	
Safety	» Do you feel safe in your home? In your neighbourhood? At school/work? » Do you feel safe in your relationship (if applicable)? » Have you ever experienced sexual, physical, verbal or emotional abuse? When was the last time? » Do you have other safety concerns (e.g. if in areas of conflict)	

ADDITIONAL RESOURCES

» Psychosocial Factors to be Measured Table: Provides a measurement tool to explore psychosocial factors among HIV-positive adolescents; the full article can be found here: https://doi.org/10.1371/journal.pone.0109302.

» The Tree of Life Tool (Catholic Relief Services): A psychosocial support tool based on narrative approaches. It uses parts of a tree as metaphors to represent different aspects of our lives. The use of metaphors and carefully formulated questions invites children and others to tell stories about their lives in ways that make them stronger and more hopeful for the future. https://www.crs.org/sites/default/files/tools-research/tree-of-life.pdf

CHAPTER 2: HIV IN CHILDREN AND ADOLESCENTS

INTRODUCTION

Providing an overview of HIV prevention, diagnosis and treatment, this chapter includes approaches to care and retention. Children acquire HIV mainly through mother-to-child (vertical) transmission; similarly most adolescents grow up with perinatally acquired HIV. However, children and especially adolescents may also acquire HIV via consensual or non-consensual sex, needles or blood products containing HIV. This chapter includes information on HIV prevention, testing, diagnosis, antiretroviral therapy, and follow-up. Note that ***Chapter 9*** provides more information on helping children and adolescents adhere to treatment.

HIV PREVENTION AMONG CHILDREN AND ADOLESCENTS

Various HIV prevention methods are presented in **Table 2.1.** (AIDSFree n.d.).

Table 2.1 Interventions for Prevention of HIV Infection in Children and Adolescents

Behavioural interventions	» Delaying the start of first intercourse » Decreasing the number of sexual partners » Increasing correct and consistent use of effective prevention approaches including condoms and pre-exposure prophylaxis (PrEP) » Providing counselling through HIV testing services.
Biomedical prevention interventions	» Prevention of mother-to-child transmission (PMTCT) » Consistent and correct use of ART by people living with HIV to maintain an undetectable viral load » Treatment of sexually transmitted infections (STIs) » Voluntary medical male circumcision (VMMC) » Correct use of oral PrEP » Post-exposure prophylaxis (PEP) in cases of rape, sexual abuse, or other exposure to HIV » Safer medical/surgical practices » Safe blood transfusion » Contraception to prevent unplanned pregnancies among pregnant adolescent girls » HIV testing services » Use of vaccines and microbicides is still being researched and may be implemented in the near future

Structural HIV prevention interventions	» Addressing stigma and discrimination » Addressing gender-related barriers » Reducing the age of consent for HIV testing among children and adolescents

APPROACH TO CARE FOR HIV-POSITIVE CHILDREN AND ADOLESCENTS

Comprehensive care includes the 10-Point Service Package presented in **Box 2.1**.

BOX 2.1. ANECCA 10-POINT SERVICE PACKAGE

1. Determine HIV status at first contact.
2. Counsel and support the mother and the family on optimal infant feeding and monitor growth and development of the child.
3. Provide prophylaxis (ART, cotrimoxazole, isoniazid) according to national guidelines as appropriate.
4. Ensure that immunizations are started and completed according to national guidelines
5. Actively look for and treat all infections.
6. Provide ART for all HIV-infected infants, children and adolescents.
7. Provide regular monitoring of clinical and laboratory parameters and adherence; refer to higher levels of specialized care as necessary.
8. Educate the caregivers on all aspects of care.
9. Provide ongoing psychosocial support for the family and child and refer to community-based support programs as appropriate.
10. Ensure that the mother and family members are receiving appropriate care, support, and treatment.

HIV DIAGNOSIS IN CHILDREN AND ADOLESCENTS

HIV testing is the entry point to services: after accurately diagnosing HIV infection, HCPs can ensure early access to prevention, treatment and/or support services. HTS should be made available to all children and adolescents at risk of HIV infection and should be provided as early as possible after identifying risk. HTS delivery includes four major steps (**Table 2.2**, WHO 2013).

Table 2.2. Steps in the HTS Process for Children and Adolescents

STEP	ACTIVITY	DESCRIPTION
1.	Pre-test information giving and counselling	Educate patient/caregiver on the transmission of HIV and basic HIV preventive measures, benefits of HIV testing, possible test results and services available, informed consent and confidentiality; conduct a child risk assessment, and fill out the HTS card. Allow patients/caregivers to ask questions.
2.	HIV testing and diagnosis	Blood sample provided for test. For those under 18 months, use the DNA PCR (EID/DBS) test and for those above 18 months use the antibody test. Refer to the national testing algorithm.
3.	Post-test counselling (individual/couple/ family)	Assess readiness of patient or caregiver to receive results, give results simply; address concerns, disclosure and partner testing, risk reduction, provide information about basic HIV care and ART care; complete the HTS card and HTS register.
4.	Linkage and referral to other services, and follow-up to ensure that patient remains in care	Provide information about services referred for; fill the copies of referral form; when enroled, enter the patient's information on relevant records. Follow up to make sure that patient was linked to care. Use linkage networks to track patients and retain them in care.

There are two types of laboratory tests for HIV:

1. **Antibody test:** Antibody tests can diagnose HIV in children aged 18 months and above, including adolescents and adults. Examples include HIV ELISA, Western blot, and rapid tests (Determine, Statpak, Bioline, Unigold) and are performed by laboratory personnel, HCPs, or counsellors trained in rapid testing methodology. Rapid tests are the most commonly used and take 15–20 minutes to receive results.
2. **Virological tests (DNA PCR):** Recommended test for determining the HIV status in infants and children below 18 months of age. The sample for testing should be collected using dried blood spot (DBS)/ EID specimens or whole blood. The first DNA PCR test should be done at 4–6 weeks of age or the earliest opportunity thereafter (refer to the country's national guidelines). Interpretation of the results and further testing are guided by the national testing algorithm.

After diagnosis, the HIV-positive child or adolescent needs to be linked into long-term care. **Figure 2.1** is an example of how this linkage can be done in the same facility.

Figure 2.1. Internal Linkage Facilitation Steps

POST-TEST COUNSELLING

- Provide results accurately
- Provide information about care available at facility and elsewhere in catchment area
- Describe the next care and treatment steps
- Discuss the benefits of early treatment initiation and cons of delayed treatment
- Identify and address any barriers to linkage
- Involve the patient/caregiver in the decision-making process regarding care and treatment
- Fill in patient card and include referral notes
- Fill in referral form
- Introduce the patient to the linkage facilitator to ensure engagement
- If same day linkage is not possible, book an appointment for the patient at the clinic and follow to ensure the patient attends

PATIENT LINKS TO THE HIV CLINIC

- Linkage Facilitator escorts patient to ART clinic with linkage forms
- Hand over patient to responsible staff at that clinic
- Patient is enroled same day or, if not possible, then within seven days

ENROLMENT AT HIV CLINIC

- Register the patient in the pre-ART register
- Open an HIV/ART card/file for the patient
- Offer ART preparatory counselling
- Conduct baseline investigations
- If the patient is ready to start ART and baseline investigations are normal, start ART
- Coordinate care and provide integrated care: TB/HIV treatment, Mother-baby pair receiving care together
- Continue discussion on disclosure and psychosocial support
- Discuss and make an appropriate appointment with the patient/caregiver

ANTIRETROVIRAL THERAPY

Antiretroviral therapy (ART) slows down replication of HIV. A combination of three or more antiretroviral medicines (cART) is more effective than using just one medicine (monotherapy) to treat HIV. However, the drugs do not kill or eliminate the virus when taken in combination; they can prevent multiplication of the virus, get rid of the virus circulating in the blood and slow down progression of HIV. **Table 2.3** shows **first-line, second-line, and third-line regimens** based on WHO's 2018 recommendations. HCPs should refer to their national guidelines to determine the appropriate first-line ART regimen and when to switch to second-line regimens.

Table 2.3. First-Line, Second-Line and Third-Line ART Regimens (WHO 2018)

POPULATION	FRIST-LINE REGIMEN	SECOND-LINE REGIMEN	THIRD-LINE REGIMENS
Adults and adolescents (including women and adolescent girls who are of childbearing potential or are pregnant)[a]	Two NRTIs + DTG[b]	Two NRTIs + (ATV/r or lopinavir/ritonavir (LPV/r))	Darunavir/ritonavir (DRV/r)[g,h] + DTG[i] + 1–2 NRTIs (if possible, consider optimization using genotyping)
	Two NRTIs + EFV[c]	Two NRTIs + DTG[b]	
Children	Two NRTIs + DTG	Two NRTIs + (ATV/r[d] or LPV/r)	
	Two NRTIs + LPV/r	Two NRTIs + DTG[e]	
	Two NRTIs + NNRTI	Two NRTIs + DTG[f]	

a An optimized NRTI backbone should be used such as zidovudine (AZT) following TDF or abacavir (ABC) failure and vice versa.

b Women and adolescent girls of childbearing potential with consistent and reliable contraception and who are fully informed of the benefits and risks can use DTG.

c If population-level pretreatment resistance to EFV or NVP is ≥10%, the choice of alternative options to EFV needs to be made weighing the drug availability and toxicity profile. DTG (with consistent and reliable contraception among adolescent girls and women of childbearing potential) or ATV/r are the drug options to be considered.

d ATV/r can be used as an alternative to LPV/r among children older than three months, but the limited availability of suitable formulations for children younger than six years, the lack of a fixed-dose formulation and the need for separate administration of a ritonavir booster should be considered when choosing this regimen.

e This applies to children for whom approved DTG dosing is available. RAL should remain the preferred second-line regimen for the children for whom approved DTG dosing is not available.

f ATV/r or LPV/r should remain the preferred second-line treatment for the children for whom approved DTG dosing is not available. This applies to children for whom approved DTG dosing is available.

g For PI-experienced people, the recommended DRV/r dose should be 600 mg/100 mg twice daily.

h Children younger than three years should not use DRV/r.

i DTG-based third-line ART following the use of integrase inhibitors must be administered with DTG twice daily.

All HIV-positive children and adolescents should be initiated on ART. The decision to initiate ART requires the consideration of many factors. HCPs should complete the following steps prior to initiating a child or adolescent on ART:

1. Assess for opportunistic infections, such as tuberculosis (TB)
2. Assess readiness to start ART
3. Identify the proper regimen
4. Choose the correct formulation (i.e., tablet, syrup, or pellet)
5. Prescribe the correct dose

The child/adolescent and caregivers need to be prepared for and educated on ART; consider pill burden, frequency of dosing, appropriate formulation, side effects, food requirements/ relationship with food, drug–drug interactions, and drug storage.

FOLLOW-UP AND RETENTION IN CARE

The lifelong nature of HIV treatment requires keeping children, adolescents, and their family members in care and treatment (known as retention). Retention in care and adherence to ART are critical for optimal success of HIV treatment for patients, families, and communities (**Box 2.2**). Retention serves to routinely monitor effects of drug therapy, prevent medication interruptions, prevent development of HIV drug resistance, and facilitate PSS (Murray et al. 2017)

BOX 2.2. ROLE OF HCPS IN DIAGNOSIS, LINKAGE, RETENTION, AND FOLLOW-UP

- HCPs should use intensified, integrated approaches to quickly identify children and adolescents living with HIV, initiate them on ART, retain them in care, and conduct routine follow-up.
- Each day HCPs should use appointment schedules to identify and follow up with any patients who missed an appointment.
- Retention on ART requires the HCP to provide psychosocial support and link patients to other health and community services.
- Follow-up includes support to help children and adolescents adhere to their ART regimen.

ADDITIONAL RESOURCES

- HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV (WHO): These guidelines provide specific recommendations and expert suggestions —for national policymakers and programme managers and their partners and stakeholders—on prioritising, planning, and providing HIV testing, counselling, treatment, and care services for adolescents. http://www.who.int/hiv/pub/guidelines/adolescents/en/
- Adolescent HIV Testing, Counselling And Care. Implementation Guidance For Health Providers And Planners (WHO): This new interactive tool is designed as a companion to "HIV and adolescents: guidance for testing and counselling and care for adolescents living with HIV." http://www.who.int/maternal_child_adolescent/documents/hiv-testing-counselling/en/
- Family-Based Index Case Testing to Identify Children with HIV (WHO): Testing the family of HIV-positive adults or children 'index' cases can serve as an entry point for identification of children living with HIV not identified through PMTCT programme testing. This type of family-based approach to HIV testing and service delivery enables parents and their children to access care as a unit. http://www.who.int/hiv/pub/paediatric/family-based-case-testing-paedHIV/en/
- HIV Diagnosis and ARV Use in HIV-Exposed Infants: A Programmatic Update from the WHO: This programmatic update describes changes in strategies for the identification, prevention and treatment of HIV in infants. This update also highlights new information on the implementation of a postnatal package of care for HIV-exposed infants. http://www.who.int/hiv/pub/paediatric/diagnosis-arv-infants/en/

CHAPTER 3: GROWTH AND DEVELOPMENT

INTRODUCTION

Healthy development includes intellectual, emotional and social development in a child or adolescent. Untreated HIV in children may be associated with cognitive, motor, language, and psychological developmental deficits (Jao, Agwu, and Mhango 2015). Sometimes, signs of developmental delay or growth failure may be the first sign of HIV infection in children. Development is assessed in four main domains:

- Physical development
- Cognitive development
- Language (communication) development
- Social and emotional development

ROUTINE ASSESSMENT OF GROWTH

HCPs must routinely assess the growth and development of children and adolescents, inform caregivers on their findings, and provide timely support, including PSS and care, counselling and referral. Assessment of a child's growth and development at every visit is crucial not only to optimise growth and development of the child, but also to determine the timing of various interventions in the child's or adolescent's care, such as disclosure of HIV status or choice of antiretroviral drug formulation (Soc et al. 2015).

The following are the parameters and equipment used to assess growth:

- History: Take a thorough history. Ask caregivers about any changes in weight and height.
- Examination: At each visit conduct and record the following growth assessments:
  - Weight
  - Height/length
  - Head circumference
  - Mid-upper arm circumference (MUAC)
- Equipment
  - Age-appropriate weighing scales
  - Height boards
  - Stadiometer

- Infantometer
- Tape measure (MUAC tapes).

ABNORMAL CHILD/ADOLESCENT DEVELOPMENT

Environmental factors, genetics, nutrition or malnutrition, infections such as HIV, congenital malformations, and hormonal disturbances can all affect the pattern of growth and development in children and adolescents (Phillips et al. 2016; Cohen et al. 2015). Parental well-being, survival, employment, economic situation, and mental health may also have impacts, as can maternal substance use during pregnancy, and the level of stimulation within the home (Lachman, Cluver, and Boyes 2014). HIV in children and adolescents remains a risk factor for neurological and neuropsychological problems, and should be assessed.

A child, or especially an adolescent, who is achieving particular development milestones (physical, emotional, social) may experience psychological challenges that need to be addressed either by the caregiver or the HCP. At times, the caregiver may also need support to accept and handle the challenge (Lachman, Cluver, and Boyes 2014). **Table 3.1** can be used as a tool to identify normal and abnormal growth and development. Early intervention, including referrals to early childhood development experts and other specialists, should occur when abnormalities are identified.

ROUTINE ASSESSMENT OF DEVELOPMENT AMONG ADOLESCENTS

Adolescence is a special transition phase of growth and development from childhood to adulthood and is characterised by rapid physical, cognitive, and emotional changes as well as social development (Emmanuel and Bokor 2017). Four main areas of cognitive development occur among adolescents:

1. They develop more advanced reasoning skills, including the ability to explore a full range of possibilities inherent in a situation, hypothetical thinking, and use of logical thought processes.
2. Their interest tends to focus on the present, thoughts of the future is limited.
3. They can think abstractly; intellectual interests expand and gain importance.
4. They are in a transition from impulse-oriented behaviours (e.g., risk-taking behaviours such as experimenting with tobacco, alcohol, and sexual acts) as they increase their capacity for critical thinking.

Perinatally infected adolescents may experience slow skeletal growth and delayed pubertal maturation, linked to HIV's effect on metabolic and endocrine functions. Delays in growth and sexual maturation may also have an impact on the adolescent's psychosocial development, including strong feelings of frustration and anger because they look different from their HIV-negative peers.

HCPs can assess adolescents' development by using Tanner staging for boys and girls, as shown in **Figure 3.1 and 3.2** to help identify abnormal physical development patterns for closer monitoring/referrals as required (Emmanuel and Bokor 2017). It is important to identify which developmental assessment tools are used in your country to ensure that they are culturally appropriate and effective.

Figure 3.1. Tanner Staging: Male Genitalia and Pubic Hair

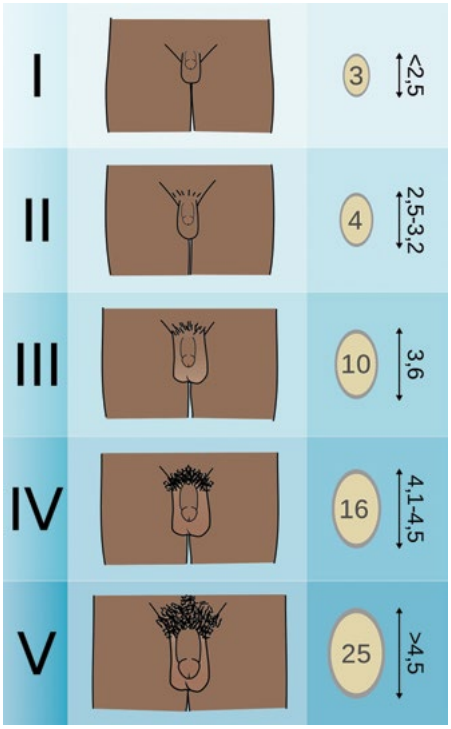
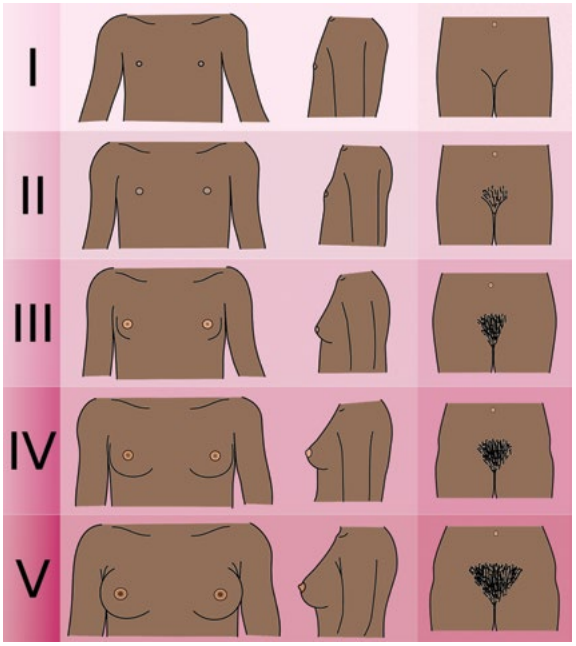


Figure 3.2. Tanner Staging: Female Breasts, Genitalia, and Pubic Hair



Source: Illustrations in figures 3.1 and 3.2 were originally created by the Vermont Department of Health and adapted by AIDSFree.
https://www.medschool.lsuhsc.edu/medical_education/undergraduate/spm/SPM_100/documents/tannerstagescard.pdf

ADDITIONAL RESOURCES

- Adaptation and standardization of a Western tool for assessing child development in non-Western low-income context (Abessa et al.): This article details adaptation of the Denver Developmental Screening Test (available in Handbook) to the Ethiopian context. This methodology may be used to adapt the tool to other African settings. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4964036/pdf/12889_2016_Article_3288.pdf
- The WHO Child Growth Standards: This web page describes growth standards and provides instruction on how to measure various aspects of child growth and development. http://www.who.int/childgrowth/standards/en/

Table 3.1. Normal Growth and Development in Children and Adolescents (adapted from WHO)*

	INFANCY (BIRTH TO 12 MONTHS)	TODDLER (12 – 24 MONTHS)	EARLY CHILDHOOD (2 TO 5 YEARS)	MID-CHILDHOOD (6-9 YEARS)	EARLY ADOLESCENCE (10-13 YEARS)	ADOLESCENCE (14-18 YEARS)
Physical	Rapid development—hands, feet, head Needs to be held, cuddled, stimulated 6 months: can bring hand or toy to mouth 6 months: can sit alone in tripod position 8 months: can sit without support and engage in play	Becomes mobile, explores, exercises 1 year can stand independently from a crawling position 13 months: can walk and toddle quickly 15 months: can run	Gains muscle coordination can dress and feed self Starts to throw, catch, and run Enjoys pens and pencils	Growth slows, motor skills improve, lots of energy	Rapid growth—may feel awkward and lack coordination. Signs of puberty begin, hormonal changes start	Physical development into the final stages of adulthood
Cognitive	Learns about language Interested if they are involved	Rapid brain growth Starts to talk and remember Understands symbols, imitates, imagines and pretends	Understands complex ideas such as time, letters, counting Understands and speaks	Longer attention spans, likes complex challenges, learning, discovering for themselves, masters skills through practice	Develops abstract thinking skills; begins to think about future life roles; is able to postpone gratification	Thinks like adults, may try risky behaviours, mood swings Rewards are pleasurable, may ignore consequences
Emotional/ Social	Responds to a warm, loving environment	Feels uneasy when separated from loved ones Does things on their own, sets stage for conflict	Displays range of emotions—anger, jealousy, Imitates others	Form close same-sex friendships, guided by behaviour and beliefs of peer group, likes to be acknowledged	Increasingly self-conscious about their bodies and how they look. Strong desire to conform to peer group	Mood swings common; heavily influenced by peers; Quest for identity and same-sex friendships are important
Sex/Gender Language & Communication	Not aware of sex/ gender in their life	Describes self as a boy or girl	Sex/gender Curious about their body parts Examines their bodies and those of their peers when adults are not around	Increased self-awareness about anatomical differences, curiosity about sexual activities	Sex organs assume adult form; maturity may be early or late	Many begin romantic/ sexual relationships

**Based on Denver Developmental Screening Test (Frakenburg, Dodds, and Archer 1992)*

CHAPTER 4: MENTAL HEALTH

INTRODUCTION

Mental health is a critical yet often neglected facet of the health and well-being of children and adolescents who are living with HIV. Children and adolescents who are HIV-positive experience higher levels of anxiety and depression, among other mental health symptoms, compared to their HIV-negative peers (Dow et al. 2016). Parents' and caregivers' mental health symptoms can mirror their child's symptoms. Poor mental health relates closely to other health and developmental concerns in children and adolescents—notably lower educational achievement, harmful substance use, violence, and poor reproductive and sexual health (Nalukenge et al. 2018; Sherr et al. 2014). Mental health *problems* are common in HIV-positive children and adolescents and, if not addressed, can lead to development of more serious mental health *illnesses*—for example, untreated depression can escalate to severe levels, sometimes leading to suicide. HCPs should be able to assess and identify cases of mental health problems and manage or refer appropriately.

MENTAL HEALTH MANAGEMENT

Common mental health problems in children and adolescents living with HIV include depression and anxiety. The HCP needs to know the signs and symptoms of these conditions in order to identify them and manage them or refer them as appropriate. See **Box 4.1** for diagnostic criteria for anxiety and **Box 4.2** for depression.

BOX 4.1 SIGNS AND SYMPTOMS OF ANXIETY

Generalized anxiety disorder

» Excessive anxiety/worry about a number of events (HIV, loss, etc,) or activities

» Difficulty controlling worry

» The worry is associated with three or more of the following symptoms with at least some symptoms present in more days for the last six months (only one item is required in children)

- Withdrawing from play
- Restlessness or feeling on edge
- Easily fatigued
- Difficult concentration or mind going blank
- Irritability or acting out
- Muscle tension
- Sleep disturbance (excessive or limited)

» Significant distress in social situations (play), occupational functioning (schooling for adolescents)

» Unable to explain by a physiological effect of a drug or a general medical or psychiatric condition

Separation anxiety disorder

» Developmentally inappropriate and excessive anxiety emerges related to separation from an attachment figure (e.g., mother, caregiver) (Expected for toddlers but inappropriate for older children)

» Continuous worry for the caregiver's safety upon separation, leading to extreme distress and sometimes nightmares

» May refuse to attend school or sleep alone

» Repeated complaints of physical symptoms of headache, abdominal pain in anticipation of separation

» A new experience, such as a diagnosis of a chronic illness, abuse, and loss, can precipitate severe forms of anxiety, including this one.

BOX 4.2. SIGNS AND SYMPTOMS OF DEPRESSION

A child or adolescent needs to have at least 5 of the following 9 symptoms for 2 weeks, with at least one symptom being either a depressed (sad) or irritable mood or inability to enjoy normally pleasurable activities (anhedonia) to diagnose major depressive disorder:

1. Depressed or irritable mood
2. Decreased interest or enjoyment
3. Decreased concentration or indecision
4. Insomnia or hypersomnia
5. Change of appetite or change of weight
6. Excessive fatigue
7. Feelings of worthlessness or excessive guilt
8. Recurrent thoughts of death or suicidal ideation
9. Psychomotor agitation (emotional distress and restlessness) or developmental delay.

These symptoms must cause social and academic impairment and may not be due to the direct effect of a general medical condition or substance of abuse. (American Psychiatric Association 2013)

Untreated mental illness (especially depression) can become severe, sometimes leading to suicide (**Box 4.3**).

BOX 4.3. RISK FACTORS FOR SUICIDE

- Feelings of hopelessness
- Feeling rejected or not fitting in with their peers
- Feeling upset, frustrated, or angry about living with HIV
- Experiencing any significant physical illness or new symptoms/progression of existing disease (for example, major drop in CD4 cells, rise in viral load)
- Hospitalisation (particularly the first hospitalisation)
- History of past suicide attempts
- A family history of mood disorders or suicidal behaviour (particularly completed suicides)
- A history of being exposed to family violence or abuse
- Access to firearms or other potentially lethal means
- Social isolation/alienation (including because of being gay or being bullied)
- Suicide of a friend, acquaintance, or celebrity (suicide contagion)

(American Psychiatric Association 2013)

If depression is suspected, HCP should assess for suicidal thoughts by asking open-ended questions such as the ones below to explore the severity of the intention.

1. Have you ever thought of harming yourself or others?
2. Tell me about it.
3. What made you feel that way?
4. What did you do?
5. Did you actually want to die?
6. Now that you did not die, how do you feel?
7. Is there another way that you could have faced this problem?

HCPs should remember that:

- There is no confidentiality when an adolescent is talking about suicide. Do not agree to keep a secret. Also let the adolescent know that you will have to let someone know if they are considering suicide to help keep them safe. Telling someone else like a parent without telling the adolescent can ruin the relationship that you have built with the adolescent.
- Act immediately. Do not wait until clinic hours are over or until the end of the day.
- Take action even if you are not sure. "Better to be safe than sorry."
- Don't assume that someone is not the "suicidal type."
- Don't debate whether suicide is morally right or wrong and don't judge.
- Keep the person under supervision at all times until someone else takes over.

Take action immediately if a child or adolescent is:

- Talking about suicide
- Giving away possessions, suddenly clearing out belongings and getting them in order
- Obtaining a gun, knife or other means of harm
- Making a specific plan to hurt self or others
- Enacting violence in the home

If a patient is acutely suicidal, do not leave them alone and make sure they are closely monitored until they receive further mental health evaluation and are mentally stable.

SUBSTANCE USE DISORDER

Also known as drug use disorder, this is a condition in which the use of one or more drugs leads to impairment in clinical and socio-occupational functioning. For the younger adolescent, the impairment can manifest in his/her social, familial, and/or academic settings. Commonly abused substances include alcohol; tobacco; hallucinogens; inhalants like glue and gasoline; sedatives such as opioids or cannabis; and stimulants such as cocaine and amphetamines. **Table 4.1** shows the common terms and symptoms used to help recognise harmful substance use.

Table 4.1. Common Terms in Substance Use (American Psychiatric Association 2013)

TERM	SIGNS AND SYMPTOMS
Substance abuse	» Regular unhealthy patterns of substance use » Significant impairment or distress manifested by one or more of the following: • Recurrent use causing physical danger to the user • Recurrent use despite obvious impairment in school, home, and/or work • Recurrent use resulting in legal problems • Recurrent use despite social or interpersonal problems
Substance intoxication	» Experiencing a "high" or physical, mental, or emotional sensations from use » Significant unhealthy behaviour or psychological change must be present
Substance withdrawal	» Experiencing unpleasant symptoms due to stopping or reducing prolonged substance use » Withdrawal causes clinically significant distress and can impair social, family, or work functioning

ROLE OF HCP

All HCPs should routinely screen, counsel, and refer children and adolescents with mental health problems. They should also find ways to provide education to fight stigma and discrimination against mental health problems among children and adolescents living with HIV, caregivers, and communities through providing education.

The care and management of the child or adolescent with a mental health problem or illness should involve a multidisciplinary team consisting of the clinician, pharmacist, nurse, counsellor, social worker, community support groups, peers or friends, family, and others as appropriate.

HCPS OFFERING MENTAL HEALTH SERVICES SHOULD:

Assess by:

» Conducting a general assessment. Take a detailed history of the presenting complaint and a medical and social history to ascertain probable cause

» Identifying and managing any acute co-morbid illness

Offer psychosocial support by:

» Enhancing problem-solving skills

» Teaching coping skills, including lifestyle changes

- Helping the patient to identify choices
- Evaluating the value and consequences of choices
- Linking the patient to spiritual and psychological support
- Providing a solution-focused counselling approach

Involve the family to:

- Help develop the building blocks for a more functional and communicative household
- Support the wellness of the entire family
- Provide psychosocial support
- Ensure access to basic needs: shelter, food, medical care
- Help the child or adolescent plan daily or weekly activities. This encourages them to be active and retain control of their life
- Allow the child and adolescent to get enough rest and eat well
- Follow up on the agreed care plans and track progress
- Encourage peer contact and support
- Identify other peer support groups in the community whose members have adjusted to their lives and are willing to talk about it to give support and inspiration
- Identify other community resources and support groups and link the patient and family with them for financial, social support
- Discourage use of recreational drugs and alcohol because they can make mental health problems worse

ADDITIONAL RESOURCES

- mhGAP Intervention Guide - Version 2.0 for mental, neurological and substance use disorders in non-specialised health settings: This WHO guide is the second version (2016) of the mhGAP Intervention Guide (mhGAP-IG) for mental, neurological and substance use (MNS) disorders in non-specialist health settings. It is for use by doctors, nurses, and other health workers as well as health planners and managers. The Intervention Guide presents the integrated management of priority MNS conditions using algorithms for clinical decision-making. http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/
- The Child Psychosocial Distress Screener [CPDS]: This instrument assesses non-specific child psychosocial distress and the need for psychosocial treatment. The instrument is developed as a primary screener in complex emergencies (especially low- and middle-income settings), for children between 8 and 14 years old and can be used to assess needs for secondary preventive group-based psychosocial interventions. http://www.mhinnovation.net/resources/child-psychosocial-distress-screener-cpds

CHAPTER 5: CHILD PROTECTION

INTRODUCTION

Child protection is the prevention and response to violence, exploitation, and abuse against children, including commercial and sexual exploitation, trafficking, child labour, and harmful traditional practices such as female genital mutilation/cutting and child marriage. Child protection's primary focus is on preventing and responding to child maltreatment. Abuse occurs among children and adolescents from all socioeconomic backgrounds, ages, religions, and cultures.

Key guiding principles in child protection are:

- **Assure best interest of the child/adolescent is priority**: The child/adolescent's best interests are at the centre of all decision-making in policy development, programme design, and decisions for the individual child/adolescent.
- **Do no harm**: All activities maximise benefits to the child/adolescent and minimise possible risks.
- **Non-discrimination**: Treat every child/adolescent fairly, irrespective of their HIV status, race, belief systems, abilities, or family background.
- **The family is the best place for the child/adolescent**: The family is the best place for optimal growth and development. In the event that the family are the perpetrators of child abuse, the HCP should participate in finding alternative care arrangements, in collaboration with local child protection officers, and always refer to the respective country-level child protection policies and guidelines, including alternative care guidelines, to ensure appropriate actions/implementation (United Nations n.d.; UNICEF n.d.).

CHILD ABUSE AND ROLE OF HCP

Child abuse/maltreatment refers to the physical and emotional mistreatment, sexual abuse, neglect and negligent treatment of children, as well as to their commercial or other exploitation (Long 2011). The HCP has key roles in supporting the child/adolescent to address child abuse, as outlined in **Table 5.1**.

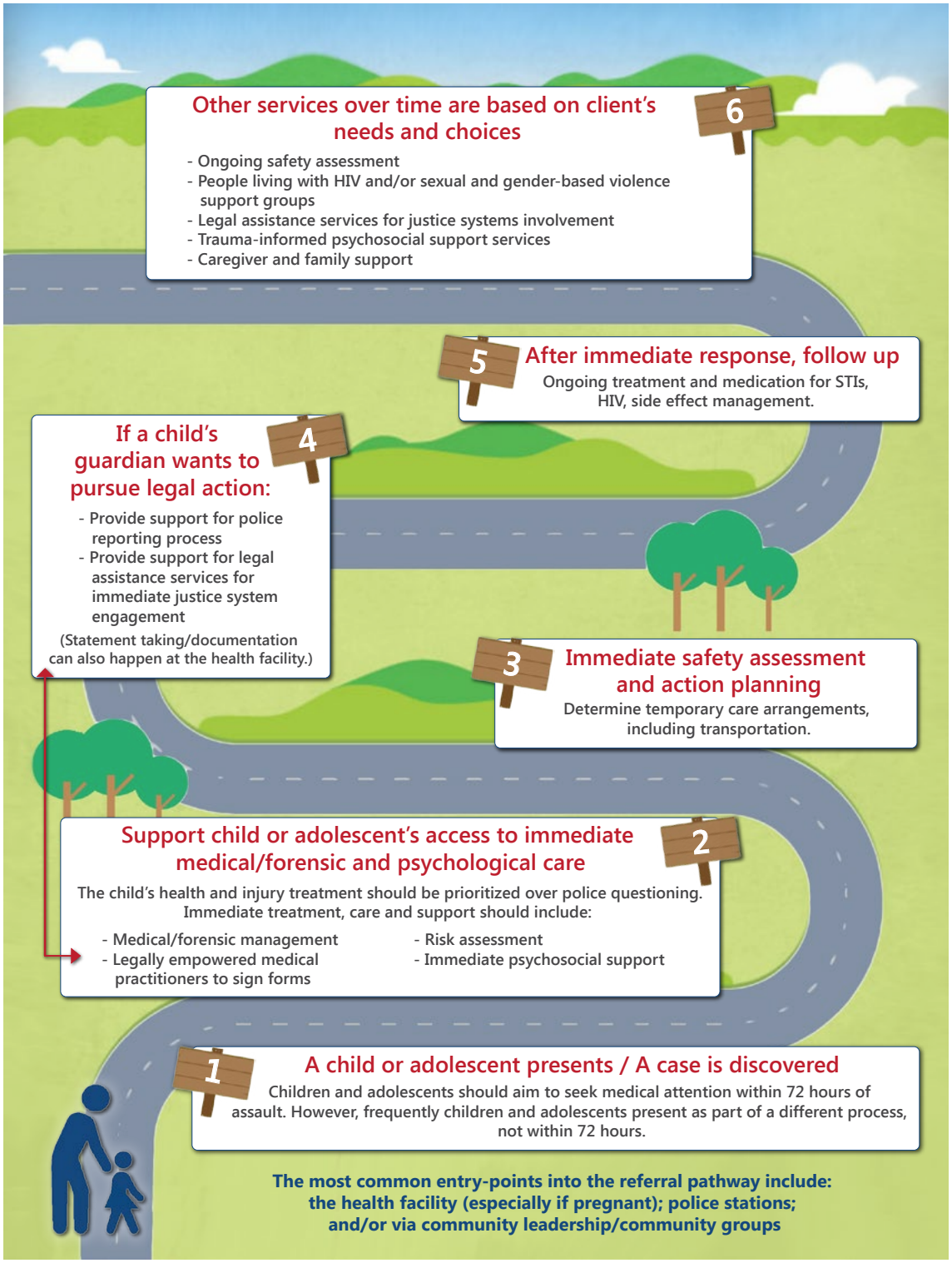
Table 5.1. Different Forms of Child Abuse among Children and Adolescents and Role of HCP

FORM OF ABUSE	ROLE OF HEALTH CARE PROVIDER
Physical Abuse: The intentional use of physical force against a child that results in—or has a high likelihood of resulting in—harm for the child's health, survival, development or dignity.	Provide preventive education to caregivers, as well as the use of "positive (non-corporal) discipline"; Treat physical injuries; Refer to other support services such as social work, counselling, child protection, and psychiatry.
Emotional/Psychological Abuse: Includes restricting a child's movements, belittling, ridicule, threats and intimidation, discrimination, rejection and other non-physical forms of hostile treatment.	Provide preventive education to caregivers on what is considered abuse and the dangers of abuse; Provide counselling and refer to other support services such as social work, counselling, child protection, and psychiatry.
Sexual Abuse: Participation of a child/adolescent in a sexual act aimed towards the physical gratification or the financial profit of the person committing the act.	Educate child/adolescent and caregivers on recognising sexual abuse and dangers; Provide preventive education; Treat physical injuries; Provide counselling on pregnancy prevention, STI testing and treatment, and PEP based on country guidelines; Refer to other support services such as police, legal support, social work, child protection, counselling and psychiatry.
Neglect: The failure of a parent or other person with responsibility for the child, to provide needed support to the degree that the child's health, safety or well-being may be threatened with harm.	Educate child/adolescent and caregivers on recognising, preventing neglect and on the dangers of neglect; Link to treatment services, such as treatment for malnutrition; Refer to other support services such as social work, parenting education, counselling and other services.

HCPs need to appropriately refer and link the abused child/adolescent (Survivor); **Figure 5.1** below shows a referral pathway that can be utilised when child/adolescent abuse is suspected.

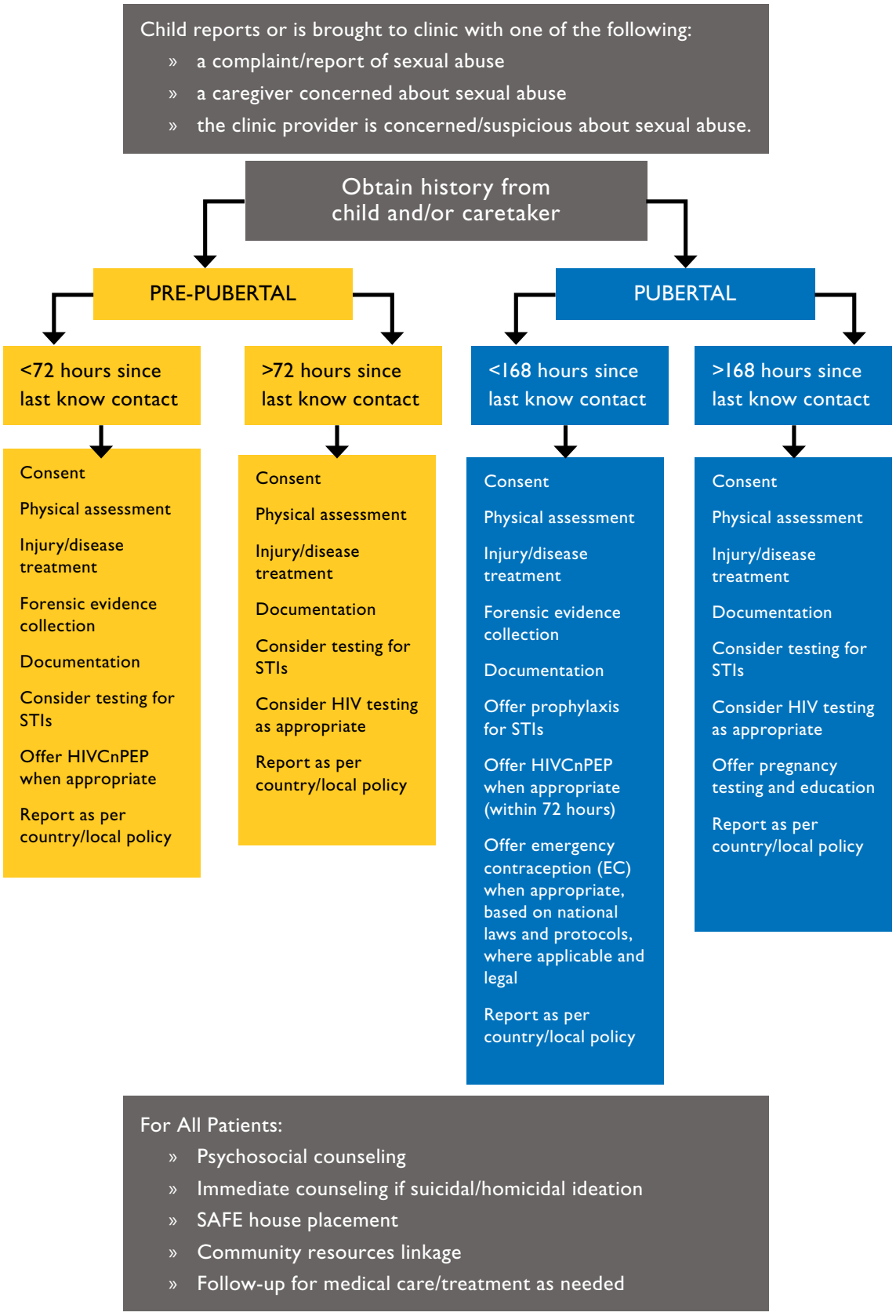
When sexual abuse is suspected, the HCP can follow the care algorithm reflected in **Figure 5.2**.

Figure 5.1. Referral Pathway for a Child/Adolescent Who Has Been Abused



Source: Levy, Marcy, Lyn Messner, Malia Duffy, and Jennifer Casto. 2016. Strengthening Linkages Between Clinical and Social/ Community Services for Children and Adolescents who Have Experienced Sexual Violence: A Companion Guide, available at https://aidsfree.usaid.gov/sites/default/files/2016.2.1_aidsfree_comp_guide_gender_tagged.pdf

Figure 5.2. Care Algorithm for Child/Adolescents Who Have Experienced Sexual Abuse



Source: Day, Kim and Jennifer Pierce-Weeks. 2013. The Clinical Management of Children and Adolescents Who Have Experienced Sexual Violence: Technical Considerations for PEPFAR Programs, available at http://www.cecinfo.org/custom-content/uploads/2013/08/USAID-PEPFAR-Sexual-Assault-Guidelines-2013.pdf

ADDITIONAL RESOURCES

- Clinical Management of Children and Adolescents Who Have Experienced Sexual Violence: This document can help medical providers better address and respond to the unique needs and rights of children who have experienced sexual violence and exploitation. https://aidsfree.usaid.gov/resources/prc-tech-considerations
- Strengthening Linkages between Clinical and Social Services for Children and Adolescents who Have Experienced Sexual Violence: A Companion Guide: This document serves as a companion guide to the above listed resource and provides a framework, examples, and resources for HCP and managers to facilitate linkages with critical social and community services for comprehensive care of children and adolescents who have experienced sexual violence and exploitation, take additional steps to help children and adolescents receive information and support their needs, and contribute to changes in sociocultural norms that perpetuate a culture of violence and silence that can also increase HIV risk and vulnerability. https://aidsfree.usaid.gov/resources/prc-companion-guide

CHAPTER 6: COUNSELLING AND COMMUNICATION

INTRODUCTION

Counselling and communication with children and adolescents is different from that of adults; the language, methods, general skills and techniques should be age-appropriate, purpose-driven, and aligned to developmental needs. The goal is to bring healing, facilitate expression of feelings and concerns, and improve functioning of children and adolescents in their environments. The objectives of counselling and communication with children and adolescents are to help them:

- Deal with painful emotional issues
- Achieve satisfaction of being oneself
- Express thoughts, emotions, and behaviours
- Feel good about themselves
- Accept their own limitations and recognise their strengths
- Change their behaviour and minimise negative consequences
- Learn to function comfortably
- Adapt to the external environment (home, school, and family)
- Act, change, adopt, and/or achieve specified desired results

USE OF MEDIA AND ACTIVITIES

HCP can use techniques below to allow for avenues to help a child express him/herself (also see **Box 6.1**).

- **Play**: Children's natural language is play. It is more than just recreation, since through play children process and understand their experiences. Try to use play to enable children express themselves.
- **Drawing**: This allows children to make pictures which depict events, and make children feel powerful and in control (Woollett et al. 2017).
- **Books and stories**: These encourage the child to alter/direct the narrative, and encourage interactions with the outside world.
- **Games**: These can be selected according to the child's specific skills.

BOX 6.1. WAYS OF ENHANCING CHILDREN'S SELF-EXPRESSION

- Use a quiet tone of voice to help the child feel safe, and show empathy
- Make gestures such as nodding (or others that are culturally appropriate) to encourage the child to continue to talk.
- Use an appropriate degree of eye contact to engage the child; this will vary by culture.
- Listen attentively and demonstrate that you have heard the child—summarise what has been said and seek clarification show that you are actively listening.
- Show respect for the child's feelings through reflection—(e.g., "that must have made you feel very sad/angry."
- Convey empathy so that the child feels that you identify with their situation and feelings.
- Avoid interrupting the child.
- Ask open-ended questions to encourage the child to explain something in his/her own way: for example, a question such as "tell me about your school and friends."

THE COUNSELLING PROCESS FOR CHILDREN

Counselling consists of different activities to help the patient engage in behaviours to resolve the patient's problems. Structured steps and processes provide a clear framework to guide the counselling process; these steps are different in children and adolescents (**Box 6.2**).

BOX 6.2. SEVEN STEPS FOR COUNSELLING CHILDREN

1. **Receive referral**: Collect information about child's behaviour, emotional state, personality, history, cultural background, and the environment in which the child lives.
2. **Contract with parents**: Consult with the parents first, without the child being present to get history, parental understanding, expectations and care thus far.
3. **Join with the child**: Sit with the child in the waiting room. The process begins by first joining with the parents or primary caregiver to allow the child to feel safe and comfortable in the care of their parents.
4. **Enable the child to tell their story**: Builds trust with the child through a conducive environment, including the use of media.
5. **Empower the child**: Let child lead to reinforce his/her mastering of the problem.
6. **Move on—help the child think and behave differently**: Stimulate new ways of thinking and behaving with the child.
7. **Final assessment and evaluations**: Collaborate with the child and the parent or primary caregiver and confirm that further work is not required and offer recommendations. After the final assessment and evaluation, the counselling process can be terminated and the case can be closed.

COUNSELLING AND COMMUNICATION WITH ADOLESCENTS

HCPs working with adolescents should understand adolescent "language" and use the steps below (**Table 6.1**) to effectively counsel them.

Table 6.1. Five Steps for Counselling Adolescents

STEP 1: RAPPORT AND RELATIONSHIP BUILDING

Building a close relationship with adolescents is important for counselling and should be built before counselling starts and maintained from the beginning until the last phase of the counselling intervention. The relationship has been built with the client when the following situations occur:

- The client is willing and feels comfortable enough to talk with you and answer your questions
- The client feels relaxed when talking with you
- The client makes eye contact with you
- The client is actively talking with you

STEP 2: ASSESSMENT

The process of collecting and classifying information related to the adolescent's personhood and reasons for seeking counselling (define problems of concern) by:

- Asking the adolescent directly
- Using a questionnaire: an example is the HEEADSSS assessment tool (***Chapter 1***)
- Determining what the adolescent wants to know and what he/she already knows

STEP 3: GOAL-SETTING

» Work with adolescent to establish concrete goals (guided decision-making)

» Mutually define the process of setting goals. Goal setting involves the counsellor teaching the adolescent how to establish attainable goals by providing the adolescent with appropriate health information.

» The ultimate goal is to change the adolescent's life style into a healthy one

STEP 4: INITIATING INTERVENTIONS

The counsellor needs to provide the adolescent with accurate health information about all available intervention strategies (also a guided decision-making component), including:

- Description of all relevant and potentially useful treatment approaches for this particular adolescent with this particular problem
- Rationale for each procedure that will be used
- Description of the HCP's and adolescent's respective roles in each intervention
- Possible discomforts or risks that may occur as a result of the intervention
- Expected benefits that will occur as a result of the intervention
- Estimated time and cost of each intervention

STEP 5: TERMINATION AND FOLLOW-UP

When the counselling goals are achieved, start a termination process that involves several steps:

Summarising Progress:

- Provide an accurate summary of the adolescent's responsiveness to counselling and to specific types of interventions
- Validate the adolescent's accomplishments and encourage them to take credit for all the steps they have taken towards their goals
- Inject some caution if some counselling gains need reinforcement or monitoring by the adolescent.

Generalising Change:

- The HCP and adolescent should look to how those new behaviours, attitudes, or relationships relate to the client's world. The basic goal of the implementation step is to test the adolescent's willingness and ability to adopt learned skills such as lifestyle changes, or new attitudes to situations other than those that provoked the original problem.

Planning For Follow-up:

- Determine the nature and amount of professional contact that occurs between the HCP and the adolescent after termination of counselling.
- Check whether there is a reoccurrence of the risk behaviour.
- Check whether the adolescent encounters any new health crises or problems.
- For adolescents who believe termination is appropriate but experience anxiety at the prospect, then a 3- or 6-month check-up is suggested and follow-up is dependent upon the adolescent's response.

COUNSELLING FOR HIV DIAGNOSIS IN CHILDREN AND ADOLESCENTS

The aim of HIV testing services (HTS) is to accurately diagnose HIV infection early, and to ensure early access to prevention, treatment and/or support services. HTS should be provided in a non-discriminatory way using a human rights approach that observes the 5 Cs: **C**onfidentiality, **C**onsent, **C**ounselling, **C**orrect test result, and **C**onnection to appropriate services (WHO 2015).

HTS delivery involves four major steps (**Table 6.2**).

Table 6.2. Steps in the HTS Process for Children and Adolescents (WHO, 2013)

STEP	ACTIVITY	DESCRIPTION
1.	Pre-test information giving and counselling	Educate patient/caregiver on the transmission of HIV and basic HIV preventive measures, benefits of HIV testing, possible test results and services available, informed consent and confidentiality; conduct a child risk assessment, and fill out the HTS card. Allow patients/caregivers to ask questions.
2.	HIV testing and diagnosis	Blood sample provided for test. For those under 18 months, use the DNA PCR (EID/DBS) test and for those above 18 months, use the antibody test. Refer to the national testing algorithm.
3.	Post-test counseling (individual/couple/ family)	Assess readiness of patient or caregiver to receive results, give results simply; address concerns, disclosure, partner testing, and risk reduction; provide information about basic HIV care and ART care; complete the HTS card and HTS register.
4.	Linkage and referral to other services, and follow-up to ensure that patient remains in care	Provide information about services referred for; fill the copies of referral form; when enroled, enter the patient's information on relevant records. Follow up to make sure that patient was linked to care. Use linkage networks to track patients and retain them in care.

PRE-TEST COUNSELLING

Age-appropriate methods should be used to provide pre-test education, including posters and other educational resources in waiting rooms. According to WHO, providers should educate children, adolescents and their caregivers on the following (WHO Regional Office for Africa 2014):

- Benefits of HIV testing
- Meaning of an HIV-positive and an HIV-negative diagnosis
- Services available in the case of an HIV-positive diagnosis, including where ART is provided
- Potential for incorrect results if a person already on ART is re-tested
- Prescription of prevention options and the importance of partner testing
- Confidentiality of the test result and any information shared by the patient
- Access to HIV-related services/medical care will not be denied if the patient refuses testing; this is a right
- Potential risks of testing to the patient in settings where there are legal implications for those who test positive and/or for those whose sexual or other behaviour is stigmatised

- Benefits of taking ART to the individual and to onwards HIV transmission. When the individual's viral load is undetectable, it translates into the virus not being transmissible, i.e. *Undetectable viral load = Untransmittable HIV ("U=U")*[2]
- Patient's right to ask the provider questions

POST-TEST COUNSELLING

The outcome of the HIV test determines the type of post-test counselling that each patient receives. HIV-positive children and adolescents will need extensive counselling and information for themselves and caregivers prior to their prompt initiation of ART. For those who test negative, counselling need not be extensive—but HCPs should remind high-risk patients to retest at least annually.

HIV-negative diagnosis: Retesting is only required for HIV-negative children and adolescents who report recent or ongoing risk of exposure, such as risky sex (e.g., unprotected sex, commercial sex work, multiple sexual partners) and injecting drug use. Members of key populations should retest at least once a year. Adolescents boys who test negative should be referred to VMMC services if necessary, and adolescent girls who test negative should be referred to (or informed of) PrEP. When sharing HIV-negative results to a child/adolescent, HCP should assess readiness to receive and understand results.

If patient is under age 12 and not participating in high-risk behaviours, HCP should:

- Give results first to caregiver present and equip parents/caregiver to give the results to the child.
- Encourage explaining results to younger child using language he or she will be able to understand.
- Discuss feelings around the result.
- Discuss how HIV is transmitted and how to reduce future risk.
- Explore any psychosocial service needs and identify referrals needed to community-based services.
- Introduce the patient to the linkage facilitator to ensure engagement.

For adolescents:

- Give results to the adolescent first; if caregiver is present, ensure he/she understands the results.
- Explore reactions to the test results.
- Review the meaning of the results.
- Discuss HIV exposure and risk reduction.

2 Undetectable = Untransmittable. Available at: https://www.preventionaccess.org

- Explore motivation to avoid HIV infection.
- Identify barriers to safer practices and identify strategies to overcome the barriers.
- Discuss retesting where applicable.

If the patient is sexually active, or thinking about having sex, HCP should:

- Educate on methods to prevent HIV acquisition and provision of male or female condoms, lubricant and guidance on their use.
- Emphasise the importance of knowing the status of sexual partner(s) and information about the availability of partner and couples testing services.
- Refer and link to relevant HIV prevention services, including VMMC for HIV-negative men, PEP, and PrEP for people at substantial ongoing HIV risk.
- Recommend retesting based on the patient's level of recent exposure and/or ongoing risk of exposure.
- Use this as an opportunity for the patient to ask questions and request counselling.
- Advise on healthy relationships; review relationship safety; and provide gender-based violence (GBV) counselling and link to available resources.

HIV-positive diagnosis: HCP should equip parents/caregivers with the skills to disclose the child's HIV status to them. HCP and counsellors can act a source of support throughout the process.

Key considerations for children

- Children like to communicate with people they trust, who love them, and who provide a sense of security.
- HCP/counsellors can build relationships between children and their caregivers.
- Counsellors must not take over responsibility of the caregiver.
- Each child should be treated as an individual.
- Ensure the child and caregivers understand the consequences of the test.

When sharing results with children/adolescents, HCPs should:

- Meet with child/caregiver separately.
- Recap information from last session with the child and caregiver together.
- Provide and discuss HIV test results.
- Address fears and support appropriately and invite for follow-up visits.
- Use same explanations used in pre-test counselling.
- Allow time for reactions.
- Show positive body language (e.g., sit next to the child, hold his/her hand, talk to him/her directly).

- Acknowledge caregiver's reaction but encourage him/her to support the child.

If sharing HIV-positive results to a child/adolescent, HCPs should say:

- You have a germ that lives in your blood.
- Having this germ means that you may get sick sometimes.
- When the child is ready, say:
  - The name of the germ you have is HIV.
  - What have you heard about HIV? Or, What do you know about HIV?

Correct any misinformation, then tell the child:

- HIV can make someone sick, and medicines are necessary to keep you healthy.
- HIV can harm healthy cells that protect you from sickness.
- (Where applicable) HIV was in your blood when you were born.
- (Where applicable) You got the virus when you were in your mother's tummy.
- You cannot give HIV to anyone just because you are near them.
  - It is okay to play, go to school, and hug your friends and family.
  - They will not get the virus just because you are close to them.
- If you fall and hurt yourself and are bleeding, don't let others touch your blood.
- When healthy cells are damaged by the virus (HIV), your body has trouble staying healthy.
- Without healthy cells you can get sick with a bad cough, diarrhoea, or other things that make you feel bad.
- The medicine that you take will fight this bad virus (HIV) in your blood.
- If you take your medicine every day, your healthy cells can grow back and you can stay healthy.

ADDITIONAL RESOURCES

- Patient Support, Education & Counselling Guideline for Children and Adolescents Living with HIV (Medecins Sans Frontieres): This guideline is designed to provide practical tools and guidance for staff providing patient support education and counselling to children and adolescents aged between 0-18 years and infected with HIV. https://samumsf.org/sites/default/files/2018-02/HIV%20Children%20and%20adolescents%20PSEC%20guideline%202017%20FINAL%20150917.pdf
- Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers (ICAP): Module 4 on Communicating with and Counseling Adolescents reviews and addresses the clinical, social, and psychological manifestations of HIV disease in adolescents, as well as the comprehensive health care needs of ALHIV. http://files.icap.columbia.edu/files/uploads/Module_4_-_PM_Adolescent.pdf

CHAPTER 7: DISCLOSURE TO CHILDREN AND ADOLESCENTS

INTRODUCTION

Disclosure is the gradual process of giving children and adolescents age-appropriate information regarding their HIV status, leading to full disclosure when the child/adolescent has the cognitive and emotional maturity to process this information. HIV status disclosure to children and adolescents is often a sensitive issue. Parents, caregivers, and HCP alike find it difficult to initiate the disclosure process. Many children/adolescents have been tested for HIV and are receiving treatment but have not yet been made aware of their HIV status (Ozoya 2016). Non-disclosure interferes with quality of care and psychosocial support offered. Disclosure to the child/adolescent of their HIV status is important to facilitate developing coping mechanisms which impact self-care including adherence (WHO 2011).

BARRIERS TO HIV STATUS DISCLOSURE

Disclosure barriers may arise from factors within the child/adolescent; they could be parent/caregiver related; or they could arise from HCPs, as outlined in **Table 7.1**.

- **Child/adolescent barriers**: Age of the child or adolescent, cognitive abilities, and illness.
- **Parent/caregiver barriers**: Concerns about self-disclosure, psychological harm, stigma, and guilt.
- **HCP barriers**: Inadequate skills, guidelines, and tools to support the child/adolescent and caregivers through the disclosure process

BENEFITS OF HIV STATUS DISCLOSURE

- **Children/Adolescent benefits**: higher self-esteem, improved adherence and enhanced social support, facilitates transition to self-care.
- **Adolescent-specific benefits**: Allows the opportunity to identify role models, effectively express needs, and gain experience self-managing their health. It builds coping skills and improves self-esteem in a supportive environment with peers who have similar life experiences. It also enables informed sexual and reproductive health decisions including prevention of onwards HIV transmission, use of protection, and partner HIV testing.
- **Parent/caregiver benefits**: Enables children, adolescents, and caretaker to have increased access to complete support, including medical, psychological, and social support.

- **HCP benefits**: Enables improved and open discussion on HIV infection, including HIV disease management with the child, adolescent and their caregivers.
- **Community Benefits**: Reduces stigma and discrimination and myths and misconceptions regarding HIV and promotes a supportive environment for HIV-positive children/adolescents and their families.

DISCLOSURE DEFINITIONS AND CRITERIA

HCP should always consider each child's cognitive-developmental ability when determining readiness for disclosure (Sariah et al. 2016). Children have greater capacity to understand illness, its causes, and its consequences as they grow older and cognitively mature. As such, disclosure is a process that occurs over time (WHO 2011). **Table 7.1** summarises the different types of disclosure and the typical ages at which each of these is expected to occur.

Table 7.1. Disclosure Definitions and Criteria

TYPE	DEFINITION	CRITERIA (WHO, 2016)
Non-disclosure	Non-disclosure happens when the child or adolescent is unaware of his/her HIV status. This is typical in younger children. In older children, negative effects of non-disclosure include: » Anxiety, depression, phobias, and exclusion from peer support groups » Burdens on the caregiver and the HCP due to not revealing the HIV status to the child or adolescent » Loss of trust negatively impacting the relationship with the caregiver, as the child or adolescent may learn about their HIV status from another source. » Poor adherence due to a lack of understanding about why the child is taking his/her medicine	Under 2 years old

TYPE	DEFINITION	CRITERIA (WHO, 2016)
Partial disclosure	Refers to a situation in which the child/adolescent is not fully aware of his/her HIV status but is suspicious. During partial disclosure: » The caregivers either have postponed disclosure or conceal the truth about the diagnosis (disease) and instead tell the children they have another disease, such as heart disease, asthma or sickle cell anaemia during the disclosure process to the child/adolescent. This may be done as an intermediary to full disclosure, when caregivers and HCPs explain that the child has a disease and that the medicines s/he is taking are to keep his/her body healthy, but do not give the disease or the medicines a name. This is particularly important for children under 8 years of age. » The child or adolescent may have learned of their HIV status from a person external to their social network, or through overhearing others discussing it. » There is a tendency for the child or adolescent to ask the HCP or their caregiver questions about HIV infection, disease, and treatment. In some instances, the child or adolescent may have misconceptions around the disease and ART, including thinking that ART is a cure.	3-9 years of age
Full disclosure	When the child or adolescent, caregiver, as well as the HCP, mutually agree that the child/adolescent know their HIV status and understand its management. The provider should work towards achieving full disclosure, while mutually engaging the child/adolescent and caregiver	Starting at 10 years of age

THE DISCLOSURE PROCESS

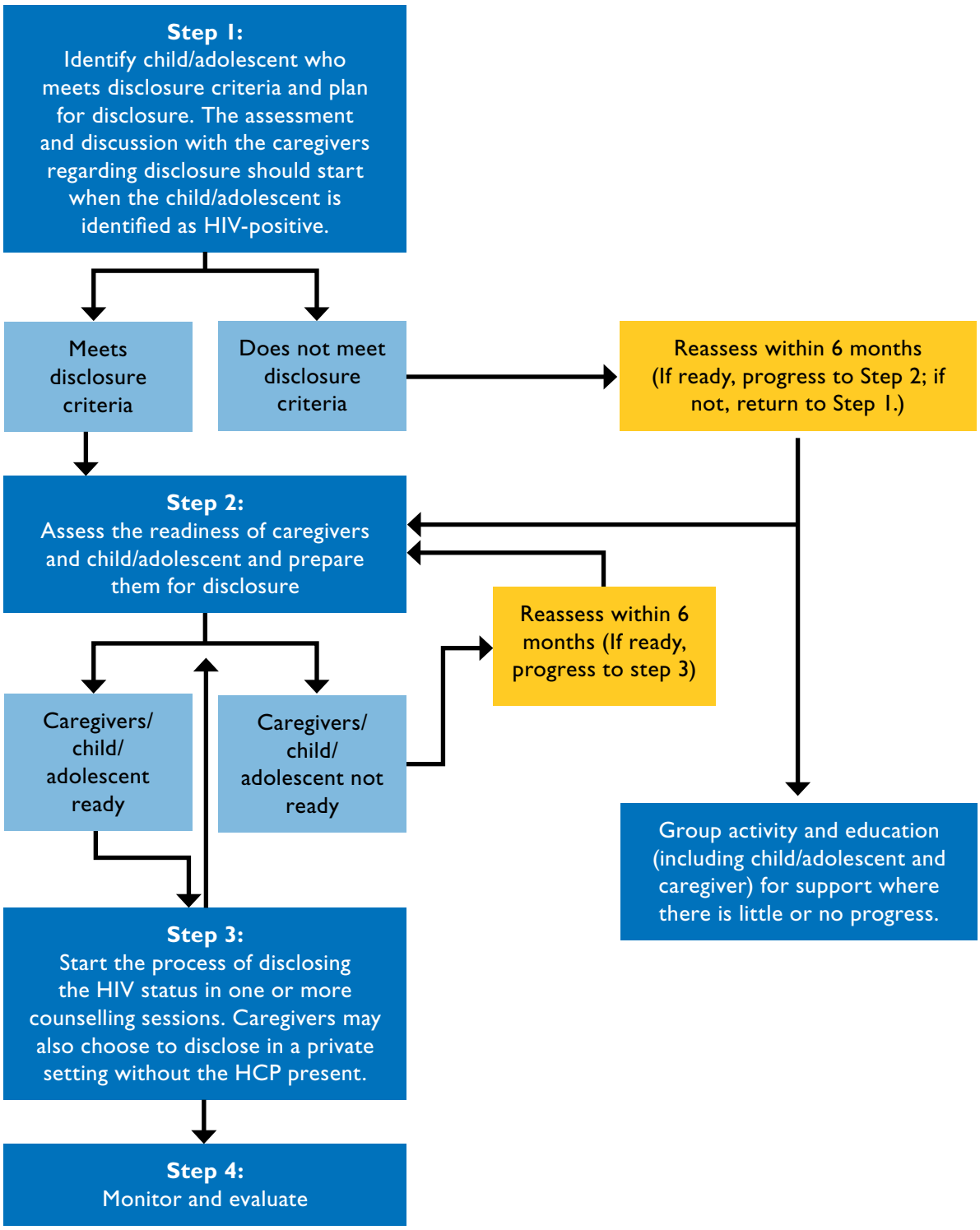
Disclosure is not a onetime event but a gradual process that involves various phases/steps, as illustrated in **Figure 7.1**

ADDITIONAL RESOURCES

» Patient Support, Education & Counselling Guideline for Children and Adolescents Living with HIV (Medecins Sans Frontieres): This guideline is designed to provide practical tools and guidance for staff providing patient support education and counselling to 0–18-year-old HIV-positive children and adolescents. https://samumsf.org/sites/default/files/2018-02/HIV%20Children%20and%20adolescents%20PSEC%20guideline%202017%20FINAL%20150917.pdf

» Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers (ICAP): Module 4 on Communicating with and Counseling Adolescents reviews and addresses the clinical, social, and psychological manifestations of HIV disease in adolescents, as well as the comprehensive health care needs of ALHIV. http://files.icap.columbia.edu/files/uploads/Module_4_-_PM_Adolescent.pdf

Figure 7.1. Steps in Disclosure of HIV to Children and Adolescents



CHAPTER 8: LOSS, GRIEF, AND BEREAVEMENT

INTRODUCTION

Grief is a neglected aspect of care for HIV-positive children and adolescents. Many HCPs are not trained to address grief. Recent advances in HIV care, including widespread use of ART, have led to fewer children and caregivers being terminally ill or experiencing loss; which is a positive development. For those children and adolescents who do experience bereavement in childhood, that experience can increase vulnerability to mental health problems later in life (Woollett et al. 2017). Addressing loss, grief, and bereavement in HIV-positive children/adolescents can mitigate psychological complications, facilitate resilience, and help these young people live positive lives—and possibly help others do the same (Li et al. 2015).

HELPING CHILDREN AND ADOLESCENTS RESPOND TO LOSS, GRIEF, AND BEREAVEMENT

Table 8.1. Effects of Grief and Age-Appropriate Responses

AGE-RELATED RESPONSE	HCPs' ROLE
Babies (0–3 years old)	
» Inability to talk about grief, expressing it physically » Crying, regressive behaviour » Delayed progress in speech, walking » Fearfulness, clinginess » Problems with eating, sleeping, or toilet habits » Development of comfort habits, such as thumb-sucking	» Patience—it can take a year or longer before progress is made in independence and confidence » Showing love, attention, and patience » Familiar routines » Prayer in family's spiritual tradition

AGE-RELATED RESPONSE	HCPs' ROLE
Preschoolers (3–5 years old)	
» More difficult to calm down » Naughty behaviour, due to emotional stress and hurt » Physical expressions of grief » Outbursts » Refusal to be comforted » Fluctuation between being happy and sad within minutes » Repetition of questions » More understanding than is verbalised » Regressive behaviour » A developed sense of right and wrong	» Patience—recovery can take up to two years » Hugs, attention, cuddles » Making them feel important by, for example, asking them to help with activities in the home » Encouraging them to talk about the event through stories, puppets, and art » Helping them understand it is not their fault; and that they can't wish something into being » Memory work (appropriate for all ages) » Maintenance of routines » Prayer in family's spiritual tradition
Children (6–12 years old)	
» Ability to think logically, talking and remembering » Ability to understand what causes death » Tendency to recover faster than younger children » Grief similar to adults and older children » Loss of concentration and poor school work » Aggression » Aches and pains » Nightmares and anxiety attacks » Feelings of helplessness and vulnerability to further loss	» Non-judgemental listening » Encouraging expression of feelings through means such as art » Allowing the name of the deceased person to be mentioned » Supporting a loving relationship with the caregiver » Providing structure and stability » Allowing the child to be a child, to have fun without guilt » Providing opportunities to help others, regain sense of control, value, and belonging » Prayer in family's spiritual tradition
Adolescents	
» Feelings of weakness and helplessness » Understanding that death is irreversible/final » Ambivalence about their bodies » Life crisis of transition to adulthood » Denial of feelings, seeing the need for consolation as immature » Anger and rebellion » Lack of trust, feelings of being let down » Risky behaviours including running away, seeking out undesirable peers, promiscuity, substance abuse, eating disorders, suicidality, depression, morbid thoughts	» Peer support » Recreation » Having a trusted adult to talk to » Respite, such as walks or camp with caregiver » Creating interest in the future » All interventions described above for children 6 to 12 years old

HCPs main role, when a child or adolescent is grieving, is to provide support. To do this, they should:

- Show genuine concern and care.
- Not be afraid to let a child see you cry or express your sadness in other ways.
- Be available to the child. Listen to them, talk with them, give them a hug, or whatever else seems needed at the time.
- Provide more attention and physical contact at times of loss.
- Express sorrow about what happened and the pain the child must be feeling.
- Allow the child to express as much grief as he/she is feeling and as much as she/he wants to share.
- Talk about the physical changes that occur after death. For example, the dead person's body stops all functions–heart stops beating, breathing stops, and can no longer feel pain. Otherwise, the child may have terrible thoughts about the burial process.
- Use caution in explaining death. For example, referring to death as a sleep can result in tremendous fears about sleep. In addition, describing the deceased loved one as having "gone away" may lead the child to feel abandoned and feel that the deceased had a choice.
- Allow the child to talk about the loved one who has died as much and as often as he/she wants to. Sometimes this may become extremely repetitive, but it is useful to the child in understanding and coping with his/her loss.
- Answer questions the child asks, even if they seem to be strange questions. It may be useful to ask him/her what thoughts led to the question. Sometimes this technique can reveal misunderstandings about death.

When dealing with children and adolescents living with HIV, there are situations when a child will need to be told about unpleasant aspects of their illness; possibly including an impending death. Sharing a terminal diagnosis requires careful preparation, using a series of steps as shown in **Table 8.2**.

Table 8.2. Sharing Difficult Information

STEPS	HCP'S ROLE
Step 1: Set up the session	» Arrange for privacy and make sure that there will be no interruptions » Involve significant others as appropriate » Sit down » Connect with the patient using eye contact and touch (as appropriate) » Tell the patient that you have time to spend with them.

STEPS	HCP'S ROLE
Step 2: Assess the person's perception	» Use open-ended questions; for example: "What have you been told about your condition so far?" » Gather information to explore the patient's perception of the situation » Explore ideas, concerns, and expectations » Correct misinformation as necessary » Determine whether the patient is in denial
Step 3: Obtain the person's invitation	» Find out how the patient would like to receive the information (this is also a useful step at the time of ordering tests, so both doctor and patient are prepared for the way the results should be given) » Gauge how much information the patient wants
Step 4: Give knowledge and information to the person	» Warn the patient that bad news is coming; one could say: "Unfortunately I have got some bad news to tell you" » Break the information into small chunks » Use appropriate language and check for understanding of each chunk of information
Step 5: Address the person's emotions with empathic responses	» Look out for the patient's emotional reaction » Identify the emotion, such as anger and sadness » Identify the reason for the emotion, asking the patient if necessary » Make an empathic statement to acknowledge the emotion
Step 6: Strategize and summarise	» Present treatment options » Share decision-making » Reach consensus » Plan follow-up: this should be based on reactions; to begin, it can be weekly, then monthly, and subsequently quarterly » Link the patient to community resources, such as peer support and community-based organisations

ADDITIONAL RESOURCES

» No Secrets: Helping Families and Carers Talk to Children About Life-limiting Illness Guide for Healthcare Workers in Malawi: This illustrated booklet is designed to help health care workers to encourage families and carers to talk to children about their life-limiting illness. http://www.comminit.com/hiv-aids-africa/content/no-secrets-helping-families-and-carers-talk-children-about-life-limiting-illness-guide-h

CHAPTER 9: ADHERENCE TO ANTIRETROVIRAL THERAPY

INTRODUCTION

As children/adolescents initiate ART, adherence remains critical for optimal health. Consistent adherence can improve clinical outcomes, reverse severe HIV-related diseases, and decrease the risk of developing drug-resistant mutations. Also, because ART adherence suppresses HIV viral loads, it can reduce risk of HIV transmission both to sexual partners and to an unborn child. HCP should continually assess ART adherence and address adherence barriers to optimise positive living (Shubber et al. 2016; Kim et al. 2016).

ADHERENCE COUNSELLING

The "5 A's" (**Table 9.1**) are used during adherence counselling; they include **A**ssess, **A**dvise, **A**gree, **A**ssist, and **A**rrange and to can help HCPs assess knowledge of HIV, ART and potential barriers to adherence; provide knowledge about HIV and ART and work with the child/adolescent to derive an agreed position on ensuring adherence (Achappa et al. 2013).

Table 9.1. Guidance on Use of the 5 As for Adherence Preparation and Support

GUIDE	COMPONENTS
Assess	**Assess knowledge of HIV, ART, and potential barriers to adherence:** » Knowledge about HIV and ART » Identify myths and misconceptions about HIV and ART » Potential barriers to adherence » Psychosocial concerns and needs that may hinder adherence to ART » Willingness and commitment to take medicines correctly » Readiness to honour subsequent appointments for treatment support » Availability of support systems at family and community level » Disclosure status and implications

GUIDE	COMPONENTS
Advise (information giving)	**Provide knowledge about HIV and ART:** » How ART stops the multiplication of HIV » Provide information on adherence to ART; including the 5 Rs: (taking the **R**ight medicine, at the **R**ight time, in the **R**ight dose, the **R**ight way, and the **R**ight frequency) » Demonstrate how ART is taken » Provide information on the side effects of ART, improved quality of life while on ART, changes that may occur in a person's life once on treatment » Describe benefits of disclosure and support systems to adherence » Outline how patients will be monitored once on treatment and frequency of monitoring; also other ways of assessing adherence and response to treatment, including pill counts » Emphasise the importance of attending all the clinic appointments for review and support » Discuss the Positive Health, Dignity, and Prevention package (available in the Handbook) » Describe the risks associated with not adhering to treatment » Explain what the viral load test is, and the meaning of suppressed and unsuppressed viral load
Assist	**Assist the adolescent and or caregiver to:** » Evaluate the possible barriers to adherence and how to overcome them » Identify support systems such as treatment supporters, or social support groups that will help him or her to take the medications and to regularly visit the facility » Disclose to a trusted person of their choice such as a treatment supporter, social support group, etc. » Develop an individual adherence support plan » Document the agreed-upon options on the ART card
Agree	**Agree upon:** » An adherence plan » Family and community support systems (such as an expert patient in the community) » Possible home visit and consent » Possibility of testing other family members, including sexual partner and children » The child/adolescent 's readiness to start ART

GUIDE	COMPONENTS
Arrange	**Arrange:** » For the patient to see a clinician for ART prescription if they are ready to start » Follow-up adherence counselling and psychosocial support sessions: • At 1 month for patients who have initiated ART • At agreed time, but probably a week, for those who were not ready for ART at the initial visit » For patient to join PSS groups and use support systems » Follow-up appointment system (home visiting where appropriate, phone call reminders and text messages where appropriate) » Monthly counselling sessions for drug adherence » To review the action plans at every encounter » When to bring other family members for testing » Supported disclosure where it has not happened

ASSESSING ART ADHERENCE

Self-Report: Self-reporting of missed ART doses is quick, inexpensive, and easily carried out (**Table 9.2**). It entails asking questions regarding missed doses to establish adherence levels; elicit knowledge of the medication regimen, number of tablets to be taken, frequency of medications, and any barriers/enhancers to good adherence (Stirratt et al. 2015).

Table 9.2. Questions to Assess Self-Reported Adherence to ART

QUESTIONS	RESPONSE
1. How many doses did you miss/child miss over a defined period (1, 3, or 7 days)?	
2. What medication regimen do you/does the child take?	
3. What medicines do you/does your child take (name/appearance)?	
4. How many tablets and how many times do you/does your child take per day?	
5. What factors have led you not to take or give medicines very well?	

Pill Counts: Adherence levels can also be assessed via counting pills (Achappa, Madi, and Bhaskaran 2013). To do this, HCPs can:

- Count the number of pills the patient has in the medicine bottle.
- Determine the number of pills the patient should have taken since the last clinic visit.

  Compute the % adherence using the formula below:

$$\%\ adherence = \frac{number\ of\ pills\ taken}{Total\ number\ of\ pills\ expected\ to\ have\ been\ taken} \times 100$$

- After computing % adherence, determine the adherence level and support the patient accordingly.
- The adherence level is then determined with an action plan, as summarised in **Table 9.3**

Table 9.3. Action Plan Based on Adherence Levels from Self-reports and Pill Counts

MISSED DOSES PER MONTH		PERCENTAGE ADHERENCE	ADHERENCE RANKING	RECOMMENDED ACTION
ONCE-DAILY DOSING	TWICE-DAILY DOSING			
<2 doses	≤ 2 doses	≥95 percent	Good	Review adherence plan. Support to continue adhering well.
2-4 doses	4–8 doses	85-94 percent	Average	Address the causes of average/poor adherence. Review adherence plan.

SUPPORTING OPTIMAL ART ADHERENCE

Interventions to support children/adolescents and their caregivers should be selected carefully and in context with the child/adolescent's clinical status. At every opportunity, the HCP should assess for barriers to adherence using the HEEADSSS tool (**Table 1.1**) and use the 5 "As" (**Table 9.1**) to address them. HCP should be proactive and support children/adolescents to have sustained good adherence to ART. **Box 9.1** offers further guidance.

BOX 9.1. GUIDANCE ON SUPPORTING CHILDREN/ADOLESCENTS TO ENSURE SUSTAINED GOOD ADHERENCE TO ART

- Build a strong relationship with the child/adolescent client and their parent/caregiver as age appropriate.
- Customise the treatment regimen to the individual child/adolescent's lifestyle in alignment with national guidelines.
- Manage any co-existing medical conditions, such as mental illnesses and stigma-related issues, which may affect adherence.
- Provide appropriate information to guide decision-making and influence behaviour.
- Defer treatment until adherence is more likely or while adherence-related problems are aggressively addressed. [**Note**: If deferral of treatment is decided, it should to be in the best interest of the child/adolescent; the deferment should be ***brief*** with rapid implementation of planned interventions to support adherence and close follow-up to avoid delays in the initiation of life-saving treatment]
- Empower the child/adolescent to deal with adherence challenges and use motivational enhancement approaches.
- Evaluate adherence at regular intervals.
- Provide ongoing adherence support through social support structures; and address all possible barriers to adherence at every opportunity, using family and peer support. Share barriers in PSS groups, and help strengthen adherence by sharing barriers and working out possible solutions.
- For older adolescents, handle the transition process to adult care clinics cautiously, especially for those who have not attained full functional autonomy, to avoid creating a break in positive adherence behaviour.

ADDITIONAL RESOURCES

- Ariel Adherence Clubs: An approach to Increase Retention and Adherence among Children and Adolescents living with HIV in Tanzania. Described on the PEPFAR Solutions platform, this resource provides an overview of the evidence-based adherence clubs that can be contextualised for each country setting to enhance adherence among children and adolescents living with HIV. https://www.pepfarsolutions.org/infants-children/2018/1/13/ariel-adherence-clubs-an-approach-to-increase-retention-and-adherence-among-children-and-adolescents-living-with-hiv-in-tanzania#
- Supporting children, adolescents and young people living with HIV to start and stay on HIV treatment. This case study provides an overview of the Zvandiri programme's Community Adolescent Treatment Supporters peer-led model. https://www.aidsalliance.org/assets/000/003/310/alliance_zvandiri_case_study_jan_2018_web_original.pdf?1516015222

CHAPTER 10: ADOLESCENT SEXUAL AND REPRODUCTIVE HEALTH

INTRODUCTION

Adolescence is a unique period in life. During adolescence, girls and boys undergo extensive biological and psychological changes while simultaneously experiencing changing societal roles and expectations. It is a continuum of physical, cognitive, behavioural, and psychosocial change characterised by increasing levels of individual autonomy, a growing sense of identity and self-esteem, and progressive independence from adults. The developmental, physiological, and behavioural changes that take place during adolescence can contribute to an increased risk of contracting HIV and other STIs and unplanned pregnancy (WHO 2015b).

ASSESSING FOR SEXUAL AND REPRODUCTIVE HEALTH NEEDS

HCPs sometimes find it challenging to discuss sex-related topics with adolescents. However, it is critical to provide adolescents with information on sexual activity, risky behaviours that may lead to unintended health outcomes, and protective behaviours, and to assess for the presence of STIs in boys and girls so that they can protect themselves and their loved ones when they choose to become sexually active. **Table 10.1** outlines questions that can be used to assess sexual and reproductive health (SRH) needs of adolescents to determine service and counselling needs and referrals.

Table 10.1. SRH Needs Assessment and Counselling Tool: Guiding Questions

QUESTIONS AND DISCUSSION TOPICS
Have you thought about having children one day? *Discuss general concepts of conception and pregnancy, as well as roles of parenting for young men and young women.*
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 an overview of family planning methods and options. For adolescent males, have discussions regarding fatherhood and how they can have considerations with their partners for mutually agreed-upon decisions that will support both their desires/goals.*

QUESTIONS AND DISCUSSION TOPICS
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 options to change to another method, 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 the risk of HIV transmission via unprotected sex.*
Tell me what you know about reducing the risk of transmission between you and your partner when trying to conceive. *Explain the safest times (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. Explain the basics of mother-to-child transmission.*
What do you know about PMTCT services? Let's talk about reducing the risk of transmitting HIV to your baby. *Link to PMTCT 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?

Source: Duffy, Malia H., Heather Bergmann, and Melissa Sharer. 2014. Toolkit for Transition of Care and Other Services for Adolescents Living with HIV. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1, available at http://pdf.usaid.gov/pdf_docs/pnaec759.pdf

CONTRACEPTION OPTIONS FOR ADOLESCENTS LIVING WITH HIV

Contraception (birth control) prevents pregnancy by interfering with the normal process of ovulation, fertilisation, and implantation. There are different kinds of birth control that act at different points in the process.

Family planning is when an individual or couple makes a voluntary, informed decision on when to start having children, how much time they need between babies, how many children to have, and when to stop having children. This can be done by using a family planning method of their choice. Family planning can be used by anybody irrespective of age, socioeconomic status, and marital status. **Table 10.2** outlines examples of family planning methods and the clinical scenarios where they are applicable (Nanda et al. 2017).

Table 10.2. Family Planning and Clinical Scenario Guidance

METHOD	INDICATION
Spermicides	» Not indicated for HIV-positive women and HIV-negative women at high risk of HIV, as they may increase risk of HIV acquisition.
The Pill, ring, patch, combined injectable, or mini-pill	» Not indicated for women on ART regimens containing ritonavir » Women taking other ART regimens (NRTIs and NNRTIs) CAN use these methods. » Women taking NRTIs and NNRTIs should take a preparation containing a minimum of 30 micrograms of Ethinyl Estradiol. » Rifampicin and rifabutin (used for TB treatment) lower effectiveness of the Pill, patch, ring, combined injectable, NET-EN injectable, mini-pill, and implants. Use of other contraceptives should be encouraged for women who are long-term users of either rifampicin or rifabutin. » The effectiveness of DMPA injectable is not decreased when taken with ART. » Correct use of the method with condoms increases contraceptive effectiveness.
IUD	» Not indicated if she has a current purulent cervicitis, gonorrhoea or chlamydia, cervical cancer awaiting treatment, or is unwell with an AIDS-related illness.
Condoms alone	» Prevent transmission of HIV and other STIs during sexual intercourse. » Effective in preventing pregnancy—when used consistently and correctly.
Condoms and a hormonal method (dual protection)	» More effective protection from pregnancy than condoms alone, particularly if partner will not always use condoms.

SCREENING FOR STIS

HCPs should provide routine education about STIs, how they are transmitted and screening for their symptoms and signs. Those with risk factors for STI should be counselled and if they are already infected, provided with prompt treatment or referred. **Table 10.3** outlines common signs and symptoms and which STI they suggest (WHO 2018).

Table 10.3. Common Signs and Symptoms That May Suggest an STI

SYMPTOMS	POSSIBLE CAUSE
Discharge from the penis—pus, clear or yellow-green drip	Commonly: Chlamydia, gonorrhoea Sometimes: Trichomoniasis
Abnormal vaginal discharge or pain during sex	Chlamydia, gonorrhoea, pelvic inflammatory disease
Burning or pain during urination	Chlamydia, gonorrhoea; herpes
Lower abdominal pain or pain during sex	Chlamydia, gonorrhoea, pelvic inflammatory disease
Swollen and/or painful testicles	Chlamydia, gonorrhoea
Itching or tingling in the genital area	Commonly: Trichomoniasis Sometimes: herpes
Blisters or sores on the genitals, anus, surrounding areas, or mouth	Herpes, syphillis, chancroid
Warts on the genitals, anus or surrounding areas	Human papillomavirus
Unusual cervical discharge – changes from normal vaginal discharge in colour, consistency, amount, and/or odour	Most commonly: bacterial vaginois, candidiasis. Commonly: Trichomoniasis Sometimes: Chlamydia, gonorrhoea

Adapted from: Family Planning: A Global Handbook for Providers, 2018 Edition

SCREENING FOR CERVICAL CANCER

Adolescent girls living with HIV experience higher risk of acquiring human papillomavirus (HPV) which predisposes them to cervical cancer. WHO recommends the HPV vaccine for girls between the ages of 9–13 years. Immunocompromised individuals including adolescents living with HIV should therefore be screened for cervical cancer and managed as per the findings (WHO 2013). **Table 10.4** provides some information about cervical cancer and how it can be assessed for and prevented.

Table 10.4. Cervical Cancer: Screening and Prevention

WHAT IS CERVICAL CANCER?
» Results from uncontrolled, untreated growth of abnormal cells in the cervix as a result of the human papillomavirus (HPV) infection.
» HPV is found on skin in the genital area and also in the tissues of the vagina, cervix, and mouth. It is primarily transmitted through skin-to-skin contact.
» While cancer of the cervix takes many years to develop following HPV infection, HIV-positive girls and women experienced increased morbidity and mortality due to cervical cancer, particularly in sub-Saharan Africa, where cervical cancer screening and treatment are suboptimal. Cancer of the cervix usually takes 10 to 20 years or more to develop following HPV infection, and so there is a long period of opportunity to detect and treat changes and precancerous growths before they become cancer. ***The goal of cervical cancer screening is early detection and treatment of precancerous growths before they become cancerous.***

WHO IS AT GREATEST RISK?

Some factors make women more likely to be infected by HPV and progress to cervical cancer, for example:

- Having many sexual partners now or over the years
- Having a sexual partner who has or has had many other sexual partners
- Having a weak immune system (includes women living with HIV)
- Having other sexually transmitted infections, such as herpes simplex, chlamydia, and gonorrhoea
- Having had many births (the more births, the greater the risk)
- Young age when she first gave birth
- Smoke tobacco
- Have used combined oral contraceptives for more than 5 years. (This factor is weak. WHO notes that it is not in a woman's interest to discourage or prevent her from using COCs)

SCREENING AND TREATMENT

- Screening for cervical cancer is simple, quick, and generally not painful.
- Women aged 30 years and older and all women living with HIV should be screened for cervical cancer.
- The screening should be repeated every 3 to 5 years.
- Any precancerous cervical changes that are detected can be treated successfully.
- If a test finds precancerous changes, they must be treated to prevent progression to cancer.
- These changes can be removed by freezing with a probe (cryotherapy) or cut away using a hot wire loop (loop electrosurgical excision procedure [LEEP]).
- Treatment for cervical cancer includes surgery or radiation therapy, sometimes together with chemotherapy.
- Treatment can be effective if the cancer is detected early.
- Women with advanced cervical cancer, however, have a high mortality rate.

PREVENTION

- Vaccines against HPV exist
- The vaccines are most effective when administered to girls before they become sexually active.

Adapted from:Family Planning: A Global Handbook for Providers, 2018 Edition

ADDITIONAL RESOURCES

- The Essential Packages Manual: Sexual and Reproductive Health and Rights Programmes for Young People (COMMINIT) is designed to be a comprehensive guide for successful sexual and reproductive health and rights (SRHR) programmes for young people. It seeks to help organisations to critically review programmes and identify gaps and areas to improve a programme in line with a rights-based, gender-transformative, and youth-centred approach. http://www.comminit.com/hiv-aids-africa/content/essential-packages-manual-sexual-and-reproductive-health-and-rights-programmes-young-peo
- Sexual Orientation, Gender Identity, HIV and Human Rights: An Advocacy Toolkit (COMMINIT) provides user-friendly guidance, case studies and tools specifically directed at strengthening and promoting advocacy towards the rights of lesbian, gay, bisexual, transgender and intersex individuals in Southern and Eastern Africa. http://www.comminit.com/hiv-aids-africa/content/sexual-orientation-gender-identity-hiv-and-human-rights-advocacy-toolkit

CHAPTER 11: TRANSITION OF SERVICES

INTRODUCTION

Transition refers to a purposeful, planned process that provides comprehensive, developmentally appropriate health care in a coordinated and uninterrupted manner to children and adolescents living with HIV. Focused on developing skills for self-management of HIV, transition should be child-/adolescent-centred and facilitate the pathway to an adult-oriented health care system of HIV care and support. Transition takes into consideration both age and developmental readiness, in the context of the patient's physical, medical, psychological, and social needs. It focuses on building greater self-management skills for HIV care so that the child/adolescent gradually takes on greater responsibility for their own health-seeking behaviours and well-being over time (Dahourou et al. 2017). The model of transition depends on the structure and setting of the health care services. **Figure 11.1** shows the commonly adopted models and **Figure 11.2** shows the steps that typically occur during transition.

Transition of services may involve any one or more of the following:

- Changing physical space where the health care is provided
- Transitioning to specialised clinic days
- Transitioning to a specialised care team

In many cases, the child or adolescent may not physically transition to a different provider or service location, but instead will transition to self-management of their own care within the same service framework, gradually increasing their independence in making appointments, collecting their medicine, and contacting their health provider with questions or when they feel ill. For these reasons, it is critical to build the knowledge and self-management skills of all clients regardless of whether a physical transition occurs (Duffy, Bergmann, and Sharer 2014).

Transition is a process that occurs over time while the HCP, child/adolescent, and family/caregiver work together to build the child/adolescent's knowledge and self-care skills so that they are able to move towards the next step in their care (i.e., adolescent or adult health services).

TRANSITION OF CARE BENEFITS AND BARRIERS

Health transition benefits:

- Promotes positive self-image.
- Promotes self-reliance.
- Promotes a sense of competence.

- Allows for meaningful independent living.
- Supports social and emotional development.
- Supports long-term planning and working to achieve life goals.
- Broadens systems of interpersonal and social support (Hussen et al. 2015).

Barriers may be encountered throughout transition. Anticipating these can help them to be addressed at all levels (individuals/adolescent, the family, the community, the HCP, the health system). **Table 11.1** summarises common barriers and solutions.

KEY CONSIDERATIONS FOR TRANSITION

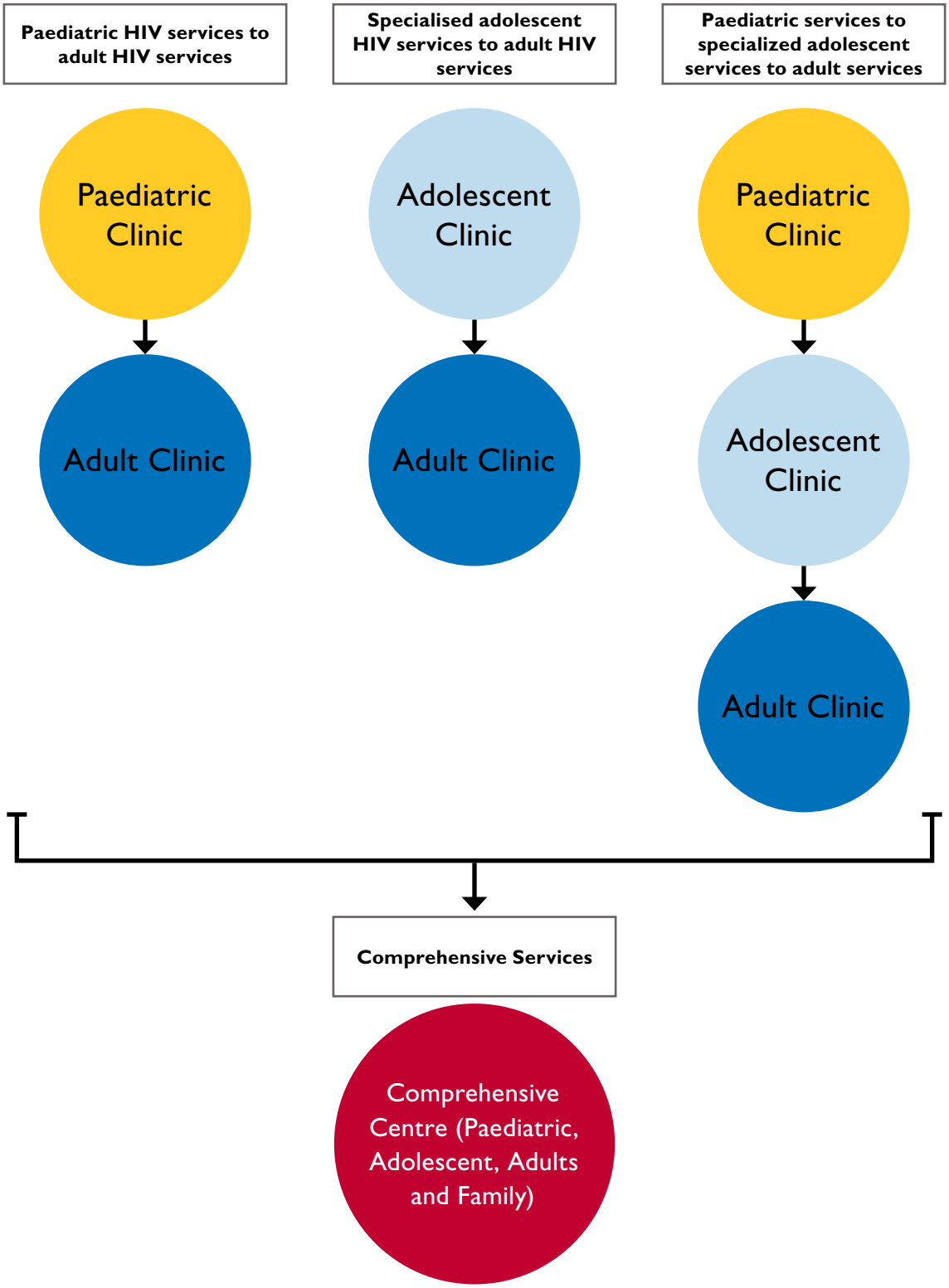
To facilitate a smooth transition, the following should be carried out:

- Individualising the approach for each child and adolescent based upon where they are developmentally and their ability to take on greater self-management of care.
- Identifying HCPs who are willing to engage in the transition process.
- Beginning the transition process early.
- Developing and following an individualised plan together with the child/adolescent and parent/caregiver.
- Using a multidisciplinary transition team.
- Addressing comprehensive care including clinical and psychosocial needs of each child/adolescent.
- Allowing children and adolescents to express their opinions.
- Educating HIV care teams and staff about transitioning.

Throughout this process, there are discussions that need to be held with children and adolescents at various ages to ensure they gain the necessary knowledge and self-care skills. Example talking points for the different age groups are reflected in the **Table 11.2**.

At least bi-annually, HCP should work with the child/adolescent to establish self-management goals and assess self-management skills. **Table 11.3** can be used to track self-management goals and accomplishments over time to monitor readiness for transition. When the adolescent has accomplished the outlined self-management tasks, they should be prepared for service transition.

Figure 11.1. Transition Models[3]



3 Adapted from Barton, Tess, Ana Puga, and June Trimble. 2015. "Transition from Adolescent to Adult Care: Practices and Pitfalls." University of Texas Southwestern: Dallas, TX. https://doi.org/http://dx.doi.org/10.1016/j.jns.2015.09.290.

Figure 11.2. Transition Steps

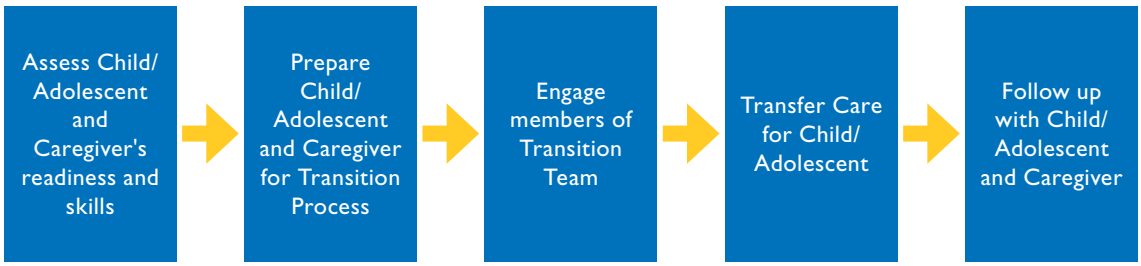


Table 11.1. Common Transition Barriers[4] and Solutions

BARRIERS TO TRANSITION	ADDRESSING THE BARRIERS
Adolescent related • Delayed cognitive ability to engage in the transition process • Emotional attachment to paediatric HCP, especially for OVC • No transport funds • Not accessing or sporadically attending services • Not applying information and support • Not aware of diagnosis • Not understanding transition requirements • Pregnancy • Resists transition • Self-stigma • Stress of diagnosis	1. **Time the transition**: Paediatric and adolescent HCPs should begin discussing the transition process with children and adolescents early, preferably shortly after disclosure occurs or early in adolescence—preparing patients and families well ahead of time for the transition to adult services. 2. **Coordinate between paediatric, adolescent and adult services**: As much as possible, all HCPs, including paediatric, adolescent and adult providers, should interact closely and communicate the progress and impact of the transition on the child, adolescent, and caregiver. • The best possible option would be to have a focal HCP to oversee the transition process in each respective health care setting. • The focal HCP should facilitate communication and ensure good communication between adolescent and adult providers that includes monitoring and sharing information about the progress of the transition. 3. **Develop an individualised transition plan**: An individualised transition plan should be developed to track the adolescent's mastery of self-management tasks and progress moving towards transition. • The transition plan should take into account the medical, psychosocial, and financial aspects of transitioning.
Family related • Not promoting adolescent autonomy • Not engaged in the care of the adolescent • Not able to provide full support for transition • Stretched thin by not having enough resources to support the family • Resists the physical transition	

4 Sharer, Melissa, and Fullem Andrew. 2012. Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

BARRIERS TO TRANSITION	ADDRESSING THE BARRIERS
Arising from communities • Unsupportive social setting • Stigma • Peer pressure • Unsupportive or absent • Family network • No universal family counselling and testing • Weak institutional support • Weak community support	4. **Link with adult providers who have skills/interest in working with young clients**: HCPs should identify and use adult care providers who are willing to care for and provide PSS to adolescents and young adults. Where possible, the adult provider can visit the paediatric location one time/ week or month (as scheduling allows) to meet the transitioning individuals in a comfortable environment before they transition. 5. **Counsel to reduce concerns**: HCPs should use counselling and information-sharing to address any resistance to transition of care caused by lack of information, concerns about stigma or risk of disclosure, and differences in practice styles. 6. **Orient clients to adult services:** HCPs should build adolescents' skills in navigating the health care system, including: • Appropriate use of a primary care provider • How to manage appointments • The importance of prompt symptom recognition and reporting • The importance of self-efficacy in managing medications HCP can also consider using a "buddy system" where adolescents transition with a peer to help keep them on track.
HCP related • Weak understanding of what is needed to transition • Paediatric providers have insufficient time • Emotional attachment to clients • Adult providers do not understand adolescents' holistic needs • Adult provider not comfortable with adolescents • Unable to plan with adolescents, services, and families for transition • Lack of communication between paediatric and adult providers • Insufficient time for adult HCP to spend with adolescents who have recently transitioned • Resists the transition	

BARRIERS TO TRANSITION	ADDRESSING THE BARRIERS
Health system barriers • Not adolescent-friendly • Focus on clinical management and not inclusive of PSS needs • Information is poorly delivered • Risk of loss to follow-up • Not all adolescents have access • Abrupt transfer • Adult services not adolescent-friendly • Differences between paediatric/family care and adult/individual care • Transition based on chronologic versus developmental readiness • Lack of validated tools to assess transition readiness	7. **Educate staff**: HCPs or other staff should educate HIV care teams and staffs about transitioning 8. **Develop enabling policies**: Develop policy advisory groups composed of adolescents to adapt policies to be more adolescent-friendly.
Arising from National Policies • Lack of formal policies and dentitions • Lack of transition definition • Lack of family-focused counselling and testing policies and protocols • Lack of training to facilitate transition	

Table 11.2. Key Talking Points during Transition for Different Age Groups

AGE CATEGORY	TALKING POINT
Late Childhood (8–10 years)	» Start the disclosure process » Encourage caregivers to disclose to child » Solicit direct conversation with child » Increase private meetings with adolescent and ascertain disclosure was completed » Begin to explain medications » Deal with early adherence issues » Link to support groups and/or counselling » Start making a transition support plan (**Table 11.3**)

AGE CATEGORY	TALKING POINT
Early Adolescence (11–13 years)	» Review the transition plan and assess if all that was planned was implemented » Focus on knowledge and understanding of diagnosis, needed medications, health precautions including who else to disclose to, and others services for adolescents including prevention and sexual and reproductive health » Update explanations about medications and transmission routes » Discuss puberty and sexual development » Discuss growing up challenges: taking more responsibility, starting independence, choices and consent » Review changing relationships in family, with peers and schools » Address concerns about support for parent/care during transition » Connect adolescent to teen-based adherence programme
Middle Adolescence (14–16 years)	» Focus on sexual health and relationships and prevention of HIV transmission » Discuss wider disclosure and confidentiality issues: who needs to know and how to negotiate this sharing » Address increasing independence and responsibility for self and how to take more control of health, medicines; and keeping appointments » Discuss peer support networks » Review role of support agencies for adolescents, such as those that offer skills training » Address management of specific or individual needs, such as physical disabilities » Discuss plans for future, such as school and college » Provide copies of medical records and forms of identification » Review medical history » Promote questions about care regimen and possibilities for future changes in regimen
Late Adolescence (17–19 years)	» Focus on preparation and support for transfer to new service (adolescent or adult) » Discuss discharge summary and identify specific services needed by individual » Focus on future plans, such as education, employment and housing » Provide youth with substantial medical and entitlements history » Help identify appropriate adult providers through visits to the adult clinic » Transfer medical records to new provider, highlighting key challenges » Hold support meetings with adult service providers and caregiver » Get an orientation meeting and physically take the adolescent to the adult clinic and introduce him/her to the adult care team » Do a post-transitional assessment to assess the integration process

Table 11.3. Comprehensive Transition Checklist

SELF-MANAGEMENT TASK	EXPECTED AGE RANGE FOR TASK (YEARS OF AGE)	DISCUSSED (Y/N)	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			
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			

SELF-MANAGEMENT TASK	EXPECTED AGE RANGE FOR TASK (YEARS OF AGE)	DISCUSSED (Y/N)	GOAL FOR TASK (MONTH & YEAR)	GOAL REACHED? (Y/N)
Explains reasons for disclosure and disclosure methods.	11–14			
Attends first peer support group.	11–14			
Describes side effects of medications.	15–19			
Verbalises when and how to call HCP.	15–19			
Identifies members of the health care team, roles, and how to contact them.	15–19			
Lists community services for ALHIV and accesses them independently	15–19			
Takes medication independently and is adherent to medications.	15–19			
Makes and attends appointments independently.	15–19			
Sets up transportation for appointments independently.	15–19			

Adapted from Colton, Tayla, Virginia Allread, Elaine Abrams, Anne Schoeneborn, Beatriz Thome, and Ruby Fayorsey. 2012. "Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers Trainer Manual 2012." New York City, NY: ICAP. http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf

ADDITIONAL RESOURCES

» Toolkit for Transition of Care and Other Services for Adolescents Living with HIV: This toolkit is designed to support health care and community care providers, families, caregivers, and the adolescents themselves with the transition of care, support and transition services from paediatric to adult care. A trainer's manual for HCPs is also included. https://aidsfree.usaid.gov/sites/default/files/final_alhivtoolkit_web.pdf

- Resources to Support Transition of Adolescents from Pediatric to Adult HIV Care: TREAT Asia has developed tools to help providers manage the transition of adolescents from paediatric to adult HIV clinics. Among the tools is a flipchart for use during provider-patient discussions around transition, which is available for download in multiple languages. https://www.amfar.org/resources-support-transition-of-adolescents/
- U.S. Centers for Disease Control and Prevention Transition Plans: These tools provide assessments for 21 years and under and 24 years old. They include space to plan for educational/career plans, transportation, family/caregiver support, housing, and timing for transition. https://cdn.hivguidelines.org/wp-content/uploads/20180726095226/NYSDOH-AI-Adolescent-Transition-to-Adult-Care-2-Adolescent-Individualized-Transition-Plan_6-6-2018_HG.pdf

CHAPTER 12: FAMILY, COMMUNITY, AND HCP SUPPORT SYSTEMS

INTRODUCTION

Identifying, enroling, and retaining children and adolescents living with HIV requires a wide network of support that includes families, the community, HCPs and other systems. To help patients develop their full potential, HCPs need to understand some basic information about families and support systems, and to know how to locate and use the network of social and institutional resources to support children, adolescents, and caregivers when traditional support systems do not function. This chapter provides guidance for HCPs to mobilise these resources.

ROLE OF HCP IN PROVIDING SUPPORT

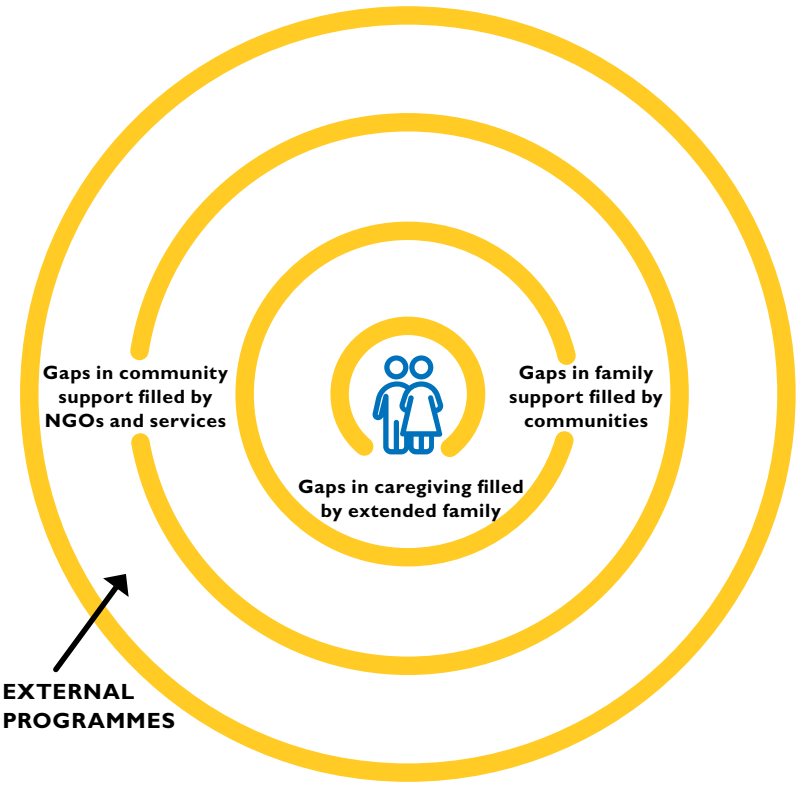
Elements of a support system include the family, community groups, schools, nongovernmental organisations, faith-based institutions, and government departments all working together to promote the well-being of children and adolescents (**Figure 12.1**).

HCPs can strengthen community support through referrals to, or interactions with, numerous resources that communities can offer (**Box 12.1**).

BOX 12.1. ROLE OF HCPS IN STRENGTHENING COMMUNITY SUPPORT

- Assess the effects of community situations on the well-being of children, adolescents, and their families.
- Build on the positive effects and minimise the negative impacts of communities on the well-being of children, adolescents, and their families.
- Assess the accessibility, availability, and quality of community services that are available to children and adolescents living with HIV.
- Map out and develop a referral directory of community resources in the care for children, adolescents and their families.
- Strengthen community systems that provide services, protection, and support to children, adolescents, and families.
- Link children, adolescents, and their families to community resources.
- Continuously monitor and evaluate the role of community resources in the care for patients and families.
- Advocate for the provision of quality health, education, and economic strengthening services, and formulation and implementation of appropriate laws and policies, to enhance family functioning and care for children and adolescents living with HIV.

Figure 12.1. Circles of Support, Gaps, and Alternatives[5]



Peer support groups, community- or facility-based, can be a major source of support for children. Members of a peer support system mutually give and receive help from one another, building on the key principles of respect, shared responsibility, and mutual agreement of what is helpful. The effectiveness of peer groups comes from understanding another's situation and showing empathy through shared experiences of emotional and psychological pain. When people find affiliation with others whom they feel are "like" them, they feel a strengthening connection. **Box 12.2** describes the role of HCP in peer support groups.

BOX 12.2. ROLE OF HCPS IN PEER SUPPORT GROUPS

- Mobilise children, adolescents and caregivers to form support groups.
- Train support group leaders.
- Provide information as needed to address members' emerging concerns.
- Take opportunities to integrate age-appropriate health services into peer support programmes.
- Link support groups to other sources of support beyond the health care system (community development, civil society, economic strengthening, vocational skills training, violence prevention, support services, and others) to help members address their needs.

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5 Adapted from: Richter L, Foster, G., and Sherr, L. 2006. Where the Heart Is: Meeting the Psychosocial Needs of Young Children in the Context of HIV/AIDS, available at https://www.unicef.org/violencestudy/pdf/Where%20the%20Heart%20Is.pdf

Many children and adolescents living with HIV are in school. Thus, school settings can be a source of support or a barrier to use of HIV prevention, care, and treatment services (**Box 12.3**). For instance, stigma in schools can hinder adherence to ART. To maximise the benefits of HIV interventions, it is important that HCPs continuously engage with school management and teachers to help them create an enabling environment for supporting children and adolescents living with HIV. In addition, it is important to engage with developers of school curricula to ensure that content on SRH and HIV education and prevention avoids language that propagates fear of HIV and stigmatises any persons living with HIV.

BOX 12.3 ROLE OF HCPS IN SUPPORT OF SCHOOL-GOING ADOLESCENTS

- Assess the needs of children and adolescents within the school setting.
- Train school staff (head teachers, senior women and men teachers, and school nurses) and peers on meeting the needs of children and adolescents living with HIV.
- Raise awareness of children in schools to support fellow students who are living with HIV and avoid stigmatisation, discrimination, and isolation of these children.
- Build self-esteem of children and adolescents living with HIV to overcome stigma.
- Provide information on HIV prevention and care, including positive prevention.

ADDITIONAL RESOURCES

- Family Matters Program is an evidence-informed, parent-focused intervention designed to promote positive parenting and effective parent-child communication about sexuality and sexual risk reduction, including risk for child sexual abuse and GBV, for parents or caregivers of 9-12 year olds in Africa. https://www.cdc.gov/globalaids/publications/fmp-2-pager-final-jan-2014.pdf
- Peer Support and Family Support. WHO has collected resources and programme examples on sources of support for adolescents living with and affected by HIV. http://apps.who.int/adolescent/hiv-testing-treatment/page/Additional_sources_of_support
- Peer Support Zvandiri describes Zvandiri's approaches, including the use of Community Adolescent Treatment Supporters (CATS), HIV-positive people aged 18–24 years who work between health facilities and the homes of ALHIV to increase uptake of testing, linkage, adherence, retention in care, and services related to sexual, reproductive, and mental health. https://www.pepfarsolutions.org/adolescents/2018/1/13/zvandiri-peer-counseling-to-improve-adolescent-hiv-care-and-support

CHAPTER 13: MONITORING AND EVALUATION OF PSYCHOSOCIAL SUPPORT OUTCOMES

INTRODUCTION

Monitoring and evaluation (M&E) is a very important management tool for keeping a check on all aspects of a holistic psychosocial response, to ensure learning and accountability, and to assess if the implemented activities are having the desired effect of improving psychosocial well-being. M&E forms the basis for clear and accurate reporting on the results achieved by a psychosocial project or programme.

M&E GUIDANCE

M&E for PSS can be done in three steps: baseline assessment, monitoring outcomes, and reporting on the outcomes, as described below.

STEP 1: BASELINE PSYCHOSOCIAL ASSESSMENT

- Conduct a psychosocial assessment with each child and adolescent patient before the psychosocial intervention using an assessment/screening tool (an example psychosocial assessment guide is provided below in **Table 13.1**). This assessment should explore key aspects of child/adolescent life including moods, activities, alcohol/substance abuse, sexual health, disclosure, stigma, friends and support, living situation, and adherence and retention in care.
- Record any important information from the patient's responses to help identify immediate psychosocial gaps, next steps, important areas for follow-up, and how best to support the patient's psychosocial well-being over the long term.
- Make sure the patient and/or parents/caregivers have time to ask questions, allow time to summarise the session, and agree upon next steps.
- Record key information from the psychosocial assessment on the form and keep it in the patient's file for reference during follow-up visits.

STEP 2: MONITORING PSYCHOSOCIAL OUTCOMES

- During every psychosocial visit, record the patient's progress in dealing with the causes

of psychosocial distress using a psychosocial monitoring tool for children (an example is provided in **Table 13.2**).

- Document other patient concerns that require additional support and follow-up during subsequent psychosocial support visits.
- At the end of the agreed psychosocial support period, conduct an assessment of the outcomes of the intervention using the Psychosocial Evaluation Tool for children (an example is provided in **Table 13.3**).

STEP 3: REPORTING PSYCHOSOCIAL OUTCOMES

- Report psychosocial outcomes based on the baseline/outcome indicators, comparing baseline indicators and outcome indicators to assess progress at the end of the psychosocial intervention.
- The report should cover the major psychosocial issues identified at baseline, and quantitative and qualitative results of the psychosocial support intervention.

A psychosocial intervention report consists of the following:

- Facility names
- Reporting period
- Psychosocial issues/behavioural observations
- Outcomes of the psychosocial intervention
- Challenges and recommendations

Table 13.1. Psychosocial Assessment Guide for Adolescents Living with HIV

Introduce yourself, and give a short explanation of your role. Explain that this discussion will be confidential.
Can you tell me how things have been going since you learned your HIV status (or since we last met)? How are you coping? *Explore and discuss patient's coping strategies.*
Tell me about your mood now. Do you feel sad or stressed? What changes have you noticed in your mood? What about your eating and sleeping habits? *Assess risk of depression and need for referral.*
How often in the last week have you used cigarettes, alcohol, or other drugs? *Assess children >10 years for harmful coping strategies, such as drug/alcohol use, provide counselling and referrals.*
To whom have you disclosed your HIV status? What was their reaction? Do you want to disclose to anyone else? What concerns do you have about disclosure? *Counsel on disclosure.*

Who do you feel close to? Who can you go to for emotional support?

Counsel on importance of social support.

Do you belong to a community/religious organisation or support group? Would you be willing to join a support group to meet other ALHIV?

Make referrals as needed.

Tell me about any negative attitudes or treatment you've experienced. Has anyone caused you harm (e.g., been violent, made unwanted sexual advances)?

Counsel and discuss support services; consider gender-based violence services, if appropriate.

Some adolescents have sex with their partners. It's important for you and your partner to do this safely. Are you having sex? If so, what are you doing to prevent pregnancy and the spread of STIs and HIV? If you are having sex; is it with a boy or a girl?

Screen children >10 years for sexual risk-taking and counsel on safer sex, dual protection, etc.; give condoms.

Let's talk about your living situation. Who are you living with? How long have you lived with them? How well do you get along? If not living with parents, ask: Where are your parents? When did this happen? How did this affect you?

Assess living situation.

Tell me what you do most days. Do you, for example, go to school or work outside the home? Where do you go to school/work? How is this going for you?

Assess school/work situation.

Do you have financial support from your family or partner, a regular source of income, or do you receive help, such as social grants or food?

Refer to social worker and community-level support.

Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?

Identify additional services that may be of assistance and refer.

How do you/will you remember to come to this clinic for your appointments and refills? How do you/will you manage it with your school or work? Who can help you?

Counsel on adherence to care.

How do you/will you remember to take your medications every day? How do you/will you remember when to come back to the clinic? Who can help you?

Counsel on adherence and briefly discuss:

- WHO will give or manage your medicines?
- WHEN will you take them?
- WHERE will you store them?
- HOW will you remember to take them? (e.g., reminders including alarms, pillboxes, etc.)

What other questions or concerns do you want to discuss today? Would you like to bring someone else into our conversation—today or at another visit (e.g., family member, partner)?

Summarise the session and review immediate plans and next steps, including the next clinic visit date.

Adapted from Colton, Tayla, Virginia Allread, Elaine Abrams, Anne Schoeneborn, Beatriz Thome, and Ruby Fayorsey. 2012. "Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers Trainer Manual 2012." New York City, NY: ICAP. http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf.

Table 13.2. Psychosocial Monitoring Tool

EMOTIONAL ADJUSTMENT
Can you tell me how things have been going since your last psychosocial support visit? How are you coping? *Explore and discuss patient's coping strategies.*
Tell me about your sleeping patterns. Do you get bad dreams/nightmares? How often do you get nightmares? *Record how often the patient gets nightmares.*
Can you name things that you are good at and proud of about yourself?
Tell me about the daily life (social, cultural, recreational) activities that you enjoy doing.
SOCIAL FUNCTIONING AND ENGAGEMENT
Do you belong to any community/religious organisation or support group? Where do you seek help to solve your problems in the community?
Do you have any negative (verbal and physical) interactions at home and school? Share negative interactions, if any. *Counsel and discuss support services; consider gender-based violence services, if appropriate.*
Tell me how you relate with your peers and how you resolve conflicts. *Assess for cooperative behaviour.*
ACQUISITION OF SKILLS
How are you able to share feelings and opinions with other children, parents and teachers?

Table 13.3. Psychosocial Evaluation Tool

PSYCHOSOCIAL OUTCOMES	STRONGLY DISAGREE 1	DISAGREE 2	NEUTRAL 3	AGREE 4	STRONGLY AGREE 5	
Emotional well-being (intrapersonal)						**Total**
1. Reduced troubling thoughts and feelings						
2. Child shows more self-confidence						
3. Increased ability of the child to cope with stress						
Social well-being: improved social engagement (interpersonal)						**Total**
4. Improved social relations of the child in the home						
5. Improved social relations of the child at school						
6. Improved social relations of the child in the community						
Skills and knowledge/competencies						**Total**
7. Increased positive self-expression						
8. Increased problem-solving skills						
9. Enhanced knowledge in dealing with psychosocial issues						

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