



# HANDBOOK

## 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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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**

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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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Appreciation goes to the writers of this Handbook who volunteered their time to put together this excellent resource 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 Handbook 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](http://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
DBS	dried blood spot
DOT	directly observed therapy
ECP	emergency contraception pill
EID	early infant diagnosis
eMTCT	elimination of mother-to-child transmission
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
MTCT	mother-to-child transmission
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
PI	protease inhibitor
PITC	provider-initiated testing and counselling
PMTCT	prevention of mother-to-child transmission
PrEP	pre-exposure prophylaxis
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

# PREFACE

In 2013, the Joint United Nations Programme on HIV/AIDS (UNAIDS) proposed the ambitious “fast-track” goals to end the global HIV epidemic by 2030, including reducing new HIV infections among children and adolescents from 500,000 annually to 200,000 annually (2014). Donor- and country-driven investments have dramatically strengthened the HIV response around the world. Despite these major commitments and advances, HIV incidence is on the rise in young people; and in Africa, AIDS remains a leading cause of death in adolescents. The proportion of HIV-positive children and adolescents receiving HIV services, including ART, has also continued to lag well behind that of adults. Evidence of this gap from the World Health Organization (WHO) shows that 52% of children compared to 59% of adults were on ART in 2017 (2018). Controlling the epidemic, within countries and globally, must include preventing, testing for, and treating HIV in children and adolescents, including addressing psychosocial issues experienced by these populations to enhance their ability to manage the disease and live positively.

To improve access to HIV services, several African countries have decentralised HIV care to primary health facilities. However, health care providers (HCPs) in many primary care settings do not have access to up-to-date clinical resources to build their knowledge so they can provide comprehensive HIV care for children and adolescents. HIV care for children and adolescents is complex, and requires not only addressing their medical needs, but also caring for their psychological well-being—to keep them healthy, retain them in care, and enable them to live positively. HCPs often have limited skills to counsel and provide psychosocial support (PSS) to children and adolescents living with HIV. While there have been specific in-service training courses designed to address this challenge, high staff turnover reduces their impact. The *Handbook on Counselling and Psychosocial Care for Children and Adolescents Living with and Affected by HIV in Africa* seeks to address this gap and serves as a comprehensive reference to provide HCPs with practical information to provide effective counselling and PSS for children and adolescents living with and affected by HIV.

## PURPOSE OF THIS HANDBOOK

The African Network for the Care of Children Affected by AIDS (ANECCA) developed the *Handbook on Counselling and Psychosocial Care for Children and Adolescents Living with and Affected by HIV in Africa*, with support from the Strengthening High Impact Interventions for an AIDS-free Generation (AIDSFree) Project, implemented by JSI Research & Training Institute, Inc. (JSI) with funding from USAID/PEPFAR, as a comprehensive guide for the HCPs who work in counselling and psychological care of children and adolescents. The Handbook 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 material provided in the Handbook aims to equip HCPs with important information 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 or affected by HIV.

## HOW TO USE THE HANDBOOK

The 13 chapters in this Handbook cover all major aspects of psychosocial and clinical care for children and adolescents living with and affected by HIV. The text emphasises providing integrated, child-centred care and, to the greatest extent possible, engaging the *child/adolescent* and the *family/caregiver* in every discussion and every decision. Information in each chapter draws from the most up-to-date guidance from WHO and PEPFAR. Each chapter describes approaches for HCPs to use to provide non-judgemental, context-specific, and confidential medical and psychosocial services that meet the specific needs of children or adolescents and help them to cope with their diagnosis, adhere to treatment, and find ways to live healthy lives.

Each chapter includes definitions of key terms, topic summaries, and useful tools. Summaries at the beginning of each chapter, and boxes at the end of chapter sections, synthesise overall lessons to keep in mind. Where appropriate, the chapter includes gender-related considerations. Also, since the Handbook looks at the *whole* child—and because physical, mental, and socio-emotional well-being are intertwined—text within a given chapter references other relevant chapters for more information. Overall, the Handbook can be read as a manual/resource for treating HIV-positive children and adolescents—or providers can refer to specific chapters to refresh their knowledge on a specific topic, or seek approaches or resources to use in their work. There is a companion *Pocket Guide on Counselling and Psychosocial Care for Children and Adolescents Living with and Affected by HIV in Africa*, also developed by ANECCA, which presents key information from this Handbook in a more concise way so that HCPs can access the information quickly during clinical consultations. ANECCA designed this Handbook, and the Pocket Guide, to help HCPs guide children and adolescents in their care towards the best possible health outcomes and mental well-being, so that they can live their lives fully and positively.

## SELECTED RESOURCES DIRECTED AT CHILDREN, ADOLESCENTS OR CAREGIVERS

This Handbook is directed at HCPs who take care of child and adolescent clients, but for HCPs who may wish to recommend materials to these clients, the authors suggest the following selected resources that are directed at children or adolescents themselves, or to their caregivers. This list is by no means comprehensive, as numerous materials serving this purpose exist at global and national levels, but is a concise starting point for key additional resources.

- 1. AIDSFree Paediatric and Youth Disclosure Materials.** This series of booklets is designed to aid caregivers of children living with HIV in the step-by-step paediatric disclosure process. The booklets are available for download in colour and black and white. Accompanying cue cards offer guidance for HCPs to use in introducing these booklets to caregivers. These booklets and resources are also available in French, Xhosa, and Portuguese. <https://aidsfree.usaid.gov/collections/pediatric-youth-disclosure-materials>
- 2. AIDSTAR-One Adolescents Living with HIV Transition Toolkit.** Increasing numbers of perinatally infected children are surviving to adolescence and adulthood. This group is emerging as a unique population and a unique challenge for policy makers, programmers and service providers, thus requiring attention and a stronger understanding of their unique needs

to support their continued health and development. 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.

<https://aidsfree.usaid.gov/collections/aidstar-one-adolescents-living-hiv-toolkit>

- 3. ICAP Positive Voices, Positive Choices: A Comprehensive Training Curriculum for Adolescent Peer Educators.** Positive Voices, Positive Choices is designed to train and support adolescents living with HIV both as adolescent peer educators and active members of multidisciplinary HIV care teams. The curriculum draws on experiences and lessons learned from adult and youth peer education programmes and on a growing body of literature on adolescent HIV prevention, care, and treatment.

[https://icap.columbia.edu/tools\\_resources/positive-voices-positive-choices-a-comprehensive-training-curriculum-for-adolescent-peer-educators/](https://icap.columbia.edu/tools_resources/positive-voices-positive-choices-a-comprehensive-training-curriculum-for-adolescent-peer-educators/)



**CHAPTER I.**  
INTRODUCTION TO  
PSYCHOSOCIAL CARE  
FOR CHILDREN AND  
ADOLESCENTS LIVING  
WITH HIV



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## SUMMARY

- » Children and adolescents who are living with HIV need comprehensive services, including PSS services, to help them stay adherent to antiretroviral therapy and healthy.
- » Children and adolescents have individual needs, and must be given personalised care.
- » HCPs play a critical role to help address the psychosocial needs of HIV-positive children/adolescents and their caregivers.
- » PSS has many levels of intensity, encompassing both basic and specialised needs.
- » Stigma and discrimination remain significant barriers to the success of HIV care for children and adolescents.

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***When a child is diagnosed with HIV, a journey begins. Throughout this journey, children, families, and caregivers will need information and support.***

## I.0. DEFINITIONS OF TERMS

**Child:** A person under the age of 18 years.

**Adolescent:** A person aged 10 to 19 years, inclusive.

**Child or Adolescent living with HIV (CLHIV or ALHIV):** A child or adolescent who has been diagnosed with HIV. He or she may or may not display signs and symptoms.

**Child or Adolescent affected by HIV:** A child or adolescent from a household with an individual or multiple individuals who are HIV-positive. These individuals may include a parent, sibling or other relative who may be alive or have passed away.

**Caregiver:** The person who provides basic care for the child or adolescent; this person could be a parent, other relative, or guardian.

**Coping:** The ability to find an appropriate reaction to challenges that an individual experiences.

**Health care provider (HCP):** The health care professional who provides routine health care including but not limited to HIV services.

**Psychosocial support (PSS):** Attendance to the emotional, psychological, social, spiritual, and practical needs and wishes of the individual within the context of their family, friends, neighbours, and associations with others. In this Handbook, counselling is one form of PSS.

**Psychosocial well-being:** A state in which an individual, family, or community has material, cognitive, emotional, and spiritual strength combined with positive sociocultural relationships and a positive economic and political environment.

**Resilience:** Human capacity to face, overcome, and be strengthened or otherwise transformed in a positive way by problems of life, i.e., the ability to “bounce back” after stressful and potentially traumatising events.

**Vulnerability:** A state of high risk or of being susceptible to being ill or experiencing harm.

**Vulnerable household:** A household that is unable or has diminished capacity to fulfil the basic needs and rights of its members.

## I.1. WHY PROVIDE PSYCHOSOCIAL SUPPORT FOR CHILDREN, ADOLESCENTS, AND THEIR CAREGIVERS?

HIV infection affects physical, psychological, social, and spiritual elements of a child’s 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. HIV infection can result in a chain of psychosocial issues in CLHIV and ALHIV, 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). Children affected by HIV may also experience the death of a parent, resulting in the loss of their basic needs (food, shelter, health care), along with possible household moves,

change in caregivers, and other challenges often associated with orphanhood that increase children's and adolescent's vulnerabilities (L. Sherr et al. 2014). These vulnerabilities include: 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 2006).

Psychosocial support can lead to an enhanced quality of life by addressing these vulnerabilities experienced by children and adolescents, including helping them to make informed decisions to cope with HIV, and deal effectively with stigma and discrimination. The shortage of professional providers, counsellors and social workers specialised in psychosocial services means that HCPs (whether nurses, clinical officers, or doctors) can be a critical and front-line source of support for a child or adolescent. HCPs who are able to identify the PSS needs of children and adolescents and those of their caregivers can provide them direct support and link them to appropriate health and community resources. Such resources can help improve the child's or adolescent's physical health, increase their ability to manage their own HIV, and/or cope with the illness of an HIV-positive family member. Given the unique needs of children and adolescents living with and affected by HIV, providing tailored PSS at the individual level is critical.

## 1.2. PRINCIPLES OF PSYCHOSOCIAL SUPPORT

The key principles of PSS are child/adolescent-centred-ness, gender equity, empowerment, cultural sensitivity, strengths based, and measurable impact. Below are brief descriptions of each.

**Child/adolescent-centred-ness:** PSS places the child or adolescent at the core of the intervention while also recognising the child's interaction with family and peers, community, and other social structures. These relationships are critical influencers related to how children/adolescents experience and cope with HIV. It is vital for HCPs to remember that each child/adolescent is unique, and their needs will vary based upon their individual experiences and environments.

**Gender equity:** Addressing gender norms and inequities is essential to reducing HIV risk. A principle of PSS is to recognise that girls and boys have different socially constructed gender identities. Understanding these identities is critical to attend to their varying psychosocial vulnerabilities and support their continuing well-being. HCPs should identify and address gender-related differences that influence the health and psychosocial experiences of boys and girls, including child protection, gender-based violence, engaging men and boys in care, and being sensitive to the unique needs of key population members. Health care facilities should have both female and male staff, giving the child a choice, so as to provide gender-responsive HIV services.

**Empowerment:** Empowerment means strengthening a person's confidence and enabling them to take steps on their own behalf. Empowerment increases the capacity of children and adolescents and their caregivers, to make informed choices, understand and claim their rights, and become more confident in controlling their own life and health care decisions. For children/adolescents, meaningful, age-appropriate participation in their own care can help build positive self-identity and enhance psychosocial recovery.

**Cultural sensitivity:** PSS should be responsive to each individual child or adolescent's family values, beliefs, and perceptions and the context within which they reside, thus HCPs must be sensitive to different cultural, spiritual, political, and social contexts in order to provide respectful and unbiased

care. The culture or circumstances of each child or adolescent and his or her caregiver(s) must be respected.

**Strengths based:** HCPs should seek to improve and sustain the well-being of children and adolescents with HIV and their caregivers. This requires a flexible approach: constantly identifying and responding to new needs, changing behaviours, and developing policies to improve the quality of PSS. HCPs that focus on enhancing the capacity of families and community members to strengthen caregiving skills and recognise signs of psychosocial stress may actually strengthen the resiliency of children and adolescents in times of crisis.

**Measurable impact:** PSS should demonstrate a positive impact on the psychosocial status of children and adolescents and their caregivers. Determining this impact requires using validated tools and approaches that identify changes in psychosocial well-being at individual, interpersonal and community levels. PSS approaches should have clear objectives, precise indicators, and systematic analysis of programme activities along with the sharing of best practices outcomes and impact on the child or adolescent. The objectives chosen should be *SMART*: **S**pecific, **M**easurable, **A**chievable, **R**ealistic, and **T**ime-bound. **For details on monitoring and evaluation of psychosocial interventions, refer to Chapter 13.**

## APPROACH TO PSYCHOSOCIAL SUPPORT

- 1. Providing support to children and adolescents living with HIV:** PSS is a multi-step process that should begin with a thorough assessment, always building on the premise that they are children and adolescents first and foremost (see Figure 1.1). Basic psychosocial services at the bottom of the pyramid should be provided to all children and adolescents living with HIV. Addressing these basic needs, and specific vulnerabilities as early as possible, can reduce the need for the more resource-intensive specialised services shown at the top of the pyramid.
- 2. Basic services and security:** Assess access to basic needs that all children and adolescents require: food, water, shelter, health care, rest/sleep, clothing, security, and education.
- 3. Community and family supports:** Once gaps have been identified, children and adolescents and their families can be linked to existing community services that any child/adolescent, regardless of HIV status, would benefit from—as well as linkages to support for ART adherence and retention in HIV care for CLHIV/ALHIV.
- 4. Focused non-specialised supports:** Once family supports and linkages have been established, children and adolescents should also receive non-specialised support in line with their needs; for example, general medical care.
- 5. Specialised services:** If a child or adolescent demonstrates severe challenges, the next step is to address specific conditions and comorbidities that require specialised expert services, such as psychiatric/psychological care, dental services, early childhood development services, etc.

Figure 1.1. Multi-Layered, Integrated Psychosocial Support



Source: [www.repsi.org](http://www.repsi.org)

## 1.3. COMMON PSYCHOSOCIAL PROBLEMS AFFECTING CHILDREN AND ADOLESCENTS AND THEIR CAREGIVERS

### HIV-RELATED STIGMA

Reducing HIV-related stigma and discrimination is key to achieving global HIV control and eradication. Stigma affects many behaviours of HIV-positive and affected children, including disclosure and optimal ART adherence, which in turn affect viral load suppression and disease progression. It is important to identify children, adolescents and caregivers who are experiencing stigma and discrimination, and to provide them with PSS to help improve disclosure, adherence, viral suppression, and improve quality of life.

### DEFINITION, TYPES, CONSEQUENCES, AND MANIFESTATIONS OF STIGMA

The Joint United Nations Programme on HIV/AIDS (UNAIDS) defines HIV-related stigma as “the negative beliefs, feelings, and attitudes towards people living with HIV and/or associated with HIV.” Stigma may affect those suspected of being HIV-positive, those who are related to someone living with HIV, or those most at risk of HIV infection, such as people who inject drugs, sex workers, men

who have sex with men, and transgender people. **Stigma, especially internalised stigma, is a common barrier to help-seeking behaviours.** There are five types of stigma:

- » **Public stigma or social/enacted stigma** refers to obvious acts of discrimination, such as violence and rejection.
- » **Self/internalised stigma** refers to an individual's acceptance of negative beliefs, views, and feelings towards the stigmatised group they belong to and towards oneself.
- » **Stigma by association** refers to experiences of family members and friends who are stigmatised by their mere association with the HIV-positive individual.
- » **Institutional stigma** occurs when negative attitudes and behaviours about HIV are incorporated into policies, practices, and cultures of organisations and social systems, including health care systems.
- » **Double stigma** refers to a person holding more than one stigmatised identity (i.e., a person who is HIV-positive and also suffering from a mental illness).

**Consequences of stigma:** Stigmatised individuals are at risk of experiencing a variety of negative outcomes, including:

- » Social avoidance and/or isolation
- » Non-disclosure
- » Low self-esteem
- » Depression
- » Delays in HIV testing, treatment, and health-seeking behaviours
- » Loss to follow-up
- » Decreased ART adherence
- » Failure to achieve viral suppression

**Stigma index:** The *People Living with HIV Stigma Index* is a tool developed to measure and detect changing trends in relation to stigma and discrimination experienced by people living with HIV. Developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation, and UNAIDS, the stigma index aims to address stigma relating to HIV while also advocating for solutions on the key barriers and issues perpetuating stigma (GNP+ n.d.). The index questionnaire has been translated into more than 50 languages, and the study conducted in over 90 countries. Accessing national reports can help inform you of the specific stigma and resiliency experiences of PLHIV in your country.

## STIGMA AND SEXUAL IDENTIFY

As children and adolescents grow, so does their awareness related to their sexual orientation and gender identity (SOGI). Both of these may shift and change over one's lifetime. HCPs should be aware that awareness related to SOGI is part of adolescence, and that discrimination and stigma are often felt by those whose sexual identity might be in the minority, for example men who have sex with men. The term sexual orientation refers to one's emotional and sexual attraction to (and intimate and sexual relations with) individuals of any sex. Gender identity refers to one's



**Table I.1. Stigma Action Plan for Children and Adolescents**

PROBLEM	ACTION STEP	RESOURCES NEEDED	BY WHOM	BY WHEN	CONSEQUENCES OF ACTIONS AND THEIR MITIGATION IF NEEDED
<b>Sample Problem</b> I feel lonely since being diagnosed with HIV	a. Tell my best friend to let her know how I am feeling	None	I will talk with her.	After school tomorrow	S/he may tell others.
	b. Make an appointment to speak with a counsellor	A counsellor who works at the clinic or in a community organisation	I will make the appointment, and I will tell my caregiver that I am going to do it so that they will encourage me to follow through.	I will do this the next time I have an appointment at the clinic.	S/he may not have time to talk when I need someone to listen.
	c. Join a peer support group	Access to a peer support group	When I ask about the counsellor, I will ask for information about peer support groups.	I will do this the next time I have an appointment at the clinic	I may be associated with an HIV-positive group.
	a.				
<b>Problem #1</b>	b.				
	c.				
	a.				
<b>Problem #2</b>	b.				
	c.				
	a.				
<b>Problem #3</b>	b.				
	c.				
	a.				

Adapted from: Siyamkela Project. n.d. Resource Pack: To Reduce Stigma Related to HIV and AIDS. Pretoria, South Africa: POLICY Project and Centre for the Study of AIDS.

internal and individual experience of gender, which may or may not correspond with their sex at birth (International HIV/AIDS Alliance et al. 2018). SOGI may shift and change during the course of a lifetime. Many youth across the world face discrimination, abuse and violence because of their gender expression, who they love, who they have sex with and how they look. It is important for HCPs to know that as SOGI emerges during adolescence, some adolescents may be particularly vulnerable to violence, abuse, social marginalisation, and criminalisation. They may be fearful and reluctant to disclose personal information to adults including HCPs. HCPs must use effective adolescent-friendly approaches to engage these adolescents, be attentive to signs of trauma, and refer them for protective services in addition to routine health and psychosocial support services.

## MANAGING STIGMA

Stigma management requires identifying children/adolescent's risks of stigma, identifying symptoms of stigma, and understanding its consequences. Table I.1 can be used as a tool for identifying various sources of stigma and co-developing actions plans to address these challenges. Providers can help each patient to identify sources of stigma within his/her life and provide counselling to help determine the best ways to address the stigma. HCPs should be aware that some children and adolescents may need more time before they are ready to take steps to address stigma.

**Stigmatisation by HCPs** is a serious barrier that keeps many HIV-positive people, including children and adolescents, from seeking or staying in care. Addressing this barrier requires interventions focused on individual HCPs, as well as the health care environment (i.e., the health care facility itself, and the policies in place). Stigma emerges and must be addressed at individual, interpersonal and community levels including in the health care setting. A summary of these interventions are in Table I.2.

**Table I.2. Interventions to Reduce Stigma in Health Facilities**

LEVEL	INTERVENTION
<b>Individual HCP</b>	<ul style="list-style-type: none"> <li>» Address HCPs' fears and misconceptions about HIV transmission</li> <li>» Practice universal precautions to reduce HCPs' fears</li> <li>» Enable HCPs to separate persons living with HIV from the behaviours considered improper or immoral which are often associated with HIV</li> </ul>
<b>Environment/ Health Facilities</b>	<ul style="list-style-type: none"> <li>» Provide information, supplies, and equipment necessary to practice universal precautions and prevent transmission of HIV (e.g., gloves, sharps containers, adequate water, and soap or disinfectants for handwashing)</li> <li>» Provide post-exposure prophylaxis in cases of occupational HIV exposure</li> <li>» Implement systems and procedures that avoid unintentional disclosure of patients' HIV status</li> <li>» Ensure available private space that allows for maximum information sharing and reduced fears of unintended disclosure</li> </ul>
<b>Ministries of Health/ National Policies</b>	<ul style="list-style-type: none"> <li>» Put in place policies that prevent discrimination against people living with HIV. Policies should be developed in a participatory manner, clearly communicated to staff, and routinely monitored after implementation</li> </ul>

*(Adapted from The Policy Project n.d.)*





## **CHAPTER 2.**



# **HIV AND ART IN CHILDREN AND ADOLESCENTS**



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## SUMMARY

- » Children and adolescents require focused attention in all HIV responses.
  - » Children and adolescents frequently acquire HIV through vertical HIV transmission.
  - » Children and adolescents require a range of care services including early diagnosis, treatment, counselling, and psychosocial care, with secondary prevention services for those living with HIV.
  - » HCPs play a critical role to ensure that children and adolescents living with HIV receive quality clinical, counselling, and PSS services that are responsive to their comprehensive and changing needs.
-

## 2.0. INTRODUCTION

In 2017, 80 percent of pregnant and breastfeeding women living with HIV worldwide received services to prevent mother-to-child transmission, including ART, both for their health and the health of their infants (WHO 2018b). Yet only approximately half of HIV-exposed babies were tested for HIV by the age of 2 months, and about half of children under age 15 years living with HIV were on treatment (UNICEF 2016). Also in 2016, adolescents aged 15–19 years accounted for an estimated 15 percent of new adult infections worldwide, with girls accounting for two-thirds of all new HIV infections among adolescents. Despite this high burden, adolescents are also less likely to know their HIV status and be enrolled in treatment. Sub-Saharan Africa remains the region most heavily affected by the HIV epidemic. To achieve the UNAIDS strategic targets aimed at eliminating the HIV epidemic, all HIV-positive individuals, including children and adolescents, must be identified quickly, linked to HIV services immediately, and started and retained on ART (UNICEF 2018).

Without any health interventions, about 30–40 percent of HIV-positive children will die before one year of age and about 50 percent will die by their second birthday. In rare cases, HIV will progress slowly even without access to treatment. Where global efforts to test children for HIV and scale up ART for those who are positive have been successful, they have contributed to high numbers of HIV-positive infants surviving into adolescence and beyond, increasing the numbers of perinatally infected adolescents living with HIV.

As HIV-positive children and adolescents age, their treatment, care, and support needs change. They face challenges including self-disclosure of HIV status and disclosure to sexual partners or trusted peers; development of skills to successfully self-manage their health (e.g., medication adherence, accessing and navigating health services); and transitioning from paediatric to adolescent and adult services. They also undergo many emotional and physical changes as well as relational and social changes as they move from childhood to adulthood with increasing independence. To successfully address these challenges, these patients require PSS to improve their health and well-being. The childhood and adolescent periods provide many opportunities to include caregivers, allowing them to work as a team to build a foundation for optimal health, nutrition, and education behaviours that influence social and economic drivers, contributing to a healthy and productive adult life.

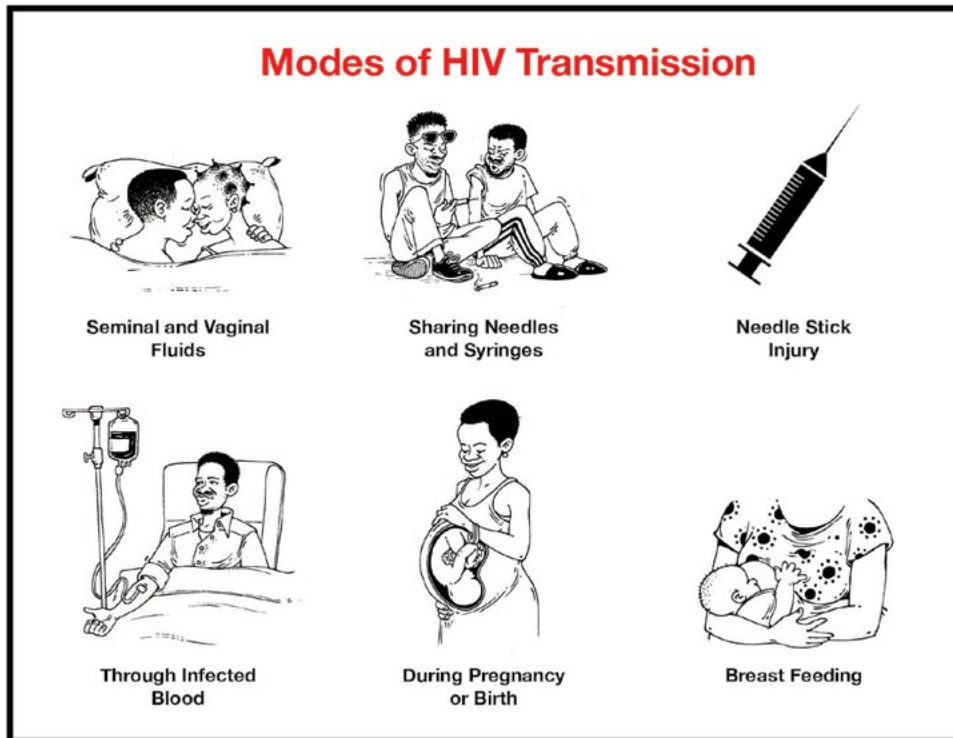
This chapter gives details on HIV infection in children and adolescents. The first sections outline the biology of HIV and its impacts in children, and summarise approaches for preventing HIV in this group. Section 2.5 provides comprehensive information on ART, including testing, diagnosis, ART regimens, and referrals. Note that **Chapter 9** provides comprehensive information on retaining children and adolescents in care.

## 2.1. MODES OF TRANSMISSION

Children and adolescents can acquire HIV in two ways: through vertical transmission and horizontal transmission. Horizontal transmission mainly includes sexual and parenteral (or blood) transmission (Figure 2.1).



Figure 2.1. Modes of HIV Transmission



Source: NACO

**Vertical (mother-to-child) transmission:** Mother-to-child transmission is the spread of HIV from an HIV-positive mother to her child during pregnancy, labour, delivery, or breastfeeding. In the absence of any preventive care, transmission rates range from 15 percent to 45 percent. Effective preventive care can reduce transmission to below 2 percent. Despite the effectiveness of prevention of mother-to-child transmission (PMTCT) programmes, there remain many challenges that include identifying HIV-positive pregnant women, initiating and keeping them on treatment, and retaining them in care through delivery including providing infant HIV prophylaxis and testing. These known gaps in PMTCT services result in more children contracting HIV vertically. Globally approximately 16 million births per year are to adolescent girls, and adolescents are known to access PMTCT and other types of health care less often than adults. To date PMTCT programmes have demonstrated robust results, however these gaps need to continue to shrink to eliminate vertical transmission.

**Horizontal transmission:** Horizontal transmission occurs in two ways: sexual transmission and parenteral (or blood) transmission. There are social and contextual factors that make adolescents vulnerable to horizontal HIV infection. Vulnerable adolescents include those from key populations, as well as orphans, migrants and refugees, prisoners, and those from other socially marginalised or stigmatised groups. Conflict, violence, displacement, and food insecurity also heighten risk. The HIV epidemic can also increase vulnerability; adolescents orphaned by AIDS can be more vulnerable to HIV if their circumstances lead them to engage in sex with older and/or multiple partners for economic or emotional support.

**Sexual transmission:** Children and adolescents can acquire HIV through unprotected sexual intercourse, which may include sexual exploitation involving coercion, abuse, or rape. Adolescents and young people remain extremely vulnerable to contracting HIV, especially adolescent girls who live in settings with a generalised HIV epidemic or who are sex workers.

**Parenteral (or blood) transmission:** Non-sexual transmission among adolescents can involve injection drug use, traditional practices (e.g., female genital mutilation/cutting with shared razor blades and traditional treatments requiring cutting of the skin) and certain medical procedures such as unsafe surgical procedures, injections, and blood transfusions.

HCPs should routinely screen children and adolescents for potential HIV exposure and infection. Potential indications of vulnerability to HIV infection include having a deceased parent, being in an age-disparate relationship with a man, or at risk for participating in sex work. It is important to determine if young patients are participating in condomless sex, or have experienced sexual coercion or rape. It should also be determined if the child or adolescent has features suggestive of TB (or has been treated for TB) or has experienced recurrent hospitalisations.

Box 2.1 includes questions that can help to identify children and adolescents who require HIV testing. A “Yes” answer to any of the questions should prompt child/adolescent-friendly HIV testing and counselling.

### BOX 2.1. SCREENING TOOL TO IDENTIFY OLDER CHILDREN LIVING WITH HIV (BANDASON ET AL. 2016)

- » Has the child been admitted to hospital before?
- » Does the child have recurring skin problems?
- » Are one or both parents of the child deceased?
- » Has the child had poor health in the last 3 months?

## 2.2. HIV PREVENTION

Sub-Saharan African countries have embraced the UNAIDS *Start Free, Stay Free, AIDS Free* framework for ending AIDS in children, adolescents and young women by 2020 (2016). Undiagnosed HIV infection is substantially higher in children and adolescents compared to adults. Among those diagnosed with HIV, ART initiation and coverage varies from one country to another, but consistently lags behind that of adults. Effective HIV prevention in children and adolescents requires a combination of behavioural, biomedical, and structural interventions—a mixed approach that addresses immediate risks as well as underlying causes of vulnerability.

**Behavioural interventions** aim to modify behaviours that make individuals more vulnerable to becoming infected or infecting others with HIV. These interventions generally emphasise condom use or mutual faithfulness (monogamy) and abstinence. Behavioural strategies have various goals, including:

- » 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** aim to reduce the risk both before and after the exposure. Examples include:

- » PMTCT
- » Consistent and correct use of ART by PLHIV to maintain an undetectable viral load
- » Treatment of STI (STIs)
- » Voluntary male medical circumcision (VMMC)
- » Correct use of oral PrEP
- » Post-exposure prophylaxis (PEP) in cases of rape, sexual abuse and other exposures to HIV
- » Safer medical/surgical practices
- » Safe blood transfusion
- » Contraception to prevent unplanned pregnancies among pregnant adolescent girls
- » HIV testing services
- » The use of vaccines and microbicides is still being researched and may be implemented in the near future

**Structural HIV prevention interventions** are a set of activities that aim to reduce HIV risk at the individual and/or group level. The activities take into consideration those elements that have the potential to influence people's vulnerability to HIV infection, including: **social**, e.g., stigma, gender inequality; **legal-political**, e.g., discriminatory laws, policies and regulations; **cultural**, e.g., cultural beliefs; or **economic**, e.g., lack of livelihood/economic opportunity. Structural interventions are designed to implement or change laws, policies, physical structures, social or organisational structures, or standard operating procedures to affect environmental or societal change to prevent transmission of HIV. One example of a structural intervention includes reducing the age of consent for HIV testing, so adolescents as young as 12 years are able to decide to learn their status and to take appropriate actions.

The most common prevention interventions for children/adolescents are biomedical and behavioural. However, HCPs should always be aware of the influence of stigma- and gender-related barriers, and should seek ways to address them in every aspect of service provision (see Box 2.2).

### BOX 2.2. KEY PREVENTION INTERVENTIONS FOR CHILDREN AND ADOLESCENTS

- » PMTCT
- » Promotion of abstinence and delaying the onset of first sexual intercourse for young people
- » VMMC
- » PEP in cases of rape, sexual abuse, and other exposures to HIV
- » Safer medical/surgical practices
- » Safe blood transfusion
- » HIV testing
- » Addressing stigma and gender-related barriers to accessing services
- » PrEP for sexually active adolescents

## 2.3. THE BIOLOGY OF HIV

Understanding how HIV infects the cells of the human body is important to explain how ART fights the virus.

- » The HIV life cycle (see Figure 2.2) is the term used to describe the process by which HIV infects a single CD4 cell and multiplies its genetic material to produce many new viruses. HIV attacks white blood cells called CD4 T cells (or CD4 T-helper cells). These cells are important for a healthy immune system as they help to fight off diseases and infections. HIV cannot grow or reproduce on its own, so it makes new copies of itself inside CD4 cells. These new viruses are released into the blood and can infect many other CD4 cells, perpetuating the life cycle of HIV.
- » HIV can also persist in a single infected CD4 cell for the life of that cell. The virus does this by inserting genetic material into the genetic material of the host cell (Step 4 of Figure 2.2). If the virus is not suppressed by ART, it can reactivate and produce more copies of itself. The risk of reactivation is why a person who is HIV-positive must remain on ART for life.
- » Over time, infected CD4 cells are destroyed, depleting and weakening the immune system and increasing the body's vulnerability to opportunistic infections. Figure 2.3 illustrates the multiplication process of HIV and the destruction of CD4 cells.
- » The rate of viral multiplication depends on a person's general health status, early diagnosis, starting and staying on treatment, and taking ART as prescribed.
- » Testing the blood of an HIV-positive person identifies the number of existing CD4 cells (CD4 cells per millilitre of blood), the percentage of CD4 cells of all white blood cells, as well as the amount of virus per millilitre of blood (viral load). The response to ART can be monitored by testing the CD4 cell count/percentage or viral load regularly following national guidelines. For patients on ART for at least 6 months, the viral load should be less than 1000 copies per millilitre of blood.
- » ART works by interrupting different phases of the HIV life cycle (see Figure 2.2), including reducing HIV's ability to multiply and protecting the immune system from depletion.

**Figure 2.2. The HIV Life Cycle**

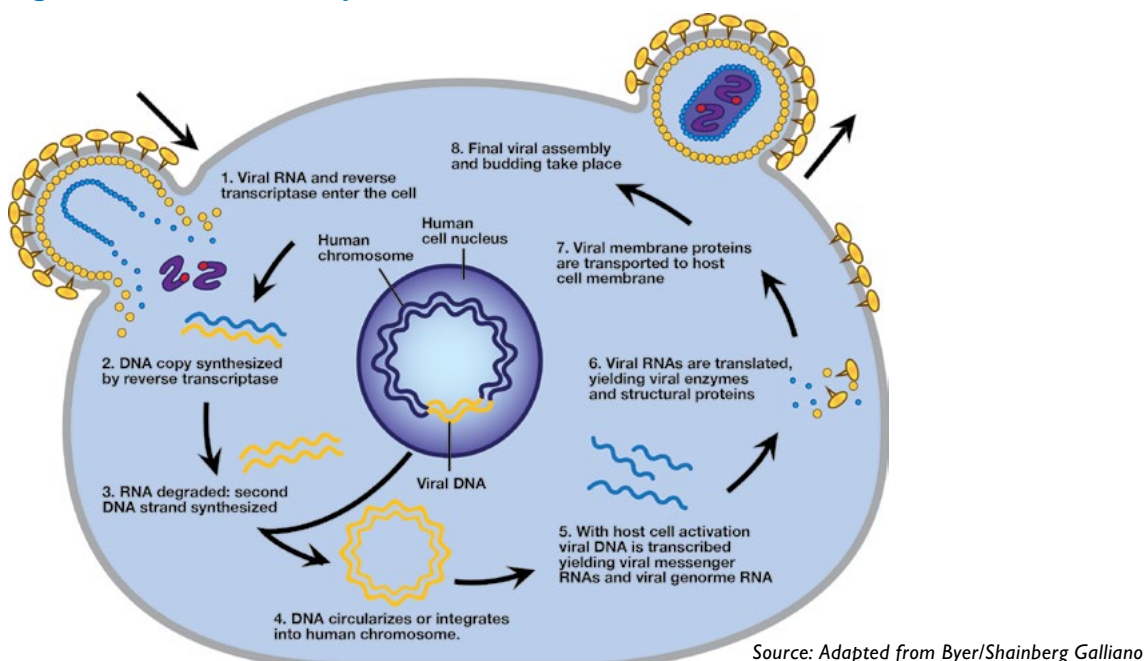
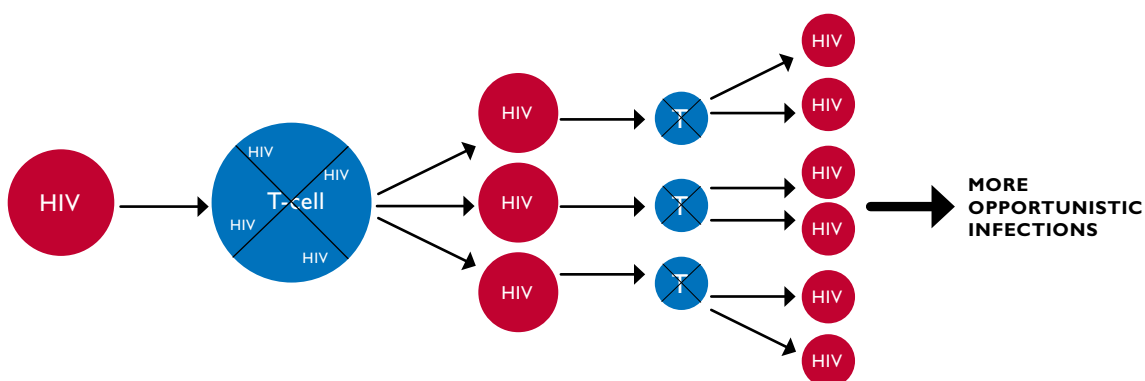


Figure 2.3. Model of Multiplication of HIV and Destruction of CD4 Cells



## 2.4. HIV DISEASE PROGRESSION IN CHILDREN

Children infected with HIV as infants, when their immune systems are still immature, can experience very rapid, uninhibited viral multiplication and disease progression. Early immune depletion occurs when the CD4 cell count drops and the viral load increases. In some infants, there is slow or intermediate immune depletion where the CD4 cells stabilise at low levels and the viral load is low. In cases of severe immune depletion, CD4 cell levels fall to an extremely low level with few antibodies and very high viral load levels.

Categories of HIV progression in untreated infants:

1. **Rapid progressors:** Acquire infection in utero or at birth; about 20–30 percent die by one year of age. In the first year of life, most deaths occur within the first 6 months.
2. **Intermediate progressors:** Develop symptoms early; about 50–60 percent die by the age of 3 to 5 years.
3. **Slow progressors/long-term survivors:** Constitutes about 5–25 percent of infected infants; live up to age 8 or longer.

HCPs treating HIV-positive children and adolescents need to understand critical aspects of the HIV life cycle to provide these patients with the care they need (see Box 2.3).

### BOX 2.3. KEY MESSAGES FOR HCPS

- » Start every infant and child on treatment as soon as they are diagnosed with HIV.
- » HIV uses CD4 cells for multiplication, and in the process destroys the immune system.
- » Disease progression in infants and children is faster than that in adults and requires early diagnosis and treatment.
- » Diagnosis of HIV in an infant is an emergency; many die within the first 6 months of life. It is essential to closely and actively follow up with mother-baby pairs to ensure that infants receive DNA PCR (DBS or EID) testing at 6 weeks of age.
- » Antiretroviral drugs work by interrupting various steps in the HIV life cycle, thereby preventing viral multiplication and CD4 cell destruction, allowing preservation of the immune system.

## 2.5. ANTIRETROVIRAL THERAPY

Antiretroviral therapy (ART) is the combination of several antiretroviral medicines used to slow the rate at which HIV makes copies of itself (replicates) in the body. A combination of three or more antiretroviral medicines (combination ART, or cART) is more effective than using just one medicine (monotherapy) to treat HIV. The drugs do not kill or eliminate the virus; however, 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. cART is a highly active form of HIV treatment that, when taken regularly and consistently, helps prevent drug resistance. HIV usually becomes resistant when the medicines someone is taking do not keep the virus under control. This usually happens when treatment is not followed correctly, allowing the virus to transform and modify itself in order to become resistant to the medicines. About 10 percent of acquired HIV infections are strains that are already resistant to one or more antiretroviral medications; this is known as transmitted resistance. The best way to prevent resistance is by taking ART as prescribed.

The goals of ART medication include:

- » Providing maximal, long-term suppression of HIV multiplication
- » Restoring and maintaining immune function
- » Restoring normal growth and development
- » Reducing HIV-related illnesses and death
- » Improving quality and duration of life

### CLASSES OF ANTIRETROVIRAL DRUGS

Each class or type of antiretroviral drug attacks HIV in a different way, by interrupting a step in the life cycle of HIV, as outlined in Table 2.1.

ART is usually provided to patients in a combination of three or more drugs. If possible, the combination uses drugs from two or more classes for a better response because they act on different steps of the HIV life cycle. Table 2.2 shows **first-line, second-line and third-line regimens** based on WHO 2018 recommendations. To switch to second-line regimens, the individual should have failed on the first-line regimen as indicated by clinical, immunological (low CD4) and virologic (high viral load) parameters. HCPs should refer to the national guidelines to determine the appropriate first-line ART regimen and when to switch to second-line regimens.

**Table 2.1. Types/Classes of Antiretroviral Drugs**

<p><b>Nucleoside/nucleotide reverse-transcriptase inhibitors (NRTI).</b> These drugs block step 2 of the life cycle in Figure 2.2, where the HIV genetic material creates DNA from RNA. Examples include:</p> <ul style="list-style-type: none"> <li>» Zidovudine (AZT)</li> <li>» Lamuvudine (3TC)</li> <li>» Abacavir (ABC)</li> <li>» Tenofovir (TDF)</li> <li>» Emtricitabine (FTC)</li> </ul>	<p><b>Non-nucleoside reverse-transcriptase inhibitors (NNRTIs).</b> These also block step 2 of the life cycle in Figure 2.2. Examples include:</p> <ul style="list-style-type: none"> <li>» Nevirapine (NVP)</li> <li>» Efavirenz (EFV)</li> <li>» Etravirine (ETR)</li> <li>» Rilprivine (RPV)</li> </ul>
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<p><b>Protease inhibitors (PIs).</b> These block step 6 in Figure 2.2 above, where the raw materials for new HIV copies are cut into specific pieces. The common PIs are listed below:</p> <ul style="list-style-type: none"> <li>» Lopinavir (LPV)</li> <li>» Atazanavir (ATV)</li> <li>» Darunavir (DRV)</li> <li>» Ritonavir (RTV or r)</li> </ul> <p><i>Ritonavir is used commonly as a booster for other PIs drugs, i.e., LPV/r, ATV/r, DRV/r</i></p>	<p><b>Integrase inhibitors (INSTIs).</b> These act on step 4 in Figure 2.2 of the HIV life cycle by preventing HIV from inserting its genetic code into the human cells. Examples include:</p> <ul style="list-style-type: none"> <li>» Raltegravir (RAL)</li> <li>» Dolutegravir (DTG)</li> <li>» Elvitegravir (EVG)</li> <li>» Cabotegravir (CAB)i</li> </ul>
<p><b>Entry (fusion) inhibitors</b> prevent HIV from entering the human cell by blocking step 1 in Figure 2.2 of the HIV life cycle. Examples include:</p> <ul style="list-style-type: none"> <li>» Enfuvirtide (ENF, T-20)</li> <li>» Maraviroc (MVC)</li> </ul>	

**Table 2.2. First-line, Second-line and Third-line ART Regimens for Adults, Pregnant Women, and Children (WHO 2018)**

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

- 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  $\geq 10\%$ , 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.

## Steps for initiating ART

ART initiation requires consideration of many factors associated with the child or adolescent. Box 2.4 describes the essential messages about ART initiation; however, before initiating a patient on ART, HCPs must complete several steps:

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, pellet, etc.)
5. Prescribe the correct dose

### BOX 2.4. KEY MESSAGES ON ANTIRETROVIRAL THERAPY

- » Refer to current national HIV treatment guidelines to identify the correct regimen and apply the right principles of regimen substitution and switching.
- » 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.
- » Determine HIV status at first contact.
- » Counsel and support the mother and the family on optimal infant feeding and monitor growth and development of the child.
- » Provide prophylaxis (ARVs, cotrimoxazole, isoniazid) according to national guidelines as appropriate.

## PREPARING CHILDREN AND ADOLESCENTS FOR ART

While deciding on the right ART regimen for a child or adolescent, HCPs should consider the factors that will support or hinder adherence to a specific regimen:

- » Where does the child or adolescent live?
- » Who is in the family and who lives at home?
- » Who knows about the child's or adolescent's diagnosis?
- » What is the attitude of family members to disease and treatment?
- » Who will be responsible for dosing and providing ART to the child or adolescent?
- » What is the family's routine schedule and how does it vary?
- » Can more than one family member/caregiver be identified that can be educated/trained to assist the child or adolescent?
- » Will the child or adolescent cooperate?
- » How will the drugs be obtained?
- » Where will the drugs be stored, in particular if the medication is heat sensitive?
- » How will the drugs, if liquid formulations, be measured?

- » How will dosing be scheduled relative to meals, school, work, and sleep?
- » How will family members remember to give medications?
- » Does the child or adolescent's school provide an enabling environment for adherence?

Decisions require discussion with patients and caregivers. **Chapter 6** offers additional information on communicating with HIV-positive children and their families about ART; **Chapter 8** provides information on addressing loss and grief that children may feel upon diagnosis.

## 2.6. APPROACH TO CARE FOR AN HIV-POSITIVE CHILD AND ADOLESCENT

Comprehensive care of HIV-positive children and adolescents includes PMTCT, nutritional assessment, counselling and growth monitoring, prevention and treatment of opportunistic infections, protection, and psychosocial support, all of which are feasible within resource-constrained settings and significantly improve survival. Box 2.5 summarises the ANECCA 10-Point Service Package.

### BOX 2.5. 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-positive 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 programmes as appropriate.
10. Ensure that the mother and family members are receiving appropriate care, support, and treatment.

A detailed description of the comprehensive service package components of care for children and adolescents is in **Appendix I** (for children), and **Appendix II** (for adolescents). Descriptions of HIV diagnosis, linkage, and follow-up are below. For descriptions of other components of the package, such as counselling and support for the child and caregiver, see **Chapter 6** (on counselling children and adolescents); **Chapter 9** (on ensuring adherence); and **Chapter 12** (on support systems, including support for caregivers and the HCP).

## HIV DIAGNOSIS IN CHILDREN AND ADOLESCENTS

HIV testing is the entry point to HIV prevention, care, treatment, and support services. 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. To improve access and efficiency, HTS should be made available to all children and adolescents at risk of HIV infection using cost-effective and high-impact approaches. HTS delivery includes four major steps (Table 2.3). HCPs should refer to their national HTS policy and implementation guidelines while carrying out each of these steps. .

**Table 2.3. 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 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 enrolled, 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.

### STEP I. PRE-TEST COUNSELLING

With the use of rapid diagnostic tests, individualised counselling and risk assessments of children and adolescents undergoing HIV testing is not recommended. Instead, age-appropriate methods should be used to provide pre-test education, including making posters, websites, videos, and other educational resources available in waiting rooms. According to the WHO, providers should educate children, adolescents, and their caregivers on:

- » 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 retested
- » 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 ART to the individual
- » Benefits of taking ART in terms of onwards HIV transmission. i.e., *Undetectable viral load = Untransmittable HIV (“U=U”)*<sup>1</sup>
- » Patient’s right to ask the provider questions

### Key considerations when counselling children and adolescents for HIV testing

- » Assess the child’s knowledge and their understanding of HIV and AIDS.
- » Prepare the child and their caregivers for HIV testing.
- » Explore the reasons the child has come for testing. In whose interest is the child being tested?
  - Who is asking for the child to be tested?
  - What is the relationship? Is it the parent, guardians, or a neighbour?
  - What are the reasons for the test?
  - Are they thinking about the best interest of the child or their own needs?
- » Give age-appropriate HIV information to the child and the caregiver
- » Explain consent for a child’s/adolescent’s HIV test
- » Orientate the child/adolescent and the caregiver for the HIV test and setting (You may need to meet with child and caregiver separately)
- » Understand reasons for referral
- » Assess HIV knowledge and correct misconceptions for both child and parent/caregiver
- » Discuss the *advantages and disadvantages* of testing
- » Relay the consequences of the test results (positive/negative)
- » Promote positive living
- » Identify support systems (who will the child tell and why)
- » Obtain informed consent in writing or verbal (if parent/guardian gives consent, child to give assent)
- » Provide information on test procedure and set appointment for post-test

Table 2.4 was developed for counselling children aged 12 years and under, but the principles described are relevant for all young people.

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<sup>1</sup> Undetectable = Untransmittable. Available at: <https://www.preventionaccess.org>

**Table 2.4. Considerations for Counselling and Testing Young People**

WHAT	HOW
Build a relationship of trust	Provide non-judgemental and respectful support, explain role of health care provider; stress confidentiality.
Allow time	Give children and adolescents more time than adults if necessary.
Establish a contract	Explain purpose and process of pre- and post-test counselling (including assessment of capacity and best interests if part of counselling); discuss confidentiality and its limits (including requirement to report sexual activity if applicable).
Discuss support systems	Inform of right to test without parental consent; encourage involvement of parents or guardians if supportive and child/adolescent is willing, or identify individuals/organisations who could provide support after testing.
Assess knowledge of HIV and explain purpose of HCT	Assess knowledge of acquisition and transmission, give simple explanations and probe to confirm understanding, encourage questions, use teaching aids if available.
Assess likelihood of exposure; explain purpose of testing and procedures	Address risk behaviours; provide information and referrals on sexual and reproductive health where appropriate.  Explain purpose of the test and ensure understanding of test procedure; emphasise need for further testing if result is negative.
Discuss implications of the test	Discuss risks, benefits and social implications of a positive result; discuss strategies for coping with positive/negative result.
Determine if test is in the child's/adolescent's best interests	Consider child's/adolescent's physical, emotional, moral and spiritual welfare; be prepared to postpone if risk exceeds benefit.
Assess need for further support	Draw attention to services available or refer to services e.g., sexual and reproductive health.
Discuss availability of services	Stress availability of prevention, treatment, care and support for children and adolescents
Discuss receiving results	Explain when, how, and by whom the results will be given; stress privacy and confidentiality, including any limits to confidentiality, e.g., other health care team members involved in the child's/adolescent's care.
Obtain informed consent	Prepare to offer the child/adolescent more than one visit before he or she decides to test. If consent is given, obtain verbal or written permission to conduct the test.

Source: Grant, K., et al. 2012.

## The 5 Cs of HTS

HTS is provided in a non-discriminatory way using a human rights approach that observes the 5 Cs: **C**onfidentiality, **C**onsent, **C**ounseling, **C**orrect test result, and **C**onnection to appropriate services. The text below is excerpted directly from WHO's *Consolidated Guidelines on HIV Testing Services: 5 Cs: Consent, Confidentiality, Counseling, Correct Results, and Connection* (2015).

- » **Confidentiality:** HCPs should ensure privacy during HTS. All information discussed with patients or caregivers should not be disclosed to another person without the patient's or caregiver's consent.
- » **Consent:** Age of consent is variable, it is important to know the policy in your country. For example, those aged 12 years can consent to testing in Lesotho, South Africa, and Uganda. However, in Namibia, Swaziland, and Zambia, adolescents must be 16 years to consent to testing. Many times HCPs can make consent exceptions for a younger child or adolescent who is sexually active, pregnant, already a parent, head of a household, or a sex worker. Some countries have emancipated minor clauses in age of consent laws; HCPs should determine if their country laws have emancipated minor clauses. In situations where consent cannot be obtained, the child's parent or guardian, next of kin, or legally authorised person may consent.
- » **Counseling:** All persons receiving HTS should be provided with quality counselling before and after testing as per the national HTS protocol.
- » **Correct test result:** HTS providers should adhere to the national testing algorithm and must follow the standard operating procedures for HIV testing to ensure that patients receive correct HIV test results. As per WHO guidelines, infants with an initial positive result should begin ART immediately while waiting for the confirmatory test results.
- » **Connect to other services:** Providers should link HTS patients to appropriate HIV prevention, treatment, care, and support services. For HIV-positive children, this also includes the provision of HTS to the biological mother, father, and siblings, as appropriate.

HCPs should place special focus, and seek to identify, **vulnerable/priority populations** with high levels of HIV risk and high HIV burden (Box 2.6).

### BOX 2.6. PRIORITY POPULATIONS FOR HIV TESTING

- » Children of sex workers
- » Long-distance truck drivers
- » Fisher folks
- » Commercial motorbike ("boda-boda") riders
- » Uniformed forces
- » eMTCT couples
- » Infants and young children exposed to HIV
- » Sexually abused children and adolescents
- » Adolescents and youth, especially girls
- » Young women
- » Emancipated minors
- » Orphans and other vulnerable children
- » Children out of school
- » Children with mental illness
- » Children and adolescents with disabilities
- » Internally displaced children and adolescents
- » Refugees
- » Prisoners

## STEP 2. HIV TESTING AND DIAGNOSIS

To improve access to and efficiency of HTS, providers should offer a mix of health facility- and community-based testing approaches, including those offered in clinics by HCPs, in homes and communities, and through outreach. Self-testing should also be offered for high risk children and adolescents including members of key populations, and siblings and children of HIV-positive individuals where available.

### Health facility-based approaches

**Index testing:** Also known as family-based HTS, this is a form of provider-initiated testing and counselling where HCPs test all children/immediate family members or sexual partners of HIV-positive individuals. Index testing is a highly effective method to identify HIV-positive children and adolescents.

**Provider Initiated Testing and Counselling (PITC):** HCPs routinely offer HTS to all individuals attending health care services with the purpose of better patient management and early HIV diagnosis. Included among these individuals are children and adolescents; clients at both inpatient and outpatient departments and all patients, whether symptomatic or not. HCPs should prioritise PITC for patients at maternal and child health clinics, adult and paediatric patient wards, TB clinics, family planning clinics, STI clinics, nutrition units, children/immediate family members or sexual partners of HIV-positive individuals (*index patient contact tracing*), clinics managing survivors of sexual abuse and in HIV care clinics, particularly in low generalised prevalence settings. HCP should assess all patients at OPD, MCH (EPI) for HTS eligibility. PITC is to be offered as an “opt-out” HTS service.

**Client Initiated Testing and Counselling (CITC):** In this approach, formerly known as voluntary counselling and testing, individuals and couples seek HTS on their own. These patients receive HIV testing and counselling from trained and certified HTS providers including lay providers, professional counsellors, laboratory personnel, and medical workers at any entry point in the facility.

### Community-based HTS approaches

**The index patient contact tracing** can help identify the subsequent patient contacts (including sexual contacts and family members) for testing. Index patient contact tracing can occur via:

- » Home-based HIV testing and counselling services (HBHTS), which is provided in the home setting, and may be through an index HIV patient invitation. Index-patient HBHTS is prioritised for household members of HIV-positive individuals, as well as for immediate family members of confirmed and presumptive TB patients.
- » With the partner notification approach (previously referred to as the “snowball approach”), the HTS team works with the index patient to invite other people they interact with for HTS. This approach is recommended for use among sex workers and men who have sex with men, and could also be used with adolescents.

**Outreach approaches** target specific populations that otherwise have limited access to HTS services including:

- » **Door-to-door HIV testing** in high HIV prevalence settings or communities of adolescent key populations and priority populations, such as hotspots for sex workers and fisher folks
- » **HTS integrated into health outreaches** like immunisation (where babies of mothers who test positive also receive testing) or VMMC; in high prevalence settings.



- » **HTS outreach in locations frequented by target adolescents**, such as key population hotspots, sporting events or workplaces. These outreaches may include moonlight testing and mobile clinics.
- » HTS can be offered at **workplaces** to minimize the inconvenience and cost of travelling to a clinic.

## HIV diagnosis

### HIV can be diagnosed two ways:

- » **Clinical diagnosis** is based on the symptoms and signs the child or adolescent is presenting. This should always be confirmed by laboratory tests.
- » **Laboratory diagnosis** is used for routine HIV testing and to confirm suspected HIV infection in a sick child or an adolescent. It may also be used to determine HIV exposure status in children under 18 months of age. There are two types of laboratory tests for HIV:
  - **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.
  - **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 four-six 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.

**Considerations in HIV-exposed infants:** A positive DNA PCR test result indicates that the infant is HIV-positive and should be initiated on ART. Another blood sample should be collected to confirm the positive DNA PCR HIV test result. However, ART initiation should not wait for the confirmatory results to return. A negative first DNA PCR test result means that child is not infected, but could become infected as long as they are still breastfeeding. Infants testing HIV-negative on DNA PCR should be retested using DNA PCR six weeks after cessation of breastfeeding. Infants with a negative second DNA PCR test should have a final rapid antibody test performed at 18 months. For those that breastfeed up to or beyond 18 months, a final rapid antibody test should be done three months after cessation of breastfeeding. In all settings, children with a parent living with HIV who have not yet been tested should be offered HIV testing and, if found to be either positive or at high risk of infection through breastfeeding, linked to services for treatment or prevention.

**Confirming HIV test results:** All HIV-positive individuals should receive confirmatory HIV testing when an initial HIV test result is positive. ART should be initiated while patients wait for the confirmatory test results. Retesting should be performed by a different tester, using the approved national HIV testing algorithm at the ART initiation care point. All babies testing HIV-positive at the first or second DNA PCR HIV test should be retested for HIV. The repeat DBS sample should be collected on the day the child is initiated on ART.

## STEP 3. 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 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.

### Talking to children about their sero-status

#### Guiding Principles

- » The parent or caregiver should talk to the child
- » Health workers/counsellors should be a source of support
- » Parents/caregivers should be equipped with proper skills and supported by health workers

#### Key considerations

- » Children like to communicate with people they trust, who love them, and who provide a sense of security.
- » Health workers/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 caregiver understand the consequences of the test.

### HCP role in talking to children about their sero-status

#### When sharing results to children/adolescents HCPs should:

- » Meet with child/caregiver separately
- » Recap information from last session; 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., sitting next to 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-negative results to a child/adolescent HCP should:

- » Assess **readiness** to receive and understand results

» **For younger children:**

- Give results first to caregiver present
- Empower the care giver to give results
- Encourage explaining results to younger child using language he or she will be able to understand
- Facilitate the caregiver to give the results

» **For adolescents:**

- Give results to the adolescent first, if caregiver 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
- Explore **motivation** to avoid HIV infection
- Identify **barriers** to safer practices
- Discuss strategies to overcome barriers
- Discuss **retesting** where applicable

**If sharing HIV-positive results to a child/adolescent, some phrases HCPs can use include:**

- » You have to come to the clinic because you have an illness; that means that you may get sick sometimes
- » You have a germ that lives in your blood
- » Another name for a germ is a “virus.”
  - Ask: “What do you know about germs and illness?”
- » When child is ready, say, “The name of the virus you have is HIV.”
  - Ask “What have you heard about HIV?” or “What do you know about HIV?” (Correct any misinformation)
- » The virus (HIV) can harm the healthy cells that protect you from sicknesses.
- » Viruses can make someone very sick, and you need medicine to stay healthy.
- » HIV was in your blood when you were born.
- » You got the virus when you were in your mother’s tummy.
- » You cannot get this virus or give it to anyone else just by being around them or by being close to them.
- » It is ok to play, go to school, and to 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

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

- » Provide the negative result briefly and clearly.
- » 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.

**If the patient is sexually active, or considering becoming sexually active, HCP should:**

- » Educate on methods to prevent HIV acquisition and provide 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.

### **Further considerations for HIV-positive diagnosis and disclosure support**

Informing a child or an adolescent about their HIV-positive status will forever change their life. The provider should always keep in mind the age of the child/adolescent as well as the 5 C's. HCPs should make sure that the child or adolescent is receiving the correct test result and follow-up with age-appropriate health education and counselling. Due to the amount of information that the child or adolescent and their caregiver will need to know, several follow-up post-test counselling sessions may be required.

The child or adolescent and caregiver may feel overwhelmed by the HIV-positive diagnosis and unable to absorb information immediately following learning of the HIV-positive test result. The information below does not have to be shared in the same visit. Topics may need to be prioritised with a plan for ongoing counselling. At the end of the visit, counsellors must have a clear idea of the child or adolescent's safety, and together with the child or adolescent, develop a clear follow-up plan, with active engagement by the counsellor/navigator for them to move to successful linkage and treatment initiation. As a standard of care, HCP should:

- » **Explain** the test results and diagnosis to the caretaker and or child/adolescent, as appropriate.

- » **Give the patient (caregiver and or child/adolescent as appropriate) time** to consider the results and help the patient cope with emotions arising from the diagnosis of HIV infection.
- » Discuss **immediate concerns** and help the patient (caregiver and or child/adolescent as appropriate) decide who in her or his social network may be available to provide immediate support.
- » Provide clear **information on ART** and its benefits for maintaining health and reducing the risk of HIV transmission (an undetectable virus is untransmittable – “U=U”), as well as where and how to obtain ART.
- » Make an **active referral** for a specific time and date. (An active referral is one in which the tester makes an appointment for the patient or accompanies the patient directly to an ART clinic and enrolment into HIV clinical care.)
- » Discuss **barriers to linkage** to care, same-day enrolment and ART eligibility assessment. Arrange for follow-up of children/adolescents who are unable to enrol in HIV care on the day of diagnosis.
- » Provide information on how to **prevent transmission of HIV**, including information of the reduced transmission risk when virally suppressed on ART; provide male or female condoms and lubricants and guidance on their use, where applicable.
- » Discuss potential disclosure pathways. Discuss **the risks and benefits of disclosure** in multiple settings to multiple audiences. **Seriously consider who “needs” to know**, the shortlist should reflect age of child/adolescent.
- » For sexually active adolescents, encourage and offer **HIV testing for sexual partners**. This can be **done individually**, through **couples testing, index testing or partner notification**.
- » **Assess the risk of intimate partner violence** and discuss possible steps to ensure the physical safety of patients, particularly female adolescents, who are diagnosed HIV-positive.<sup>2</sup>
- » Assess the risk of suicide, depression and other **mental health** consequences of a diagnosis of HIV infection.
- » Provide **additional referrals for prevention, counselling, support and other services** as appropriate (for example, TB diagnosis and treatment, prophylaxis for opportunistic infections, STI screening and treatment, contraception, antenatal care, opioid substitution therapy, and access to sterile needles and syringes, and brief sexuality counselling).
- » Encourage and **provide time** for the child/adolescent and caretaker to ask additional questions.

#### **Adolescents may also require:**

- » **Tailored help** to link with HIV care and treatment services
- » Counselling, referral, and linkage to specific **psychosocial and mental health services** personalized to the context of HIV status/knowledge and the developmental age of the individual
- » Information on adolescents’ **rights and responsibilities**, especially their **right to confidentiality**

2 <https://www.ncbi.nlm.nih.gov/books/NBK316035/>

- » An opportunity to ask questions and discuss **sexuality** and the challenges they may encounter in relationships, marriage, and childbearing (see **Chapter 10** for more information)
- » Individualised planning on **how, when and to whom to disclose** HIV status and engage families and peers in providing support<sup>3</sup>
- » Referrals for **small-group counselling and structured peer support groups**, which may particularly benefit adolescents with HIV.

### Talking to children about pediatric HIV treatment

Children, adolescents, and families will need to clearly understand that ART has benefits and risks, including side effects and drug interactions. Providers should provide clear education on the prescribed regimen and ensure that both patients and caregivers understand their instructions. HCP should reinforce:

- » **Adherence is critical.** HIV **will** become resistant and the medication **will** stop working unless all medications are taken correctly.
- » **Follow up regularly.** Appropriate supportive services are essential to overall health and well-being.
- » **Encourage communication.** Communicate any potential problems or questions immediately.
- » **Demonstrate.** Show the child and family each medication, its dosage, and how to take it (e.g.: demonstrate LPV/r pellet use in the clinical setting).
- » **Explain.** Describe and when possible demonstrate **dosing techniques and tricks**.
- » **Train.** Strengthen the child or adolescent's ability to take the medication. Select a modality by which to remember to take their medications (phone alarm, SMS message, before going to school, etc).
- » **Repeat.** Ask the caregiver and child or adolescent to: name medications; give dosing times and restrictions (e.g., meals), and demonstrate dosing.
- » **Encourage questions.** Families should ask:
  - What should you do if child refuses medication?
  - What should you do if you run out of a medication?
  - When should you contact us?
- » **Provide written instructions.** Give a written or diagrammed schedule.
- » **Provide aids for use.** Use pillboxes or other aids as needed.
- » **Require follow-up.** Give written contact information and a follow-up appointment.

## STEP 4. LINKAGES AND REFERRAL

### Linkage

Linkage refers to the act/process of connecting individuals from one service point to another. Linkage to HIV testing or care is successful if the patient receives the services he or she is linked

<sup>3</sup> <https://www.ncbi.nlm.nih.gov/books/NBK316035/>

to receive. For all patients who test HIV-positive, linkage should occur immediately, or if not possible, within seven days for units within the same facility; and within 15 days for inter-facility or community-to-facility referrals - or according to national policy and guidelines. Lay providers (community and facility-based) can act as linkage facilitators. Linkage and referrals can be *external*, involving outside agencies and experts, or *internal*—involving different departments within a facility.

## Referral

Referral is the process of directing a patient to another service provider for appropriate/additional services or treatment. Box 2.7 lists potential service points for referral, which again can be within or outside the facility.

### BOX 2.7. POTENTIAL CLINICAL AND PSYCHOSOCIAL REFERRAL POINTS FOR CHILDREN AND ADOLESCENTS

#### Clinical

- » HIV testing services
- » HIV care and treatment
- » Routine well-baby or well-child care
- » Health care in specialized practice
- » TB services
- » STI screening and treatment
- » Family planning services
- » Mental health services
- » Treatment and support for drug and alcohol abuse

#### Psychosocial

- » Formal education
- » Peer support groups
- » Adolescent HIV-positive mother clubs
- » Protection and legal services
- » Services for gender-based violence survivors
- » Nutrition education and support services
- » Community- and home-based care services
- » Faith-based and community organizations
- » Skills training and microfinance groups

As with other elements in the HIV care cascade, linkage and referral consists of a series of basic steps:

1. Assess the patient's service needs including clinical and psychosocial
2. Describe available services to the patient and caregiver
3. Assess and address potential barriers to attending referral (transportation, lack of funds, fear of stigma, non-disclosure by parents or caretakers)
4. Ensure that patients and caregivers understand the purpose of referrals
5. Document referrals accurately
6. Discuss confidentiality
7. Provide correct documentation for referrals, including time, location, and contact person
8. Ask patients and caregivers for feedback on referral
9. Document and evaluate (monitor) referrals
10. Establish a mechanism with referral agencies to facilitate feedback
11. Reassess barriers when there are challenges to attending referral services

HCPs should use all available resources to **enable linkages and referrals**, which may include routine use of comprehensive, bi-directional referral forms, good communication systems (email or phone) with both patients and referral institutions, and linkage facilitators. Linkage Facilitators are professional or lay counsellors who can help patients move between services and follow up on patients who do not link to referred services.

Strong linkage/referral systems are critical, because patients can be lost to follow-up at every stage of the care cascade, and children and adolescents are especially vulnerable to this. The **consequences of poor linkages** include costly service duplication and higher expenses for patients, along with gaps in services (including failure to test, diagnose, and treat HIV-positive patients). Adolescent girls, who are lost to follow-up may present back to PMTCT programmes only during another pregnancy thus losing the benefits of ART for themselves and their children.

**Creating and maintaining linkage and referral networks** is important since there are many actors who are part of these processes. The network needs to be monitored and kept current to ensure that all patients can receive timely services as needed. A network can be maintained through several means—for example:

- » A lead organisation/district/health facility to coordinate
- » Regular meetings of service providers including network updates
- » Newsletters or method of communication

**Maintaining directories:** For effective referral, it is important that HCPs develop and regularly update their referral directories. A sample referral directory is in **Appendix IX**. This directory should be developed, populated, and updated on a routine basis so that HCP know what referral organisations and services are available within the community and have a means to contact them.

HCPs, or the designated network coordinator, should **routinely monitor** network resources. Feedback from referrals is necessary to ensure service quality and track linkages. Referring facilities/institutions are responsible for the success and appropriateness of their referrals.

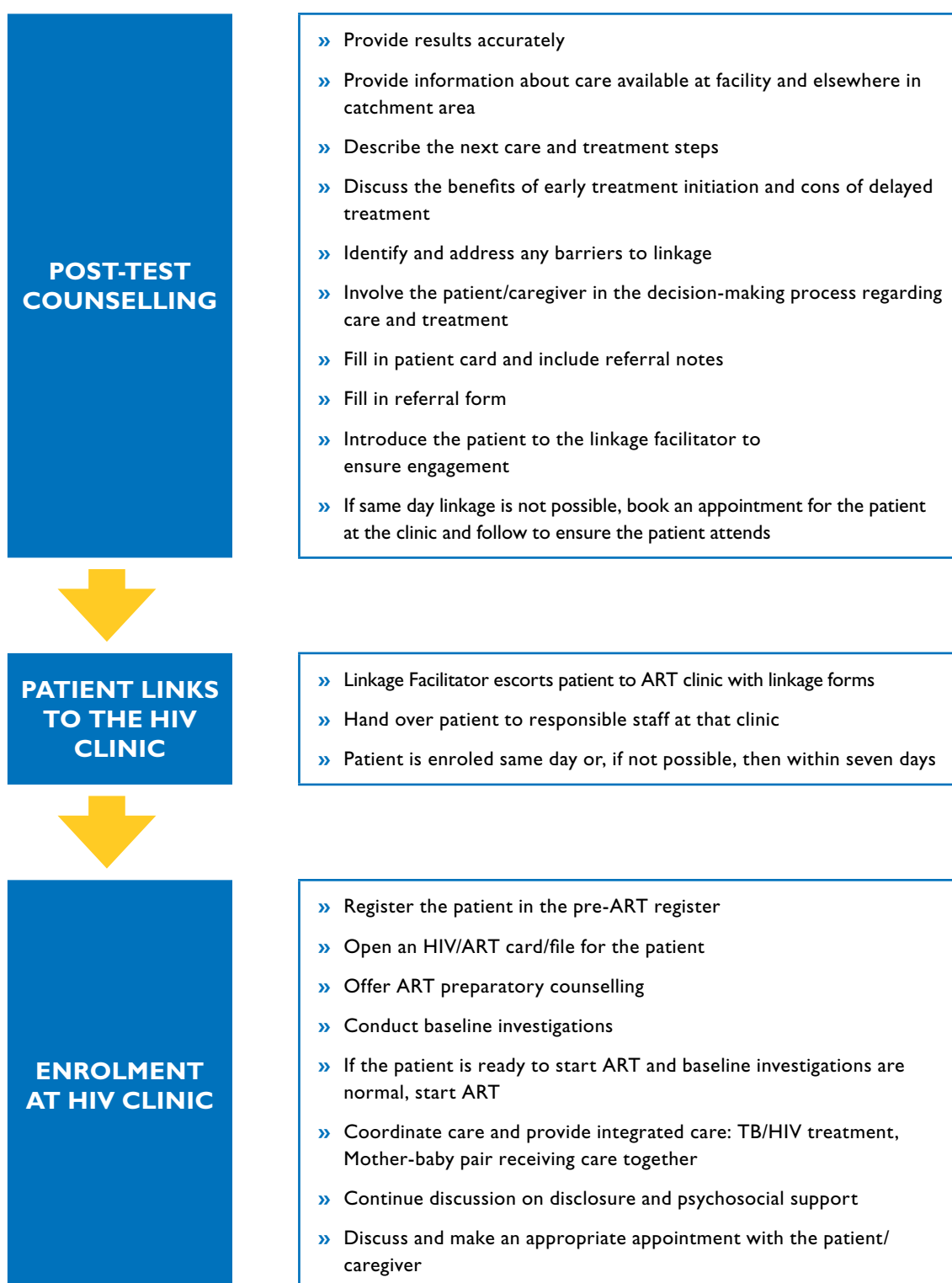
**Internal linkages:** Figure 2.4 has a sample flow chart of steps for linkages within the same facility.

## FOLLOWING UP AND RETAINING HIV-POSITIVE CHILDREN AND ADOLESCENTS

The lifelong nature of HIV treatment requires creating ways to keep children, adolescents, and their family members in care and treatment (known as retention in care). Both retention in care and adherence to ART are critical for optimal success of HIV treatment for individual patients, families, and communities. Children and adolescents living with HIV have complex medical and psychosocial needs and many may disengage from care due to poverty, marginalisation, discrimination and stigma, risk-taking behaviours, lack of a social support, and low self-perception of risk of disengaging or defaulting from care. HCPs face challenges in tracking patients who miss appointments or who are lost to follow-up due to inaccurate and changing contact information, transitory family addresses, invalid mobile phone numbers, and family relocation. Retention in care serves to routinely monitor effects of drug therapy, prevent medication interruptions, prevent development of HIV drug resistance, and facilitate PSS (see Box 2.8 and **Chapter 9** on adherence to ART).



Figure 2.4. Internal Linkage Facilitation Steps



## BOX 2.8. 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 (see *Chapter 9*)

Definitions relevant to retention include the following:

**Missed appointment:** When a patient fails to attend a scheduled health care visit/appointment.

**Lost to follow-up:** When a patient does not appear at the scheduled appointment for three or more months and does not have a future appointment, and there are at least two failed follow-up attempts by an HCP or community health worker through phone calls or a physical home visit.

**Lay counsellor:** Peer mothers, expert patients, and community members (such as members of the Village Health Team) who are trained to help HCPs and community health workers with patient follow-up.

**Follow-up of patients:** Steps taken when a patient misses health care appointments or disengages from care but has not yet been identified as lost to follow-up.

**Peer mother:** Peer mothers are mothers who are trained to provide other mothers (including adolescents) with information on PMTCT, family planning, HIV prevention, and other support. Peer mothers can also help track patients who have missed appointments.

## STEPS FOR SUCCESSFUL FOLLOW-UP FOR MISSED APPOINTMENTS OR DISENGAGEMENT FROM CARE

Patient follow-up is a process that can be systematised so that all actors work together to track missing patients. Careful, routine documentation is essential to ensure patient retention, and is also vital for accurate reporting and disease tracking at local, district, and national levels. The steps below are guidance for HCPs to:

1. **Enrol patients** in a tracking system by giving them appointments for the next visit. Scheduling appointments should be done in accordance with the patient's condition and available resources at the health facility. When making appointments, HCPs should consider dates and times that are convenient for the patient and consider school and caregiver schedules where appropriate. Appointment dates should be documented on each medical record and appointment card, and in the appointment book in the unit.
2. **Flag missed appointments daily.** At the end of each clinic day, have one member of facility staff review the patient appointment register to identify patients who have missed

clinic appointments. Daily, obtain the address and phone contacts of patients who miss a clinic appointment from the following medical records (patient data tools):

- ANC register
- HIV-exposed infant care card/exposed infant follow-up register
- ART card, pre-ART or ART register
- Appointment book or any relevant register

3. **Patient Tracing.** The list of patients who miss clinic appointments should be submitted to the HCP in charge, who should share this list with the person(s) designated to track these patients. Tracking should be done weekly. The list should have the following information:
  - Patient identification number; this will either be the pre-ART number, HIV-exposed infant number, or the antenatal number (for pregnant women)
  - Patient’s name
  - Telephone contact
  - Name of caregiver
  - Date of last appointment missed
  - Alternate contact person
  - Village
  - Parish
4. **Create monthly list.** The records clerk or HCP should create a monthly record of people who have missed clinic appointments for the last three months to identify patients who have disengaged from care.
5. **Trace.** The designated person(s) should call all patients with phone contacts, make new appointments with them, and schedule and update the appointment in the appointment book and inpatients medical records (ART card/exposed infant care card, etc.).
6. **Schedule home visits.** For patients who do not have a phone contact and missed their scheduled appointments, a home visit should be attempted by the peer mother, expert patient, or community worker. For follow-up visits, patients should be assigned to a community worker, depending on their mapped catchment area.
7. **Home visit operating procedure.** The HCP should discuss home visits on the first ART clinic visit and obtain patient consent for a staff person to come to his or her home if an appointment was missed. During the home visit, the community workers should do the following:
  - Dress and behave appropriately; use discretion when speaking to avoid accidental disclosure.
  - Introduce themselves; explain where they are coming from, what they do, and why they are there.
  - Talk to the patient, (the caregiver and child, or the adolescent with or without the parent, as guidelines and circumstances permit).

- Ask if they are aware of the missed clinic appointment. Find out why they did not come to the clinic on the date of appointment, and help them overcome appointment challenges. Educate them about the purpose of keeping clinic appointments.
  - Assess for adherence on the medication provided during the previous clinic visit. Provide adherence counselling when adherence challenges are identified, and encourage a patient with good adherence. Assess the amount of remaining ARVs.
  - Make a new appointment with the patient. Schedule and document it on the patient appointment card and update it in the appointment book and on medical record forms at the health care facility. Assess the caregivers'/patients' understanding of why they need to come to the clinic.
  - For patients who changed addresses, get the new contact address and provide it to the clinic.
- 8. Report.** After following up, peer mothers, expert patients, Village Health Team members, or HCPs should make a report and give it to the HCP who generated the LTFU list at the health care facility. Include information in the ART card/Exposed Infant Care card for use by any other HCP who reviews this information.
- 9. Use data capture tools.** At the health care facility, patient data capturing tools should be updated upon receiving the report from the community.
- 10. Follow country protocol.** The monthly and quarterly Ministry of Health reports should include the followed-up and tracked patients' information from the community reports.





## **CHAPTER 3.**



# **GROWTH AND DEVELOPMENT OF HIV-POSITIVE CHILDREN AND ADOLESCENTS**



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## SUMMARY

- » The main stages of growth and development leading to adulthood are; infancy, early childhood, middle childhood, and adolescence.
  - » The domains of growth and development among children and adolescents include; motor, cognitive, language, social, and emotional development.
  - » HCPs need to understand normal growth and development to be able to identify abnormalities so that they can provide appropriate care and support to children, adolescents, and caregivers.
  - » During routine medical care, HCPs must routinely assess the growth and development of paediatric patients and inform caregivers on their findings.
-

## 3.0. DEFINITION OF TERMS

**Development:** The sequential, orderly, and progressive acquisition of various skills or abilities, such as head support, speaking, learning, expressing feeling, and relating to other people by a certain age.

**Developmental Milestones:** Behaviours or physical skills observed in infants and children as they grow and develop, such as rolling over, crawling, walking, and talking.

**Growth:** The progressive increase in the size of a child or body parts of a child.

## 3.1. INTRODUCTION

Growth and development are important indicators of an individual's health. Healthy development is a continuous process that starts in the womb and progresses in a linear manner until physical maturity. Healthy development also includes intellectual, emotional and social development in a child or adolescent. Routine medical assessment of growth and development at every paediatric visit is required for HCPs to identify abnormalities at an early stage (Ngoma, Kusanthan, and Menon 2015).

HIV infection, especially in utero, adversely affects growth and development among children and adolescents even when ART is used (Jao et al. 2015). Delayed growth and a high prevalence of wasting, particularly after the first year of birth, have been noted in children and adolescents with HIV. Sometimes, signs of developmental delay or growth failure may be the first sign of HIV infection. When abnormal growth and development is identified, HCPs should provide timely support, including PSS and care, counselling and referral. These interventions are vital to manage challenges. If an HCP identifies an infant/child with a gross motor development delay (e.g., the inability to sit unsupported after 8 months of age), the HCP should counsel the parent or caregiver on the abnormality identified and refer the child or adolescent to receive available support services.

HIV in infants has been linked to a wide range of developmental challenges, including cognitive delays, neurological symptoms, learning difficulties, and speech and language problems. HIV affects CD4 receptors located on immune cells in the brain, which can slow or stop brain development. This in turn may lead to growth and development retardation and subsequently, to delayed development milestones in nearly all domains (Phillips et al. 2016).

Untreated HIV in children may be associated with childhood cognitive, motor, language, and psychological developmental deficits. Mental and motor developmental delay may commence at as early as 4 months old, and may present either as selective or global neurodevelopmental delay. The majority of children with HIV-associated neurological disease are those infected perinatally, which leads to an increased risk of neurological brain damage, including cerebral atrophy, intracerebral calcifications, microcephaly, various degrees of developmental delays and cognitive impairments. HIV encephalopathy is the most commonly described HIV-related neurological disease among children. Some of its clinical features include:

- » Loss of or failure to achieve appropriate developmental milestones
- » Impaired brain growth
- » Global or selective impairments in cognitive, language, motor, attention, behaviour, or social skills



Research has shown that without ART, 20–50 percent of HIV-positive children develop HIV-related encephalopathy, while less than 2 percent of children on ART experience HIV-related encephalopathy (Patel et al. 2009; S. Cohen et al. 2015).

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.

## 3.2. DOMAINS OF CHILD AND ADOLESCENT DEVELOPMENT

There are four main domains of child development that are described among children and adolescents (Chatterjee 2018):

- » Physical development (motor and fine development skills)
- » Cognitive development
- » Language (communication) development
- » Social skills and emotional development

Each child and adolescent has their own pathway to reach these milestones during normal growth and development. In the setting of HIV infection, normal growth and development may be affected; and failures or delays in reaching milestones are signs of abnormal development. Table 3.1 shows one of several scales that HCPs can use to assess appropriate development during the four stages of growth. Additionally, there is strong emerging evidence that some of these domains (cognitive, social/emotional) extend into young adulthood (under 30 years of age).

## 3.3. ABNORMAL CHILD AND 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. 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. HIV infection in children and adolescents remains a risk factor for neurological and neuropsychological problems, and should be assessed.

***It is important to identify which developmental assessment tools are used in your country to ensure that they are culturally appropriate and effective.*** Table 3.2 provides information on tools that have been adapted or commonly used in sub-Saharan Africa that may be appropriate for your setting.

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)
<b>Physical</b>	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
<b>Cognitive</b>	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
<b>Emotional/ Social</b>	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
<b>Sex/Gender Language &amp; Communication</b>	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

**Table 3.2. Developmental Screening Tools**

TOOL	AGE RANGE	LINK FOR FURTHER INFORMATION
<b>Denver Developmental Screening Test*</b>	Birth to 6 years	<a href="https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/s12889-016-3288-2">https://bmcpublichealth.biomedcentral.com/track/pdf/10.1186/s12889-016-3288-2</a>
<b>The Kilifi Developmental Inventory</b>	6 to 35 months	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3908377">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3908377</a>
<b>The Developmental Milestones Checklist</b>	≤ 24 months	<a href="https://www.cdc.gov/ncbddd/actearly">https://www.cdc.gov/ncbddd/actearly</a>
<b>The Malawi Developmental Assessment Tool</b>	Birth to 6 years	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2876049">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2876049</a>
<b>Bayley Scores of Infant and Toddler Development</b>	1 to 42 months	<a href="https://www.hindawi.com/journals/isrn/2017/1631760">https://www.hindawi.com/journals/isrn/2017/1631760</a>
<b>Caregiver Reported Early Development Index</b>	≤ 36 months	<a href="https://scholar.harvard.edu/danamccoy/credi">https://scholar.harvard.edu/danamccoy/credi</a>

\*Available in **Appendix VIII**

For adolescents, it is important to also assess physical characteristics, including sexual maturation, using Tanner staging (see section 3.5), and for cognitive, social, and emotional development. A child, or especially an adolescent, who is reaching development milestones (physical, emotional, social) may experience psychological issues 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.

During each visit, despite high patient-loads, HCPs must assess expected development domains by age to detect abnormal growth and development early. Results should be compared to expected milestones and also discussed with the adolescent and caregiver. A thorough medical examination can determine if the child/adolescent has achieved the appropriate milestones for his/her age.

In addition:

- » Check whether the child has any red flags (see Table 3.3).
- » Observe the child as they enter the room and throughout the consultation.
- » Identify abnormal growth and development in children and adolescents by conducting thorough history-taking from parents/caregivers; asking questions regarding perinatal risk factors such as history of trauma, infections, immunisation and substance use; conducting physical assessments; and asking questions to assess for developmental milestones. When red flags or abnormalities are identified, provide care and counselling, and refer to early childhood development programmes, physiotherapy services, paediatric specialists, or any organisations that provide services to children with delays.

**Table 3.3. Red Flags: Signs of Abnormal Early Childhood Growth and Development**

	INFANCY (0–12 MONTHS)	TODDLER (12–24 MONTHS)	EARLY CHILDHOOD (2–5 YEARS)	MID-CHILDHOOD (6–9 YEARS)
Physical	<ul style="list-style-type: none"> <li>» Hands that are persistently fistled at 3 months</li> <li>» Unable to sit alone by 5 months or does not roll over</li> <li>» Poor head control by 5 months</li> <li>» Unable to hold or grasp an adult finger</li> <li>» Unable to transfer objects from hand to hand by one year</li> </ul>	<ul style="list-style-type: none"> <li>» Abnormal pincer grip or grasp by age 15 months</li> <li>» Unable to walk alone by 18 months</li> </ul>	<ul style="list-style-type: none"> <li>» Inability to perform self-care tasks, hand washing simple dressing, daytime toileting</li> <li>» Failure to draw a stick person (with all body parts)</li> <li>» Inability to hop on one foot</li> <li>» Inability to throw and catch a ball successfully most of the time</li> <li>» Inability to walk up and down the stairs without assistance and alternating feet</li> </ul>	<ul style="list-style-type: none"> <li>» Child walks on toes all the time</li> <li>» Gross motor skills are regressing</li> <li>» Child is exclusively clumsy</li> </ul>
Cognitive	<ul style="list-style-type: none"> <li>» Unable to follow moving objects with his/her eyes by 6 months</li> <li>» Will not reach to explore/touch objects by 6 months</li> </ul>	<ul style="list-style-type: none"> <li>» Doesn't reach to explore/touch objects by 6 months</li> <li>» Child doesn't respond to caregiver interactions</li> </ul>	<ul style="list-style-type: none"> <li>» Unable to follow directions</li> <li>» Unable to print numbers</li> <li>» Cannot count sequentially</li> <li>» Unable to describe personal experiences</li> </ul>	<ul style="list-style-type: none"> <li>» School failure; very frustrated by school assignment and tasks</li> </ul>
Emotional/Social	<ul style="list-style-type: none"> <li>» Unresponsive to familiar voices</li> <li>» No eye contact by 6 months</li> </ul>	<ul style="list-style-type: none"> <li>» Lack of interest in people and playthings</li> <li>» Will not show interest or participate in social situations</li> <li>» Not laughing in playful situations</li> </ul>	<ul style="list-style-type: none"> <li>» Lack of socialisation</li> <li>» Unable to play with other children</li> <li>» Resists discipline</li> <li>» In constant motion</li> <li>» These may point to autism or ADHD*</li> </ul>	<ul style="list-style-type: none"> <li>» Social isolation</li> <li>» Lack of friends</li> <li>» Aggressive behaviours: fights, fire-setting, animal abuse</li> </ul>

	INFANCY (0–12 MONTHS)	TODDLER (12–24 MONTHS)	EARLY CHILDHOOD (2–5 YEARS)	MID-CHILDHOOD (6–9 YEARS)
Communication/Language	<ul style="list-style-type: none"> <li>» Unresponsive to sound stimuli, deafness</li> <li>» Inability to visually fixate and follow moving objects</li> <li>» Absence of babbling at 6 months: possible hearing deficit</li> <li>» Doesn't respond when called</li> <li>» Turning head to use only one eye to look at things</li> <li>» No interest in small objects</li> </ul>	<ul style="list-style-type: none"> <li>» Lack of spoken words by 18 months</li> <li>» Non-communicative speech (echoing, repeating) may indicate autism</li> </ul>	<ul style="list-style-type: none"> <li>» Lack of eye contact</li> <li>» Frustrated when verbally communicating</li> <li>» Getting stuck with word or sounds</li> </ul>	<ul style="list-style-type: none"> <li>» Communication is not clear</li> <li>» Cannot read at all</li> <li>» Cannot follow 2- or 3-stage command</li> </ul>

Source: Adapted from Toronto Public Health. 2009. *Early Identification in Toronto: Toronto Red Flags Guide*, available at [https://assessmentschildren.weebly.com/uploads/1/1/8/3/1/18350729/red\\_flags.pdf](https://assessmentschildren.weebly.com/uploads/1/1/8/3/1/18350729/red_flags.pdf)

\*ADHD: attention deficit hyperactivity disorder

## 3.4. INTELLECTUAL DISABILITY

**Definition:** Intellectual disability is the global lack or limitations in adaptive functioning skills, including social, self-help or care, emotional, and intellectual skills. Limitations include poor memory, slow learning capacity, attention problems, poor communication skills, and lack of motivation. Symptoms are typically identified before age 18, most often in early childhood.

**Management:** Table 3.4 describes symptoms and management of all degrees of intellectual disability. There is no cure for intellectual disability. However, gradual and consistent training helps the child to acquire adaptive functioning skills for future independence.

**Role of HCP when treating a child with intellectual disability:** *Identify* symptoms of intellectual disability in paediatric patients, *explore* how the family is coping, and *recommend* reinforcement of consistency and order. Chaotic family factors experiences can worsen symptoms. Refer the patient to a paediatrician or psychiatrist or any other medical personnel with skills in working with children who experience intellectual disabilities.

Table 3.4. Diagnosis and Management of Intellectual Disability

	DIAGNOSIS	MANAGEMENT
<b>MILD: intellectual disability</b>	<ul style="list-style-type: none"> <li>» Not identified until school enrolment or third to fourth grade or when academic work becomes difficult</li> <li>» Slow in acquiring motor milestones and independence and self-help skills such as grooming, personal hygiene, and dressing, during early childhood</li> <li>» Most able to learn job skills as they mature until they achieve independence or semi- independence</li> <li>» Some adults in this category develop excellent communication and social skills by age 18 and are no longer are considered to have a disability</li> </ul>	<ul style="list-style-type: none"> <li>» Educable, especially when given an individualised programme</li> <li>» Mainstream schooling is recommended to help the child learn through association and improve on social and communication skills</li> <li>» They need stimulation, especially in areas where they show strength. HCPs can educate their caregiver on the problem and provide motivation to obtain facilitated education by engaging with the child's teachers</li> </ul>
<b>MODERATE: intellectual disability</b>	<ul style="list-style-type: none"> <li>» Show significant delay in development during pre-school years</li> <li>» Have limitations in language and expression with limited vocabulary</li> <li>» As they grow older, there appears a significant discrepancy in overall intellectual development and adaptive functioning skills between these children and their peers without disabilities</li> </ul>	<ul style="list-style-type: none"> <li>» Emphasis on achievement of as much formal education as the child can tolerate, and subsequently divert to vocational training or artisan skills</li> <li>» Training should focus on the child's strengths and perfect already learned self-help skills</li> </ul>
<b>SEVERE: intellectual disability</b>	<ul style="list-style-type: none"> <li>» Often have serious deficits in language</li> <li>» Have obvious developmental delays in all areas, including socialisation and self-help skills</li> <li>» Often require help in feeding, dressing, and personal hygiene, among others</li> <li>» Often have central nervous system damage, including other additional disabilities or health conditions, such as heart ailments</li> </ul>	<ul style="list-style-type: none"> <li>» They are trainable and can cope with artisan work in skill development (cookery, dress-making)</li> </ul>
<b>PROFOUND: intellectual disability</b>	<ul style="list-style-type: none"> <li>» Usually identified at birth</li> <li>» Associated with other congenital abnormalities</li> <li>» Some have total lack of language development</li> <li>» Totally dependent in on others for feeding, dressing, personal hygiene, etc.</li> <li>» Socialisation is very limited; hence, may not fit in a class for education</li> </ul>	<ul style="list-style-type: none"> <li>» Home schooling in terms of training is recommended</li> <li>» Training in self-help skills</li> </ul>

## 3.5. ADOLESCENT DEVELOPMENT

Adolescence is a special transition phase of growth and development from childhood to adulthood and is characterised by rapid physical, cognitive, emotional changes as well as social development.

Three 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, sexual acts) as they increase their capacity for critical thinking.

### ADOLESCENT PHYSICAL AND SEXUAL DEVELOPMENT

Physical changes (also known as puberty) are the most noticeable signs that a child is entering adolescence. For girls, puberty can start as early as eight years of age; boys usually enter puberty one to two years after girls, and continue to develop for three to four years after girls. During this period, most physical changes occur due to changes in sex hormones that signal the onset of puberty. A girl will begin menstruation, indicating that her body is developing and she can have a baby if sexually active. During menstruation, the lining of the uterus becomes thin as blood leaves through the vagina. This bleeding usually lasts for four to seven days, and happens every month. Adolescents should be taught that menstruation is normal and they should not be too concerned or worried (see Table 3.6). Perinatally infected adolescents may experience slow skeletal growth and delayed pubertal maturation. This may be due 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 frustrations and anger because they look different from their HIV-negative peers.

Adolescents living with HIV in early adolescence may be on paediatric ART regimens while those in mid and late adolescence will likely be on adult ART regimens. The HCP needs to take the adolescent's growth into consideration while making the decision to put the individual on a paediatric or adult regimen. Assessing the adolescent's growth and development can also be an important entry point for nutrition care and support.

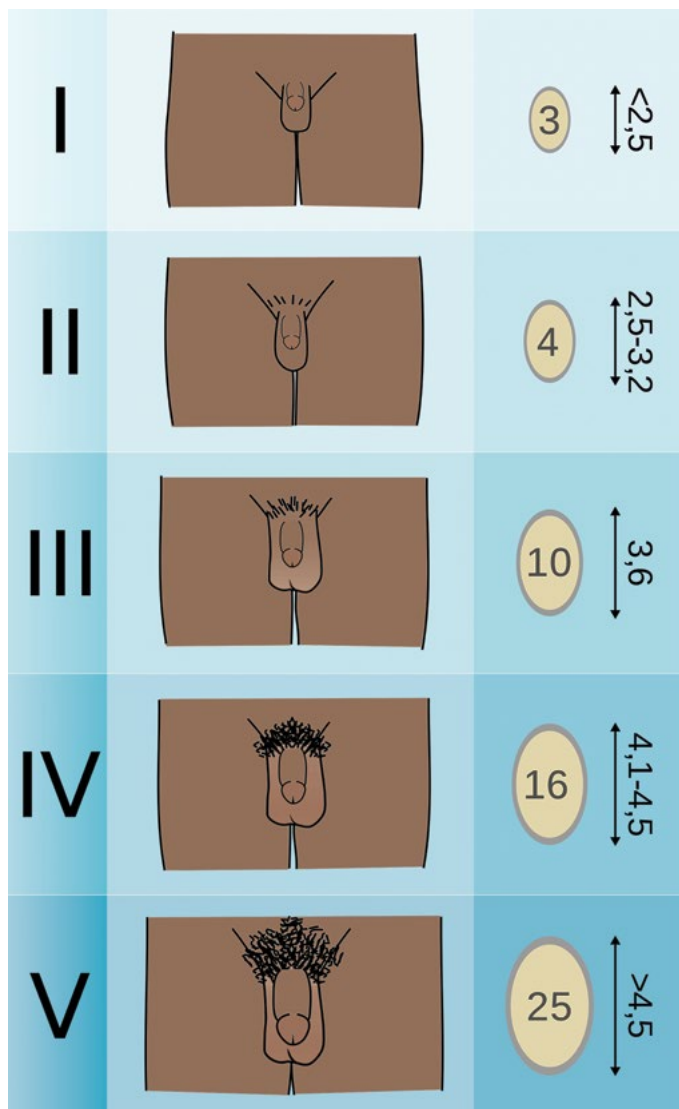
HCPs can assess adolescents' development by using Tanner staging for boys and girls, as shown in Figures 3.1 and 3.2;<sup>4</sup> details for the figures appear in Tables 3.5 and 3.6.

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4 Illustrations in figures 3.1 and 3.2 were originally created by the Vermont Department of Health and adapted by AIDSFree. [https://www.medschool.lsuhscc.edu/medical\\_education/undergraduate/spm/SPM\\_100/documents/tannerstagescard.pdf](https://www.medschool.lsuhscc.edu/medical_education/undergraduate/spm/SPM_100/documents/tannerstagescard.pdf)

**Table 3.5. Tanner Staging: Male Genitalia and Pubic Hair**

STAGE	MALE GENITALIA	PUBIC HAIR
<b>Stage I</b>	Testes small in size, with childlike penis.	None
<b>Stage II</b>	Testes reddened, thinner and larger. (1.6-6.0cc) with childlike penis	A small amount of long hair at base of scrotum
<b>Stage III</b>	Testes larger (6 -12cc), scrotum enlarging, increase in penile length	Moderate amount of curly, coarser hair extending outwards
<b>Stage IV</b>	Testes are larger (12 -20 cc) with greater enlargement & darkening of the scrotum, increase in length & circumference of penis.	Resembles adult hair but does not extend to inner surface of thigh
<b>Stage V</b>	Testes are over 20 cc with adult scrotum and penis.	Hair is adult type and extends to medial thigh surface

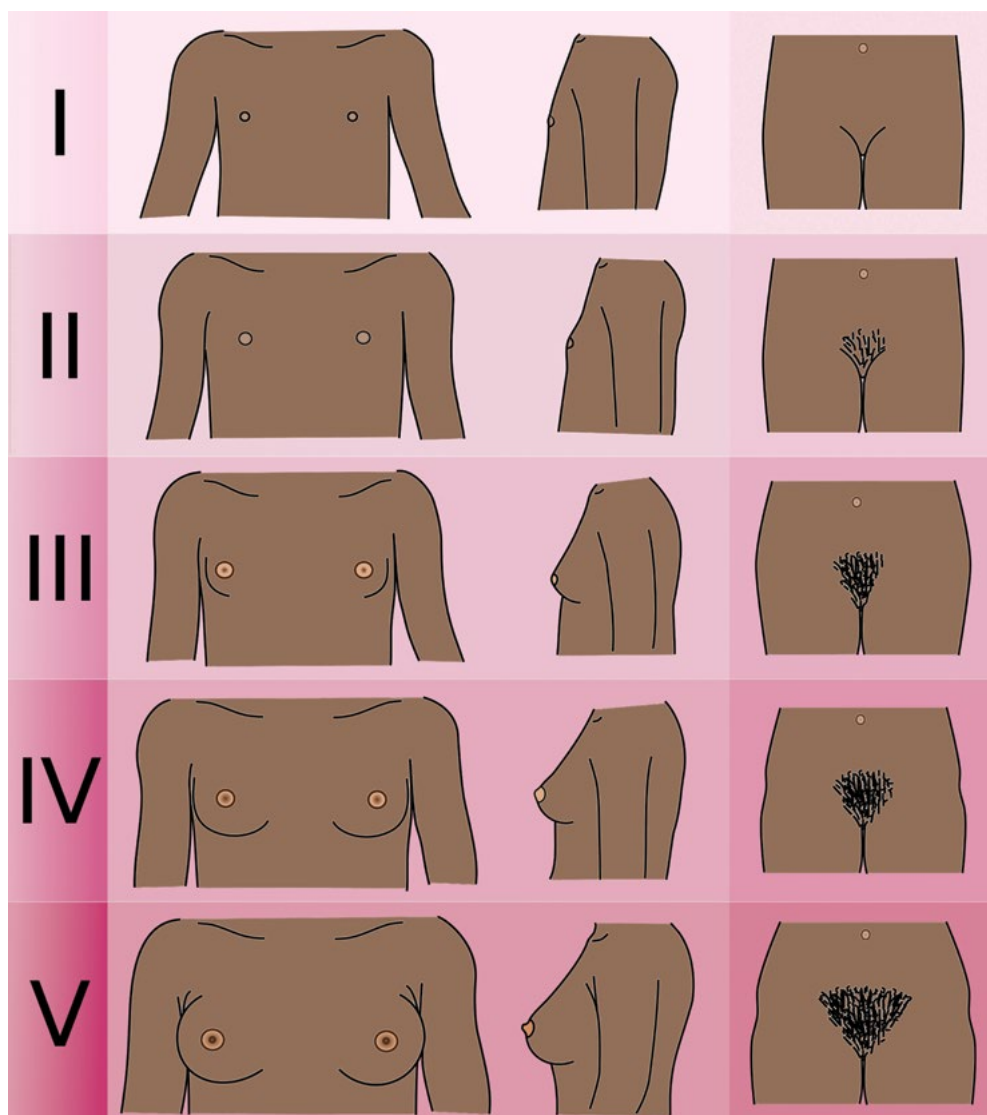
**Figure 3.1. Tanner Staging: Male Genitalia and Pubic Hair**



**Table 3.6. Tanner Staging: Female Breasts, Genitalia, and Pubic Hair**

STAGE	BREASTS	PUBIC HAIR
<b>Stage I</b>	No breast tissue with flat areola	None
<b>Stage II</b>	Breast budding with widening of the areola	Small amount of long hair at base of labia majora
<b>Stage III</b>	Larger and more elevated breasts extending beyond the areola	Moderate amount of curly and coarser hair extending outwards
<b>Stage IV</b>	Larger and even more elevated breasts, also areola and nipple projecting from the breast contours	Resembles adult hair but does not extend to inner surface of thigh
<b>Stage V</b>	Adult size with nipple projecting above areola	Adult type and quantity, extending to the medial thigh surface

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



## SOCIAL AND EMOTIONAL DEVELOPMENT IN ADOLESCENTS

Adolescence is a period of rapid emotional growth and changes in interpersonal relationships, particularly within the family unit with increasing autonomy as the adolescent progresses from early to late adolescence. Increased intimacy within friendships and romantic relationships are also noted as individuals move through the adolescent period. HIV-positive adolescents may experience social and emotional challenges, particularly in regards to developing romantic relationships and making disclosure decisions to romantic partners and peers. They may also experience low self-esteem, self-stigma, and feelings of inadequacy due to their illness, which can in turn affect their adherence to ART and their health-seeking behaviours.

Adolescents increase their ability to perceive, assess, and manage their own emotions. The skills necessary for managing emotions and successful relationships are called “emotional intelligence,” which include self-awareness, social awareness, self-management, and ability to get along with others and make friends. Social skills include the capacity to be sensitive and relate to other people. Emotional skills include developing a sense of identity, developing close friendships, using words to express feelings, realising that caregivers/parents are not perfect and have faults. Adolescents may or may not progress through the expected psychosocial (emotional and cognitive) stages of development. Therefore routine assessments should be carried out to identify potential challenges to HIV self-care including their capacity to move towards transition. Adolescents in late adolescence are more responsible for their own health and will likely transition easily into adult (self-managed) care once this stage of emotional development is achieved (please see **Chapter 11** for more information on making a smooth transition).

HCPs should consider the social ecology of the individual adolescent to consider how it may shape the adolescent’s experiences and ability to participate in health-seeking behaviours. Disclosure of HIV status to a vertically infected individual should ideally occur before adolescence, such that by mid-adolescence all ALHIV should know their HIV status. Onward disclosure of HIV status to others such as friends, sexual partners should be discussed by late adolescence. See **Chapter 7** for more information on disclosure.

At the individual level, resilience and internalised stigma can shape adolescents’ perceptions regarding their HIV diagnosis including maintaining positive attitudes and building and keeping relationships. Support at the family and peer level can contribute to treatment adherence support but may result in inappropriate status disclosures.

At the community level, stigma and discrimination, particularly within the school setting, can cause negative experiences while the presence of community-based organisations can provide important PSS.

At the structural level, health service flexibility in regards to location, hours, adolescent-friendly staff, and adolescent-friendly policies influence experiences. Addressing factors within the social ecological context of the individual patient can help improve experiences for adolescents and improve service provision including routinely providing PSS and linking patients to peer support and disclosure groups to help them address their social and emotional development needs.

## 3.6. HIV-EXPOSED UNINFECTED CHILDREN

Paediatric infections worldwide are declining due to PMTCT. Yet the number of HIV-exposed but uninfected children is increasing; 30 percent of these children are born in East and Southern Africa. There is increasing evidence that these children may be at risk for the developmental abnormalities described previously (Afran et al. 2014). Thus it is vitally important to carefully assess the growth and development of HIV-negative exposed infants and children to enable quick intervention if abnormal growth and development is identified.

HCPs should routinely conduct thorough nutrition history and assess:

- » If the infant is breastfeeding, formula feeding, or both, and how much in a 24-hour period
- » If the baby has been weaned, and what types of foods have been introduced
- » How many times a day they eat and how much; whether they complete their meals
- » How is the child's appetite?
- » Any weight gain or weight loss noted since the last appointment
- » Any challenges in the household with food security and availability

## 3.7. ASSESSMENT OF GROWTH

HIV-infected or exposed children are at high risk of growth delays, so routine growth and development assessments can identify delayed or absent milestones; this may be an early indicator of HIV infection. Growth assessments include weight (the best criterion for assessing growth, and a good indicator of a child's overall health and nutritional status), height, weight/length, head circumference, mid-upper arm circumference (or MUAC; this helps to assess the nutritional status of younger children), and chest circumference.

Standards and Equipment Used to Assess Growth

1. **History:** Take a thorough history. Ask caregivers about any changes in weight and height.
2. **Examine:** At each infant visit conduct and record the following **growth assessments:** Weight, Height/length, Head circumference, MUAC.
3. **Measure:** The equipment required for taking growth parameters includes age-appropriate weighing scales; height boards; stadiometer; infantometer; tape measure (MUAC tapes).

For each measurement, record and plot the growth parameters of each child and determine where the child is on the growth curve. Plotting growth charts, shown in the WHO growth charts in Figures 3.3 (girls; birth to 2 years) and 3.4 (boys; birth to 2 years) is an easy and systematic way to follow changes in growth over time. Monitor the growth chart at each visit to ensure that the child is progressing as expected along the growth chart, which is usually included in the child health card or health passport of the child. Some children may be on the smaller end of the chart, so ensure that they continue to progress along the growth curve as expected. Make nutritional interventions, including referrals, when children lose weight, or are not progressing as expected along the curve. There should be a low threshold for intervention for children who appear malnourished, are small at baseline, or whose parents report concerns or food supply challenges.

Figure 3.3. WHO Growth Chart for Girls from Birth to 2 Years

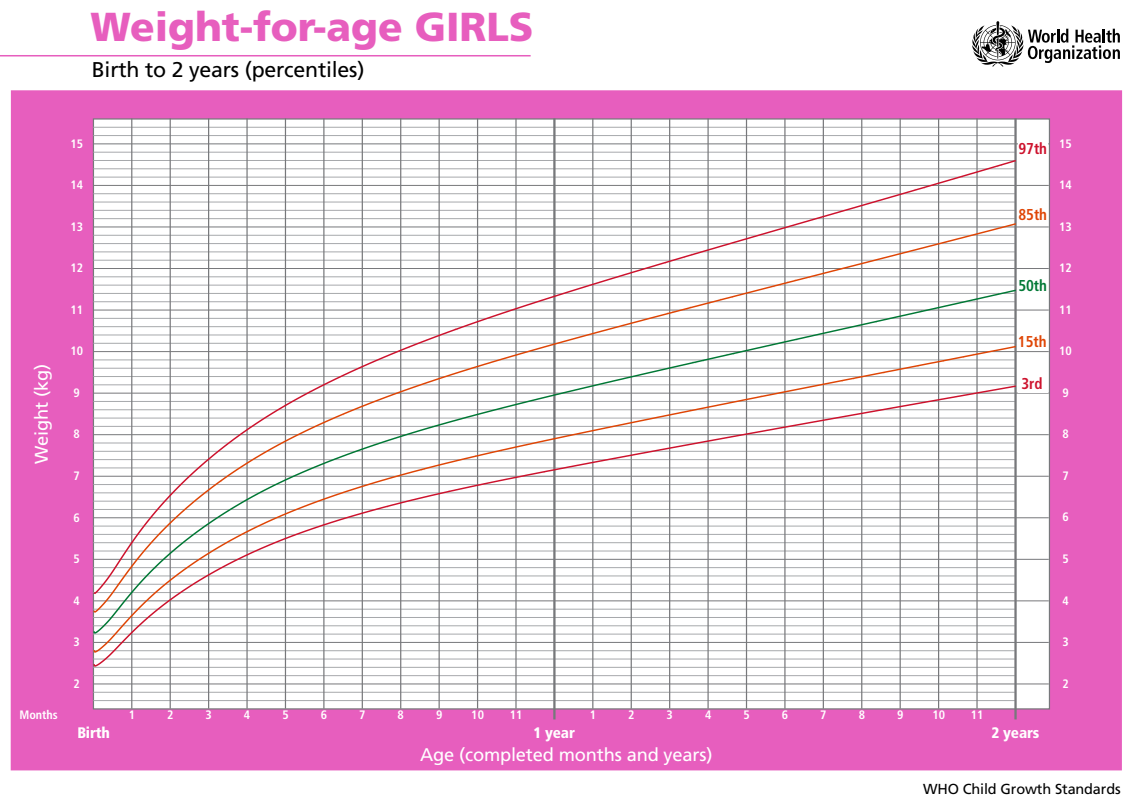
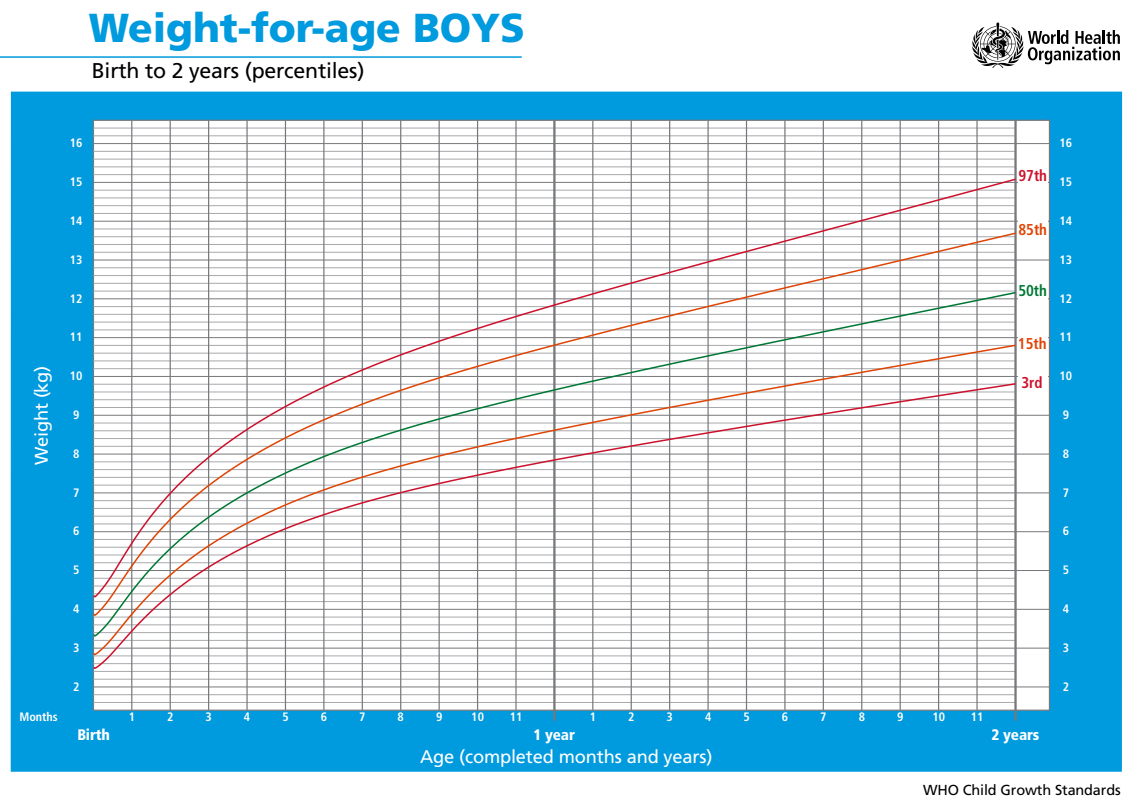


Figure 3.4. WHO Growth Chart for Boys from Birth to 2 Years of Age



## 3.8. ROLE OF HCPS IN CHILD AND ADOLESCENT GROWTH AND DEVELOPMENT

For a child to achieve full growth and developmental potential, care including psychosocial stimulation is crucial. Box 3.1 summarises the HCP's role. HCPs can offer basic psychosocial services to support normal early childhood development and help the caregiver to build a home environment that stimulates early childhood development. Providers can have a demonstration corner with play items that can stimulate a child's normal development and help to reduce impacts of developmental delays or other challenges. This also provides an opportunity for caregivers to learn about the child.

3

### **BOX 3.1. ROLE OF HCPS IN GROWTH AND DEVELOPMENT OF HIV-POSITIVE CHILDREN AND ADOLESCENTS**

- » Understand normal child and adolescent growth and development patterns.
- » Offer basic stimulation for normal early childhood development and show the caregiver how to have a home environment that stimulates normal early childhood development.
- » Assess and recognize abnormal development.
- » Conduct routine growth and developmental assessments using Table 3.1 or national guidelines.
- » Refer children and adolescents who fall outside of expected growth and development norms to child and adolescent development counselling and support.
- » Identify, counsel, and refer or follow-up in case of any abnormality in growth and development.



**CHAPTER 4.**  
**MENTAL HEALTH OF**  
**CHILDREN, ADOLESCENTS,**  
**AND CAREGIVERS**

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## SUMMARY

- » Common mental health problems in HIV-positive children and adolescents are anxiety, depression, conduct disorder, sleeping disorders, and substance use disorders. If left untreated, these problems can escalate and lead to poor health outcomes, including suicide.
- » HCPs should be able to assess and identify cases of mental health problems and manage or refer appropriately.
- » Adolescents living with HIV who are suicidal should receive emergency treatment and same-day referrals to a specialist for further assessment.
- » Adolescents with mental health problems are more likely to use harmful drugs or alcohol and to engage in risky sexual behaviours.
- » Mental health problems significantly influence adherence to HIV care and medications.
- » Caregivers, family, and friends are crucial sources of support for children and adolescents with mental health problems. They can help identify the symptoms and triggers, describe associated factors, and mitigate effects of the illness by reducing isolation and hopelessness.
- » Community-based services can provide critical support to children and adolescents with mental health problems. They also can provide support to caregivers and families as a unit.
- » Children and adolescents from key populations, like sex workers and gay communities, are more vulnerable to mental health problems and should be targeted for prevention and management.
- » Most mental health problems are preventable or manageable; therefore, HCPs need to identify them and manage them early.
- » Caregivers of children and adolescents living with HIV also have relatively high levels of depression, post-traumatic stress disorder, and alcohol dependence. Interventions that address caregivers' mental health can improve child outcomes.

## 4.0. 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. HIV-positive children and adolescents experience higher levels of anxiety and depression, among other mental health symptoms; compared to their HIV-negative peers (Lwidiko et al. 2018). 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, substance abuse, violence, and poor reproductive and sexual health. 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.

Risk factors for developing mental illness manifest at all stages of life. Risk exposure in the formative stages of life, including foetal exposure to substance use during pregnancy, insecure attachment in infancy, and family violence during childhood, can predispose children and adolescents to experiencing symptoms of mental illness many years or even decades later (Bankole et al. 2017). HIV as a chronic illness affects a child's brain and predisposes them to developing mental illness.

In the African context, there are often negative cultural perceptions of mental illness; and it is sometimes attributed to witchcraft and demonic possession (Shah et al. 2017). HCPs should be aware of these beliefs while empowering the patient to care for their mental health, and should not be dismissive of their traditional or spiritual systems that may provide support. The evidence about the impact of HIV on the mental health of children and adolescents is nascent; however, depression co-occurs in 50 percent or more of chronic medical conditions, including HIV. Adolescents with mental health problems are more likely to be sexually abused, abuse drugs or alcohol, and engage in risky sexual behaviours. Mental health problems negatively impact adherence to medications (Smith Fawzi et al. 2016).

Given that many mental disorders are manageable, it is critical for HCPs to have sufficient knowledge about common mental health issues associated with HIV among children and adolescents. About 50 percent of the mental health problems start before age 14; and lack of knowledge and stigma surrounding mental illnesses can prevent patients and families from accessing services (World Health Organization 2018a).

The sections below describe common mental health problems in HIV-positive children and adolescents; including how they manifest and are managed; and the HCP's role for each. The information draws upon WHO's Mental Health Gap Action Programme (mhGAP), the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-V), and the WHO's International Statistical Classification of Diseases and Related Health Problems (ICD-10). Intellectual disability, sometimes classified as a mental health issue, is described in **Chapter 3**. Other important childhood disorders (autism, attention deficit hyperactivity disorder, and psychosis), which may also occur among HIV-positive children and adolescents, are described in **Appendix V**.

## 4.1. DEFINITION OF MENTAL HEALTH

According to the World Health Organization, health is a state of complete physical, mental, and social well-being, not just the absence of illness.



**Mental health** is a state of well-being in which an individual is able to achieve, cope with daily challenges of life, and make contributions to the society. HCPs need to be familiar with an individual's mental health along with other aspects of the patients' well-being to provide effective care

**Mental health problem:** Normal fluctuation in mood or behaviour that has minimal effect on life's daily routines and demands.

**Severe mental illness:** A disease or condition affecting the brain that significantly influences or disrupts a person's thinking, feeling, mood, ability to relate to others, and daily functioning. Untreated mental health problems, such as severe depression, can escalate into serious, sometimes life-threatening mental illness.

## 4.2. MENTAL HEALTH PROBLEMS AMONG CAREGIVERS OF CHILDREN AND ADOLESCENTS

Although studies are limited, relatively high levels of depression, post-traumatic stress disorder, and harmful alcohol use have been reported among Southern Africans infected with and affected by HIV (Chuah et al. 2017). Also, the mental health of caregivers plays a very important role in the child's/ adolescent's physical and mental health. Children of caregivers with mental illnesses have higher rates of emotional and behavioural disturbances and delays in multiple developmental, psychological, and physical domains. Evidence suggests that interventions to address caregiver's mental health can improve child outcomes. For example, treating maternal depression may reduce behaviour problems in their children. It is therefore important to assess the caregiver's mental state regularly to improve outcomes among children and adolescents. HCPs observing mental health symptoms in caregivers should provide PSS or, if indicated, refer them for treatment (see **Chapter 5** and **Chapter 6**).

## 4.3. ANXIETY

**Definition:** Anxiety is a feeling of worry, nervousness, or unease about an issue that has uncertain outcomes. It is associated with physical symptoms, such as increased heart rate, tremors, restlessness, breathlessness, and muscle stiffness that cause significant impairment in social and occupational functioning. Studies suggest that psychiatric disorders such as depression and anxiety are more prevalent among perinatally infected adolescents compared to non-infected adolescents. Symptoms of anxiety include a vague sense of apprehension often accompanied by headache, perspiration, palpitations, tightness in the chest, mild stomach discomfort, and restlessness, manifested as inability to sit or stand still whenever a threat is perceived. Children and adolescents affected and infected by HIV may manifest anxiety symptoms after learning of their HIV status or that of their caregivers or siblings. Any loss or perceived loss of stability, schooling, and familiar environment is likely to produce a cascade of events leading to anxiety. It is important to note that a new experience or event such as diagnosis of a chronic illness, child abuse, or loss, can precipitate severe forms of anxiety, including panic disorder and separation anxiety disorder in children and adolescents.

**Role of HCPs:** The HCP should be able to recognise a child or adolescent manifesting anxiety symptoms and further explore the possible true and perceived threats. HCP should then use family education to minimise the symptoms and address the issues at hand. A referral to a psychologist, psychiatrist, social worker, or other mental health professional can prompt more intensive counselling, therapy, and/or medication management. Table 4.1 summarises the common types of anxiety disorders, outlines diagnostic criteria and describes management approaches.

**Table 4.1. Common Types of Anxiety Disorders in Children and Adolescents**

	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Generalized Anxiety Disorder</b>	<ul style="list-style-type: none"> <li>» Excessive anxiety/worry about a number of events (HIV, loss, etc) or activities</li> <li>» Difficulty controlling the worry</li> <li>» 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)               <ul style="list-style-type: none"> <li>• Withdrawing from play</li> <li>• Restlessness or feeling on edge</li> <li>• Easily fatigued</li> <li>• Difficult concentration or mind going blank</li> <li>• Irritability-acting out</li> <li>• Muscle tension</li> <li>• Sleep disturbance (excessive or limited)</li> </ul> </li> <li>» Significant distress in social situations (play), occupational functioning (schooling for adolescents)</li> <li>» Unable to explain by a physiological effect of a drug or a general medical or psychiatric condition</li> </ul>	<ul style="list-style-type: none"> <li>» Educate the patient on the physiological response of the body in a flight-fight response reaction. This includes increased heart rate, blood pressure, respiration, muscle stiffness, sweating; this is a normal response to threat and should diminish after removal of the threat, but in this case the continuous feelings of unknown threat sustain the body in a flight-fight mode—hence the anxiety</li> <li>» Use cognitive restructuring where the patient is trained to challenge his/her irrational fear</li> <li>» Teach relaxation technique using breathing in and out as he/she counts 1 to 10 and focuses on a single point</li> </ul>
<b>Separation Anxiety</b>	<ul style="list-style-type: none"> <li>» Developmentally inappropriate and excessive anxiety emerges related to separation from an attachment figure (e.g., mother, caregiver) (Separation anxiety is expected in toddlers, but abnormal for school-aged children)</li> <li>» Continuous worry for the caregiver's safety upon separation, leading to extreme distress and sometimes nightmares</li> <li>» May refuse to attend school or sleep alone</li> <li>» Repeated complaints of physical symptoms of headache, abdominal pain in anticipation of separation</li> <li>» A new experience, such as a diagnosis of a chronic illness, abuse, and loss, can precipitate severe forms of anxiety, including this one</li> </ul>	<ul style="list-style-type: none"> <li>» Educate the caregiver on the problem</li> <li>» Encourage the caregiver to reassure the child/adolescent of the intended separation and be very honest of the time of his/her return</li> <li>» The child/adolescent should be left under the care of a sensitive caregiver who will be reassuring, firm, but sympathetic</li> <li>» If the distress is too incapacitating despite the above intervention, then medication in form of anxiolytics can be administered; however, a paediatrician or psychiatrist must assess the child and the parent</li> <li>» Rule out any underlying illness</li> </ul>

	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Post-Traumatic Stress Disorder</b>	<p>This is marked by increased stress and anxiety following an exposure to a traumatic or stressful event such as diagnosis of a life-threatening illness like HIV; sexual abuse; and witnessing or being involved in a violent accident, military combat, kidnap, or natural disaster.</p> <p><b>Signs/symptoms include:</b></p> <ul style="list-style-type: none"> <li>» Recurrent involuntary stressful thought/memories of the event</li> <li>» Recurrent distressing dreams related to the event</li> <li>» Recurrent flashbacks in which the individual acts as if the traumatic event is recurring</li> <li>» In children, the traumatic specific event may be re-enacted in play</li> <li>» Intense or prolonged psychological distress at exposure to anything that causes a reminder of the event</li> <li>» Persistent avoidance of any stimuli that causes a reminder of the event</li> <li>» Inability to remember the traumatic aspect of the event</li> <li>» Marked physiological reactions to reminders of the event</li> <li>» Diminished interest or participation in activities, including constriction of play</li> <li>» Increased frequency of negative emotions</li> <li>» Irritable behaviour</li> <li>» Exaggerated startle response</li> <li>» Problems with concentration</li> <li>» Sleep disturbance either in falling asleep or sustaining sleep</li> <li>» The disturbance is not explained by the direct physiological effects of a drug or presence of a medical condition</li> </ul>	<ul style="list-style-type: none"> <li>» Remove the cause of the stress if possible</li> <li>» Apply relaxation technique (breathing exercises)</li> <li>» Allow the patient to talk about the event starting from the least to the most distressing component of the event</li> <li>» Challenge the patient to explore the parts that he/she is in control of, to help the individual to appreciate his/her strengths</li> <li>» If the child is not able to express verbally, then allow him/her to play with assorted toys or draw pictures and follow the theme being played out by making such comments as “I wonder what is happening now!”</li> <li>» Several play sessions can help the HCP explore the magnitude of the trauma</li> <li>» Play therapy is a useful venture in helping the child to vent about the trauma and resume normality</li> </ul>



## 4.4. DEPRESSION

**Definition:** Depression is a mood disorder characterised by a feeling of sadness and loss of interest. Approximately five percent of children and adolescents in the general population suffer from depression at any given time. Children under stress, who experience loss or have attentional, learning, conduct, or anxiety disorders, are at a higher risk for depression. Depression also tends to run in families.

**Possible triggers of depression in HIV-positive children and adolescents:** Numerous factors can contribute to depression in these patients, including stress, loss, major disappointment, chemical imbalance, genetic disposition, certain medications (e.g., narcotics, steroids), traumatic events (violence, abuse, neglect), social problems, unresolved family conflict, the hopelessness of living with chronic illness, the burden of non-disclosure, real or perceived stigma and discrimination, death of parent(s), siblings or friends, poverty, violence, trauma, abuse, neglect, and anger/fear about diagnosis.

**Clinical presentation:** The behaviour of a depressed child or adolescent may differ from the behaviour of a depressed adult. These symptoms include extreme sensitivity to rejection or failure, increased irritability or hostility, apathy or difficulty concentrating (sometimes leading to impaired school performance or school absences), social isolation, and talk of running away; and may also include:

- » Frequent sadness, tearfulness, crying
- » Decreased interest in activities; or inability to enjoy previously favourite activities
- » Hopelessness
- » Persistent boredom; low energy
- » Social isolation from peers, poor communication
- » Low self-esteem and guilt
- » Extreme sensitivity to rejection or failure
- » Increased irritability, anger, or hostility
- » Frequent complaints of physical illnesses such as headaches and stomach-aches
- » Thoughts or expressions of suicide or self-destructive behaviour

Children and adolescents who are depressed may say that they would prefer to be dead, or they may talk about suicide. Depressed children and adolescents are at increased risk for committing suicide, and they may abuse alcohol or other drugs as a way of trying to feel better. Troublemaking behaviour may also be a sign of depression; parents and teachers may not realise this, especially if the child does not always seem sad. When asked directly, these children can sometimes state that they are unhappy or sad. Depressed adolescents are often restless, irritable, and withdrawn, and are likely to pay less attention to personal appearance and hygiene. Academic deterioration is likely to occur due to lack of interest and reduced concentration.

**Role of HCPs:** HCP should be able to explore the symptoms, including possible substance use; lower academic performance, energy levels, and interest in normally enjoyable activities; the urge to self-harm; and withdrawal from interpersonal relationships. He/she should start psychoeducation and encourage other supportive interventions like healthy eating, sleep hygiene, and restoration of

normal functioning. As required, providers should make a bi-directional referral (that is, a referral in which the specialist/agency reports back to the original provider) to a mental health specialist who specialises in paediatric mental illness. If a specialist is not available, a referral to the most experienced clinician at the health facility and a referral for psychosocial services. Table 4.2 outlines the diagnostic criteria for depression and describes management approaches.

**Table 4.2. Symptoms and Management of Depression**

	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Depression</b>	<p>A child or adolescent needs to have at least 5 of the following 9 symptoms for a period of 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:</p> <ol style="list-style-type: none"> <li>1. Depressed or irritable mood</li> <li>2. Decreased interest or enjoyment</li> <li>3. Decreased concentration or indecision</li> <li>4. Insomnia or hypersomnia</li> <li>5. Change of appetite or change of weight</li> <li>6. Excessive fatigue</li> <li>7. Feelings of worthlessness or excessive guilt</li> <li>8. Recurrent thoughts of death or suicidal ideation</li> <li>9. Psychomotor agitation (emotional distress and restlessness) or retardation</li> </ol> <p>These symptoms must cause social and academic impairment and not due to the direct effect of a general medical condition or substance of abuse.</p>	<p><b>Mild form of depression:</b></p> <ul style="list-style-type: none"> <li>» Psychoeducation (i.e., a broad range of activities that combine education and other activities such as counselling and supportive interventions)</li> <li>» Supportive interventions (in form of educating the caregiver on depression, counselling both the caregiver and the child).</li> <li>» Therapeutic Listening</li> </ul> <hr/> <p><b>Moderate to severe depression:</b></p> <ul style="list-style-type: none"> <li>» Anti-depressant drugs</li> <li>» Cognitive behavioural therapy (i.e. recognising distorted thinking and learning to replace it with more realistic substitute ideas)</li> <li>» Interpersonal therapy by a psychiatrist</li> </ul>

## 4.5. CONDUCT DISORDER

**Definition:** Conduct disorder is a persistent set of behaviours in a child or adolescent that evolves over time and is usually characterised by aggression and violation of others' rights. Affected children and adolescents usually demonstrate behaviours in the following four categories:

- » Physical aggression or threat of harm to others
- » Destruction of their own property or that of others
- » Theft or acts of deceit
- » Frequent violation of age-appropriate rules

It is also associated with certain psychosocial factors including child abuse, harsh or punitive parenting, family discord, lack of appropriate parental supervision, lack of social competence, and low socioeconomic status. The average age of onset is younger in boys than in girls. Boys commonly meet the criteria for diagnosis by 10–12 years, whereas girls are often 14–16 years old before meeting the criteria.

**Role of HCPs:** The HCP should identify the disturbance of conduct, institute early intervention, and reduce related morbidity. Unfortunately, the majority of conduct-disordered children/adolescents are recognised very late, resulting in intervention by the criminal justice system. The co-existence of HIV and conduct disorder is challenging, given that behavioural disorders affect adherence to ART. In addition, optimal outcomes are about self-discipline and willingness to be healthy. The conduct-disordered child/adolescent will not adhere to rules of safety and adherence. Table 4.3 outlines the signs and symptoms for Conduct Disorder and describes management approaches.

**Table 4.3. Symptoms and Management of Conduct Disorder**

	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Conduct Disorder</b>	<p>Childhood onset occurs when the child manifests at least one symptom before the age of 10 years. Adolescent onset occurs when symptoms emerge 10 years onwards. An adolescent must exhibit 3 persistent behaviours among the 15 symptoms listed below; one of the behaviours must have been present in the last six months:</p> <ol style="list-style-type: none"> <li>1. The affected individual often threatens, bullies, or intimidates others</li> <li>2. Often initiates fights</li> <li>3. Has used a weapon that causes serious physical harm to others</li> <li>4. Has been physically cruel to people and animals</li> <li>5. Has stolen while confronting a victim</li> <li>6. Has forced someone into sexual activity</li> <li>7. Has deliberately engaged in fire-setting with the intention of causing serious body damage</li> <li>8. Has broken into someone else's building or car</li> <li>9. Often lies to obtain goods or avoid obligations</li> <li>10. Has stolen items of trivial value without confronting the victim (shoplifting)</li> <li>11. Often stays out at night despite parental prohibitions beginning before age 13</li> <li>12. Has run away from home overnight at least twice while living in the parent's or caregiver's home, once without returning for a lengthy period</li> <li>13. Often stays away from school without leave or explanation (truant) beginning before age 13.</li> <li>14. The symptoms cause significant impairment in socio, academic and occupational functioning.</li> <li>15. Associated disorders include ADHD, depression and learning disabilities</li> </ol> <p>The symptoms cause may significant impairment in social, academic, and occupational functioning.</p>	<p>Identify and manage as early as possible. Early (starting in early childhood, around age 5), sustained intervention can significantly alter the course and prognosis of aggressive behaviour.</p> <hr/> <p>Prevention/management focused. Application of a preventive programme that includes parent behaviour management, child social-cognitive skills, reading, home visiting, mentoring, strict classroom curricular, and problem-solving strategies.</p> <hr/> <p>School norms. School settings can also apply behavioural techniques to promote socially acceptable behaviour towards peers and discourage covert antisocial incidents like stealing and passive-aggressive bullying with teasing/foul language.</p>

## 4.6. INSOMNIA

**Definition:** The inability to obtain sufficient sleep, difficulty in falling or staying asleep, or sleeplessness.

There are anecdotal reports that insomnia is a common problem among children and adolescents living with HIV, possibly as a manifestation of other mental illnesses such as depression and anxiety. It is therefore important that HCPs know how to recognise and manage it. Table 4.4 outlines the signs and symptoms for insomnia and describes management approaches, while Box 4.1 gives tips on sleep hygiene.

**Table 4.4. Symptoms and Management of Insomnia**

INSOMNIA	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Brief Insomnia</b>	<p>Can last from one night to a few weeks. Most often associated with anxiety as a result of or in anticipation of an experience (e.g., examination, grief, loss, any life change or stress).</p> <p>Also associated with illness, emotional or physical discomfort, environmental factors (e.g., too much noise, light, etc.), some medicines, or interferences with normal sleep routine (i.e., travel jet lag).</p>	<p>Managed by practicing good sleep habits (see Box 4.1), reassurance, and support; at times through temporary period with sedatives.</p>
<b>Persistent Insomnia</b>	<p>Most often associated with depression, anxiety, chronic stress, or pain.</p>	<p>Managed by reassurance and support; practicing good sleep habits; addressing the underlying cause of the insomnia (i.e., the illness); behavioural therapy; and at times, a brief treatment with sedatives</p>
<b>Psycho-physiological Insomnia</b>	<p>Difficulty in going to sleep</p> <p>Report that insomnia has lasted for years, but do not associate it with stressful periods in their lives</p> <p>View sleep environment (such as the bed or bedroom) as the cause of insomnia</p> <p>Worry about not being able to sleep</p> <p>Try too hard to sleep</p> <p>Inability to clear their mind in order to sleep</p> <p>Increased tension when attempting to sleep</p> <p>Able to sleep better away from one's own bed</p>	<p>Managed by maintaining regular sleep schedules, practicing sleep restriction, using behavioural therapy techniques such as cognitive behavioural therapy, explore potential medication options, such as sedatives, such as diazepam; and melatonin which are associated with fewer side effects than many other sleep medicines.</p>

### BOX 4.1 TIPS ON SLEEP HYGIENE

- » Prepare to go to bed daily around the same time and to sleep for at least 8 hours.
- » The bedding should be clean and warm.
- » Ensure that he/she gets to sleep more than one hour after eating.
- » Bathe in warm water before getting to bed.
- » Reduce noise and light in the bedroom.
- » Don't watch a stimulating movie or read an exciting book before sleep.
- » One should fall asleep within 30 minutes of going to bed, but if should it not happen, one can stimulate sleep by reading a boring book, or by changing rooms and trying again in a short while.

## 4.7. SUICIDAL THOUGHTS

**Definition:** Suicide is a completed act of self-harm resulting in death. Para-suicide or suicide attempts are an act of deliberate self-harm that does not lead to death. Suicidal thoughts, attempts, and gestures are frequently but not always associated with depression. Suicidal thoughts occur in all age groups, and with greatest frequency in children and adolescents with mood disorders. Completed suicide is rare in children younger than 12 years, probably due to their cognitive immaturity.

In adolescents, completed suicide occurs five times more often among boys than girls, but suicide attempts occur three times more often among girls than boys. Suicidal thoughts come and go over time until an opportunity arises when the thoughts become an action. Suicidal behaviour in adolescents is commonly precipitated by events or challenges that the teenager finds too difficult to tolerate. Even things that seem minor to an adult can be major to a young person, who does not have the life experience to put them into perspective or the coping skills to deal with the stressful precipitating event.

**Clinical presentation:** Children and adolescents are more likely to attempt suicide if they have a history of previous attempts, a family history of suicide, exposure to family violence, substance use, impulsivity, and availability of lethal methods. A more detailed list of these risk factors can be found below. The most common methods used by older children and adolescents include poison ingestion, suffocation (commonly as hanging), and firearms, especially when they are accessible. Some adolescents may be undergoing a crisis in the form of ruptured romantic relationships, or disciplinary measures at school or at home. Some children may find themselves in a crisis and feel very helpless and hopeless, as in a situation of accidental HIV disclosure.

**Risk factors for suicide include:**

- » 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 homosexual or being bullied)
- » Suicide of a friend, acquaintance, or celebrity (suicide contagion).

**HCP Role and Management:** Management requires a thorough mental health evaluation. HCPs can use the *Pierce Suicidal Intent Scale (1981)* (**Appendix X**) to assess the seriousness of suicidal thoughts and determine the appropriate actions. Moderate and severe cases require inpatient psychiatric care if there is insufficient supervision at home. HCP should ask open-ended questions listed below to explore the severity of the intention. 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. HCPs can ask and/or select from following questions:

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?

## WHAT HCPs NEED TO KNOW

The risk of suicide is present for both children and adolescents who are HIV-positive. See Table 4.5 for warning signs. 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

**Table 4.5. Suicide Warning Signs and Statements**

BEHAVIOURAL AND PHYSICAL SIGNS	STATEMENTS
<ul style="list-style-type: none"> <li>» Previous attempts, especially if the person was alone at the time</li> <li>» Careless, risk-taking behaviours</li> <li>» Self-destructive behaviours</li> <li>» Becoming suddenly cheerful without reason after being depressed</li> <li>» Depression (very sad, down)</li> <li>» Preoccupation with their own death or taking their life</li> <li>» Difficulty concentrating (unable to focus)</li> <li>» Changes in eating, sleeping, hygiene</li> <li>» Withdrawing from friends and family (staying apart from others)</li> <li>» Personality change (Not acting like themselves)</li> <li>» Feelings of helplessness, hopelessness</li> </ul>	<ul style="list-style-type: none"> <li>» “I won't be a problem for you much longer.”</li> <li>» “I might as well kill myself.”</li> <li>» “There's no point in going on.”</li> <li>» “I can't take it anymore.”</li> <li>» “I have nothing left to live for.”</li> <li>» “I can't stop the pain.”</li> <li>» “I can't live without _____”</li> <li>» “My life keeps getting worse and worse.”</li> </ul>

HCPs should **not**:

- » **Don't** let the adolescent or child bargain you out of getting them help.
- » **Don't** rely on no-suicide contracts.
- » **Don't** make coercive statements, such as “Unless you promise not to hurt yourself, you'll have to go to the hospital.”

## 4.8. SUBSTANCE USE DISORDER

**Definition:** 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. The three most commonly abused substances globally are tobacco, alcohol, and marijuana. Use of alcohol and illicit drugs among youth is related to early sexual experience. These risky behaviours may lead to unprotected sexual intercourse which may heighten the risk of acquiring/transmitting HIV. The presence of drug use poses additional challenges in the management of HIV in young people. Table 4.6 shows the common terms and symptoms used to help recognise harmful substance use.

**Table 4.6. Common Terms in Substance Use**

TERM	SIGNS AND SYMPTOMS
<b>Substance abuse</b>	<ul style="list-style-type: none"> <li>» Regular unhealthy patterns of substance use</li> <li>» Significant impairment or distress manifested by one or more of the following:               <ul style="list-style-type: none"> <li>• Recurrent use causing physical danger to the user</li> <li>• Recurrent use despite obvious impairment in school, home, and/or work</li> <li>• Recurrent use resulting in legal problems</li> <li>• Recurrent use despite social or interpersonal problems</li> </ul> </li> </ul>
<b>Substance intoxication</b>	<ul style="list-style-type: none"> <li>» Experiencing a “high” or physical, mental, or emotional sensations from use</li> <li>» Significant unhealthy behaviour or psychological change must be present</li> </ul>
<b>Substance withdrawal</b>	<ul style="list-style-type: none"> <li>» Experiencing unpleasant symptoms due to stopping or reducing prolonged substance use</li> <li>» Withdrawal causes clinically significant distress and can impair social, family, or work functioning</li> </ul>

**Clinical presentation and management:** Dependent on the type of drug or substance that is used.

**Role of HCPs:** The HCP must explore the use of substances during any contact with the child or adolescent. HCPs should do a careful interview, observe for behavioural changes, and conduct laboratory investigations if needed and where possible (urine toxicology and liver function tests). In addition to noting symptoms of harmful substance use, the HCP should carefully explore changes in relationships with family members, changes in peer groups, unexplained phone calls, and changes in personal hygiene. These changes could be indicators of substance use that will eventually require referral to a psychiatrist or substance use treatment for further intervention.

## 4.9. SUMMARY: ROLE OF HCPs

Mental health treatment for children and adolescents living with HIV is similar to treatment approaches among HIV-negative patients. HCPs play an important role in detecting mental illness early (see Box 4.2) and supporting the family to handle the emotional stress related to the child’s or adolescent’s condition. 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.

**HCP 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 comorbid illness

**» Offer psychosocial support by:**

- Enhancing problem-solving
- Teaching coping skills, including lifestyle changes
- Helping the patient to identify choices
- Evaluate 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

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.

## BOX 4.2. HOW TO IDENTIFY SYMPTOMS OF MENTAL ILLNESS

### CLINICAL ASSESSMENT

**Appearance:** How is hygiene and grooming?

**Behaviour:** Abnormal behaviour (restless, jumpy, or slow; any repetitive actions or acting out)?

**Attitude:** cooperative or belligerent?

**Speech:** Is speech normal, loud, slow, rapid, or slurred?

**Ability to carry on with regular activities:** are there pronounced difficulties with schoolwork, truancy, lack of involvement in regular activities, changes in social behaviours or friend groups?

**Presence of environmental stress factors:** is the patient living in poverty or missing school due to lack of educational support, unemployment and family instability, or change of caregiver?



# CHAPTER 5. CHILD PROTECTION

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## SUMMARY

- » Children, adolescents, and their families or caregivers have the right to protection and care.
  - » All aspects of services for children/adolescents with HIV should centre on the patient's best interests.
  - » Children, adolescents, and caregivers should consent to the care they receive.
  - » Children and adolescents have the right to confidential treatment of their status and care.
  - » Whenever possible, families or caregivers should be engaged in the HIV-positive child/adolescent's care, and should help protect them from harm and abuse.
  - » HCPs should be able to recognise signs and symptoms of abuse and effectively respond to known or suspected abuse cases, e.g., ensure comprehensive post-abuse care, appropriate reporting to authorities, and child protection case management (in coordination with other key stakeholders and in accordance with the host country child protection policies and procedures).
-

## 5.0. DEFINITION OF KEY TERMS

**Child:** The United Nations *Convention on the Rights of the Child* defines a child as a person under the age of 18, unless the laws of a particular country set the legal age for adulthood younger (Children's Rights Alliance and United Nations 2010).

**Child abuse:** Child abuse/child 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 (Butchart and Harvey 2006).

**Child protection:** Preventing and responding 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.

**Ethical conduct:** Refers to the HCP's professional behaviour, guided by a standard code of conduct. When providing PSS, the HCP shows acceptable attitudes, behaviours, and practices that align with these articulated ethical standards.

**Legal:** Legal aspects relate to established global, national, and institutional standards. This includes law, policy, and implementation guidelines that influence the provision of PSS.

## 5.1. INTRODUCTION

Child protection concerns are a global priority, with a primary focus on preventing and responding to child maltreatment. Abuse occurs among children and adolescents from the full spectrum of socioeconomic backgrounds, ages, religions, and cultures. Countries recognise the urgency and importance of protecting the right of children and adolescents to live free of violence, exploitation, neglect, and abuse; yet millions of girls and boys worldwide are survivors of all types of abuse, and millions more continue to be at risk.

## 5.2. KEY PRINCIPLES IN CHILD PROTECTION

**Best interest of the child/adolescent:** Should be at the centre of all decision-making in:

- » **Policy development:** The process of developing policies and guidelines by various government structures. Nongovernmental organisations also need to prioritise the welfare of children/adolescents.
- » **Programme design:** Health facilities need to be knowledgeable about the policies that address interventions for children and adolescents. Health facilities designing programmes for children/adolescents need to consider the effect the programme will have on their rights, development, protection, and welfare.
- » **Decision-making for individual child/adolescent:** HCPs need to focus on the unique needs and circumstances of every child and adolescent.

**Do no harm:** HCPs need to ensure that all activities and interventions maximise benefits to the child or adolescent and minimise possible risks that may result from the activity/intervention.



**Non-discrimination:** HCPs must treat every child and adolescent fairly, irrespective of their HIV status, race, belief system, abilities, or family background.

**The family is the best place for the child/adolescent:** The family—and there are several types of families (see *Chapter 12*)—is the best place for optimal child growth and development. Therefore, any assistance offered to the child/adolescent is offered within the family context, while ensuring the development of the family's protective capacity. However, it is important to note that some abuse takes place within the family setting. In such instances, HCPs should develop linkages with social services departments such as medical social work, probation and welfare, community development, and police to explore possibilities for addressing vulnerabilities within the family. 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. **The respectful country-level child protection policies and guidelines**, including alternative care guidelines, should be followed to ensure appropriate actions/implementation. Placement of children in child care institutions, should only be a last resort when it is determined that a child or adolescent cannot be cared for safely within the home

## 5.3. ETHICAL AND LEGAL CONSIDERATIONS IN PSS FOR CHILDREN AND ADOLESCENTS

**Confidentiality:** HCPs need to ensure that personal data are only accessed by authorised persons. They should also refrain from sharing written or oral information until receiving authorised informed consent.

**Knowledgeable:** HCPs should have sufficient PSS competencies to be able to manage PSS issues among children, adolescents, and their families. Such competencies include communicating effectively with children and adolescents, conducting protection assessments/ risk screening, providing age-appropriate disclosure support to children and adolescents, and linking them to support systems and individual services per individual needs.

**Non-judgemental:** HCPs need to be able to understand each child's or adolescent's individual circumstances without assigning blame. The HCP needs to identify and correct his/her own biases and preconceptions.

**Consent:** HCPs should ensure that the following types of consent are obtained during delivery of PSS to children and adolescents and their families:

- » *Informed consent:* A caregiver, with complete knowledge of the implications of their actions, agrees to engage on behalf of the child. This type of consent is often needed when younger children are involved, but guidelines may vary from one country to another and depends on the type of services. For instance, the age of consent for HIV testing in Malawi is 13 years, and in Uganda, it is 12 years. HCPs should refer to country-specific guidelines on consent.
- » *Double consent:* Both the caregiver and the child agree to engage in an action with complete information about the implications of the action taken.
- » *Assent:* A child agrees to engage in an action after seeking consent from their caregiver. The age of assent varies from country to country; for example, in Uganda for a child to participate in research he/she should provide assent if he/she is above eight years of age.

**Engaging family members:** HCPs must always engage with children and adolescents within the context of their families and be aware of ethical considerations such as need for confidentiality, consent, safety, and being non-judgemental. With younger children or adolescents, the caregiver may initiate the child/adolescent–counsellor relationship with certain goals in mind. The child or adolescent may also bring their own goals to the counselling process. HCPs are encouraged to speak with caregivers and children together, but they should also be encouraged to hold routine, respectful meetings with children alone, especially when a caregiver is suspected of abuse. HCPs should closely observe the child’s or adolescent’s verbal and nonverbal communication when in the company of the caregiver, including sitting position, facial expression, tone of voice, and level of eye contact with the caregiver. If it is necessary to speak with the child or adolescent in private, HCPs can come up with excuses for the parent or caregiver to go to a different part of the clinic (refer to **Chapter 6** on communication and counselling for children and adolescents) so that the child or adolescent can feel safe about speaking.

**Establishing shared goals:** From the beginning, HCPs need to ensure that the goals of the relationship with the child/adolescent, and with the caregiver, are clear. HCPs should always reflect on these goals as their relationship with the child/adolescent grows, recalling that both ethical and legal considerations underlie their day-to-day work.

**Collaboration, referral, and networking with appropriate institutions/support systems:** HCPs must engage with appropriate institutions/support systems to provide comprehensive help to support the child or adolescent and ensure that their best interests are served. Providers must maintain the child’s or adolescent’s confidence and safety when collaborating, making referrals, and networking with key service providers and authorised institutions while maintaining confidentiality. Examples of child protection issues and potential referral networks are summarised in Table 5.1; also see **Chapter 2** for networking and referral.

**Values:** HCPs have personal values that guide their thinking, decisions, and actions. These subsequently have an impact on the PSS that they provide. It is important that HCPs understand their own values and how they influence the ethical decisions made in the child–counsellor relationship. It is also important that HCPs not impose their values on the families with whom they are working, being non-judgemental and supportive of the child or adolescent.

**Professional competence:** HCPs’ knowledge of their own professional limitations, their ability to work within these limitations, and their awareness of barriers to overcoming these limitations. Providers should reflect on their own professional competence within the context of the child/adolescent–counsellor relationship. They must always strive for the highest standards of ethical conduct when providing services, including PSS. As much as possible, when in doubt, the HCP must consult with colleagues/supervisors/other professionals/institutions to ensure alignment with ethical and legal guidance as well as national policy and guidelines.

**Examples of legal and ethical considerations in PSS for children and adolescents:** In the provision of PSS to children and adolescents, ethical and legal issues may arise around confidentiality in sharing HIV test results and documenting information. It is important HCPs follow these guidelines:

- » Share information only as per the country-specific laws and policies and with the consent of the child/adolescent/caregiver.
- » Guide caregivers of children and adolescents on the need to involve the child or adolescent in decisions about disclosure of their HIV status.

- » Inform the child or adolescent and caregiver if mandatory reporting of child abuse is required by law.
- » Assess if the child's or adolescent's health or safety is at risk—for instance, in cases of attempted suicide. HCPs may be required to limit confidentiality to protect the child/adolescent if this is the case. Only in these specific circumstances should confidentiality be breached. If a HCP will be breaching confidentiality, the child or adolescent should be informed directly what will be shared with whom and for what reason.
- » Ensure that all children and adolescents have access to care and treatment.
- » Address stigma and discrimination affecting children and adolescents living with HIV.
- » Educate children, adolescents, and their caregivers on ethical issues and rights as they relate to research among children and adolescents living with HIV. This includes informed consent, the benefits of research, voluntary participation, and the idea of “doing no harm.”
- » Follow country-specific laws on reporting harmful practices and attitudes towards children and adolescents, including:
  - » Defilement—having sex with a person under the age of consent, which in most settings is 18 years.
  - » Early/forced child marriage, female genital mutilation, and male circumcision.

**Table 5.1. Child Protection Issues and Examples of Referral Services**

ISSUE	POTENTIAL REFERRAL
<b>Neglect (denied basic needs)</b>	<ul style="list-style-type: none"> <li>» Social welfare: social workers, counsellors</li> <li>» Health care facility</li> <li>» Police</li> <li>» NGOs</li> <li>» Legal services</li> <li>» Community resource persons, leaders</li> </ul>
<b>Physical abuse</b>	<ul style="list-style-type: none"> <li>» Social welfare—social workers, counsellors</li> <li>» Health care facility</li> <li>» Police</li> <li>» NGOs</li> <li>» Legal services</li> <li>» School authorities</li> <li>» Community resource persons, leaders</li> </ul>
<b>Emotional abuse</b>	<ul style="list-style-type: none"> <li>» Social welfare—social workers, counsellors</li> <li>» Non-governmental organisations</li> </ul>
<b>Sexual abuse</b>	<ul style="list-style-type: none"> <li>» Social welfare—social workers, counsellors</li> <li>» Health care facility</li> <li>» Police</li> <li>» Non-governmental organisations</li> <li>» Legal services</li> <li>» Community resource persons, leaders</li> </ul>

## 5.4. DIFFERENT FORMS AND CONSEQUENCES OF CHILD ABUSE

The tables below outline some types, signs and the potential role of the HCP for physical abuse (Table 5.2), emotional abuse (Table 5.3), neglect (Table 5.4), and sexual abuse (Table 5.5).

**Table 5.2. Physical Abuse**

TYPE OF PHYSICAL ABUSE	SIGNS OF PHYSICAL ABUSE	ROLE OF HEALTH CARE PROVIDER
<ul style="list-style-type: none"> <li>» <b>Battered Child Syndrome:</b> <ul style="list-style-type: none"> <li>• Serious abuse in young children. Repeated and devastating injury to the skin, skeletal or nervous system (includes multiple fractures; head trauma, with evidence of repeated infliction)</li> </ul> </li> <li>» <b>Shaken Infant Syndrome:</b> <ul style="list-style-type: none"> <li>• Usually occurs when a parent or caregiver severely shakes the baby due to frustration or anger often because the child will not stop crying. Mainly seen in very young children (less than 1 year)</li> </ul> </li> <li>» <b>Corporal Punishment:</b> <ul style="list-style-type: none"> <li>• Punishment intended to cause physical pain in a person; this includes hitting, punching, kicking, or beating</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>» <b>Battered Child Syndrome:</b> <ul style="list-style-type: none"> <li>• Unexplained bruises (in various stages of healing)</li> <li>• Human bite marks</li> <li>• Unexplained burns</li> <li>• Unexplained fractures and a history of multiple fractures</li> <li>• Swollen areas</li> <li>• Evidence of delayed or inappropriate treatment for injuries</li> <li>• Injuries may be in areas that clothing typically hides</li> </ul> </li> <li>» <b>Shaken Infant Syndrome:</b> <ul style="list-style-type: none"> <li>• Extreme fussiness or irritability</li> <li>• Difficulty staying awake</li> <li>• Breathing problems</li> <li>• Poor eating</li> <li>• Vomiting</li> <li>• Pale or bluish skin</li> <li>• Seizures</li> <li>• Paralysis</li> </ul> </li> <li>» <b>Behavioural Signs of Physical Abuse:</b> <ul style="list-style-type: none"> <li>• Self-destructive behaviour</li> <li>• Withdrawn and/or aggressive behavioural extremes</li> <li>• Arrives at school early or stays late as if afraid to be at home</li> <li>• Chronic runaway (child/adolescent)</li> <li>• Complains of soreness or moves uncomfortably</li> <li>• Wears clothing inappropriate to weather, to cover body</li> <li>• Bizarre explanation of injuries</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>» Provide preventive education to caregivers on what is considered abuse and the dangers of abuse, as well as the use of positive (non-corporal) discipline</li> <li>» Treat physical injuries</li> <li>» Refer to other support services such as social work, counselling, child protection, and psychiatry</li> </ul>

**Table 5.3. Emotional Abuse**

TYPE OF EMOTIONAL ABUSE	SIGNS OF EMOTIONAL ABUSE	ROLE OF HEALTH CARE PROVIDER
<p>» <b>Verbal Abuse:</b></p> <ul style="list-style-type: none"> <li>• Belittling or shaming the child; name-calling, making negative comparisons to others, telling the child/adolescent he or she is “no good,” “worthless,” or “a mistake”</li> <li>• Habitual blaming, telling the child/adolescent that everything is his or her fault</li> <li>• Withholding affection</li> <li>• Ignoring or disregarding the child/adolescent</li> <li>• Stigma and discrimination linked with HIV</li> </ul>	<ul style="list-style-type: none"> <li>» Low self-confidence/poor self-image, withdrawn and detached (difficulty forming relationships)</li> <li>» Unable to trust, fearful, low empathy</li> <li>» Anxious and depressed</li> <li>» Low levels of interest and perseverance</li> <li>» Delayed emotionally, socially, and/or academically</li> <li>» Frightened for no obvious reasons</li> <li>» Displays feelings of shame and guilt</li> <li>» Child/adolescent is always crying, avoiding eye contact</li> </ul>	<ul style="list-style-type: none"> <li>» Provide preventive education to caregivers on what is considered abuse and the dangers of abuse., as well as the use of positive (non – corporal) discipline</li> <li>» Educate caregivers on recognising abuse and dangers</li> <li>» Provide counselling</li> <li>» Refer to other support services such as social work, counselling, and psychiatry</li> </ul>
<p>» <b>Extreme Punishment:</b></p> <ul style="list-style-type: none"> <li>• Usually occurs when a parent or caregiver severely shakes the baby due to frustration or anger often because the child will not stop crying. Mainly seen in very young children (less than 1 year)</li> </ul> <p>» <b>Negative Influence:</b></p> <ul style="list-style-type: none"> <li>• Influencing a child/adolescent to believe that bad behaviour is normal (e.g., engaging in criminal activities, drug or alcohol abuse, or acts of violence)</li> </ul>	<ul style="list-style-type: none"> <li>» Child/adolescent suffers from sleep, speech disorders and demonstrates compulsions, obsessions, phobias, hysterical outbursts</li> <li>» Child/adolescent is inappropriately aggressive, destructive or cruel to others</li> <li>» Child/adolescent often says negative statements about himself/herself</li> <li>» Child/adolescent does not participate in activities or experiences</li> <li>» Older children may begin to use alcohol or abuse drugs</li> <li>» Some may also try to find comfort with strangers and end up involved in illegal sex activities</li> </ul>	

**Table 5.4. Neglect**

TYPE OF NEGLECT	SIGNS OF NEGLECT	ROLE OF HEALTH CARE PROVIDER
<p>» <b>Physical Neglect:</b></p> <ul style="list-style-type: none"> <li>• Failure to provide adequate food, clothing, or hygiene</li> <li>• Reckless disregard for the child/adolescent’s safety, such as inattention to hazards in the home and leaving a baby unattended</li> <li>• Refusal to provide or delay in providing necessary health care for the child/adolescent</li> <li>• Abandoning children/adolescents or expelling children from home without providing for their care</li> </ul>	<p>» Indicators of hunger: asking for or stealing food, going through trash for food, eating too fast or too much when food is provided for a group</p> <p>» Colds, fevers, or rashes left untreated; infected cuts; chronic tiredness</p> <p>» In babies, failure to thrive; failure to relate to other people or to surroundings</p> <p>» Apparent lack of supervision: e.g., wandering alone, home alone, left in a car</p>	<p>» Educate children/adolescents and their caregivers on recognising, preventing neglect, and on the dangers of neglect</p> <p>» Link to treatment services, such as treatment for malnutrition</p> <p>» Refer to other support services such as social work, parenting education, counselling and other services</p>
<p>» <b>Educational Neglect:</b></p> <ul style="list-style-type: none"> <li>• Failure to enrol a child/adolescent in school</li> <li>• Permitting or causing a child/adolescent to miss too many days of school</li> <li>• Refusal to follow-up on obtaining services for a child’s/adolescent’s special educational needs</li> </ul>	<p>» In school: frequent absence or tardiness; troublesome, disruptive behaviour or its opposite, withdrawal</p>	
<p>» <b>Emotional Neglect:</b></p> <ul style="list-style-type: none"> <li>• Inadequate nurturing or affection</li> <li>• Exposure of the child/adolescent to spousal abuse</li> <li>• Permitting a child/adolescent to drink alcohol or use drugs or watch pornography</li> <li>• Failure to intervene when the child demonstrates antisocial behaviour</li> <li>• Refusal of or delay in providing necessary psychological care</li> </ul>	<p>» Clothes that are dirty, ill-fitting, ragged, and/or not suitable for the weather</p> <p>» Unwashed appearance; offensive body odour</p>	

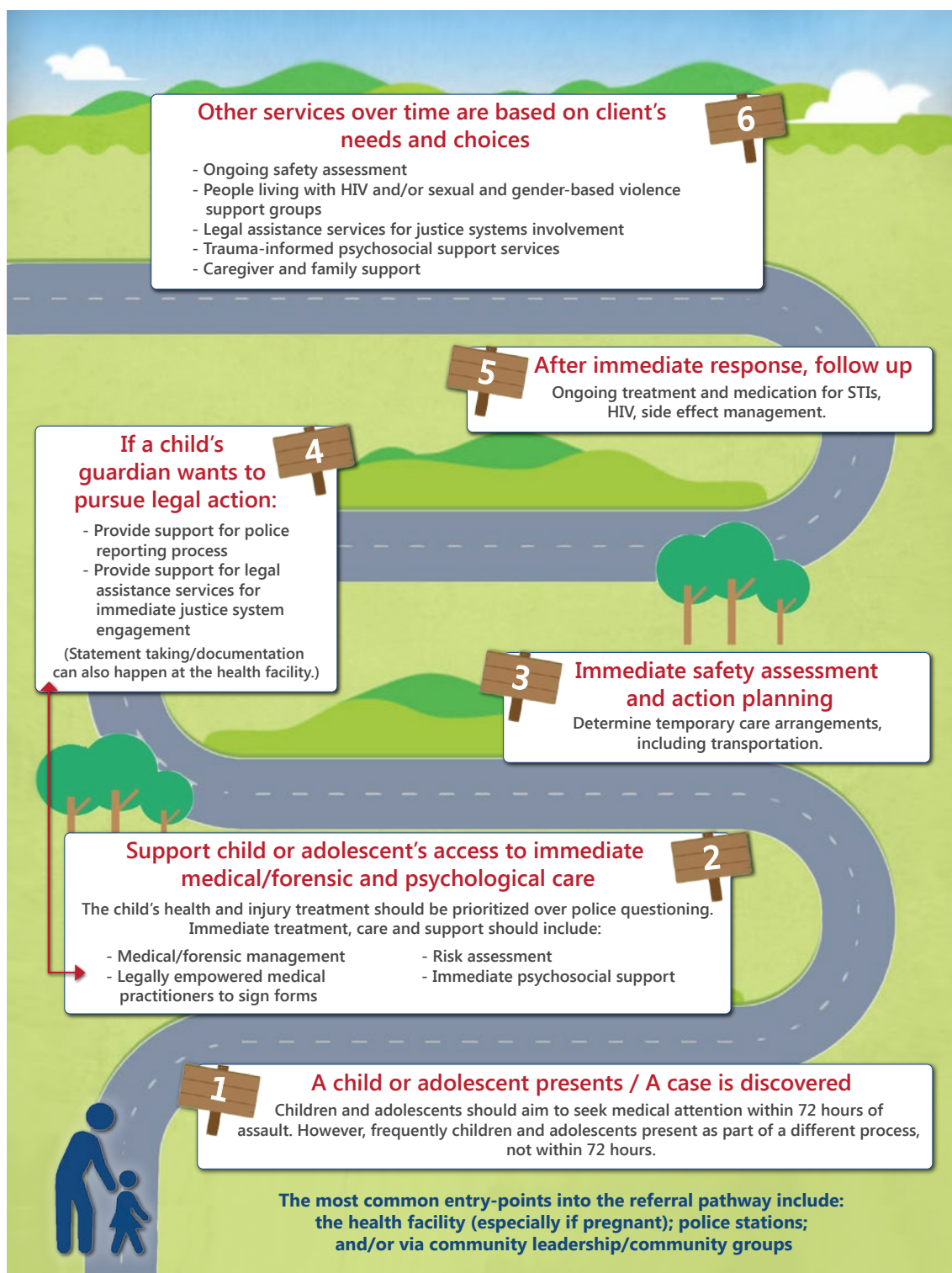
**Table 5.5. Sexual Abuse**

TYPE OF SEXUAL ABUSE	SIGNS OF SEXUAL ABUSE	ROLE OF HEALTH CARE PROVIDER
<ul style="list-style-type: none"> <li>» Behaviour involving penetration: vaginal or anal intercourse and oral sex</li> <li>» Fondling: touching or kissing a child's genitals, making a child fondle an adult's genitals</li> <li>» Violations of privacy: forcing a child to undress, spying on a child in the bathroom or bedroom</li> <li>» Exposing children to adult sexuality: performing sexual acts in front of a child, exposing genitals, telling "dirty" stories, showing pornography to a child</li> <li>» Exploitation: selling a child's services as a prostitute or a performer in pornography</li> </ul>	<ul style="list-style-type: none"> <li>» Inappropriate interest in or knowledge of sexual acts</li> <li>» Seductive behaviour</li> <li>» Unusual aggression or, at the other end of the spectrum, unusual obedience towards the opposite sex</li> <li>» Fear of a particular person or family member</li> <li>» Physical signs of trauma in genital area</li> <li>» Presence of sexually transmitted infections</li> </ul>	<ul style="list-style-type: none"> <li>» Educate children, adolescents and caregivers on recognising sexual abuse and dangers</li> <li>» Treat physical injuries</li> <li>» Provide pregnancy prevention, STI testing and treatment, PEP, counselling based on country guidelines</li> <li>» Refer to other support services such as police, legal support, social work, child protection, counselling and psychiatry</li> </ul>

## 5.5. ROLE OF HCPS IN THE MANAGEMENT OF CHILD ABUSE

HCPs have a duty to recognise child abuse and address it according to the laws and policies of the respective countries as well as professional expectations of their practice environment. Establishing and using a clear, functional referral pathway to child protection agencies (illustrated in Figure 5.1) is critical. Where possible, there should be a care algorithm/protocol in the health facility for each form of abuse. Figure 5.2 provides an example for clinical management and care following sexual abuse. In addition, HCPs should educate children/adolescents and their caregivers on recognising, managing, preventing, and reporting abuse in all forms.

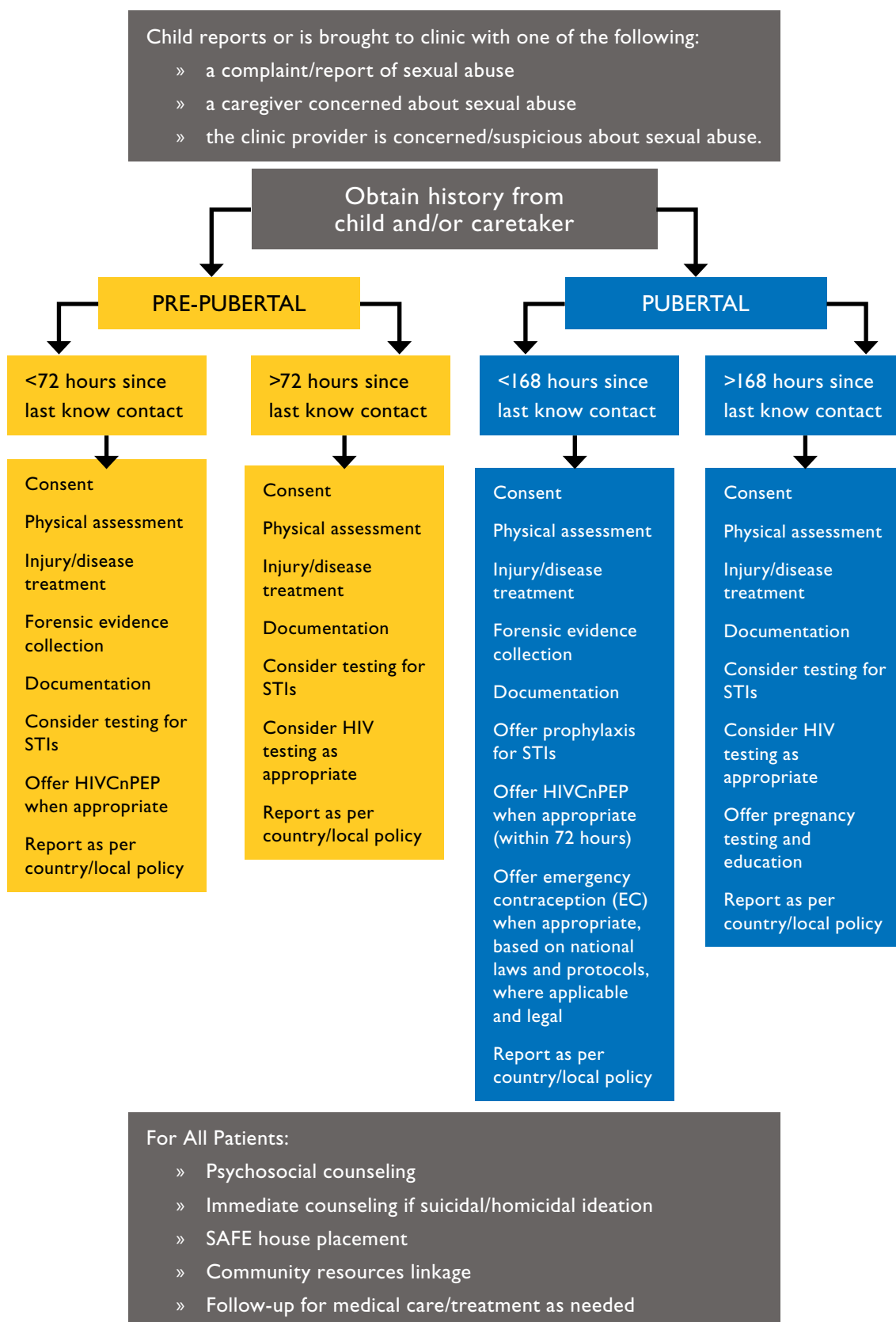
**Figure 5.1. Referral Pathway for a Child or Adolescent Who Has Been Abused**



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](https://aidsfree.usaid.gov/sites/default/files/2016.2.1_aidsfree_comp_guide_gender_tagged.pdf)



**Figure 5.2. Care Algorithm for Children and 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>



## **CHAPTER 6.**

# **COUNSELLING AND COMMUNICATION WITH CHILDREN, ADOLESCENTS, AND CAREGIVERS AFFECTED BY AND INFECTED WITH HIV**

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## SUMMARY

- » Children and adolescents infected or affected by HIV have a variety of concerns, worries and general psychosocial needs of their own. These needs, worries and concerns are often neglected in the care system because adults, including HCPs, may find it difficult to talk to children and adolescents about sensitive issues.
  - » Counselling and communication with children and adolescents is different than with adults. The language, methods, general skills and techniques used for counselling and communication should be age-appropriate and aligned to the developmental needs.
  - » Counselling and communication support can help children and adolescents infected and affected with HIV to address and cope with challenges of being infected or affected by HIV and lead meaningful lives to adulthood.
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## 6.0. INTRODUCTION

Counselling and communication are integral components of a holistic approach to caring for children and adolescents living with and affected by HIV and can facilitate expression of their concerns, worries and general perceptions which in turn forms a basis for appropriate care interventions. This population, along with their families, face significant distress and uncertainty after an initial HIV diagnosis and throughout their lifetimes, which can be accompanied by frequent illnesses, stigma, and discrimination that surround HIV infection. For example, taking ART for life without a clear explanation of why and what it entails causes distress in children and adolescents, who do not understand why they are required to take medication when they do not feel ill. Counselling from the onset of diagnosis and continuing throughout the continuum of care can help prevent or mitigate distress and uncertainty. Child- and adolescent-friendly counselling and communication requires HCPs to establish child- and adolescent-friendly spaces and to use forms of therapy appropriate for children/adolescents. Good communication and counselling support will enable children and adolescents to better express their fears, concerns, and worries, and can help them adhere to treatment and live positively with HIV (Blasco et al. 2017; Tindyebwa et al. 2006).

This chapter provides guidance for HCPs working with children infected and affected by HIV on how to facilitate expression of feelings, fears and concerns and provide age-appropriate support. The skills and techniques shared in this chapter will provide guidance to communicate and counsel children and adolescents during their own or their family member's HIV diagnosis, disclosure of HIV test results, maintaining ART adherence, coping with stigma and other issues related to living with or being affected by HIV.

## 6.1. DEFINITION OF KEY CONCEPTS

**Communication** is a two-way process. The first part of the process involves speaking by saying things in a way that encourages people to listen, hear, and understand. The second part of the process involves listening to what is being said in an understanding, receptive, and non-judgemental manner. Communication with children and adolescents uses age-appropriate language to facilitate both the passage of information to the child and the expression of their feelings.

**Counselling** is a process in which the helper expresses care and concern towards the person with a problem, facilitates that person's personal growth, and helps bring about change through self-knowledge. Counselling children and adolescents is a specialised area that requires a particular child-centred perspective; creative, flexible application of skills; and techniques to foster coping and resilience.

## 6.2. GOALS OF COUNSELLING AND COMMUNICATING WITH CHILDREN AND ADOLESCENTS

Counselling and communication with children and adolescents should be purpose-driven. Its goal is to bring healing, facilitate expression of feelings and concerns, and improve functioning of children

and adolescents in their environments. The goals 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

## 6.3. PRINCIPLES AND ELEMENTS OF EFFECTIVE INTERPERSONAL COMMUNICATION AND COUNSELLING FOR CHILDREN AND ADOLESCENTS

Counselling and communicating with children and adolescents is a learned skill that requires HCPs to understand how children communicate. Serious illness, such as HIV, often represents a traumatic change in the life of a child/adolescent. In addition, health centres, hospitals, doctors, nurses, and others in white coats are unfamiliar to children, and that unfamiliarity can cause fear and anxiety. Their observation of HCPs words, actions, and expressions, along with painful experiences such as drawing blood, convey a stream of messages to the child, which can contribute to their anxiety. Thus, HCPs should view work with HIV-affected children and adolescents as a long-term process that establishes and builds upon **trust**. Counselling and communicating with children and adolescents is a critical skill for HCPs working with HIV-positive and affected children, adolescents, and their families. A significant amount of communication with children occurs without speaking, i.e., **nonverbal communication**, which includes facial expressions, body language, body contact, eye contact, personal space and tone of voice all of which impact interactions. To strengthen their skills, HCPs working with this patient population should focus on these core characteristics in themselves:

- » **Respect:** Respect children and adolescents for who they are. Keep a non-judgemental attitude. Do not ignore their viewpoint and feelings.
- » **Empathy:** Empathy, which is related to respect, is the ability to imagine and respond to a child/adolescent's unique dilemma.
- » **Non-judgemental attitude:** HCPs must withhold judgement, and avoid punitive attitudes, regarding the child/adolescent's situation or the experiences they share with the provider. This attitude is essential to establishing trust in the relationship. The counsellor should display **acceptance**, making it clear that they understand what the child/adolescent says without judgement.

- » **The inner child:** HCPs should keep in mind their own childhood with its fears and uncertainties, while working with each patient to help them face their own challenges.

The following sets of principles are important to guide counselling and communication relationships between HCPs, children, adolescents, and their families (Catholic Relief Services 2009).

- » **Trust:** The relationship between the patient and the counsellor relies on reciprocal trust. The counsellor must provide a safe, confidential environment and offer empathy, understanding, and respect.
- » **Honesty:** Never lie to a child or adolescent. This can destroy their trust in those who are caring for them; they may fear future care, and their anxiety may increase.
- » **Information needs:** Provide age-appropriate information.
- » **Freedom of expression:** Allow children and adolescents to express their worries and anxieties through play, drawing, songs, etc. For adolescents, it is important to ask open-ended questions like “What makes you happy at home/school, with peers?” and “What makes you sad?”
- » **Participatory approach:** Include children/adolescents in discussions of their care, teach them about their illness, and encourage them to make decisions when appropriate.
- » **Unconditional care:** Treat children/adolescents equally regardless of gender, background, or socioeconomic status. Treat each child/adolescent as an individual.
- » **Patience:** Communicating well with sick or anxious children and adolescents takes time; allow them to express their feelings at their own pace.
- » **Family involvement:** Ensure that close family members or other important adults in the family are involved in the care of the child/adolescent.
- » **Ongoing relationship:** Counselling is a continuous process in which the patient and counsellor see one another routinely. The HCP should emphasise the importance of the child/adolescent spending time with him/her regularly. This helps develop mutual trust.
- » **Our own feelings:** HCPs should be careful of their own feelings; children/adolescents are very perceptive of the attitudes of those around them and may notice other people’s distress and anxiety.
- » **Touch:** When appropriate, a slight touch on the shoulder, arm, or head can convey more than words in terms of comfort and reassurance. It is important, however, to be aware of gender while using touch, especially when the provider and patient are different sexes, as it might be mistaken as a sexual advance.
- » **Cultural awareness:** Understand the background of the child/adolescent, making an effort to understand the perceptions, beliefs, values and attitudes of the child/adolescent. Do not impose your values and beliefs on the child or adolescent.
- » **Simplicity:** Provide relevant information in a language children/adolescents understand and avoid using complicated language or medical jargon.
- » **Clarity:** Providers should explain to children/adolescents and caregivers the objectives and processes of the counselling intervention.
- » **Consent:** The child/adolescent with parents/guardian should consent to counselling. Children/adolescents and their parents/guardians have the right to withhold consent if they

are not comfortable with the counselling process. They also have the right to withdraw from the counselling process at any time, even after it has begun.

- » **Contracting:** A contract is an agreement between the counsellor and the child/adolescent, where possible, and the parent/guardian on the objectives, time, and processes involved in the counselling session. Contracting should happen before the counselling begins.
- » **Confidentiality:** Confidentiality is the backbone of counselling. It is essential for building the child or adolescent's trust, and it creates a safe environment for openness. Confidentiality is kept unless there is potential harm to the child/adolescent or others. Parents/guardians should be made aware that certain information in a counselling session must be kept confidential between the counsellor and the child/adolescent; however, the parent/guardian should be informed of the progress in the counselling process.
- » **Shared confidentiality:** Involves sharing information from the session with others for the best interests of the child/adolescent. A serious ethical dilemma for HCPs is determining when and with whom to share information. A key question is whether sharing confidentiality is critical for the best interests of the child/adolescent. If in the person's best interests, this may not require the child/adolescent's consent—for example, if a child shares that a family member is sexually abusing them. It is important to refer to country-specific policies and guidelines regarding confidentiality and consent.

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## 6.4. COMMON MISTAKES BY HCPS WHILE COMMUNICATING WITH CHILDREN AND ADOLESCENTS

Good counselling is critical to a healthy relationship and effective support, since it can allow for children and adolescents to express their worries, concerns, and needs. HCPs can feel uncomfortable in trying to involve children and adolescents in their care, neglecting to include them on the pretext that information on the child's or adolescent's experiences or feelings can be obtained from caregivers. Box 6.1 summarises other common communication mistakes to avoid while counselling children/adolescents living with HIV.

### BOX 6.1. COMMON COUNSELLING MISTAKES

- » Giving unsolicited advice
- » Offering premature or inappropriate reassurance
- » Giving too much or too frequent encouragement
- » Asking closed-ended questions (that only require a yes/no response)
- » Interrupting or finishing the child's/adolescent's sentences
- » Talking too much
- » Forming pre-judged conclusions
- » Deliberately changing focus

## 6.5. DIFFERENCES IN COUNSELLING CHILDREN VERSUS ADULTS

Children are not small adults: their needs and abilities are significantly different from adults (see Table 6.1). Communicating with children requires understanding these norms (Catholic Relief Services 2009):

- » Adults mainly communicate through words, communicating with children, especially those under 12 years, involves use of play. “Adults talk and children play.”
- » When communicating with children, go to their level, engage with them in whatever style of communication suits the individual—for example, by sitting on the ground and through play.
- » Use language and concepts appropriate to the child’s age, stage of development, and culture.
- » Children who have had traumatic experiences usually find it extremely difficult to trust an unfamiliar adult.
- » It may take a great deal of time and patience before the child is comfortable communicating openly.
- » Children may view their situation in ways distinctively different from that of adults.
- » Children may fantasise, invent explanations for unfamiliar or frightening events, express themselves in symbolic ways, and emphasise issues that may seem unimportant to adults.

**Table 6.1. Counselling Children versus Counselling Adults**

SIMILARITIES	DIFFERENCES
<ul style="list-style-type: none"> <li>» Can feel hurt and vulnerable</li> <li>» Have the need to build enough trust</li> <li>» Need acceptance</li> <li>» Need motivation to change</li> <li>» Won’t accept imposed changes</li> <li>» Are affected by circumstances and situations</li> </ul>	<ul style="list-style-type: none"> <li>» Children need a variety of communication media to aid communication, such as drawing/painting and role-playing</li> <li>» Adults communicate primarily through words and actions</li> <li>» Children communicate through play</li> <li>» Children are more open</li> <li>» Children are dependent on their caregivers</li> </ul>

## 6.6. ENHANCING CHILDREN'S SELF-EXPRESSION

- » Use a quiet tone of voice to help the child feel safe, and shows that the adult is sympathetic.
- » Make gestures such as nodding (or whatever is appropriate within the particular culture) to encourage the child to continue to talk.
- » Use eye contact appropriately to help the child: this will vary with culture.
- » Listen attentively and demonstrate that you have heard the child—summarise what has been said and seek clarification. This can confirm to the child that you are actively listening.
- » Show respect for the child’s feelings—for example, reflect feelings (“that must have made you feel very sad/angry”).



- » Convey *empathy*— the capacity to identify with the child’s situation and feelings.
- » Avoid interrupting the child.
- » Ask open-ended questions, this may encourage the child to explain something in his/her own way: for example, a question such as “tell me about your school and friends.”

## 6.7. USE OF MEDIA AND ACTIVITIES TO COMMUNICATE WITH CHILDREN

**Play:** Children’s natural language is play. It is more than just recreation, as through play children process and understand their experiences. Play is vital to healthy development; it allows the child to explore and “master” their world; it is pleasurable and is intrinsically motivating. Play offers a safe place to act out feelings, gain understanding, and try out change.

**Drawing:** This allows children to make pictures which depict events, and makes children feel powerful and in control.

**Books, songs, 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. It is important to give a child the opportunity to perform well.

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## 6.8. CHILD COUNSELLING ATTITUDES, SKILLS, AND TECHNIQUES

Counselling children requires particular skills, attitudes, and techniques to facilitate coping and resilience. HCPs need these competencies so that they can help children express themselves, cope and live positively, and change their behaviours. Along with cultivating important attitudes—respect, acceptance, non-judgement, empathy, confidentiality, and contact with the inner child—counsellors can learn and use specific skills and techniques to help children achieve the maximum benefits from their time together. Table 6.2 and Box 6.2 outline the required skills and techniques.

### BOX 6.2. COMMUNICATING WITH DISTRESSED CHILDREN AND ADOLESCENTS

- » Allow the child to set the pace
- » Give adequate time to the child
- » Provide emotional support and encouragement to the child
- » Accept the child’s emotions, such as guilt and anger
- » Never give false reassurance
- » Talking about difficult situations may enable children to work out their own solutions
- » Forming pre-judged conclusions

**Table 6.2. Skills and Techniques for Counselling Children**

SKILLS/ TECHNIQUES	EXPLANATION
<b>Listening skills</b>	Listen carefully and do not question the child or adolescent too frequently. Encourage child/adolescent to vent through his/her listening.
<b>Commenting on the “process”</b>	Talk about what you observe. The counsellor may sense or observe a change of mood when a particular issue is raised (e.g., anger, bitterness, fear, crying, raised voice, not talking); consider asking: “When I mention your father you seem uncomfortable; please tell me what happened.” This helps to find clarity, but also makes the patient aware of his/her behaviour.
<b>Taking a “one-down”</b>	The client is the expert about their own self and their environment. Consider yourself a learner, and allow the client to educate you. This is more respectful to the client, and also promotes his/her responsibility for his/her own carer. Examples of guiding questions: “How are such problems normally solved in your family?” “I am not sure what happens at your school; please help me understand the true picture.”
<b>Empty Chair</b>	Bring in a vacant chair; pretend this is a new person (HCP, family member, etc). This can help the child act out the voice of an absent person. It also helps the patient to communicate to absent people and prepare to enact solutions. One can use a chair or imagine the chair.
<b>Vacation</b>	Use if the presence of another person in the session makes the child uncomfortable; the HCP properly negotiates for them to leave (vacation). HCP then agrees with the child on what to share with the absent person later. This helps empower the child/ adolescent.
<b>Blocking</b>	Use to manage the parent/guardian who may be dominating the discussion and overshadow the child. This can be changed by directly addressing the child by name, changing the position of their chair to face them or using the hand to bring attention to them.
<b>Widening the system</b>	Expand outwards, look for support from the systems surrounding the patient, such as a caring neighbour, grandparent, or teacher. Ask the child about people who care for their emotions, even if they’ve never asked those people for support before.
<b>Scaling</b>	Size the problem, make a graph to see how big a problem is and gradually telling how it is improving over time, e.g., by using hands, paper, and/or numbers 0–10.
<b>Exceptions</b>	Share exceptions, they can uncover patterns. Exceptions can help understand what or who at times causes or worsens the trouble. They are used to find longer-term solutions to the problem.
<b>Clarifying</b>	Seek clarification of what the client has said—check understanding. “Are you saying that.....?”, “Did I get you right.....?” <b>NEVER</b> make assumptions in counselling.
<b>Enactment</b>	Ask the client to act out events: i.e., the problem and solution. Enactment can help children who may not describe details in a session with more than one person present. Observe and comment. Ensure that physical fighting does not happen.
<b>Externalising</b>	Separate the behaviour from the child. This helps to build the child’s self-esteem. Also the child avoids self-blame and finds solutions on how to deal with the problem—for example, if a child is abusing drugs and was influenced by peers; the behaviour can be attributed to peer pressure.

SKILLS/ TECHNIQUES	EXPLANATION
<b>Silence</b>	Use silence to allow the child to reflect on her/his feelings. Not talking can be powerful and allow the child to open up.
<b>Refocusing</b>	Redirect if the child is going off track or talking in circles, get him/her back to maintain the theme without hurting his/her feelings.
<b>Questioning</b>	Ask open-ended questions, so that children open up, rather than relying on too many closed-ended questions which are often interrogative or prescriptive. An example of an open-ended question is: “Can you tell me about your experiences with your parents at home?” An example of a closed-ended question is: “Are you happy at home?”
<b>Prioritising</b>	Ask child to rank problems when many are presented. It is important to ask them which one should be discussed first. Only in cases where the child expresses suicidal thoughts or is experiencing bereavement should the HCP decide what to discuss first.
<b>Role reversal</b>	Ask the child to assume the position of the person they are in conflict with and facilitate the discussion.

## 6.9. THE COUNSELLING PROCESS

Counselling consists of different activities a counsellor undertakes to help the patient engage in those types of behaviour that will lead to a resolution of 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. There are seven steps in the child counselling process (Box 6.3).

### BOX 6.3. SEVEN STEPS FOR COUNSELLING CHILDREN

1. **Receiving referral:** Obtain information about child's behaviour, emotional state, personality, history, cultural background, and the environment in which the child lives.
2. **Contracting with parents:** Consult with the parents first, without the child, to get history, parental understanding, expectations, and care thus far.
3. **Joining with the child:** Sit with the child in the waiting room, join with the parents or primary caregiver, allowing the child to feel safe and comfortable.
4. **Enabling the child to tell their story:** Build trust through a conducive environment, including the use of media.
5. **Empowering the child:** Enables the child to “master” the problem. This process will grow over several sessions.
6. **Moving on—helping the child to think and behave differently:** Help the child to learn new ways of thinking and behaving, and to be able to function adaptively (if previous behaviour had negative consequences).
7. **Final assessment and evaluations:** Do in collaboration with the child and the parent or primary caregiver. Confirm that further work is not required at that time; effectiveness of the work done; and recommendations. After the final assessment and evaluation, the process can be terminated and the case can be closed.

## 6.10. COUNSELLING AND COMMUNICATION WITH ADOLESCENTS

Adolescents tend not to have preconceived ideas regarding the treatment process. They need time to build trust in HCPs and to settle into the counselling process. Adolescents may have difficulty engaging in care and being adherent with medication or other treatments if they are unable to feel comfortable or at ease in the health care environment. Many adolescents feel they are not respected, their views are not appreciated, or the care environment is judgemental or not friendly. In addition, they are less likely to seek health care from other sources, including health centres.

To gain trust and nurture stability, adolescents need positive responses from adults and a balance between structure and freedom to express their feelings. If adolescents receive a positive response, they are able to develop new inner resources such as identity, purpose in life, independence, responsibility, and the ability to endure problems. This change takes place through a series of steps, described in Table 6.3.

Counselling and communication with adolescents involves identifying individual assets or strengths and encouraging responsibility. Counsellors can be creative in their approach—for example, taking a walk together, or listening to music. HCPs who work with adolescents must be able to understand the adolescent “language.”

### TASKS FOR THE FIRST SESSION

- » Create a safe, adolescent-friendly environment
- » Establish rapport
- » Join: get to know the adolescent and help him/her feel comfortable
- » Discuss reasons for referral
- » Explore related issues
- » Assess risks, including emergent psychological concerns
- » Provide relevant information
- » Discuss the next course of action

### TECHNIQUES FOR COUNSELLING ADOLESCENTS

Each HCP should remember that they are a major instrument for providing PSS— for both adolescents and caregivers! The therapeutic alliance/relationship is crucial to moving forward, and is key to all future stages of therapy. So, it is important for HCPs to demonstrate warmth and empathy as these qualities are what is most likely to help adolescents; see Table 6.3 for more information on key steps. It is equally important for the HCP to connect the adolescent to peer support or positive support groups. Finally, HCPs should help adolescents learn life skills to deal effectively with their condition (see section 6.13).

**Table 6.3. Five Steps for Counselling Adolescents**

### STEP 1: RAPPORT AND RELATIONSHIP BUILDING

Counselling for adolescents requires friendly care /responsive environments that provide confidentiality and privacy. In addition, an adolescent-friendly environment should prevail; for example, don't let adolescents sit for long periods in the waiting room with adults. It all begins from the waiting room. Focus on building and maintaining the relationship from the beginning throughout the last phase of the counselling intervention. These are the signs that the relationship has been built:

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

### STEP 2: ASSESSMENT

Collect and classify information about the adolescent and his/her reasons for seeking counselling (define problems of concern) by:

- » Asking the adolescent directly
- » Using a questionnaire: an example is the HEEADSSS assessment tool used in Uganda in **Appendix III**
- » Determining what the adolescent wants to know and what he/she already knows

### STEP 3: GOAL-SETTING

- » Work with adolescents to establish concrete goals (guided decision-making) which can help them feel less confused and clearer about themselves and their needs.
- » Mutually define the process of setting goals.
- » Allow for some mentoring, show the adolescent how to establish attainable goals, by providing the adolescent with appropriate health information.
- » Focus on the ultimate goal, promoting a healthy lifestyle

### STEP 4: INITIATING INTERVENTIONS

Provide the adolescent with accurate health information about all available intervention strategies connected with the overall counselling process, along with a guided decision-making component as needed. Convey:

- » A description of all relevant and useful treatment approaches for this particular adolescent with this particular problem
- » A rationale for each procedure that will be used
- » A description of the HCP's role in each intervention
- » A description of the adolescent's role 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
- » The 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:

### **Summarise 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:** Look to how those new behaviours, attitudes, or relationships relate to the patient's world. Test the adolescent's willingness and ability to adapt 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 required after termination of counselling.
- » Check whether there is a recurrence of the risk behaviour during the revisit.
- » Check whether the adolescent has encountered any new health crises or problems during the revisit.
- » Some adolescents may believe termination is appropriate but experience anxiety at the prospect. Schedule a 3- or 6-month check-up as needed, depending upon the adolescent's response.

## CHALLENGES FACED WHEN COUNSELLING ADOLESCENTS

HCPs encounter several challenges while counselling adolescents, which include:

**Biological challenges:** There are changes that occur due to rapid hormonal changes during adolescence that affect emotions. Rapid mood changes can impact relationships at home with parents and siblings, socially with friends or at school, and even with HCPs in the counselling session.

**Cognitive challenges:** During adolescence, individuals develop cognitively from "concrete operations" to "formal operations"; they are increasingly able to deal with ideas, concepts and abstract theories. However, it takes time for confidence to build to use these newly acquired skills, often resulting in poor judgement. Additionally, adolescents tend to be egocentric: they can become self-conscious, thinking they are being watched and judged by others, while at other times behaving as if they are on a stage, performing for an audience. Furthermore, adolescents may think they are invincible and cannot be hurt, since they usually lack experience with death and mortality has not yet become a reality for them.

**Psychological challenges:** Adolescents must cope psychologically with moving from childhood to adulthood. This transition includes changing rules, increased responsibilities, and expectations to meet standard norms and behaviours as they get older. During adolescence, the process of individuation occurs, which involves the development of relative independence from family relationships, with weakening ties to objects and people who were previously important to the young person, coupled by an increased capacity and societal expectation to assume a functional role as a member of adult society. As adolescents continue their journey of self-discovery, they continually have to adjust to new experiences as well as to the other changes happening to them biologically and socially. These adjustments can be both stressful and anxiety provoking. It therefore is not surprising that adolescents can have a decreased tolerance for change; it becomes increasingly more difficult for them to modulate their behaviours which are sometimes displayed

by inappropriate mood swings and angry outbursts. Adolescents may feel that no one is capable of understanding them or how they are feeling.

HCPs need to be aware of these challenges and work with the adolescent to deal with the challenges and the consequences of their decisions and actions. (Counselling Connection n.d.)

## 6.II. EMPOWERING PARENTS AND CAREGIVERS TO COMMUNICATE EFFECTIVELY WITH CHILDREN AND ADOLESCENTS

Counselling and communication with children and adolescents involves working in partnership with and empowering caregivers to offer continued support. Communication with parents or caregivers should encourage appropriate support for the child/adolescent, and should take into account the perceptions, feelings and needs of the parent or caregiver.

There are many reasons to involve caregivers:

- » Children and adolescents still depend on their parents/caregivers.
- » Standard care includes involving parents/caregivers.
- » Parents/caregivers spend more time with children/adolescents compared to HCPs.
- » Parents/caregivers are expected to give continued support to children/adolescents after counselling ends.
- » Parents/caregivers provide consent for children who are under age. [**Note:** “under age” varies based on country context, but typically this refers to children under 18 years of age.]

Helping caregivers communicate with children and adolescents will strengthen the provider-caregiver relationship and may enable a clearer understanding of the relationship between the caregiver and the child. HCPs should help caregivers understand the importance of their role and address communication challenges more effectively. Through discussions and by example, the HCP should help the caregiver appreciate the importance of clear communication with children/adolescents, including use of age-appropriate language to speak with children.

To enhance caregivers' engagement, HCPs should employ principles of respect and non-judgement, supporting families and loved ones to build their confidence about communication, and expressing appreciation for their contributions and strengths.

## 6.I2. LIFE SKILLS FOR CHILDREN AND ADOLESCENTS LIVING WITH AND AFFECTED BY HIV

Counselling children and adolescents living with HIV is incomplete if it does not address life skills. Individuals, including those living with HIV, can strengthen their life skills to improve how they function in their socio-ecological environment. Life skills increase the child's/adolescent's ability to function appropriately in their environment and relate easily to other people in society. These skills

enable children and adolescents to make positive, healthy choices, to make informed decisions, to practice healthy behaviours, and to recognise and avoid health risks and risky behaviours. Life skills education facilitates the practice and reinforcement of psychosocial skills in a culturally and developmentally appropriate way; it contributes to the promotion of personal and social development, the prevention of health and social problems, and the protection of human rights (Ghasemian and Kumar 2017). The importance of life skills is described in Box 6.4.

Life skills are divided into 3 categories:

1. Those to do with **knowing and living with oneself**: self-awareness, self-esteem, making effective decisions, assertiveness, coping with emotions, coping with stress, focus and self-control.
2. Skills that relate to **knowing and living with others**: interpersonal relationships, friendship formation, empathy, peer pressure/resistance, negotiation, and effective communication.
3. Skills for **making effective decisions**: decision-making, critical thinking, creative thinking, and problem-solving.

The details of these life skills appear in **Appendix VI**.

#### BOX 6.4. IMPORTANCE OF LIFE SKILLS

- » An individual needs life skills to operate effectively, actively, and constructively in society
- » Young people need personal and social skills to function confidently and competently with themselves, other people, and the wider community.
- » Life skills help create an environment in which self-discipline and respect for others are important values.
- » Life skills help provide equal opportunities for adolescents to fulfill their personal, social, and academic potential.

## 6.13. CULTURAL AND GENDER ISSUES IN COUNSELLING AND COMMUNICATING WITH CHILDREN AND ADOLESCENTS

Different cultures have different norms about interpersonal communication and counselling services. In many societies, there are rules about what topics can be discussed with young girls or young boys—for example, girls in some cultures may only discuss sexual topics with aunts or grandmothers, and may be even be forbidden from having contact with anyone outside of the family.

Professionals who need to communicate with children and adolescents need to understand the cultural norms for expressing feelings. In some societies, for example, it would be a source of great shame for children—especially boys—to cry. It is important that those trying to help children and adolescents do not make matters worse by encouraging them to talk and express feelings in a way that violates such norms. There are also cultural norms about what forms of expression are appropriate—the use of physical touch, or eye contact, for example, will vary between cultures—



while the degree of formality and social distance between adults and children may, in some societies, limit the exchange of personal information and feelings.

## 6.14. ROLE OF THE HCP

### **BOX 6.5. ROLE OF THE HCP**

- » Identify and advocate for the counselling needs of children/adolescents and their families and provide support.
- » Uphold and follow principles for counselling and communication with children and adolescents
- » Empower caregivers to communicate effectively, including offering basic counselling support
- » Conduct multidisciplinary team meetings to respond to the counselling needs of children and adolescents
- » Plan and implement appropriate referrals for children, adolescents, and their families.
- » Build collaborative networks to offer quality, comprehensive counselling support to children and adolescents
- » Establish adolescent- and child-friendly spaces at health facility settings



# CHAPTER 7.

## DISCLOSURE OF HIV STATUS

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## SUMMARY

- » Disclosure to children and adolescents of their own HIV status is vital to achieving optimal health outcomes.
  - » When children and adolescents are not aware of their own HIV status, they are more likely to experience adherence and emotional challenges.
  - » HCPs should work with children, adolescents, and their caregivers to discuss and agree on disclosure benefits, address barriers, and support the disclosure process.
  - » Disclosure is a process for adolescents and actions should support them to disclose their own HIV status to potential sexual partners, friends, family, and significant others.
  - » Post-disclosure follow-up plans should be made to provide further support as needed.
-

## 7.0. INTRODUCTION

Disclosure to the child or adolescent about their own HIV status is a sensitive and important topic that requires comprehensive psychosocial care and support throughout the process; it is not a one-off event. Conveying the importance of HIV treatment to a young child or adolescent can be challenging, especially where there has been partial disclosure or non-disclosure of their HIV status. Often caregivers delay for too long telling their child or adolescent about their own HIV-positive status. Delays in disclosure may be due to anxiety about anticipated stigma from the community, guilt regarding transmission, uncertainty on how to disclose, and fears of negative reactions or difficult questions from the child or adolescent (Madiba 2016).

Many perinatally infected children survive to adulthood, and this requires disclosure to enable them to have access to complete care and support and to self-manage their own health care as they grow older (Montalto et al. 2017). Knowledge of one's HIV status benefits children overall; and parents who have disclosed their children's status to them may experience less depression than those who have not. Disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context.

HIV disclosure is challenging for HIV-positive parents and HCPs. Depending on the setting, between 25 percent and 90 percent of school-age children with HIV do not know their status (WHO 2011). Some of the reasons given by family members for not disclosing HIV status include concerns about the impact that disclosure may have on a child's emotional health and fear by the parents that the knowledge will negatively affect a child's will to live. Therefore, it is very important for HCPs to have appropriate skills to support children, adolescents, and their caregivers through the disclosure process, maximising the positive outcomes of disclosure while limiting negative impacts.

## 7.1. DEFINITION OF DISCLOSURE

Disclosure is a gradual process of giving age-appropriate information regarding one's diagnosis, leading to full disclosure when the child has the cognitive and emotional maturity to process this information. **The three principal entities in disclosure are the child/adolescent, the family/caregivers, and the HCPs.** Communication among them should be as open and clear as possible.

## 7.2. THREE TYPES OF DISCLOSURE

### NON-DISCLOSURE:

- » Non-disclosure happens when the child or adolescent is unaware of his/her HIV status. This is typical in younger 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

## 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 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.

## COMPLETE/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.

## 7.3. BENEFITS OF DISCLOSURE

Children and adolescents who know their HIV status may have higher self-esteem and improved ART adherence compared to those who are unaware of their status. In addition, despite the threat of possible stigmatisation, several studies have emphasised the positive correlation between disclosure and social support (Gyamfi et al. 2015; Bikaako-Kajura et al. 2006). Benefits include:

- » For children and adolescents:
  - Promotes improved adherence to medication
  - Contributes to the overall well-being of the child/adolescent
  - Promotes reduction of self-stigma
  - Facilitates transition to self-care
  - Prevents resentment and anger towards HCP and caregivers when the HIV disclosure happens elsewhere or the child/adolescent discovers the diagnosis on their own.

- » For adolescents specifically:
  - Provides the opportunity to identify role models, express their needs more effectively, and gain experience in disease management.
  - Facilitates progress towards development of coping skills and improved self-esteem in a mutually supportive environment of peers with similar life experiences.
  - Enables adolescents to make informed sexual and reproductive health choices, including preventing further HIV transmission.
  - Enables discussion on matters of sex and reproductive health and facilitates partner HIV testing—with important public health benefits in terms of preventing further transmission of HIV to sexual partners.
- » For parents and caregivers:
  - Enables children, adolescents, and caregivers to have increased access to complete support including medical, psychological, and social support.
  - Promotes reduction of self-stigma.
- » For HCPs:
  - Improves and opens discussions on HIV infection, including HIV disease management, with the child, adolescent, and their caregivers.
- » For communities:
  - Promotes reduction of stigma and discrimination, as well as myths and misconceptions regarding HIV, and promotes creation of a supportive environment for HIV-positive children, adolescents and their families.

## 7.4 BARRIERS TO DISCLOSURE

Several barriers keep rates of HIV status disclosure to children and adolescents low in developing countries:

- » **Child and adolescent barriers:**
  - **Age of the child or adolescent:** The age by which the disclosure process starts will differ, but generally, children and adolescents will learn about their HIV status by the age of 8 to 12 years (Atwiine et al. 2015). It is important to note, however, that younger children have difficulty understanding the meaning of an HIV-positive status. It is for this reason that partial disclosure to these younger children is beneficial.
  - **Cognitive abilities of the child or adolescent:** It is important for HCPs to assess a child's or adolescent's cognitive abilities to determine how to proceed with the disclosure process. It is also important to note that some children and adolescents have developmental delays that reduce their ability to understand information about HIV and ART.
  - **Illness in the child/adolescent:** HCPs must consider the stage of the child/adolescent's medical condition, because fear and pain further compromise emotional energy not only of the child or adolescent, but also of the family, during the disclosure process. HCPs should avoid disclosure during a medical or acute illness.

- » **Parent and caregiver barriers:** One of the greatest psychosocial challenges faced by parents and caregivers of HIV-positive children and adolescents is disclosing their HIV status to them.
- » **Age of child:** Caregivers may feel that children younger than 13 years are immature and incapable of understanding their illness; this may be due to:
  - **Psychological harm:** At times parents may underestimate the child or adolescent’s ability to handle disclosure, and may be overly concerned about possible psychological harm or the child’s reaction towards the HIV-positive parent.
  - **Stigma:** Caregivers often fear that the child may not be able to keep their HIV diagnosis confidential. They also fear possible exposure to stigma and discrimination towards the whole family if the child or adolescent chooses to disclose their diagnosis with peers, partners, or the public.
- » **Guilt:** For perinatally infected children and adolescents, caregivers may experience fear and guilt for transmitting the virus to them, and may feel uncomfortable answering questions on how the child or adolescent got the HIV infection.
- » **HCP barriers:** HCPs often have limited skills in addressing disclosure, and may lack guidance, guidelines, or tool to help the child or adolescent and his/her caregiver through the disclosure process.
- » **Community barriers:** Stigma and discrimination is one of the most common barriers associated with non-disclosure of HIV status to children and adolescents. In most communities, families with children and adolescents with HIV often become victims of this negative behaviour, making caregivers cautious and causing them to guard the information, regardless of the effects of non-disclosure.



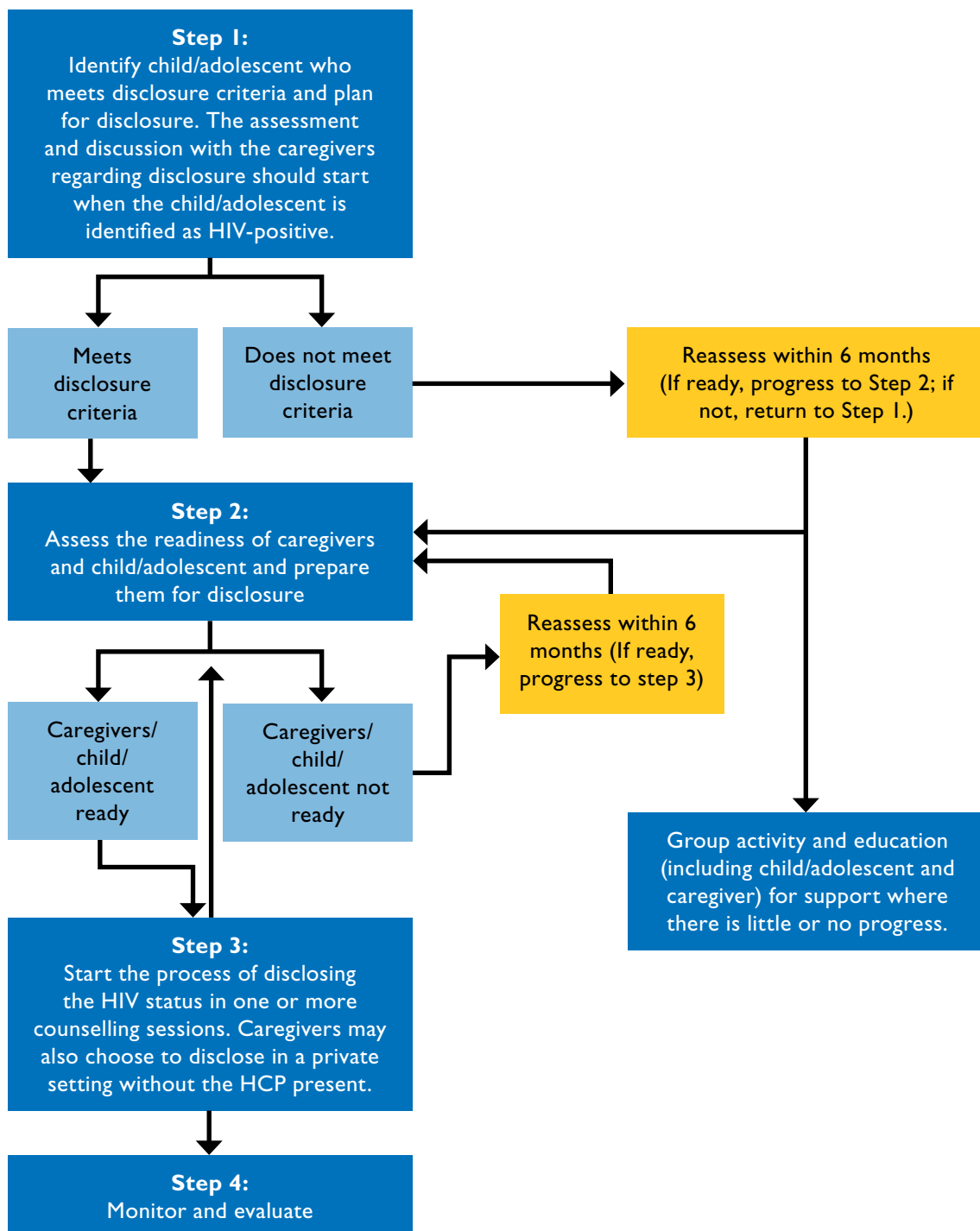
## 7.5. HOW TO DEAL WITH BARRIERS AND FEARS OF DISCLOSURE

It is important for HCPs and caregivers to identify, recognise, and appreciate disclosure barriers and their own fears; and to understand how these factors affect children, adolescents, and their caregivers and work together to come up with ways to reduce their impact. Successful disclosure requires an encouraging environment. In this environment, we need to maximise **facilitators** and overcome **barriers**. Facilitators are factors that support the process of disclosure. Examples include skilled HCPs, child- and adolescent-friendly services, and age-appropriate tools. It is vital to spend sufficient time and energy preparing and supporting primary caregivers to commit to full disclosure; strong understanding of the child/adolescent’s situation (see **Chapter 2**) and good counselling practices (see **Chapter 6**) can help to ensure that each patient and caregiver is ready to disclose or receive disclosure as appropriate.

## 7.6. ROLE OF THE HEALTH CARE PROVIDER IN THE DISCLOSURE PROCESS

Disclosure is not a one-time event but a process that involves various phases (see Figure 7.1) The HCP should take a phased approach and follow the steps to disclose the status of the child or adolescent in Figure 7.1, and the steps are described in detail in the text that follows.

**Figure 7.1. Steps in HIV Disclosure for Children and Adolescents**



### STEP 1: IDENTIFY IF THE CHILD OR ADOLESCENT MEETS CRITERIA FOR DISCLOSURE AND PROPOSE DISCLOSURE COUNSELLING TO CAREGIVERS

The HCP identifies the child or adolescent who meets disclosure criteria (defined according to the context of each health facility setting), and after obtaining consent from a stable and supportive caregiver. In the event that the primary caregiver is the biological parent, the HCP should probe on



whether they have disclosed to their spouses or other family members. The disclosure of the child's HIV status is linked to the parents and caution should be taken, discussing the process with caregivers directly, listening to their concerns, and offering disclosure counselling service to those caregivers whose child/adolescents are eligible. It is important to use this process to reinforce the stability and strengths that exist in the child/adolescent's environments. Disclosure should always be done in the best interest of the child, taking into consideration confidentiality and that disclosure to any other family member focuses on supporting the child/adolescent and his/her family. All children should begin the disclosure process after their parents'/caregivers' consent is obtained. Disclosure should be geared towards their age and developmental status. A study in Zambia in 2017 among 127 adolescents aged 11 to 15 years revealed that only 38% had their HIV status disclosed to them, even though majority (74%) were on ART. The adolescents who were not disclosed to in this study were more likely to have emotional difficulties, suggesting a need for interventions to promote disclosure (Menon et al. 2007). One such intervention, which involves the HCP assisting with disclosure, is shown in Box 7.1.

### **BOX 7.1. HCP-ASSISTED DISCLOSURE: AN INTERVENTION**

1. HCPs are taught to support caregivers' decisions whether to disclose the HIV diagnosis, and they respect the family timing. They do not rush the disclosure process but instead stay alert and sensitive to the families' feelings and needs as they evolve through the phases of disclosure
2. The HCPs are taught to respect caregivers' reasons to fear and resist the disclosure process.
3. The family receives a detailed explanation of the disclosure model before disclosure
4. During educational sessions the staff member prepares family members to answer embarrassing or painful questions that the children are likely to ask (e.g., about sexual practices)
5. The team of HCPs assist caregivers in revealing other family secrets, such as adoption.
6. Caregivers who have disclosed to their adolescents with good psychological adjustment serve as peer supporters to other caregivers.
7. HCPs must consider the stage of HIV and the child's medical condition because fear, pain and fatigue further compromise the child's and family's emotional energy levels during the disclosure process. They avoid disclosure during a medical crisis or acute illness.
8. Emphasizing confidentiality, the HCP engages the patient in a partnership based on confidence and trust.
9. Throughout the sessions the HCP ensures that the child seems curious and ready to learn more about his/her medical condition.

## **STEP 2: PREPARE CAREGIVERS AND CHILDREN/ADOLESCENTS FOR DISCLOSURE**

After caregivers (or in some cases, adolescents) consent to receiving the disclosure counselling service, the HCP should further assess their readiness for disclosure through counselling that requires both assessing and preparing the child/adolescent for disclosure. Explore any concerns or fears the caregivers might have about disclosure and help caregivers explore advantages and barriers/challenges of disclosure, and prepare them to respond accordingly.

Building relationships with the child or adolescent to strengthen their communication and stress management skills is critical. It may take several visits to do this particularly for those that are younger. Avoid discussing or assessing the child or adolescent's perceptions of their HIV diagnosis in this step; this may cause unintentional disclosure of the HIV diagnosis when the child/adolescent or caregivers are not yet ready. If the caregiver or the child or adolescent is not ready for disclosure, the HCP may have to reassess in subsequent visits. The disclosure process may vary depending on individual circumstances as well as the age of the child or adolescent. HCP may want to examine the family's coping skills with younger children and respond to any questions that they have before moving on with disclosure. Adolescents have a greater capacity to understand what is occurring. In these circumstances, disclosure should occur at the time of testing

### STEP 3: DISCLOSE HIV STATUS TO CHILD OR ADOLESCENT DURING A COUNSELLING SESSION

Disclosure can occur at home or at the facility.

- » After the caregivers and child/adolescent are ready and prepared for disclosure, the caregiver may decide to disclose the HIV status to the child or adolescent by themselves at home. However, studies show that most children and adolescents prefer to know their HIV status from the health care facility (Kidia et al. 2014).
- » Alternatively, the caregiver may want the disclosure to occur in the health facility, where they can either disclose the status to the child or adolescent by their self with assistance from a HCP, or have the HCP disclose to the child or adolescent. HCPs should schedule a counselling session regardless of the chosen disclosure approach.

The purpose of the disclosure session is threefold: 1) disclosing HIV status to the child or adolescent; 2) providing correct information about HIV and self-care practices; and 3) assessing and supporting the child/adolescent's emotional reactions. Messages are described below.

#### Age-appropriate disclosure messages (children 4–7 yrs.)

For children in this age group, *partial disclosure* should be considered. The **statements** which could be used in the disclosure status include:

- » You have a germ that lives in your blood.
- » Having this germ means that you may get sick sometimes.
- » You therefore need to take medicine to keep you healthy.

#### Age-appropriate disclosure messages (children 7–9 yrs.) (Catholic Relief Services 2009)

For children in this age group, the HCP should assess /evaluate whether the:

- » Child knows why they come to the clinic.
- » Child knows why they are taking medicine.
- » Child has come to the clinic because they have an illness.

Statements the HCP may use during the disclosure process to explain HIV infection include:

- » You have a germ that lives in your blood.

- » Having this germ means that you may get sick sometimes.
- » What have you heard about HIV? (Or what do you know about HIV?)
  - The real name of the germ is HIV.
  - (Correct any misinformation.)
- » HIV can make someone sick, and medicines are necessary to keep you healthy.
- » HIV can harm healthy cells that protect you from sickness.
- » You should only discuss your HIV status with their parents/caregivers. If you think that you want to discuss your HIV status with someone else, you should discuss with your parents/caregivers first and make a decision together.

**Explain mother-to-child transmission of HIV:**

- » HIV was in your blood when you were born.
- » 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 go to school, and hug your family and friends.
- » If you fall and hurt yourself and are bleeding, don’t let others touch your blood.

[**Note:** For children who come with their parents/caregivers, encourage and empower the caregivers to be the ones to give this information to the child.]

**Age-appropriate disclosure messages specific to adolescents (10–19 years):**

- » Begin with assessing what they know about HIV and handle accordingly.
- » Explain transmission modes.
- » Inform them about their HIV status.
- » Talk about the health benefits of disclosing their own status to others, especially sexual partners, to prevent further transmission of HIV.
- » Provide benefits of optimal adherence to ART, including “U=U”; Undetectable viral load = Untransmittable HIV; sexual partners are more likely to be protected if the adolescent is adherent.

**Supporting adolescents to disclose their HIV status to others:**

Adolescents should be counselled about the potential benefits and risks of disclosing their HIV status to significant people in their lives. They should be empowered and supported to determine if, when, how, and to whom to disclose. It is important to equip adolescents considering disclosure with information to ensure that they can answer questions and manage the reactions of those they disclose to.

Depending on the country's legal framework, non-disclosure to sexual partners may be a criminal act, and adolescents from key populations, such as those engaging in sex work, may face specific legal consequences. It is important for HCPs to be aware of relevant national laws and policies on disclosure and to pass legal information on to adolescents to inform them of their responsibilities as well as their rights, especially their right to confidentiality.



As mentioned earlier in section 7.3, disclosure offers adolescents important opportunities to obtain emotional and practical support, helping them deal with their diagnosis and often enhancing adherence. Disclosure can also facilitate open discussion about sexual and reproductive health and encourage partner HIV testing, with potentially important public health benefits.

Adolescents need the time to explore the potential benefits and risks of HIV disclosure to others, taking into full consideration family, friends, sexual partners, work and education circumstances, religious leaders, and the community—and how disclosure will affect all of these. Write out a plan of what to discuss with the adolescent, and practice possible questions and responses through role-plays to help the adolescent feel prepared. Talking with other adolescents living with HIV who have disclosed to others may also help prepare the adolescent considering how to disclose. There are serious potential negative consequences that exist for adolescents, with different degrees of risk. Disclosure may result in physical harm, discrimination, stigma, unwilling onward disclosure, and isolation, so proceed with caution. Consider the following:

- » Adolescents should think about when and where the best time and place to disclose is. They may want to consider if they have come to terms with having HIV, if they feel prepared, or whether there are other major stressors at the time (such as starting HIV treatment). It is important to ensure a safe environment for the adolescent when disclosing. Some adolescents may prefer to disclose their status with the presence of a provider in a clinic setting, or with another individual who already knows their status.
- » After the adolescent has disclosed their HIV status, it is beneficial to debrief with him/her to reflect on challenges and successes, and how they would do it differently in the future. Some adolescents may wish to bring someone they disclosed to with them to the clinic, so they also have an opportunity to ask any questions. Particularly for sexual partners, this provides an opportunity to discuss HIV testing and counselling options.

**[Note:** Overemphasising disclosure—especially to parents or sexual partners—may discourage adolescents from accessing services. Similarly, mandatory disclosure by HCPs (i.e., to authorities) can keep adolescents from accessing HTS, particularly those from key populations. Disclosure needs to be handled sensitively, always consider and respect the adolescent's wishes throughout the process.]

## STEP 4: POST-DISCLOSURE SUPPORT

Providers should expect to spend three or more months providing post-disclosure support to address patients' emotional and practical concerns and responses. After learning that they have HIV, adolescents often feel anxiety, depression, and self-blame. If in a relationship, there may also be strains on the adolescent. HCPs should work with children/adolescents and their caregivers to recognise and address these feelings.

The disclosure process should include a follow-up plan to address reactions. The plan should specify immediate, intermediate, and long-term follow-up—for example, at two weeks post-disclosure, at one month, and at three months.

During follow-up, HCPs should explore changes in the child/adolescent and caregiver after disclosure, including their understanding of their health status and self-care practices. Providers' approaches should consider the influence of religion and spirituality; sometimes, after seeking pastoral care from their faith leaders, patients believe that their faith and prayers miraculously

healed them from HIV; providers need to ensure that they understand that their treatment must continue. The follow-up plan should make it as easy as possible for patients/caregivers to comply and keep coming to the facility. If possible, HCPs should arrange to visit them at the home, or make phone calls where applicable or refer them to support groups, peer support, or home visit support services when available. Throughout the post-disclosure process, the HCP should be careful to recognise and address any negative reactions in the child, adolescent, or caregiver, and to answer questions that may follow disclosure.

### Peer support groups for children and adolescents following disclosure

It is important to link children and adolescents to appropriate support groups that will enable them to cope with disclosure. These include; peer support groups like teen clubs and Ariel clubs as well community support groups like adherence support groups. For more information on peer support groups, refer to **Chapter 12**. Patients may also use social media platforms such as WhatsApp groups and Facebook groups.

## 7.7. PARENTAL HIV DISCLOSURE TO CHILDREN AND ADOLESCENTS

Maternal/parental HIV disclosure involves mothers/parents revealing their own HIV status to their child/adolescent, and can be challenging. It is very important for children and should ideally happen before the children/adolescents are told of their own HIV status to facilitate having the child or adolescent learn their own status. A recent study from South Africa has revealed some benefits associated with mothers disclosing to their child/adolescent. The women (mothers/ female caregivers) in the study were interested in leading disclosure to their children or teenagers who acquired HIV perinatally (Rochat et al. 2017). This desire was rooted in their concerns about negative outcomes for the child/adolescent, including the effect of disclosure on the mother-child relationship, the child or adolescent's emotional and psychological well-being, and the fear that their children may believe their mother led an irresponsible life and is "to blame" for her HIV status. However, the study showed that maternal HIV disclosure resulted in benefits that included improved adherence and self-care by the child/adolescent, better mother-child and family relationships, and reduced stigma. HCPs can discuss with mothers who are positive the importance of them disclosing to their child/adolescent and can highlight:

Benefits of maternal/parental HIV disclosure to **the child/adolescent** (Armistead 2001):

- » Provides opportunity for anticipatory grieving and open communication between mother/parent and child/adolescent about the mother's illness.
- » Allows for formal and informal social support for the child/adolescent to cope with the mother's/parent's status.
- » Facilitates clarification of any misconceptions that the child holds regarding HIV infection.

Benefits of maternal/parental HIV disclosure **to the mother/parent** (Rochat et al. 2017):

- » Improves HIV treatment adherence and compliance.
- » Facilitates parent-child and family relationships.
- » Improves mental health and reduces stigma.



**CHAPTER 8.**  
**LOSS, GRIEF, AND**  
**BEREAVEMENT IN CHILDREN**  
**AND ADOLESCENTS**

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## SUMMARY

- » Loss, grief, and bereavement in children and adolescents are often deeply felt and inadequately addressed.
  - » With recent advances in ART, fewer children/adolescents will experience the loss associated with death; however, many more may have to deal with the loss and grief associated with living with and/or having a family member living with a chronic illness (Smith 1999).
  - » Loss, grief, and bereavement have negative health and social impacts on children and adolescents.
  - » Providing bereavement counselling and support to children and adolescents can strengthen coping and resilience skills.
-

## 8.0. INTRODUCTION

Grief is a neglected aspect of care for HIV-positive children and adolescents. Indeed, many HCPs (and often most community members) are not trained to address grief. Recent advances in HIV care, including widespread use of ART, has led to fewer children and caregivers being terminally ill or experiencing loss, and is a positive development. However, studies have shown that those children and adolescents who do experience loss, demonstrate increased vulnerability to mental health problems later in life. 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 (Lorraine Sherr 2017; Woollett et al. 2017).

Adults have much greater access to support for loss, grief, and bereavement; yet children and adolescents are also traumatised and fearful after losing a family member or learning their own HIV status, and they undergo a unique grieving process that, if not addressed, can have serious emotional, health, and social impacts (Woollett et al. 2017). Societies often keep information from children and adolescents, denying them the opportunity to address their grief in the name of protecting them. Culture may play a significant role in how children and adolescents are prepared for an imminent loss and how grief is expressed once a loved one has passed away. HCPs should be aware and respectful of these cultural nuances throughout the caring process. (J. A. Cohen, Mannarino, and Deblinger 2017)

HCPs have an opportunity to play an important role in helping parents and other adults in understanding the way grief and loss manifests in children and adolescents, which by extension helps them to provide comfort and support. This entails allowing children to participate and be involved in decisions about their illness to the fullest extent possible so that they can achieve control over their own living and dying.

## 8.1. DEFINITIONS OF KEY CONCEPTS

**Bereavement:** The period after a loss during which a person experiences grief and mourning occurs. Although bereavement is a factual situation of loss, how individuals respond to loss can be highly varied. Bereavement will differ from culture to culture, from person to person, and from situation to situation for any one person.

**Grief:** This is the normal process of reacting to a loss; it is a staged or phased process. Grief is a psychological feeling, as well as a social and emotional reaction to loss; and consists of emotional, psychological, and physical dimensions. Feelings and reactions can include anger, guilt, anxiety, sadness, and despair.

**Complicated grief:** The state of chronic grieving beyond the period expected in “acute grief” (which is 4 to 6 months post-death). It is characterised by intense separation distress, intrusive and unwelcome thoughts about the deceased or the event, a sense of meaninglessness, trouble accepting the reality of the loss, and various difficulties “moving on” with life.

**Loss:** A situation when something is taken away from the bereaved person. A loss occurs when individuals view an event as negative; such an event results in long-term changes in one’s social situations, relationships, or way of viewing the world and oneself. Traumatic or stressful events may cause several losses; and each loss can have multiple consequences. Therefore, when children,

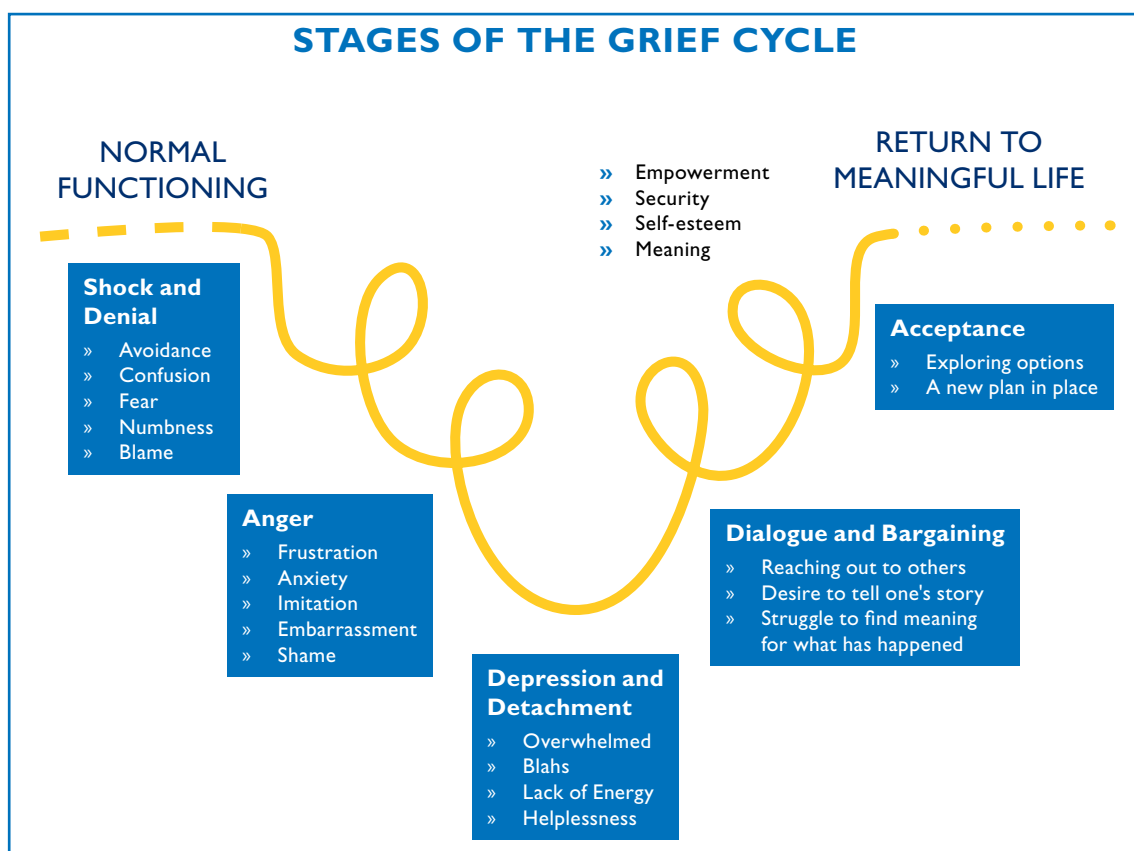


adolescents, and their families have chronic illness, they experience multiple losses that can cause physical or mental deterioration. Losses may include diminished self-esteem related to having the disease, the stigma of being with a chronically ill parent, being ignored by peers, or being unable to discuss one's own condition.

## 8.2. THE GRIEVING PROCESS

**Stages of grief:** Both terminally ill patients and people who have lost a loved one or are experiencing other loss such as that associated with being diagnosed with a chronic illness, experience grief, which often happens in phases. These phases can overlap and are many times not linear. The five stages are denial, anger, depression, bargaining, and acceptance. These stages can be experienced more than once, and each step helps in the healing process (Figure 8.1) (Kübler-Ross 1973).

Figure 8.1. Stages of Grief



Adapted from Kubler-Ross, 1969

## 8.3. THE CONCEPT OF GRIEF IN CHILDREN AND ADOLESCENTS

Children and adolescents experience grief differently from adults. An individual's grief and mourning process is directly related to their developmental stage, which influences their efforts to make sense of and deal with the concept and experience of death (Li et al. 2015). HCPs working with children on such issues need to understand a framework of grieving that is specific to children and that takes account of children's comprehension of death at various ages and stages of growth and development.

Behavioural changes are often a signal that a child is experiencing bereavement and that they may be experiencing challenges in handling these feelings.

Children develop emotionally and physically at different rates; studies have shown that the same is true about their understanding and responses to serious illness, death, and bereavement. Their experiences with and exposure to loss, grief, and bereavement also influence their understanding and coping. For example, children who have lost their loved ones and gone through grief themselves understand it better than those who have not. Table 8.1 provides a basis to assess and help children and adolescents in accordance with their own context, developmental stage, and experience.

**Table 8.1. Concepts of Grief and How to Address It**

AGE	CONCEPT OF LOSS, GRIEF AND BEREAVEMENT IN CHILDREN AND ADOLESCENTS	HOW TO HELP
<b>0-5 Years</b>	<ul style="list-style-type: none"> <li>» A very young child, or a baby, is aware of separation from someone who cares for them. They can be aware that the person is “missing”/not there, and may get anxious.</li> <li>» Cognitively they may not fully understand the implications of the loss, but their behaviour may indicate their feelings of someone missing.</li> <li>» The concept of death as an unchangeable, permanent state is a difficult idea for this age.</li> <li>» They may think that death is reversible.</li> </ul>	<p>It is important for such children to have a significant person to be there for them.</p>
<b>5-10 Years</b>	<ul style="list-style-type: none"> <li>» Children in this age group are developing an understanding of death as permanent and irreversible.</li> <li>» They are beginning to understand that death is universal and that one day they will die.</li> <li>» Children are likely to ask many questions, and to be very emotional at times. At other times, they may seem insensitive, playing as though nothing had happened. This is a natural coping defence after loss.</li> <li>» Children may display curiosity about rituals, such as funerals, and what happens with the body after it is dead. They may act things out as a way of understanding what has happened.</li> <li>» They may also use play as a way of making sense of something that has not been explained to them in an age-appropriate manner.</li> </ul>	<p>It is important to be honest and consistent with explanations, and to use appropriate language. For example, one should not say “the person has gone to heaven.” This may imply that this person is going to return any time. Instead, one should say, “S/he has died.” Death is permanent and the dead person will not be seen again. The child should be told good things about the person who has died, and should be reassured that s/he is not to blame for the death, and that nobody is to blame.</p>
<b>11-18 Years</b>	<ul style="list-style-type: none"> <li>» At this age, individuals have developed a greater awareness of death, the long-term consequences of loss, and especially its emotional aspects.</li> <li>» They gradually develop a more complete understanding of the impact and consequences of death. This understanding makes the fact of death more fearsome.</li> <li>» It is important to remember that a teenager is still not fully grown up emotionally, and should not be expected to be treated like, or behave like, an adult.</li> </ul>	<p>Teenagers, like all children, require reassurance that they are loved and cared about when faced with these experiences. They also need information and access to support when they feel they need it.</p>

## 8.4. EMOTIONS CHILDREN AND ADOLESCENTS COMMONLY EXPERIENCE IN RESPONSE TO A LOSS AND DEATH OF A LOVED ONE

Table 8.2 displays the effects of grief and age-appropriate responses. In addition, some common emotions are listed below.

- » **Sadness and depression:** Sometimes it may be clear that the child or adolescent is sad about the loss. Other times it may seem that the child/adolescent is sad about something else.
- » **Fear and anxiety:** Children and adolescents may experience fear for their own lives, or fear of another loved one's death. This may lead to a fear of separation.
- » **Anger and irritability:** These emotions are often expressed towards the loved one who has died, towards doctors, the hospital, and other logical targets; or the child may simply have a quicker temper, often becoming angry at completely unrelated things.
- » **Confusion:** The death of a loved one may change a child or adolescent's entire understanding of the world.
- » **Difficulty sleeping:** This may include difficulty getting to sleep, waking during the night, or early morning waking, as well as nightmares. The child or adolescent may also develop a fear of sleep.
- » **Problems with schoolwork:** These difficulties will sometimes begin weeks or months after the loss.
- » **Interest in death:** This may at times seem morbid to adults, but is a common part of children's attempts to understand death.
- » **Awakening of past feelings about death or other losses:** This is observed particularly in adolescents, but may occur in younger children as well.

**Table 8.2. Effects of Grief and Age-Appropriate Responses**

AGE-RELATED RESPONSE	WHAT CAN HELP
<b>Babies 0 to 3 years old</b>	
<ul style="list-style-type: none"> <li>» Inability to talk about grief, expressing it physically</li> <li>» Crying, regressive behaviour</li> <li>» Delayed progress in speech, walking</li> <li>» Fearfulness, clinginess</li> <li>» Problems with eating, sleeping, or toilet habits</li> <li>» Development of comfort habits, such as thumb-sucking</li> </ul>	<ul style="list-style-type: none"> <li>» Patience—it can take a year or longer before progress is made in independence and confidence</li> <li>» Showing love, attention, and patience</li> <li>» Familiar routines</li> <li>» Prayer in family's spiritual tradition</li> </ul>

## AGE-RELATED RESPONSE

## WHAT CAN HELP

### Pre-schoolers 3 to 5 years old

- |                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>» More difficult to calm down</li><li>» “Naughty” behaviour, due to emotional stress and hurt</li><li>» Physical expressions of grief</li><li>» Outbursts</li><li>» Refusal to be comforted</li><li>» Fluctuation between being happy and sad within minutes</li><li>» Repetition of questions</li><li>» More understanding than is verbalised</li><li>» Regressive behaviour</li><li>» A developed sense of right and wrong</li></ul> | <ul style="list-style-type: none"><li>» Patience—recovery can take up to two years</li><li>» Hugs, attention, cuddles</li><li>» Making them feel important by, for example, asking them to help with activities in the home</li><li>» Encouraging them to talk about the event through stories, puppets, and art</li><li>» Helping them understand it is not their fault; and that they can’t wish something into being</li><li>» Memory work (appropriate for all ages)</li><li>» Maintenance of routines</li><li>» Prayer in family’s spiritual tradition</li></ul> |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

### Children 6 to 12 years old

- |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>» Ability to think logically, talking and remembering</li><li>» Ability to understand what causes death</li><li>» Tendency to recover faster than younger children</li><li>» Grief similar to adults and older children</li><li>» Loss of concentration and poor school work</li><li>» Aggression</li><li>» Aches and pains</li><li>» Nightmares and anxiety attacks</li><li>» Feelings of helplessness and vulnerability to further loss</li></ul> | <ul style="list-style-type: none"><li>» Non-judgemental listening</li><li>» Encouraging expression of feelings through means such as art</li><li>» Allowing the name of the deceased person to be mentioned</li><li>» Supporting a loving relationship with the caregiver</li><li>» Providing structure and stability</li><li>» Allowing the child to be a child, to have fun without guilt</li><li>» Providing opportunities to help others, regain sense of control, value, and belonging</li><li>» Prayer in family’s spiritual tradition</li></ul> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

### Adolescents

- |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                              |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>» Feelings of weakness and helplessness</li><li>» Understanding that death is irreversible/final</li><li>» Ambivalence about their bodies</li><li>» Life crisis of transition to adulthood</li><li>» Denial of feelings, seeing the need for consolation as immature</li><li>» Anger and rebellion</li><li>» Lack of trust, feelings of being let down</li><li>» Risky behaviours including running away, seeking out undesirable peers, promiscuity, substance abuse, eating disorders, suicidality, depression, morbid thoughts</li></ul> | <ul style="list-style-type: none"><li>» Peer support</li><li>» Recreation</li><li>» Having a trusted adult to talk to</li><li>» Respite, such as walks or camp with caregiver</li><li>» Creating interest in the future</li><li>» All interventions described above for children 6 to 12 years old</li></ul> |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

## 8.5. HCPs' ROLE IN RESPONDING TO CHILDREN AND ADOLESCENTS EXPERIENCING LOSS, GRIEF, AND BEREAVEMENT

Understanding how children and adolescents experience loss, grief and bereavement empowers HCPs to respond to effects of grief and loss in children and adolescents. An HCP's main role, when a child or adolescent is grieving, is to provide support. However, it is important to be aware of the possibility of suicide and be sensitive to the child's reactions to the death. Even young children sometimes attempt suicide. Sometimes, when a child hears a description of the beautiful place to which their loved one has gone, the child chooses to join the loved one. For details on assessment for and dealing with suicidal thoughts and attempts, refer to **Chapter 4**. Overall, the HCP's role is to be there for the child and adolescent. HCPs 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 comfort, do what seems needed at the time. Children and adolescents may need a little 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 stops breathing forever or 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.

## 8.6. END-OF-LIFE CARE FOR CHILDREN AND ADOLESCENTS

When a child is diagnosed with a progressive, life-limiting illness, a journey begins. Throughout this journey, children, families, and caregivers will need information and support. End-of-life care for children and adolescents prepares them for the many situations and issues they may face as they

live with the illness. It is important to assess for individualised needs, and to know where to go for specific information and support to meet these needs.

Children's need for information is often neglected, sometimes on the pretext that their understanding is limited, or because they are sick. However, even young children need information in a language understandable to them. In the absence of reliable information, a child's fantasy may be far more distressing than the reality. Sharing a terminal diagnosis requires careful preparation, using a series of steps (see Table 8.3).

**Table 8.3. Breaking the Bad News**

STEPS	HCP'S ROLE
<b>Step 1: Set up the session</b>	<ul style="list-style-type: none"> <li>» Arrange for privacy and make sure that there will be no interruptions</li> <li>» Involve significant others as appropriate</li> <li>» Sit down</li> <li>» Connect with the patient using eye contact and touch (as appropriate)</li> <li>» Tell the patient that you have time to spend with them.</li> </ul>
<b>Step 2: Assess the person's perception</b>	<ul style="list-style-type: none"> <li>» Use open-ended questions (e.g., "What have you been told about your condition so far?")</li> <li>» Gather information to explore the patient's perception of the situation</li> <li>» Explore ideas, concerns, and expectations</li> <li>» Correct misinformation as necessary</li> <li>» Determine whether the patient is in denial</li> </ul>
<b>Step 3: Obtain the person's invitation</b>	<ul style="list-style-type: none"> <li>» 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)</li> <li>» Gauge how much information the patient wants</li> </ul>
<b>Step 4: Give knowledge and information to the person</b>	<ul style="list-style-type: none"> <li>» Warn the patient that bad news is coming; one could say: "Unfortunately I have got some bad news to tell you"</li> <li>» Break the information into small chunks</li> <li>» Use appropriate language and check for understanding of each chunk of information</li> </ul>
<b>Step 5: Address the person's emotions with empathic responses</b>	<ul style="list-style-type: none"> <li>» Look out for the patient's emotional reaction</li> <li>» Identify the emotion, such as anger and sadness</li> <li>» Identify the reason for the emotion, asking the patient if necessary</li> <li>» Make an empathic statement to acknowledge the emotion</li> </ul>
<b>Step 6: Strategize and summarise</b>	<ul style="list-style-type: none"> <li>» Present treatment options</li> <li>» Share decision-making</li> <li>» Reach consensus</li> <li>» Plan follow-up: this should be based on reactions; to begin, it can be weekly then monthly, and subsequently quarterly</li> <li>» Link the patient to community resources, (e.g., peer support and CBOs)</li> </ul>

## ASSESSING CHILDREN/ADOLESCENTS' NEEDS IN END-OF-LIFE CARE

If you do not know what the child or adolescent's problems are, you will not be able to address them. Palliative care needs change often quite rapidly. Assessment in end-of-life care is crucial, and forms the basis for developing a management plan and providing quality, comprehensive care. It is not a one-time event but a process that should be constantly revisited and updated. The options for assessing needs are:

1. Ask the child. This is the quickest, most accurate method.
2. Ask the family/known caregiver: this is next best, and it is usually worth doing as a cross-check even when the child has already told you.
3. Assess the situation yourself; this is the least desirable option, but better than nothing if no other option is possible.

## BASIC PRINCIPLES OF ASSESSMENT IN END-OF-LIFE CARE

- » Take time to assess properly.
- » Keep the child/adolescent as the centre of your focus; respect their autonomy, and address confidentiality and consent. Also, stay aware of the child/adolescent's concerns and worries about death and dying.
- » Trust the child/adolescent and the family; they are the experts in the care of the child. Appreciate and respect the information that is being shared during assessments, and use this information to offer support and respond to concerns.
- » The home should be the centre of care and the model of caring. If the patient must be hospitalised, model the hospital care environment after that of the home where possible. Most patients prefer spending their last days with their loved ones at home.
- » Listen. The child and family will tell you what their ideas, fears, and needs are—and when needed, provide a shoulder to cry on.
- » Be open, clear, and honest; talking about death and dying is hard, but studies have shown that most children and families prefer to know of the impending death.
- » Be holistic; assess physical, psychological, social, and spiritual needs.
- » Foster partnership. The HCP's main partnership is with the child and family. Other key partnerships are with the community and other HCPs.
- » Identify a key contact; if more than one HCP is involved, it is sensible to negotiate and agree on one key individual as the main contact.
- » Review at every visit; there should be a review of the issues and progress in dealing with them.

## 8.7. GENDER ISSUES IN GRIEF, LOSS, AND BEREAVEMENT FOR CHILDREN AND ADOLESCENTS

Literature and experience show that boys experiencing bereavement have increased risk for complicated grief compared to bereaved girls. Boys exhibit higher levels of emotional and behavioural difficulties following bereavement. They are also typically found to display higher levels of externalising behaviour problems, while girls are more likely to internalise problems. In most parts of Africa, however, boys are expected to be strong, and are consequently given less support than girls to express their grief. HCPs should monitor for signs of grief in boys and girls and respond appropriately.







# CHAPTER 9.

## ADHERENCE TO ANTIRETROVIRAL THERAPY

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## SUMMARY

- » As children/adolescents start ART, they and their caregivers need to be prepared to ensure adherence.
  - » HCPs should continually assess ART adherence and address barriers to adherence that they face.
-

## 9.0. INTRODUCTION

This chapter describes the benefits of ART adherence and common barriers that may hinder children and adolescents from achieving good adherence. It also describes adherence assessment and monitoring strategies, and strategies to address barriers and prepare children and adolescents who are beginning ART, to help them attain and sustain good adherence.

## 9.1. DEFINITION OF ART ADHERENCE

Adherence to ART means *consistent action*: taking the *right* medicine, at the *right* time, in the *right* dose, in the *right* way, and in the *right* frequency—*consistently*. This is known as the “five R’s” of adherence. Numerous factors influence adherence to ART: the drug regimen, patient and family factors, and the child/adolescent-provider relationship. Adherence to ART is an informed choice, so children and adolescents should participate in making the adherence plan. Though the physical role of looking after a child diminishes as the child grows older, caregivers need to be reminded that they remain critical in the child’s care at every age.

## 9.2. BENEFITS OF ART ADHERENCE

A child or adolescent with good adherence to ART can suppress viral replication and restore immune function, which is critical to positive living. 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 an unborn child.

## 9.3. CONSEQUENCES OF NON-ADHERENCE

By contrast, failure to adhere to ART as prescribed may lead to continued HIV multiplication with a high viral load, continued destruction of the immune system and decreased CD4 cells, and HIV disease progression, which may lead to development of opportunistic infection, such as tuberculosis. Non-adherence is the main cause of developing HIV drug resistance; it also increases the risk of HIV transmission.

**[Note:** Though non-adherence is the main cause of developing HIV drug resistance, even in the presence of good adherence, a patient may have a high viral load. This could result from a poorly constructed ART regimen; or the patient may have contracted a virus that was already resistant to the medications, a phenomenon called primary drug resistance.]

## 9.4. BARRIERS AFFECTING ART ADHERENCE

Adherence is complex and demanding; and many factors can help or hinder adherence in children and adolescents (Kim et al. 2014). This section first describes common barriers among caregivers, HCPs, the larger system, and ART medication itself that can affect adherence by children and young people. Second, the section describes factors specific to children and adolescents that can impede adherence.

## BARRIERS AFFECTING A CHILD OR ADOLESCENT'S ENVIRONMENT

**Caregiver factors:** The behaviour and life situation of families and caregivers may affect a child/adolescent's behaviour and ultimately their adherence to ART:

- » *Inappropriate caregivers:* Caregivers must commit to supporting the HIV-positive child/adolescent—which requires supporting ART adherence. Although the death or extended absence (e.g., in cases of migrant labour and those seeking remote employment opportunities) of parents may leave children and infants living with HIV in the care of older children and adolescents, these situations are not ideal. The older children may not developmentally be able to undertake such tasks as regularly dispensing medication; the same may also be true of the very old. These inappropriate caregiving situations can lead to disrupted routines with a potential for poor communication and loss of consistent adherence support.
- » *Social and health issues* within a family (dysfunctional families) can be due to numerous factors, including substance abuse, poor physical or mental health, unstable housing, poverty, involvement with the criminal justice system, limited financial and social support, forgetting doses, changes in routine, being too busy, travel, and child refusal by one of the parents. For further information on other support systems, see **Chapter 12**.
- » *Undisclosed HIV status* of the caregiver or child can have a negative impact on adherence, see **Chapter 7**.
- » *Not involving children/adolescents in decisions* about their care limits their opportunities to discuss their concerns, and could diminish their ownership of their illness.
- » *Not understanding ART*—poor comprehension of treatment plans and why they are important—can impede proper adherence.
- » *A feeling of guilt*, especially if the child was infected through mother-to-child transmission, sometimes leading to negative behaviour towards adherence.
- » *Poor adherence by caregivers.* Caregivers whose own adherence is poor may not support the child's adherence; such lack of support for a child could be a sign of abuse and neglect.
- » *Spiritual beliefs* can affect beliefs about ART and opting for other HIV management interventions/alternative HIV medicines and treatment, including “spiritual healing.”
- » *Poor access to services*—for example, by remote populations—can affect caregivers, children, and adolescents, and poses a significant barrier to treatment and adherence.

**HCP factors:** The HCP's role in supporting children and adolescents on ART is crucial; adherence can falter if the HCP lacks:

- » Knowledge and skills to offer *paediatric HIV care*
- » Knowledge about *ART and ART counselling skills*
- » *Psychosocial skills* to support children and caregivers to address the barriers to adherence
- » *Empathy:* negative or judgemental attitudes towards HIV-positive adolescents/children can undermine support for adherence

**ART drug factors:** Supply logistics and, especially in young children, palatability can make consistent adherence difficult:

- » Limited availability of once-daily and single-tablet (fixed-dose combinations) formulations for infants and children (up to 9 years), leading to a high pill burden
- » Limited choice of paediatric formulations, requiring use of syrups that are hard to dose correctly and administer properly
- » Poor taste of some medicines
- » Frequent dosing changes, which may confuse the caregiver and the child, possibly affecting adherence behaviour

**Health system factors:** Though treatment for adults has improved, many health systems are overburdened, and are not yet prepared to support adherence among children and adolescents. Limitations include:

- » Absence of child- or adolescent-friendly services, including age-appropriate counselling tools
- » Poor support for the transition of services from childhood to adolescence, or from adolescence to adulthood; this can make it difficult for adolescents to manage self-care or navigate the health care system, and could increase risk of unintended disclosure
- » Poor organisation of the care services, making it hard for the adolescent to access care, pick up medicines, access counselling and supportive services, or join psychosocial support groups
- » Stock outs of a drug entirely, or stock outs of a particular formulation, which may require regimen alteration and can lead to confusion
- » Understaffing or lack of HCPs trained in provision of counselling services which affects the quality of counselling offered to children/adolescents and their caretakers.

## BARRIERS SPECIFIC TO CHILDREN AND ADOLESCENTS

Infants, children, and adolescents can all experience barriers affecting their adherence to ART; and some of these factors may persist through childhood and into adolescents.

**Children:** A child's changing abilities and needs, both physical and emotional, create changing needs and challenges over time. Children who have been adherent to ART at younger ages may develop adherence problems as they grow into adolescence. Factors that may influence adherence among children include:

- » Being *young and dependent* on others for medication administration
- » *Refusing medicine* (especially in toddlers and pre-school children)
- » *Not understanding* the disease and need for treatment, due to their developmental age, and especially before disclosure in a child who feels well
- » *Difficulty swallowing* medicines and unpleasant taste to liquid formulations
- » *Stigma and discrimination* due to taking medicines routinely and failure to fit in with peers
- » *Growth and development delays* (for example, HIV-related encephalopathy may affect understanding of the need to take ART, or make taking medicine very complicated)
- » *Treatment fatigue*
- » *Denial* of HIV status and refusal to take ART

**Adolescents:** Adolescents living with HIV are especially vulnerable to specific adherence problems because of their psychosocial and cognitive developmental stage (Kim et al. 2014). They need comprehensive systems of care to serve their medical and psychosocial needs to avert suboptimal adherence to ART. Adolescents infected in their teen years may face different adherence barriers compared to those who were perinatally infected, so HCPs should consider these factors when addressing adherence and its barriers. Both the adolescent and his/her caregivers should participate in the plan to address barriers and secure adherence. It is important to remember that some of the barriers to adherence observed among adolescents may begin in childhood.

- » The adolescent's *growth and development stage* may affect their ability to appreciate the long-term importance of ART adherence—short-term priorities such as appearance, social/sexual relationships, and overall identity, may divert them from taking ART. Denial and fear of their HIV infection may also be a factor.
- » The adolescent may have *misinformation or limited knowledge* about HIV and treatment, especially in the absence of symptoms.
- » *Distrust of the medical establishment* (including providers and medicines, fear of ART, and lack of confidence in the effectiveness of medications) can impact adherence.
- » *Low self-esteem, stigma and discrimination.*
- » *Chaotic lifestyles, which can lead to inconsistent daily routine.*
- » *Medical complications, including advanced HIV disease, comorbid illness, and mood disorders.*
- » *Delayed development* (especially vertically infected adolescents), limiting patients' ability to fully understand treatment and adopt appropriate adherence behaviour.
- » *Negative peer influences* including alcohol and substance use may stop adolescents from taking ART.
- » *Changing lifestyle* (as part of adolescence), which can keep patients from conforming to a routine, including taking ART at scheduled times.
- » *Poor provider-adolescent relationships* may affect communication and follow-up of adherence plans.
- » *Food insecurity* may lead to missing ART doses.
- » *Sharing:* Some adolescents share ART with friends, resulting in insufficient medication.
- » *Visible side effects:* lipodystrophy (HIV-related changes in fat distribution), loss of hair, discoloration of the nails, and diarrhoea may cause considerable distress and lead to poor adherence.

## 9.5. ADHERENCE SUPPORT FOR CHILDREN AND ADOLESCENTS

HCPs should provide support for ART adherence both to children/adolescents living with HIV and their caregivers. Strategies to support adherence include easy-to-administer **ART regimens** tailored to the child or adolescent's lifestyle without compromising future treatment options; **patient-focused treatment plans** that accommodate specific needs like attending school; **counselling** to help integrate medication administration into daily routines; and **social and community support services** including peer support groups and community-based psychosocial support groups. Rather than offering a single intervention, it may be more effective

to offer multifaceted approaches that include regimen-related strategies; educational, behavioural, and supportive strategies focused on children, adolescents, and their families (including use of reminders); and strategies that focus on HCPs. There may be the need to implement directly observed therapy (DOT)<sup>5</sup> to improve adherence as well.

Research has identified approaches that help to provide patient appropriate counselling, individualised treatment plans, and social support to make adherence easier. There are five strategies that have demonstrated benefits in improving adherence for sustained viral suppression, these are:

## STRATEGY I. PROPER PRE-ART PREPARATION (INITIAL INTERVENTION STRATEGIES FOR THOSE INITIATING ART)

The main strategy for promoting medication adherence in children and adolescents is providing health education to both children/adolescents and their caregivers. Educating families about adherence should begin before or as soon as ART is initiated or changed, and should include a discussion of the goals of therapy, the reasons for making adherence a priority, and specific plans for supporting and maintaining a child's medication adherence. Caregiver education strategies should include providing both information and adherence strengthening tools. The initial preparation should provide patients and caregivers with full information on treatment course and strategies for coping—also mentioned in the ART section of **Chapter 2**. HCPs should:

- » Establish trust and identify mutually acceptable goals for care.
- » Obtain explicit agreement on the need for treatment adherence.
- » Educate the older child/adolescent and significant caregivers about the critical role of adherence in therapy outcomes, including the relationship between suboptimal adherence to ART resistance and the potential impact on future drug regimen choices.
- » Identify barriers to adherence—for example, depression, low self-esteem, substance abuse, or other mental health issues in the child/adolescent and/or caregiver—that may decrease adherence. Evaluate and initiate treatment for mental health issues before starting ART, if possible (refer to **Chapter 4**).
- » Identify support structures: for example, family, friends, health team members, and others who will support positive adherence behaviours.
- » Work with the patient and family to make specific plans for taking medications as prescribed and supporting adherence. For example:
  - Help them to arrange for administration medicine in day care, school, and other settings, when needed.
  - Consider home delivery of medications.
  - Develop a treatment plan that the patient and family understand, and to which they feel committed.
  - Schedule a home visit to review medications and determine how they will be administered at home.
- » Establish readiness to take medication through practice sessions or other means.

5 DOT (also called “directly administrated antiretroviral therapy,” or DAART) is an approach for administering medication in which a HCP is present to observe while the patient takes the medication (at home, in a community center, or in another location). Supervision may diminish over time as the patient learns proper self-administration.



## STRATEGY 2. ENGAGING PEER COUNSELLORS

Children and adolescents need their peers. HCPs should make every effort to ensure that adolescent patients have access to individuals or groups in their age range who understand their experience and can offer support and advice.

- » **Peer-led support/groups:** Older children, adolescents, and caregivers usually relate better to their peers. HIV-positive treatment adherent adolescents, expert patients, and caregivers can act as peer counsellors. They can support older children, adolescents, and caregivers to adopt behaviours that favour good adherence, which can improve adherence among children and adolescents. These peers can lead dialogues discussing challenges and barriers to adherence, and helping individuals come up with possible solutions.
- » **Treatment buddies:** A treatment buddy is an individual identified by the patient to take on the role of a treatment supporter. This person reminds/gives the patient their medication whenever it is time, and also reminds them of their refill dates.

## STRATEGY 3. TRAINING ON BEHAVIOURAL SKILLS AND MEDICATION ADHERENCE (ADOLESCENTS AND CAREGIVERS)

Training interventions are geared towards designing and following plans to address behaviours that impede adherence, like missing clinic appointments for drug refills, forgetting to take ART, drug fatigue, sharing medicines, or skipping doses due to study or work schedules. For example, HCPs should use health education to share information about the benefits of adhering to ART and help problem-solve adherence challenges. This training provides knowledge that can improve life skills, attitudes, and behaviours related to adherence plans, and can individually reinforce ART adherence over time and in different circumstances. Ultimately, the information can help adolescents adopt behaviours that support lifelong adherence.

## STRATEGY 4. USE OF REMINDER DEVICES

HCPs can help patients take ART regularly by recommending or providing personal reminder calendars, pillboxes, blister packaging, alarm clocks/watches /mobile phone alarms, and diaries for use by adolescents, older children, and their caregivers. Other reminders are sent through mobile phone alarms and SMS text message reminders. These should be used only with the adolescent's or caregiver's consent. The patient or caregiver should provide the appropriate phone numbers to avoid accidental disclosure.

## STRATEGY 5. MEDICATION STRATEGIES FOR CHILDREN AND ADOLESCENTS

ART regimens for children and adolescents often require taking multiple pills, some of which taste unpleasant, and others need to be taken as multiple daily doses. If they are available, HCPs should prescribe simplified ART regimens that can improve adherence. For example:

- » Use fixed-dose combinations and the simplest regimen possible, this reduces pill burden and dosing frequency.
- » When choosing a regimen, consider the patient's/family's daily and weekly routines/activities and variations.

- » Choose the most palatable medicine possible—for example lopinavir/ritonavir (LPV/r) pellets over the lopinavir/ritonavir syrup, if the child meets the appropriate weight and age criteria. (**Appendix VII** – Information and decision tool on LPV/r provides an example of how information can be used to make a decision on choosing an appropriate LPV/r formulation).
- » Choose drugs with the fewest side effects, and provide anticipatory guidance for management of side effects.
- » Simplify food requirements for medication administration.
- » Prescribe drugs carefully to avoid adverse drug–drug interactions.
- » Assess pill-swallowing capacity and offer pill-swallowing training and aids (pill-swallowing cup and pill glide).
- » Where possible provide medications where the pill size is appropriate for children.
- » Provide anticipatory guidance for missed doses (e.g., ask the child or adolescent, “What would you do if you forgot to take your medication before leaving for school?”).

## 9.6. PREPARING CHILDREN AND ADOLESCENTS FOR ART

This section describes the process of preparing children and adolescents as they start taking ART to ensure they adhere to their medications and attain good adherence all the time. The pre-ART assessment should examine and address medical, social, and behavioural factors that may influence adherence. It is important to obtain a patient’s explicit agreement with the treatment plan, including strategies to support adherence, the potential adverse effects of ARV drugs (e.g., nausea, headaches, and abdominal discomfort), and the importance of informing the clinical team if these occur. During a pre-ART assessment, a number of questions will likely arise (Table 9.1). When providing patient education for younger children, keep the language more simple. Focus on the most important points such as taking the medication daily to stay healthy. Slowly add more information as they become more developmentally able to understand more complex information.

**Table 9.1. Commonly Asked Questions about HIV and ART Adherence**

QUESTIONS	ANSWERS
<b>What does it mean to be HIV-positive?</b>	It means your body has HIV, a virus that causes AIDS.
<b>How does HIV affect my body?</b>	HIV destroys your body defence system (the CD4 cells,) leaving your body weak and unable to fight against infections/diseases.
<b>What are ARVs or ART?</b>	These are drugs that are used to help you stay healthy. There are several of them, and they work in different ways to stop the replication of HIV as a treatment plan.
<b>How does ART work in my body?</b>	It stops HIV from multiplying in the body.

QUESTIONS	ANSWERS
<p><b>What are the benefits of taking ART?</b></p>	<ul style="list-style-type: none"> <li>» ART stops the multiplication of HIV in the body.</li> <li>» When HIV does not multiply, the cells of the immune system are not destroyed, and this helps the body to fight opportunistic infections and reduces your risk of falling sick, so that you can keep going to school, working, or providing for yourself and your family.</li> <li>» You will grow and develop well, attend school, and achieve future dreams.</li> <li>» As a caregiver, when your child is well, you will be able to carry on with your other duties normally, and may save money on hospital bills.</li> <li>» Among those that are sexually active, the risk of transmitting HIV to your uninfected partners or baby (for pregnant or breastfeeding women) is also reduced.</li> </ul>
<p><b>When should an HIV-positive person start ART?</b></p>	<p>As soon as one is confirmed to be HIV-positive he/she qualifies to start ARVs. However, the HCP must make sure that the person starting ARVs is prepared to start ART, and will adhere to it as prescribed.</p>
<p><b>How much ART should the patient take daily and how often?</b></p>	<p>For ART to work well for you or the child you are looking after, you and the child (anyone who is HIV-positive) must take the correct dose. The dose is determined basing on the child/adolescent's weight. Each medication has a calculated dose and this dose should be taken as prescribed. Some medication is taken once a day, and others are taken twice a day.</p>
<p><b>What are some of the side effects of ART?</b></p>	<p>Different ART plans have different side effects but overall ART is well tolerated by most people. Common side effects include: severe anaemia, vomiting, skin rash, diarrhoea, nightmares, convulsions, hypersensitivity, and Steven Johnson's syndrome (severe skin rash). Always report anything making you unwell or uncomfortable that is related to taking ART to your HCP for management.</p>
<p><b>How can I know that I have side effects and what should I do?</b></p>	<ul style="list-style-type: none"> <li>» If you experience conditions that were discussed as side effects of the drugs given during the adherence counselling when you were starting ARTs, you should report to the HCP or the health facility that provided the treatment.</li> <li>» If you are far away from the health facility where you were prescribed the ART, you should go to the nearest health facility <i>along with your patient prescription book</i>.</li> <li>» If not sure of what to do, contact the expert patient in your area for support.</li> <li>» If possible, call the health facility telephone line for support.</li> </ul>
<p><b>How often should I return for HIV care?</b></p>	<ul style="list-style-type: none"> <li>» You should always return for care and monitoring as scheduled by your healthcare provider.</li> <li>» Return when you or the child you are looking after experience a side effect or a psychosocial challenge.</li> <li>» Return when you feel sick or the child you are looking after falls sick, e.g., when you have malaria.</li> </ul>

QUESTIONS	ANSWERS
<b>Why should I start ART when I don't feel sick?</b>	<ul style="list-style-type: none"> <li>» HIV harms you on the inside even when it not seen on the outside. It destroys cells that help your body fight diseases. It is good for you to start ART as soon as you are diagnosed to stop HIV from multiplying and destroying your immune system.</li> <li>» Starting ART early helps to prevent TB, heart disease, HIV-related cancer, and other infections that may occur if one's immunity is low.</li> </ul>
<b>What are the benefits of adhering to ART?</b>	It maintains the right amount of ART in your body to effectively stop HIV from multiplying and developing drug-resistant forms of HIV.
<b>What are the consequences of not adhering to ART?</b>	<p>The amount of ART in your body will decrease, and HIV will multiply and increase in your body, and as a result:</p> <ul style="list-style-type: none"> <li>» The virus will continue to destroy your immune system and decrease the CD4 count.</li> <li>» When the CD4 count is low, you will be prone to opportunistic infections, and you will develop more severe disease.</li> <li>» The virus in your body may also become resistant to ARVs and you will have limited options for treatment and require more costly ARVs for your treatment which may not be readily available in the country.</li> <li>» You will become less productive and may not meet your life goals and future dreams.</li> <li>» You may start getting the life-threatening condition of AIDS, which leads to death.</li> <li>» If you are pregnant or breastfeeding, the chance of transmitting HIV to your unborn or breastfeeding child is increased.</li> </ul>

## Preparing children for ART

When children start ART, the following approaches can be useful to ensure good adherence:

- » Closely link their care services to adult services using family-centred approaches.
- » Start the disclosure process early and ensure that it is complete by 12 years of age.

## Preparing adolescents for ART

Adolescents should be supported to understand why they must take and adhere to ART, especially when they are asymptomatic. HCPs should discuss the risks of delaying ART and the benefits of starting it. They should emphasise that failure to adhere to ART may result in the loss of available regimen options in the future, due to development of resistant HIV mutations.

- » HCPs need to consider the environment where the adolescent stays and the potential support systems to facilitate adherence.
- » Where appropriate, adolescents may benefit from the reminder systems such as phone apps, beepers, timers, and pillboxes, and DOT for those experiencing excessive stigma.

## SUGGESTIONS FOR SUPPORTING ADOLESCENTS TO ENSURE SUSTAINED GOOD ADHERENCE TO ART

- » Build a strong adolescent-provider relationship (see **Chapter 6** on counselling).
- » Customise the treatment regimen to the individual adolescent's lifestyle in alignment with national guidelines.
- » Manage any co-existing medical conditions, such as mental illnesses (see **Chapter 4**) and addressing stigma that 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. For example, use an adherence-testing period in which the adherence to other medical recommendations or treatments for other medical conditions is assessed.
- » Empower the adolescent to deal with adherence challenges and use motivational enhancement approaches (refer to **Chapter 6** on counselling and communication).
- » 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 autonomy, to avoid creating a break in positive adherence behaviour (refer to **Chapter 10** on transition).

These interventions should be tailored to each adolescent and should be made carefully and in context with the adolescent's clinical status. Periodically (e.g., every 6 months), the HCP should assess for barriers using the HEEDSSS tool (**Appendix III**);<sup>6</sup> and follow the 5 As (Assess, Advise, Assist, Agree upon, Arrange, see Table 9.4) to address them.

## HANDLING AND STORAGE OF MEDICATIONS AT HOME

ART, like many other medicines, can be destroyed by too much heat, cold, light, or water. It should be kept in the original containers or blister packs to protect it from those conditions; otherwise, the drugs can lose their potency.

Caregivers and adolescents should avoid mixing their ART tablets with other medicines in the same container—for example, do not keep tenofovir/lamivudine/efavirez (TDF/3TC/EFV) and cotrimoxazole (Septrin/Bactrim) in the same container. In addition, if ART is not dispensed as fixed-drug combinations, the drugs should not be mixed and stored in the same container; for example, do not keep single-tablet nevirapine (NVP) with a duo-fixed combination tablet of AZT/3TC.

Encourage caregivers to keep the medicines where they can be accessed by those involved in the care of the child/adolescent but out of reach of young children. All the medicine bottles should be clearly labelled with the names of the drug and the instructions for use; and with the name of

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<sup>6</sup> The Home, Education, Eating, Activities, Drugs, Sexuality, Suicide/Depression, and Safety tool, or HEEDSSS, is a structured screening tool to assess the risks that adolescents face, starting with less sensitive topics and progressing to more personal ones.

the individual, especially if several people in the household are on ART. Encourage caregivers and adolescents, especially those in school, to keep information leaflets on the medications with each medicine container, because each leaflet contains special instructions on use and storage of the medicines. Most of medicine containers have desiccants, and caregivers and adolescents should be encouraged to keep the desiccants within the containers, because they protect the medicines from spoilage, especially by cold and water. HCPs should clearly state that desiccants are not medicines, and should not be taken internally.

## 9.7. ROLE OF THE HCP IN ART ADHERENCE: BEST PRACTICES

The process of supporting children, adolescents, and their caregivers to adopt behaviours that reinforce good adherence needs to begin early in a provider's relationship with the family. Some HCP actions that have been associated with improved adherence include:

- » Consistently giving information and support to ensure adherence.
- » Avoiding use of rewards to enhance adherence, especially among children; instead one should reinforce and applaud positive behaviours.
- » Allowing time for questions and clarification from the children, adolescents, and their caregivers.
- » Having technical expertise in counselling and communication to deliver the information and offer PSS.
- » Committing to following up on the mutually agreed-upon and acceptable goals of care.
- » Creating a health care setting that is child- or adolescent-friendly and -responsive.
- » Involving caregivers in adherence support activities.
- » Providing adherence support using a comprehensive multidisciplinary care (e.g., with nurses, case managers, pharmacists, social workers, psychiatric care providers) to take care of children, adolescents, caregivers, and families with complex needs and barriers to adherence.
- » Maintaining a non-judgemental attitude and establishing trust with children, adolescents, caregivers, and their families.
- » Easing ART provision by using several services delivery models as indicated—like fast-tracking stable patients, facilitating community delivery of ART, and ensuring availability of ART regimens that are simple to take.

### DETERMINING READINESS FOR ART

Proper counselling and education before ART initiation and during ART provision is vital for good adherence. While preparing children and adolescents for ART, HCPs should look for the following components of readiness:

- » The extent of disclosure (non-disclosure, partial or complete) and extent that the child/adolescent accepts their HIV-positive status. There should be a documented disclosure plan for those children and adolescents who have not been fully disclosed to.

- » Patient/caregiver understanding and knowledge of HIV, ART, and adherence.
- » Patient commitment/consent to taking lifelong therapy.
- » Patient demonstrates willingness to keep clinic appointments.
- » Patient has adherence support (treatment buddy, treatment supporter, other social support structure).
- » For children, a committed primary caregiver has been identified and counselled.
- » Patient/caregiver has an adherence plan.

Assessing these components can guide the process of making an adherence plan. The tools below can be used to further assess readiness (Table 9.2) and develop an adherence plan (Table 9.3).

**Table 9.2. Assessment for ART Readiness**

	YES	NO	COMMENT
<b>A. Psychosocial/knowledge criteria (applies to patients and caregivers)</b>			
1. Understands how HIV affects the body and benefits of ART			
2. Has screened negative for alcohol or other drug use disorder			
3. Is willing to disclose/has disclosed HIV status to a sexual partner and significant other			
4. Has received demonstration of how to take/administer ART and other prescribed medication			
5. Has received information on predictable side effects of ART and understands what steps to take in case of these side effects			
6. For patients dependent on a caregiver: caregiver is committed to long-term support of the patient, daily administration of ART, and meets the criteria above			
7. Other likely barriers to adherence have been identified, and there is a plan in place to address them (e.g., frequent travel for work, plan to deal with unexpected travel, distance from clinic, etc.)			
8. Patient/caregiver has provided address and contact details			
9. Patient/caregiver feels ready to start ART today			
<b>B. Support systems criteria (applies to patients and caregivers)</b>			
10. Has identified convenient time/s of the day for taking ART			
11. Treatment supporter has been identified and engaged in HIV education, or will attend next counselling session			
12. Is aware of the support group meeting time/s			
13. If the facility has SMS reminder system: Has enrolled into SMS reminder system			

	YES	NO	COMMENT
14. Other support systems are in place or planned (e.g., setting phone alarm, pill box)			

**C. Medical criteria (Applies to some countries)**

15. Patient newly diagnosed with TB: Refer to national guidelines			
16. Patient diagnosed with cryptococcal meningitis or has symptoms consistent with cryptococcal meningitis (headache, the presence of seizures, altered consciousness, photophobia and neck stiffness) Refer to national guidelines			

*The only absolute criteria for differing ART is yes to question 15 and 16 (in some countries)*

*If the response to any question in Section A or B is “No”: develop a strategy to address the issue as quickly as possible, and consider assigning an expert patient to follow-up. ART may be initiated with adequate adherence support while the criteria are being addressed, or ART may be deferred until the criteria are met, on a case-by-case basis.*

*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](http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf).*

**Table 9.3. Making an Adherence Plan: Ten Guiding Questions for Developing an Adherence Plan**

QUESTIONS	PATIENT/CAREGIVER RESPONSE
1. How many pills of the medicine will you take/give per day? (patient demonstrates as you observe)	
2. What time will you take/give the medicine?	
3. How will you remember to take/give the medicine?	
4. Where will you keep the medicine?	
5. What will motivate you to take/give the medicine?	
6. Who have you disclosed to/plan to disclose to?	
7. Who is your or your child’s treatment buddy?	
8. Who will pick your/your child’s medicine if you cannot come to the clinic?	
9. How will you ensure you keep your appointments as scheduled?	
10. What challenges/factor may affect your adherence (explore for non-disclosure, alcohol and substance abuse, sexual partner/s, and stigma)?	



## USING THE 5 AS TO GUIDE THE DELIVERY OF PRE-ART ADHERENCE COUNSELLING

HCPs should provide information on the risks associated with delaying ART. Particularly focus should be on individuals at risk for negative consequences if they delay ART. This includes infants, children, and adolescents with TB; those with advanced immunosuppression and those who are at high risk of death; and those at an increased risk of transmitting HIV to others, especially pregnant and breastfeeding adolescents and those in HIV-serodiscordant relations. The health care team should use the “5 As” principle (**A**ssess, **A**dvice, **A**gree, **A**ssist, and **A**rrange; see Table 9.4) for chronic care as a guide to offer pre-ART adherence counselling.

**Table 9.4. Guidance on Use of the 5 As for Adherence Preparation Support**

GUIDE	COMPONENTS
<p><b>Assess</b></p>	<p><b>Goal: To assess knowledge of HIV, ART and potential barriers to adherence:</b></p> <ul style="list-style-type: none"> <li>» Knowledge about HIV and ART</li> <li>» Identify myths and misconceptions about HIV and ART</li> <li>» Potential barriers to adherence</li> <li>» Psychosocial concerns and needs that may hinder adherence to ART</li> <li>» Willingness and commitment to take medicines correctly</li> <li>» Readiness to honour subsequent appointments for treatment support</li> <li>» Availability of support systems at family and community level</li> <li>» Disclosure status and implications</li> </ul>
<p><b>Advise (information giving)</b></p>	<p><b>Goal: To provide knowledge about HIV and ART:</b></p> <ul style="list-style-type: none"> <li>» How ART stops the multiplication of HIV</li> <li>» Provide information on adherence to ART; include information on the 5 R's: (taking the right medicine, at the right time, in the right dose, the right way, and the right frequency)</li> <li>» Demonstrate how ART is taken</li> <li>» 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</li> <li>» Describe benefits of disclosure and support systems to adherence</li> <li>» 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</li> <li>» Emphasise the importance of attending all the clinic appointments for review and support</li> <li>» Discuss the Positive Health Dignity and Prevention package (<b>Appendix IV</b>)</li> <li>» Describe the risks associated with not adhering to treatment</li> <li>» Explain what the viral load test is, and the meaning of suppressed and unsuppressed viral load</li> </ul>

GUIDE	COMPONENTS
<b>Assist</b>	<p><b>Goal: To help the adolescent and or caregiver to:</b></p> <ul style="list-style-type: none"> <li>» Evaluate the possible barriers to adherence and how to overcome them</li> <li>» 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</li> <li>» Disclose to a trusted person of their choice such as a treatment supporter, social support group, etc.</li> <li>» Develop an individual adherence support plan</li> <li>» Document the agreed-upon options on the ART card</li> </ul>
<b>Agree on</b>	<p><b>Goal: To create a working adherence plan:</b></p> <ul style="list-style-type: none"> <li>» Develop an adherence plan</li> <li>» Identify family and community support systems (such as an expert patient in the community)</li> <li>» Plan for future possible home visit and consent</li> <li>» Explore possibility of testing other family members, including sexual partner and children</li> <li>» Clarify child/adolescent 's readiness to start ART</li> </ul>
<b>Arrange</b>	<p><b>Goal: Arrange the patient to see a clinician for ART prescription:</b></p> <ul style="list-style-type: none"> <li>» Schedule follow-up adherence counselling and psychosocial support sessions: <ul style="list-style-type: none"> <li>• At 1 month for patients who have initiated ART</li> <li>• At agreed time, but probably a week, for those who were not ready for ART at the initial visit</li> </ul> </li> <li>» Plan for patient to join PSS groups and use support systems</li> <li>» Follow-up appointment system (home visiting where appropriate, phone call reminders and text messages where appropriate)</li> <li>» Schedule monthly counselling sessions for drug adherence</li> <li>» Review the action plans at every encounter</li> <li>» Plan when to bring other family members for testing</li> <li>» Support disclosure where it has not happened</li> </ul>

## 9.8. ASSESSING ART ADHERENCE

Adherence assessment should be done at all clinic visits using a mixture of adherence assessment methods.

### METHODS USED FOR MONITORING ADHERENCE TO ART IN CLINICAL SETTINGS

#### Self-Report

Self-reporting of missed ART doses is quick, inexpensive, and easily carried out in clinical settings. Self-reporting entails asking questions regarding missed doses to establish adherence levels (Table

9.5). Remember to pose questions assessing missed doses in a non-threatening, sensitive way and to encourage older children and adolescents to speak openly. When using self-reporting to assess adherence, the guiding questions below can be used. These questions may help an HCP to *elicit knowledge* of the medication regimen, number of tablets to be taken, frequency of medications, and also identify any barriers or enhancers to good adherence. They may also help *engage* the adolescent and/or caregiver in discussion about facilitators and challenges to adherence, thus improving the adherence plan.

## USING SELF-REPORT TO DETERMINE ADHERENCE LEVELS: THE STEPS

- » Ask questions below.
- » Compute the self-report % adherence using the formula below.  

$$\% \text{ adherence} = \frac{(\text{No. of tablets taken per day as reported by client})}{(\text{Prescribed no. of tablets per day as on label})} \times 100$$
- » After computing % self-report adherence, compare with pill-count percentage and determine the adherence level (see Table 9.6) and support the patient accordingly. The adherence level is then determined with an action plan.

**Table 9.5. 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?	

\*[**Note:** These questions should be asked in a non-judgemental and non-stigmatising manner.]

### Pill Count

Pill counts are conducted through home visits or during clinic visits. Approaches include asking patients to bring medications to clinic for counting, or during home visits. Following the pill count, the HCP should calculate the adherence level. This approach compares the actual number of pills taken with the expected number that should have been taken over a given period. The effectiveness of pill counting as a method of adherence assessment is limited by the fact that patients may discard tablets not taken before their routine clinic visit, leading to an overestimated adherence level. Pill count performs better when combined with self-reported adherence.

## USING PILL COUNTS TO DETERMINE ADHERENCE LEVELS: THE STEPS

- » 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 pill count % adherence using the formula below.
 
$$\% \text{ adherence} = \frac{(\text{quantity dispensed}) - (\text{quantity remaining})}{(\text{prescribed no. of tablets per day}) \times (\text{No. days between dispensing and interview})} \times 100$$
- After computing % pill-count adherence, compare with self-report and determine the adherence level (see Table 9.6) and support the patient accordingly. The adherence level is then determined with an action plan.

**Table 9.6. Recommending Action Plan Based on Adherence Levels from Self-Report & Pill Count**

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.
≥5 doses	≥9 doses	<85 percent	Poor	

### Pharmacy Refill/Clinic Records

Providers can also assess a patient’s adherence by viewing their clinic and pharmacy records. Such records document if and when a patient or caregiver collected their ART. Irregular collection may indicate adherence challenges. Additionally, computerised pharmacy records help caregivers to assess the overall adherence. Pharmacy records are more reliable than self-reporting if documentation is accurate, and are already a part of the national monitoring and evaluation framework.

Under some circumstances, when assessing adherence is difficult, it may be useful to take targeted approaches: for example, using DOT; having the patient briefly hospitalised; or measuring blood drug concentration levels.

In research settings, more sophisticated approaches are possible, such as measuring drug concentration levels in hair; using electronic monitoring devices; using Medication Event Monitoring System [MEMS] caps (which record the number of times a bottle is opened) or Wisepill, which uses chip-based messages; mobile phone-based technologies; or interactive voice response/SMS text messaging.

## HCPs AND GOOD ADHERENCE

HCPs can support interventions that help children, adolescents, and caregivers adopt behaviours for good adherence. The HCP should carry out as many of these supportive actions as is feasible:

- » Have a member of the multidisciplinary team monitor and support adherence at each visit. If possible, have the same HCP support the adherence in order to build trust/rapport with the individual.
- » Provide follow-up in between clinic visits by telephone, home visits, email, SMS text, and social media, as needed and appropriate, to support and assess adherence.
- » Provide ongoing support, encouragement, and understanding of the difficulties associated with maintaining adherence to daily medication regimens.
- » Encourage use of pillboxes, reminders, alarms, and timers, calendars and stickers for health education and adherence.
- » Provide access to support groups, peer groups, or one-on-one counselling for caregivers, children and adolescents especially for those with factors known to decrease adherence, for example, depression, drug abuse.
- » Provide pharmacist-based adherence support, such as medication education and counselling, blister packs, refill reminders, automatic refills, and home delivery of medications.
- » Consider DOT approaches in selected circumstances such as a brief inpatient hospitalisation.
- » Always document adherence support assessment, interventions and results, and track agreed-upon action plans.
- » Have differentiated service delivery models for patients at different levels of adherence.

## INTENSIVE ADHERENCE COUNSELLING FOR CHILDREN AND ADOLESCENTS WITH POOR ADHERENCE

Caregivers of children and adolescents with unsuppressed viral loads, and those switching or substituting an ART regimen, need to be offered intensive adherence counselling. Intensive adherence counselling helps the caregiver and adolescent develop a comprehensive plan for adhering to ART and address issues which led to poor adherence. This intervention uses the 5 As approach (Table 9.7) to identify possible barriers to adherence, gain insights into barriers and explore ways to overcome them, and make a plan to adhere to ART. Like routine adherence counselling, intensive adherence counselling also requires a multidisciplinary team including clinicians, nurses, counsellors, family members and peers, who also work with older children and adolescents to develop the adherence plan. Poor adherence may require further consultations from experts or referrals to address particular challenges with stigma, disclosure, and nutrition.

**Table 9.7. Using the 5 As to Support Children/Adolescents with Unsuppressed Viral Loads**

GUIDE	COMPONENTS
<b>Assess</b>	<ul style="list-style-type: none"> <li>» Past adherence history (including past ART use, PMTCT exposure, etc.)</li> <li>» Child, adolescent and caregiver psychosocial concerns and needs</li> <li>» Willingness and commitment to take medicines correctly</li> <li>» Alcohol use or any herbal/traditional medications or prescribed medications that may interfere with ART</li> <li>» Understanding of the implications of an unsuppressed viral load</li> <li>» The barriers to ART adherence</li> <li>» Readiness to receive comprehensive counselling on a monthly basis</li> <li>» Psychological state in the past two weeks (using the HEEADSSS tool) (<b>Appendix III</b>)</li> </ul>
<b>Advise (information giving)</b>	<ul style="list-style-type: none"> <li>» Explain what a viral load test is and the results</li> <li>» Unsuppressed viral load means:               <ul style="list-style-type: none"> <li>• Either ART is not as effective as it should be, or the patient is not taking medicine correctly</li> <li>• The amount of virus in the patient’s blood is high and is going to destroy their CD4 cells quickly, reducing their protection from infections</li> </ul> </li> <li>» Emphasise that the patient will receive adherence counselling sessions according to the national guidelines and provide them with the expected schedule. A repeat viral load will be taken according to the national guidelines</li> <li>» Discuss positive health, dignity, and prevention<sup>5</sup> package (<b>Appendix IV</b>)</li> </ul>
<b>Assist</b>	<p>Assist the child/adolescent so that they can:</p> <ul style="list-style-type: none"> <li>» Disclose to a trusted person of their own and significant other for psychosocial support</li> <li>» Evaluate the possible underlying causes of the unsuppressed viral load</li> <li>» Develop an adherence plan that responds to their adherence barriers</li> <li>» Identify support systems that will enable them to take their medicines as prescribed and keep appointments for drug refills, such as a treatment supporter/buddy, peer support groups, family members, or community-based organisations</li> </ul>
<b>Agree on</b>	<ul style="list-style-type: none"> <li>» An action plan on how to ensure good adherence to achieve viral suppression including               <ul style="list-style-type: none"> <li>• Developing an adherence plan</li> <li>• Linking to support systems to help the patient implement the agreed action plan</li> </ul> </li> </ul> <p><b>[Note: Support the choices and help them own the action plan]</b></p>
<b>Arrange</b>	<p>Arrange for follow-up intensive adherence counselling and psychosocial support sessions. Emphasise that the patient will receive adherence counselling sessions monthly for at least 3 or more months consecutive months with good adherence after which a repeat viral load test will be done to determine if the current ART regimen is still effective or needs to be changed.</p> <p>The following are the actions to be followed</p> <ul style="list-style-type: none"> <li>» Joining psychosocial support groups and other support systems</li> <li>» Home visiting</li> <li>» Phone call reminders</li> <li>» Monthly counselling sessions targeting drug adherence</li> <li>» Follow up the PHDP Care Package for PLHIV</li> <li>» Review the action plans at every encounter</li> <li>» Document the actions agreed upon</li> </ul>

7 The PHDP approach is a holistic, rights-based strategy for HIV prevention, treatment, support, and care. For more information, see <https://www.gnppplus.net/resources/positive-health-dignity-and-prevention-operational-guidelines/>

## 9.9. GENDER AND ADHERENCE

Gender differences have been reported with regard to ART adherence. Studies have shown that among children on ART, males have better adherence than females. A possible explanation for this could be the gender roles that female and male adolescents play. For example, in some African settings the female adolescent is more likely to be involved in household chores than the male; depending how regular this is in a home, such an adolescent may not have time to attend clinic visits, let alone remember to take her medications. Also, the female adolescent is more likely to enter an early marriage, possibly with an older male, and the demands of a family on such a young mind will likely affect her adherence to ART.



**CHAPTER 10.**  
**ADOLESCENT SEXUAL  
AND REPRODUCTIVE  
HEALTH SERVICES**



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## SUMMARY

- » The sexual and reproductive health (SRH) needs of adolescents are often ignored by HCPs due to social norms that stigmatise adolescent sexual activity, especially for girls; mistaken assumptions that adolescents are not sexually active; and discomfort discussing sexual activity and related topics.
  - » HIV-positive adolescents have emerging SRH needs that HCPs must address to reduce these patients' health vulnerabilities and reduce onward transmission of HIV.
  - » Contraception is an important, though complex, component of comprehensive HIV care, since unplanned pregnancy can cause social, financial, and physical problems for adolescents, especially those living with HIV.
  - » SRH services should be adolescent-friendly and include accurate SRH information, sensitive and non-judgemental counselling, prevention and treatment of STIs, and access to modern contraception and pre- and postnatal care and delivery.
  - » Adolescent pregnant girls are less likely to seek maternal services and are more likely to experience poor pregnancy and birth outcomes, for themselves and their baby, when compared to older women.
  - » Adolescents should understand that the condom (male and female) is the **only** form of contraception that also protects the user and partner from STIs, including HIV.
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## 10.0. 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.

In many countries in sub-Saharan Africa, a sizeable minority of adolescents become sexually active before age of 15 years, demonstrating the need for appropriate SRH interventions to target young people before that age. Late adolescence (15–19 years) is particularly important, since sexual debut and experimentation often take place during this period (MacQuarrie, Mallick, and Allen 2017). Providing support during this critical development period includes scientifically accurate SRH information, sensitive non-judgemental counselling, prevention and treatment of STIs, and access to modern contraception and pre- and postnatal care and delivery. SRH services must be acceptable to adolescents, and also be delivered in an environment that respects their rights to confidentiality, privacy, and informed consent (World Health Organization 2016). To address SRH optimally, adolescents need to be aware of their HIV status.

Social roles and expectations change during adolescence, as many adolescents begin to transition from going to school, working, or taking care of a household. Gender roles become more prominent, and gaps in opportunities for school, livelihood, and well-being between boys and girls begin to widen. This widening gap put girls at higher risk of violence and STIs, including HIV. Risk factors for adolescents to engage in early sexual activity (< age 18) are alcohol use, peer pressure, or attending gatherings without a parent/guardian present. Some girls are forced into early sex by relatives. Girls, who experience a higher risk of contracting HIV during adolescence, typically start having sex earlier than boys, who initiate sexual activity around 20 years of age. Girls who live in poverty are more likely to practice transactional sex and engage in age-disparate relationships with older men, heightening the risk of HIV acquisition.

HCPs should engage in routine two-way discussions about SRH with children, adolescents, and their caregivers beginning at a young age (for a guide to beginning such discussions, see Tables 10.1 and 10.2 below). Over time, this approach increases the comfort levels of HCPs, children and adolescents, and caregivers with SRH. It also increases the likelihood that the adolescent will have the required knowledge and skills to access modern contraception, including use of dual protection (see definition below), prior to sexual debut. HCPs should use a range of materials for education: printed materials, videos, and social media and combine education interventions with prevention products (e.g., condoms) and gender empowerment interventions.<sup>8</sup> HCPs should review educational materials with the adolescent to improve understanding and allow opportunities for questions. Adolescents should be encouraged and given time to raise any questions or concerns they may have, or to obtain further information and products, if needed.

## 10.1. DEFINITION OF TERMS

**Gender:** The socially constructed roles, behaviours, activities and attributes that a particular society considers appropriate for men and women.

8 [http://www.who.int/reproductivehealth/topics/linkages/WHO\\_Meeting\\_Rpt\\_HIV\\_Prevention\\_AGYW.pdf](http://www.who.int/reproductivehealth/topics/linkages/WHO_Meeting_Rpt_HIV_Prevention_AGYW.pdf)

**Intimacy:** Sharing thoughts or feelings in a close relationship, with or without physical closeness

**Love:** Feelings of affection and how we express those feelings for others.

**Relationships:** The ways we interact with others and express our feelings for others.

**Sex:** The biological state of being male or female.

**Sexuality:** Includes all the feelings, thoughts, and behaviours of being female or male, including being attractive, being in love, and being in relationships that includes sexual intimacy and physical sexual activity. Sexuality emerges during adolescence, and for many adolescents this is the time of initiation of sexual activity.

**Sexual arousal:** Physiologic changes that occur within the body in anticipation of sexual activity.

## 10.2. UNIQUE SRH NEEDS OF ADOLESCENTS LIVING WITH HIV

Adolescents living with HIV have unique SRH needs, including treatment and support to reduce the risk of HIV transmission to their unborn children and infants and to their sexual partners. Just like their HIV-negative peers, they also require access to a range of modern contraception services. Adolescents living with HIV are frequently stigmatised for their SRH choices by the community as well as some HCPs—and stigma within the health care system has been shown to be one of the most destructive experiences for PLHIV. HCPs should support adolescents' SRH needs, including their right make decisions regarding sex, becoming pregnant, and breastfeeding. Adolescent-friendly antenatal care and maternal health services should also be provided. To provide adolescent-friendly antenatal and maternal health services, HCP need to observe the global standards for improving the quality of health care services shown in Box 10.1.

## 10.3. SEXUAL AND REPRODUCTIVE HEALTH (SRH)

Adolescents living with HIV have a right to make their own SRH decisions. They should be given access to contraception and an opportunity to decide the number, spacing, and timing of their children freely and responsibly, and should have the means to do so in line with local laws, customs and cultural contexts. SRH services should also safeguard adolescents' rights to privacy, confidentiality, and informed consent, and should respect local cultural and religious customs while also conforming to national and international agreements.

HCPs should emphasise to the adolescent and their family the role of education and health literacy in improving their health outcomes over a lifetime. They should provide SRH information that is consistent with children and adolescents' evolving needs and capacities, to strengthen their capacity to make informed decisions about their health and well-being. They need to understand their rights and they must also be educated on laws about defilement, rape, abortion, among others, so that they can recognise and report inappropriate and illegal sexual violence and understand their pregnancy options and rights, if needed.

## BOX 10.1. GLOBAL STANDARDS FOR IMPROVING THE QUALITY OF HEALTH CARE SERVICES FOR ADOLESCENTS

### **Standard 1:** Adolescents' health literacy

The health facility implements systems to ensure that adolescents are knowledgeable about their own health and know where and when to obtain health services

### **Standard 2:** Community support

The health facility implements systems to ensure that parents, guardians, and other community members and community organisations recognise the value of providing health services to adolescents and support such provision and the utilisation of services by adolescents

### **Standard 3:** Appropriate package of services

The health facility provides a package of information, counselling, diagnostic, treatment, and care services that fulfil the needs of all adolescents.<sup>6</sup> Services are provided in the facility and through referral linkages and outreach

### **Standard 4:** Providers' competencies

Healthcare providers demonstrate the technical competence required to provide effective healthcare services to adolescents. Healthcare providers and support staff respect, protect and fulfill adolescents' rights to information, privacy, confidentiality, non-discrimination, non-judgemental attitude and respect

### **Standard 5:** Facility characteristics

The health facility has convenient operating hours, a welcoming and clean environment, and maintains privacy and confidentiality. It has the equipment, medicines, supplies and technology needed to ensure effective service provision to adolescents

### **Standard 6:** Equity and non-discrimination

The health facility provides quality services to all adolescents irrespective of their ability to pay, their age, gender, marital status, education level, ethnic origin, sexual orientation, or other characteristics

### **Standard 7:** Data and quality improvement

The health facility collects analyses and uses data on service utilisation and quality of care, disaggregated by age and gender to support quality improvement. Health facility staffs are supported to participate in continuous quality improvement

### **Standard 8:** Adolescents' participation

Adolescents are involved in the planning, monitoring and evaluation of health services and decisions regarding their own care, as well as in certain appropriate aspects of service provision

9 WHO/UNAIDS. Global Standards for Quality Health Care Services for Adolescents. A Guide to Implement a Standards-driven Approach to Improve the Quality of Health Care Services for Adolescents. Vol. I: Standards and Criteria. Geneva: WHO, 2015. Available at: [http://www.who.int/maternal\\_child\\_adolescent/documents/global-standards-adolescent-care/en](http://www.who.int/maternal_child_adolescent/documents/global-standards-adolescent-care/en)

## 10.4. GENDER DIFFERENCES REGARDING SRH NEEDS

Specific SRH problems for adolescent girls include sexual violence and abuse, unplanned pregnancy, intimate partner violence, unsafe abortions, STIs, and complications of childbirth. Adolescent boys may be also experience sexual violence and abuse, or contract STIs. Thus it is critical to start SRH education early in life, with special attention to encouraging health-enhancing behaviours in a gender-sensitive manner.<sup>10</sup> Children as young as in nursery school should be taught about inappropriate touching from adults. For older children, HCPs should provide gender-responsive, age-appropriate SRH—e.g., education about menstruation for girls, body changes associated with puberty for both boys and girls. Because children and adolescents may feel shy and be too scared to ask questions about their SRH needs. HCPs should initiate the discussions, using a non-judgemental approach while working to support socially constructed roles for males and females—such as the African custom of having same-sex adult relatives (commonly uncles and aunts) provide sex education.

## 10.5. NORMAL SEXUAL MATURITY AND RELATIONSHIPS IN ADOLESCENCE

HCPs should tailor adolescent SRH services based on sexual activity status. The period between 10 and 14 years of age (early adolescence) is characterised by initial physical changes and rapid brain development. Note that in some children, normal puberty may start as early as age 8 years in girls and 9 years in boys (precocious puberty is defined as signs of puberty before age 8 in girls and before age 9 in boys). Since changes that take place during puberty generally take 2-5 years to complete, HCPs should not expect that because secondary sex characteristics have reached adult maturation an adolescent's cognitive, emotional, and behavioural development has also reached adulthood. Some adolescents may be physically, cognitively, emotionally, and behaviourally more like children than adults. Middle adolescence, 15–16 years, is a time when sexual orientation progressively develops. In older adolescence, 17–19 years, adolescents may look and act like adults, but may not have reached cognitive, behavioural and emotional maturity. Though these are the normal patterns, HCPs should not make assumptions about sexual activity based upon age or physical development. While an adolescent aged 10–14 may seem immature, this does not exclude them from having sex. Additionally, some adolescents with perinatally acquired HIV may experience delayed puberty, which may also exacerbate feelings of isolation and stigma as they may wish to look like their peers. HCPs should always ask about current sexual activity and plans to become sexually active.

Globally adolescent girls aged 15–19 years account for one-fifth of all girls and women of reproductive age. These girls are less likely to access maternal health services compared to older women, particularly if they had premarital sex or the pregnancy was unplanned. In the poorest regions of the world, roughly one in three girls has children by the age of 18. These adolescents are at higher risk of maternal death than any other sub-population (World Health Organization 2018b). The risk of pregnancy-related death is twice as high for girls aged 15–19 years and five times higher for girls aged 10–14 years compared to women aged 20–29 years (Women's Refugee Commission n.d.). Complications from pregnancy and childbirth are the leading cause of death among girls 15–19 years in

10 [http://www.who.int/reproductivehealth/topics/linkages/WHO\\_Meeting\\_Rpt\\_HIV\\_Prevention\\_AGYW.pdf](http://www.who.int/reproductivehealth/topics/linkages/WHO_Meeting_Rpt_HIV_Prevention_AGYW.pdf)

low- and middle-income countries. Adolescent girls and young women aged 15–24 years account for about 40 percent of all unsafe abortions worldwide.

The adverse effects of adolescent childbearing extend to their infants. Stillbirths and newborn deaths are 50 percent higher among infants of adolescent mothers than among infants of women aged 20–29 years. Newborns of adolescent mothers are also more likely to be low birthweight, with accompanying risk of long-term effects, such as malnutrition in infancy (World Health Organization 2018b).

## 10.6. THE ROLE OF THE HCP IN ADOLESCENT SRH

Given the many risk factors of adolescents living with HIV, especially girls, it is doubly important for HCPs to provide adolescent-friendly, individualised, non-judgemental, and, ideally, integrated SRH services. Such integrated services increase efficiencies and save time and resources for adolescents. As part of SRH services, HCPs should motivate adolescents to actively plan if and when they choose to have children, to make healthy decisions if they are thinking about becoming or are pregnant, and to use dual protection to protect against pregnancy (if desired), STIs, and HIV transmission. The tool in Table 10.1 provides information to assess adolescents' SRH needs and prompts HCPs to provide appropriate counselling. Information gathered from the assessment and counselling should be used to make an appropriate action plan for service delivery.

**Table 10.1. SRH Needs Assessment and Counselling Tool**

### QUESTIONS AND DISCUSSION TOPICS

Have you thought about having children one day?  
*Explain the basics of mother-to-child transmission.*

What do you think is a good age to start a family?  
*Discuss the physical (health) risks of adolescent pregnancy.*

What contraception methods to control the timing of pregnancy have you heard of?  
*Provide an overview of family planning methods and options.*

Have you used any of these contraception 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 contraception 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.*

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.*

## QUESTIONS AND DISCUSSION TOPICS

Tell me about the support systems you would have to raise a child.

*Discuss the psychological, social, and economic risks of early parenthood.*

What other questions would you like to discuss today?

Adapted from 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](http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf).

**Table 10.2. Adolescent SRH Discussion Guide**

## QUESTIONS AND DISCUSSION TOPICS

Have you been noticing any changes in your body?

*Explain physical changes that accompany puberty and what the adolescent may expect to see.*

Tell me about your moods recently.

*Review emotional changes and/or mood swings that may accompany hormonal changes.*

Have you had any romantic or sexual feelings towards anyone?

*Discuss variation within sexuality, healthy relationships, and communication.*

What does sex mean to you? Have you been sexually active? What sexual activities have you tried?

*Explain different types of sexual activities and their relative risk for STIs and pregnancy.*

Do you have a partner/boyfriend/girlfriend? Do you tell your partner(s) that you are living with HIV?

*Discuss disclosure to partners.*

What does safer sex mean to you? If you are having sex, are you using male or female condoms? Do you feel comfortable talking to your partner about condoms? Are condoms easy for you to obtain?

*Review correct and consistent condom use. Discuss where condoms may be obtained and how to negotiate their use.*

Do you drink alcohol or use drugs (not your medicines) when you have sex? How do you think this affects your decision to have sex or use condoms?

*Discuss potential increased risks with alcohol and unsafe sex.*

Has anyone ever forced you to have sex or do something sexual that you did not want to do?

*Screen for sexual abuse.*

Tell me what you know about STIs.

*Screen for exposure and link to testing services as appropriate.*

What about other forms of birth control? Tell me about what you know about family planning.

*Discuss family planning options and access to family planning methods. Link to family planning services as appropriate.*

Would you like to have children one day?

*Reinforce that it is okay and their right, discuss family planning options, and link to PMTCT services as appropriate.*

*Remind the adolescent of the importance of adherence during pregnancy and breastfeeding.*

What other questions would you like to discuss today?

*Ibid.*

HCPs sometimes find it challenging to discuss sex-related topics with adolescents. However, it is critical to provide adolescents with this information, so that they can protect themselves and their loved ones when they choose to become sexually active. Providers can use Table 10.1 and 10.2 to help guide discussions on sexual activity, risky behaviours, and protective behaviours, and to assess for the presence of STIs in boys and girls.

## 10.7. CONTRACEPTION OPTIONS FOR ADOLESCENTS LIVING WITH HIV

### Definition of Family Planning and Contraception

- » **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.

## METHODS OF CONTRACEPTION

### Short-Term Methods

- » **Hormonal methods:** These use medications (hormones) to prevent ovulation. Examples of hormonal methods include birth control pills (oral contraceptives), long-acting injectables, and implants (but see caveats below).
- » **Barrier methods:** These methods work by preventing the sperm from getting to and fertilising the egg. Barrier methods include male condom and female condom, diaphragm, and cervical cap. ***The condom is the only form of birth control that also protects against STI, including HIV.***
- » **Spermicides:** These kill sperm on contact. They are in form of jellies, foam tablets, and transparent films placed inside the vagina. Spermicides work best when they are used at the same time as a barrier method.
- » **Lactation amenorrhea method:** Breastfeeding in some women, especially in the first six months after delivery, stops ovulation. The method is more effective in women who breastfeed fully and remain amenorrheic. This method of contraception is not as reliable as other methods.
- » **Fertility awareness/natural methods:** These methods involve identifying the fertile days of the menstrual cycle (when pregnancy is most likely to occur) and avoiding sexual intercourse (or using barrier methods) during these days. The fertile days of the menstrual cycle can be obtained by the following methods; basal body temperature, cervical mucus, symptom thermal (cervical mucus and basal body temperature), and the Calendar or Standard Days Method, including CycleBeads and MoonBeads. These methods are not as effective as hormonal or barrier methods.



## Long-Term Methods

- » **Implants:** These are progesterone-based rods inserted under the skin (usually under the arm). They include Norplant™, Jadelle™, Implanon™, and Zarin™ (but see caveats below).
- » **Intrauterine devices (IUDs):** IUDs are inserted into the uterus where they stay from one to ten years. They either prevent the egg and sperm from meeting, or prevent the fertilised egg from implanting in the lining of the uterus. They include copper-bearing IUDs and Levonorgestrel IUDs.

## Additional Methods

- » **Emergency contraception pill (ECP):** This refers to hormonal contraception to prevent unintended pregnancy following unprotected sexual intercourse or instances of broken condoms. ECP should not be used as routine contraceptive method. Progesterone-only pills are the preferred ECP regimen, as they are more effective and have fewer side effects than combined oral contraceptive pills. Dedicated products like Postinor-2 (LNG 750mcg) or Levonelle-2 or NorLevo Plan B may be used. Regular progesterone-only pills, such as Ovrette and Microval, can also be used in recommended doses. ECP should be given **within 72 hours of unprotected sex**.

## Dual Protection Strategy

Dual protection means preventing STIs, HIV, and unwanted pregnancies at the same time by using male or female condoms and a second contraceptive method (most often a hormonal method). Contraception is an important component of comprehensive HIV care, as unplanned pregnancy can cause social, financial, and physical problems for adolescents, especially those living with HIV. However, contraception in adolescents living with HIV is a complex issue. Contraceptive counselling for adolescents should be sufficiently detailed to enable them to make the best contraceptive choice, ideally one that *includes* dual protection.

Some antiretroviral drugs like efavirenz and nevirapine may induce enzymes which increase the breakdown of hormonal contraceptives for example combined oral contraceptives or progestin-containing subdermal implants. This may affect contraceptive effectiveness and reduce the clinical impact of hormonal contraceptives. HCPs should be aware of these drug interactions even if there have been no findings of increased drug toxicities when ART and hormonal contraception are used together. While being aware that efavirenz-containing regimens may decrease hormonal contraceptive effectiveness slightly, adolescent girls living with HIV should have access to a full range of contraceptive methods to choose from (Nanda et al. 2017). Further details on the effectiveness of common contraceptive methods and their safety in HIV infection are in **Appendix XI**.

## SUPPORTING THE ADOLESCENT TO CHOOSE A CONTRACEPTION METHOD: GATHER APPROACH

**GATHER** is a useful memory aid outlined below to help HCPs remember the basic steps in the family planning counselling process.

A detailed description of the actions in the GATHER approach appears in Table 10.3. Table 10.4 provides guidance on how different contraceptive methods relate to different clinical scenarios.

**Table 10.3. The GATHER Approach**

STEP	WHAT TO DO
<b>Greet</b>	<ul style="list-style-type: none"> <li>» Welcome and register patient.</li> <li>» Prepare chart/record.</li> <li>» Determine purpose of visit.</li> <li>» Give patient your full attention.</li> <li>» Talk in private for confidentiality.</li> </ul>
<b>Ask</b>	<ul style="list-style-type: none"> <li>» Ask patient about her/his needs.</li> <li>» Write down patient's: age, marital status, number of previous pregnancies and births, number of living children, basic medical history, previous use of family planning methods, history, and risk for STIs.</li> <li>» Assess what the patient knows about family planning methods.</li> <li>» Ask the patient if there is a particular method s/he is interested in.</li> <li>» Discuss any patient concerns about risks vs. benefits of modern methods (dispel rumours and misconceptions).</li> </ul>
<b>Tell</b>	<ul style="list-style-type: none"> <li>» Tell the patient about the available methods.</li> <li>» Focus on methods that most interest the patient, but briefly mention other available methods.</li> <li>» Describe how each method works, the advantages and benefits, possible side effects and disadvantages.</li> <li>» Answer patient concerns and questions.</li> </ul>
<b>Help</b>	<ul style="list-style-type: none"> <li>» Help the patient to choose a method.</li> <li>» Repeat information if necessary.</li> </ul>
<b>Examine patient</b>	<ul style="list-style-type: none"> <li>» If there is any reason found on examination or while taking a more detailed history that there are precautions for the method, explain the findings and help him/her to make an informed decision.</li> </ul>
<b>Explain</b>	<ul style="list-style-type: none"> <li>» Explain how to use the method (how, when, where).</li> <li>» Explain to the patient how and when s/he can/should get resupplies of the method, if necessary.</li> <li>» Explain any procedures or lab tests to be performed.</li> <li>» Make sure s/he is using the method correctly (ask her/him how s/he is using it).</li> </ul>
<b>Return</b>	<ul style="list-style-type: none"> <li>» At the follow-up or return visit, ask the patient if s/he is still using the method.</li> <li>» If the answer is yes, ask her/him if s/he is experiencing any problems or side effects and answer her/his questions, solve any problems, if possible.</li> <li>» If the answer is no, ask why s/he stopped using the method and counsel her/him to see if s/he would like to try another method or retry the same method.</li> </ul>

**Table 10.4. Family Planning and Clinical Scenario Guidance**

METHOD	INDICATION
<b>Spermicides</b>	<ul style="list-style-type: none"> <li>» Not indicated for HIV-positive women and HIV-negative women at high risk of HIV, as they may increase risk of HIV acquisition.</li> </ul>
<b>The Pill, ring, patch, combined injectable, or mini-pill</b>	<ul style="list-style-type: none"> <li>» Not indicated for women on ART regimens containing ritonavir</li> <li>» Women taking other ART regimens (NRTIs and NNRTIs) CAN use these methods.</li> <li>» Women taking NRTIs and NNRTIs should take a preparation containing a minimum of 30 micrograms of ethinyl estradiol.</li> <li>» 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.</li> <li>» The effectiveness of DMPA injectable is not decreased when taken with ART.</li> <li>» Correct use of the method with condoms increases contraceptive effectiveness.</li> </ul>
<b>IUD</b>	<ul style="list-style-type: none"> <li>» Not indicated if she has a current purulent cervicitis, gonorrhoea or chlamydia, or cervical cancer awaiting treatment, or is unwell with an AIDS-related illness.</li> </ul>
<b>Condoms alone</b>	<ul style="list-style-type: none"> <li>» Prevent transmission of HIV and other STIs during sexual intercourse.</li> <li>» Effective in preventing pregnancy—when used consistently and correctly.</li> </ul>
<b>Condoms and a hormonal method (dual protection)</b>	<ul style="list-style-type: none"> <li>» More effective protection from pregnancy than condoms alone, particularly if partner will not always use condoms.</li> </ul>

## 10.8. SUPPORTING DEVELOPMENT OF A CONCEPTION PLAN

Individuals living with HIV have reproductive rights and need support when they decide to produce a child. The risk of HIV transmission is significantly reduced if the HIV-positive partner is on ART and has an undetectable viral load. The details of what needs to be included in preconception counselling are in **Appendix XII**.

*Always ask, is pregnancy a good idea for the couple now? What to consider as one answers this question:*

- » Their health
- » Their partner's and family's support
- » Telling others their HIV status
- » Feeding their baby and availability of medical care for the mother-baby pair

## ESTABLISH HIV STATUS

- » **Unknown status:** Test either partner; knowing can help couple decide how to decrease transmission risk while trying for pregnancy (if positive). The risk of HIV transmission is significantly reduced if the HIV-positive partner takes ART and the virus is undetectable.
- » **If HIV-negative:** one should always use condoms and other protective measures, as there is increased risk of HIV transmission to foetus/infant if the mother acquires HIV during the pregnancy/breastfeeding period.
- » **If HIV-positive:** Avoid unprotected sex during pregnancy—for example, by using condoms. This lessens the chance of acquiring STIs, which can present risks for the baby.

**Pregnancy is possible** if the adolescent's health is good with an undetectable viral load; or she is in clinical Stage 1 or 2 where CD4 count is not available; on prophylaxis to prevent opportunistic infections; or is adherent to ART and has no signs or symptoms of TB or treatment failure.

**Pregnancy may cause problems now** if the adolescent's health is not good—with CD4 <500, unknown TB status, or no prophylaxis to prevent opportunistic infections; or if she is in the first six months of starting ART. One should consider delaying pregnancy and re-evaluating again later to determine if her health is worsening or getting better.

**Consider delaying pregnancy** if her health is poor, she is in clinical Stage 3 or 4, she is on TB treatment, she has CD4 <500, or she is waiting to start ARVs, or is on ART but has features of treatment failure—clinical, immunological, or virological.

## ADDITIONAL CONSIDERATIONS FOR ADOLESCENTS

- » **Partner support**
  - A steady partner is ideal
  - The partner should know the mother's HIV status
  - The partner should be supportive and willing to help raise the baby
  - The partner knows his/her own HIV status or is willing to be tested for HIV
  - The partner's health is good
  - The partner should access HIV prevention services including condoms and PrEP.
- » **Family support**
  - Is the family supportive or would they reject the child regardless of HIV status??
  - Are family members close by and can they help?
- » **Telling others about HIV status**
  - Has the adolescent spoken with their partner about their desire to become pregnant?
- » **Feeding and caring for the baby and mother**
  - HIV-positive adolescents should be educated on the national recommendations for infant feeding and counselled and supported in the feeding practice that give their HIV-exposed infants the greatest chance of HIV-free survival.

- The mother should practice exclusive breastfeeding (no other food or liquids) for the first six months of life, with ART for the mother and nevirapine syrup from birth to age 6 weeks for the baby; introducing appropriate complementary foods thereafter; and continuing breastfeeding for the first 12 months of life. Breastfeeding should then only stop once a nutritionally adequate, safe diet without breastmilk can be provided.
  - Alternatively, the mother can avoid all breastfeeding and use replacement feeding methods if environmental and social circumstances are safe and supportive.
- Ensure availability of safe, accessible, and continuous medical care for the mother and her baby.

## 10.9. SEXUALLY TRANSMITTED INFECTIONS

Due to their limited experience and skills, adolescents are more likely to explore and take chances, which can lead to risky sexual behaviours that could expose them to infectious diseases such as STIs and HIV. Adolescent girls are more susceptible to STIs than males, based on both biological characteristics of their anatomy and their increased likelihood of sexual activity at younger ages. Gender-related vulnerability also places adolescent girls at an increased risk of experiencing sexual violence, which increases their risk of HIV, STIs, unwanted pregnancy, and unsafe abortion (Morris and Rushwan 2015). Further compounding these risks are the limited protection services available for girls who have experienced sexual violence.

Adolescents should be educated on HIV prevention, including abstinence, monogamy, reducing the number of lifetime sexual partners, risks associated with age-disparate relationships, correct and consistent condom use, and use of treatment as prevention. HCPs should offer routine HTS to all adolescents and their sexual partners, and should provide PrEP for adolescents at high risk of acquiring HIV, including those in serodiscordant relationships, sex workers, and others.

HCPs should provide routine education on STIs including signs and symptoms (or lack thereof in some cases), how they are transmitted, and strategies to reduce risk. Dual protection and information on safe conception (how to have a child in a way that is safe for the mother, her partner, and their baby) should be provided for both male and female adolescents. STI screening should be a routine part of care for adolescents once they have initiated sexual activity. Screening provides the opportunity to revisit education on safer sexual practices and informed decision-making.

### BOX 10.2. KEY POINTS FOR PROVIDERS AND CLIENTS ABOUT SEXUALLY TRANSMITTED DISEASES

1. People with sexually transmitted infections (STIs), including HIV, can use most family planning methods safely and effectively.
2. Male and female condoms can prevent STIs when used consistently and correctly.
3. STI risk can be reduced in other ways, too—limiting number of partners, abstaining from sex, and having a mutually faithful relationship with an uninfected partner.
4. STIs often have no signs or symptoms, particularly in women. People should seek care if they think that they or their partners might have an STI.
5. Some STIs can be treated. The sooner treated, the less likely to cause long term health problems, such as infertility or chronic pain, or to infect a sexual partner or a fetus.
6. In most cases vaginal discharge comes from infections that are not sexually transmitted.

## 10.10. PREVENTION OF CERVICAL CANCER

Adolescent girls living with HIV experience higher risk of acquiring human papillomavirus (HPV). Girls and women with high-risk forms of HPV are more likely to experience rapid progression towards high-grade cervical dysplasia and invasive cervical cancer. They are also more likely to experience recurrent cervical dysplasia after treatment and to respond poorly to treatment (Adler et al. 2015). For these reasons it is critical to perform annual Papanicolaou tests, or “Pap smears.” The WHO recommends the HPV vaccine for girls between the ages of 9–13 years. Girls should receive their first dose of HPV vaccine before age 15, and a second dose six months later. There is no maximum interval between the two doses; however, an interval of no greater than 12–15 months is suggested. If the interval between doses is shorter than five months, then a third dose should be given at least six months after the first dose. Immunocompromised individuals, such as adolescents living with HIV, should receive three doses (0, 1–2, and 6 months), to be fully protected (World Health Organization 2014). Where available, also offer the hepatitis B vaccine. Refer HIV-negative male partners to VMMC services to decrease the likelihood of HIV acquisition. Further details on cervical cancer, who is at risk, and prevention are in **Appendix XIII**.





**CHAPTER II.**  
TRANSITION FROM  
PAEDIATRIC TO ADOLESCENT  
TO ADULT HIV CARE



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## SUMMARY

- » Transition is an integral component of PSS of children and adolescents living with HIV. HCPs should initiate the transition process early, taking age and developmental readiness into consideration.
  - » HCPs plays a significant role in participatory planning and management during transition with both the child/adolescent and the caregiver(s), using the most appropriate process that aligns with the health care setting and general environment/cultural context.
  - » The transition process should also take into consideration the changing psychosocial needs of adolescents, prioritising their SRH needs.
-

## 11.0. 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, from a child-centred model to an adolescent-centred model, and to an adult-oriented health care system of HIV care and support. It takes into consideration both age and developmental readiness, in the context of their physical, medical, psychological, and social needs. The process of transition may involve “transfer” of services, which is a one-time event characterised by the physical movement to a new health care setting, team of HCPs, or both. A transfer unsupported by the transition process can increase morbidity and mortality (Kakkar et al. 2016).

According to the WHO, as more HIV-positive children and adolescents survive into adulthood, the transition of these young patients towards age-appropriate care and self-management should be a top priority for health services. A good transition process supports both children and adolescents to acquire knowledge and self-management skills, and build life skills, to reduce risk-taking behaviours that can interfere with ARV treatment adherence and retention in care. The transition process also recognises developmental transitions (including mental capacity, relationships, school, and work changes) beyond physical transfer into new health care settings. Adolescents' transition is especially important, since it necessitates that they have the knowledge and self-management skills required to oversee their own care.

Transition should be a gradual process that takes place over a period of years, based upon the developmental readiness of the child or adolescent. Leaving a familiar environment can cause anxiety, and poorly planned transitions can worsen these feelings. Transition should be carefully planned and managed, taking into consideration the physical, medical, psychological and social needs of the child/adolescent. The transition process must also embrace caregivers' concerns about their children/adolescents' ability to cope with the new environment.

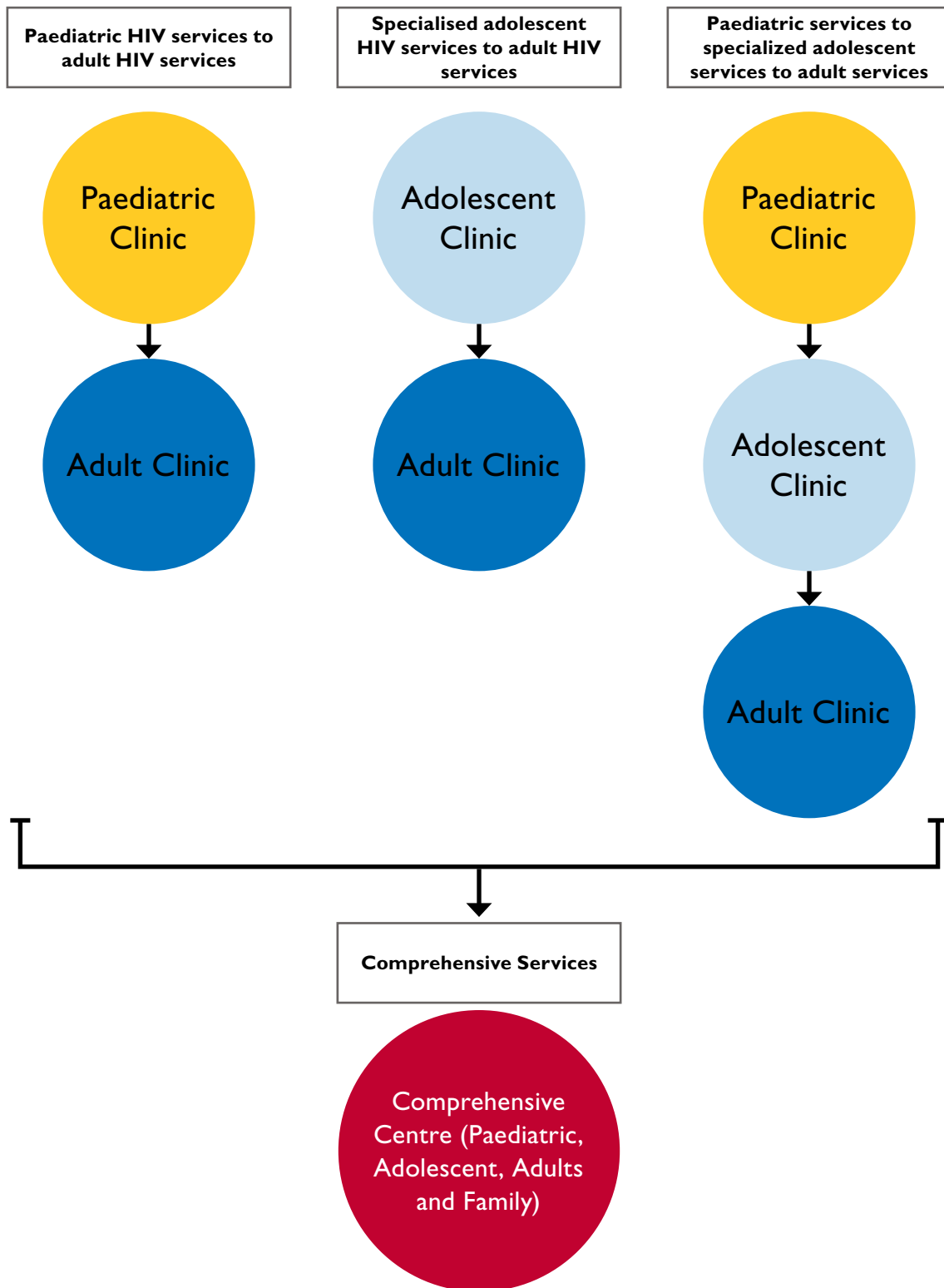
Despite agreement that transitioning is necessary, no single model for transitioning has emerged as the “gold standard” or the most cost-effective method of transitioning children/adolescents to adult-focused services (Machado, Succi, and Turato n.d.). Whatever model the transition takes, the job of the HCP is to increase the knowledge and self-management skills of the children and adolescents in their care to ensure a smooth transition. HCPs should take several key steps (see section 11.6) to ensure that children and adolescents achieve a smooth transition.

## 11.1. MODELS OF TRANSITION

To achieve successful transition, interventions to facilitate transition should be started early and cater for both the structural and emotional needs of the children and adolescents. Paying attention to these issues improves adherence to appointments and decreases the potential for the newly transitioned child or adolescent to fail in adapting to the new environment.

The model of transition depends on the structure of the health care services that are available. Figure 11.1 illustrates the four main health care settings where transition takes place. The fourth model shows the ideal model—comprehensive services, in which transition occurs from one HCP to another, or with the same HCP adopting different approaches that recognise the child/adolescent's evolving capacities and needs.

**Figure 11.1 Transition Models (Machado, Succi, and Turato n.d.)**



It is important to note that in some cases, a physical transition of services may not occur, largely due to the lack of available paediatric- and adolescent-focused HCPs. In these instances, even though a child or adolescent is staying with the same HCP, the HCP’s services should support a “mental transition” that increases the patient’s knowledge and self-management skills as they move towards adulthood.

Transition of services is often accompanied by the following:

- 1. Changing physical space where health care is provided:** This physical change of care space may retain the child/adolescent in care by the same health care team, or a totally different health care team.
- 2. Transitioning to specialised clinic days:** This occurs when the health care system sets up specialised clinic days for each age group—for example, offering care to children on designated paediatric clinic days, and seeing adolescents or adults on days designated for that specific group. Care may be offered by the same care team or a different one specialising in provision of child, adolescent, or adult HIV care. It may also be in the same physical setting or in a different physical space.
- 3. Transitioning to a specialised care team:** The child or adolescent transitions to care provided by a specialised care team. It may be in the same or different physical structures. Services may be provided on designated age-appropriate days or daily for a specified age group.

Throughout the transition period, HCPs should ensure that the emotional and psychological needs of the children and adolescents are taken care of; and the caregiver and child/adolescent should be fully involved in decisions made during the transition process. HCPs should consider preparing and transitioning children and adolescents in cohorts—a strategy for enhancing peer support and promoting retention in care. This will likely address some of the challenges and barriers associated with transitioning where some children/adolescents resist transition, or may fluctuate between visiting the paediatric/adolescent and adult clinics.

## 11.2 BENEFITS OF TRANSITION

HCPs need to accept that as children grow into adolescents, and adolescents grow into adults, their physical and emotional needs change. They must especially support adolescents as they grow into new roles, becoming increasingly able to manage their own life and health—and to maximise the benefits of the natural changes that take place during the transition process (Box 11.1).

### BOX 11.1. BENEFITS OF TRANSITIONING

- » Promoting a positive self-image
- » Promoting self-reliance
- » Promoting a sense of competence
- » Allowing for meaningful independent living
- » Supporting social and emotional development
- » Supporting long-term planning and working to achieve life goals
- » Broadening systems of interpersonal and social support

## 11.3. BARRIERS TO SUCCESSFUL TRANSITION

Transition needs to be carefully planned and managed, taking into consideration the physical, medical, psychological and social needs of the child/adolescent as well as the caregivers'. The HEEADSSS tool (**Appendix III**) may be useful to identify barriers. Use the “5 As” approach (see **Chapter 9**) to address them.

Paediatric, adolescent, and adult services require different care and treatment approaches. Paediatric and adolescent treatment and care approaches largely focus on the family, while adult treatment and care focuses on the individual and assumes that the patient is independent, hence the importance of ensuring that adolescents have the necessary skills as they transition to adult care. The transition process should support the adolescent to acquire knowledge and skills to help them attain autonomy and independence while they make this transition.

A number of factors may impede a smooth transition. After transitioning to adult services, many adolescents experience anxiety upon detaching from the connections they established at the paediatric/adolescent clinic. It is common for adolescents to continue to seek support from their paediatric/adolescent providers months after leaving the clinic, while others become lost to follow-up or only attend appointments sporadically because they were forced to navigate through the adult system on their own. Table 11.1 summarises barriers to transition at multiple levels.

## 11.4. ADDRESSING THE BARRIERS TO TRANSITION

HCPs need to identify and address barriers to ensure smooth transition of adolescents to adult-focused care. The suggestions below may be used to address some of these barriers.

1. 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. 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. 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.
4. HCPs should identify and use adult care providers who are willing to care for and provide PSS to adolescents and young adults.
5. 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. 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, and the importance of self-efficacy in managing medications.
7. HCPs or other staff should educate HIV care teams and staffs about transitioning.

Table 11.1. Barriers to Transition

ADOLESCENTS LIVING WITH HIV	FAMILIES/CAREGIVERS	COMMUNITIES	PROVIDERS	HEALTH SERVICES
<ul style="list-style-type: none"> <li>» Not accessing or sporadically attending services</li> <li>» Not understanding transition requirements</li> <li>» Not applying information and support</li> <li>» Not aware of diagnosis</li> <li>» Stress of diagnosis</li> <li>» Self-stigma</li> <li>» No transport funds</li> <li>» Resists transition</li> <li>» Emotional attachment to paediatric HCP, especially for OVC</li> <li>» Pregnancy</li> <li>» Delayed cognitive ability to take on self-management tasks, even after transition</li> </ul>	<ul style="list-style-type: none"> <li>» Not promoting adolescent autonomy</li> <li>» Not engaged in the care of the adolescent</li> <li>» Not able to provide full support for transition</li> <li>» Stretched thin by not having enough resources to support the family</li> <li>» Resists the physical transition</li> </ul>	<ul style="list-style-type: none"> <li>» Unsupportive social setting</li> <li>» Stigma</li> <li>» Peer pressure</li> <li>» Unsupportive or absent family network</li> <li>» No universal family counselling and testing</li> <li>» Weak institutional support</li> <li>» Weak community support</li> </ul>	<ul style="list-style-type: none"> <li>» Emotional attachment to paediatric patients</li> <li>» Weak understanding of what is needed to transition</li> <li>» Paediatric providers have insufficient time to spend on preparing patients for transition</li> <li>» Adult providers do not understand adolescents' holistic needs</li> <li>» Adult provider not comfortable with adolescents</li> <li>» Unable to plan with adolescents, services, and families for transition</li> <li>» Lack of communication between paediatric and adult providers</li> <li>» Insufficient time for adult HCP to spend with adolescents who have recently transitioned</li> <li>» Resists transition</li> </ul>	<ul style="list-style-type: none"> <li>» Not adolescent-friendly</li> <li>» Medicalisation of clinics</li> <li>» Information is poorly delivered</li> <li>» Risk of loss to follow-up</li> <li>» Not all adolescents have access</li> <li>» Abrupt transfer with no prior preparation</li> <li>» Adult services not adolescent-friendly</li> <li>» Differences between paediatric/family care and adult/individual care</li> <li>» Transition based on chronologic versus developmental readiness</li> <li>» Lack of validated tools to assess transition readiness</li> </ul>

\*(Sharer and Fuller 2012)

## 11.5. KEY CONSIDERATIONS FOR TRANSITION

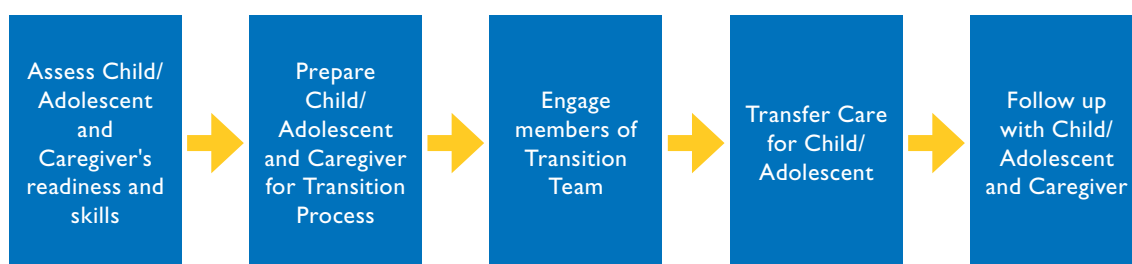
Informed decision-making is the key to mature self-care, and is the overall goal of successful transitioning. The following are key principles to guide the transition process:

- » **Individualise** the approach for each child and adolescent based upon their developmental readiness.
- » **Identify** HCPs who are willing to engage in the transition process from paediatric to adolescent, and adolescent to adult care.
- » **Begin the transition process early** and ensuring communication among the child, adolescent, caregivers, and the HCP in the adult health care setting, before, during, and after the transition.
- » Develop and follow an **individualised transition plan** for each child or adolescent in the paediatric or adolescent health care setting; in addition to developing an orientation plan in the adult health care setting. Plans should be flexible to meet the child/ adolescent's needs, and also should include provisions for any regressions that a child or adolescent may have. The checklist in Table 11.2 can be used to develop such a plan.
- » Use a **multidisciplinary transition team**, which may include peers who are in the process of transitioning or who have transitioned successfully.
- » Address **comprehensive care needs** of each child/adolescent, as part of the transition, including medical, psychosocial, and financial aspects of transitioning.
- » Allow children and adolescents to **express their opinions**.
- » **Educate HIV care teams** and staff about transitioning

## 11.6. TRANSITION STEPS

Transition occurs over a period of years while the HCP, child or adolescent, and the caregiver work together to build the patient's knowledge and skills to manage their own care in preparation for adult services. Transition should only occur when all parties have agreed that the child or adolescent has met the required criteria and is also mentally prepared. HCPs should actively involve the child or adolescent at each step (see Figure 11.2) by allowing them to explore their views, concerns, and anticipated challenges before, during, and after the transition. Working with the child or adolescent, providers should discuss and agree on how to address these concerns with the goal of empowering the child/adolescent to attain independence.

**Figure 11.2. Transition Steps**



## 11.7. ROLE OF HCPS IN TRANSITIONING CARE

During the transitioning process, HCPs should work with the child/adolescent and caregiver in the development, implementation, and follow-up of the plan (see Table 11.2).

### 1. DEVELOPING A TRANSITION PLAN

HCPs should collaborate with the caregiver and the child/adolescent at their level of understanding, to develop a transition plan detailing 1) mutually agreed-upon skills that the child or adolescent should meet before transitioning and 2) establishes goals to accomplish those skills (see Table 11.2). With children and adolescents who do not yet know their HIV status, disclosure should occur before transition planning begins. As part of the transition plan, children and adolescents should meet their new providers well in advance of their final appointment with their primary care provider.

### 2. IMPLEMENTING THE TRANSITION PLAN

During each visit, the provider should review the transition plan with the patient, assess progress made, and identify new goals. The HCP should also attend to the child/adolescent's holistic clinical and psychosocial needs, keeping in mind that these needs will change over time. The HCP, child/adolescent, and caregiver should implement the plan together appropriate to ensure that patients:

- » Demonstrate understanding of disease and its management
- » Demonstrate the ability to make and keep appointments
- » Know when to seek medical and PSS services

The actual transition of services should be implemented when the child or adolescent's disease is clinically stable, coupled with demonstrated self-management skills and verbalised readiness to transition.

### 3. FOLLOW UP ON THE TRANSITION PLAN

HCPs should follow up to ensure that the child or adolescent has settled into the new health care setting physically and emotionally, and that they have the support of the caregiver as needed. The child/adolescent and their caregiver, and the new HCP, should be asked for feedback on the transition. The key indicators of a successful transition include keeping clinic appointments at the transition setting and adhering to medication (self-report, viral load, and CD4 assessments).



**Table II.2. 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			
Explains reasons for disclosure and disclosure methods.	11–14			
Attends first peer support group.	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)
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](http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf).







# **CHAPTER 12.**

## **FAMILY, COMMUNITY, AND HCP SUPPORT SYSTEMS**

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## SUMMARY

- » Support from families, the community, HCPs, and other systems is key to ensuring that children and adolescents living with HIV are identified, enrolled, and retained in HIV care.
  - » There are many types of families and family structures, and each may predispose children to specific vulnerabilities; thus, HCPs should individualise care to address them.
  - » HCPs should identify, use, and strengthen family, community, and health care support systems in the care for children and adolescents living with HIV.
  - » HCPs need to be mindful of and address their own needs if they are function as effective providers for children/adolescents living with HIV and their caregivers.
-

## 12.0. INTRODUCTION

Identifying, enrolling, and retaining HIV-positive children and adolescents requires a wide network of support that includes families, the community, HCPs, and other systems. To help these patients develop their full potential, HCPs need to understand some basics 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. The objective of this chapter is to guide HCPs in mobilising these resources and, as importantly, to use available resources to address their own needs for support—an aspect of HIV policy and programming that is often neglected.

## 12.1. DEFINITION OF SUPPORT SYSTEM

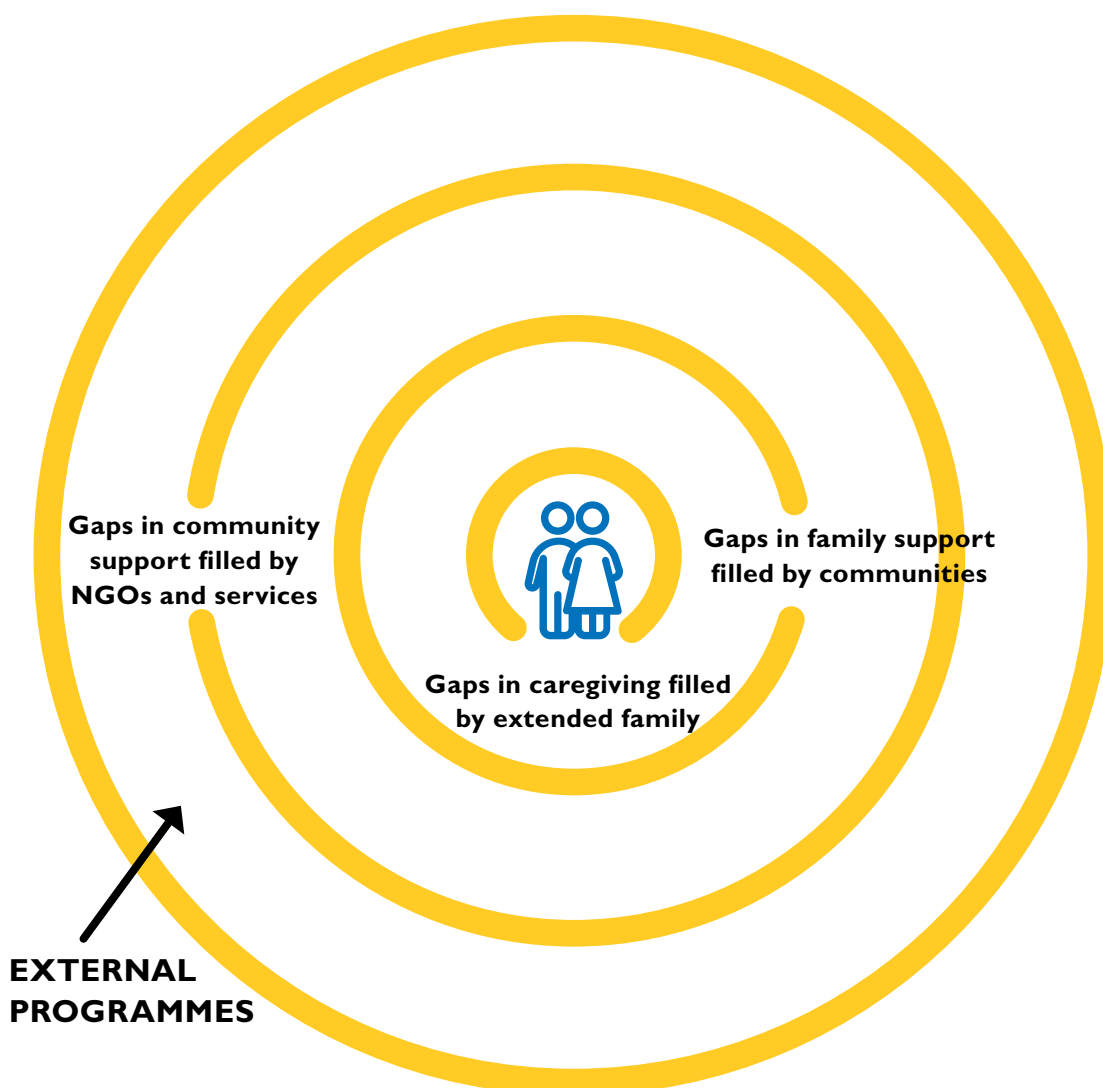
A support system describes the relationships among different actors involved in protecting and caring for individual members of society—in this case, children and adolescents living with HIV. Elements of a support system include the family, community groups, schools, nongovernmental organisations, faith-based institutions and government departments all working together to promote the well-being of children and adolescents.

## 12.2. CIRCLES OF SUPPORT

Psychosocial care and support is about helping children, families, and communities to improve their psychosocial well-being. It is about encouraging better relationships between people, and building a stronger sense of self and community. This ranges from support offered by HCPs, caregivers, family members, and the community (friends, neighbours, educators, religious leaders) to the care and skilled support offered by specialised psychological and social services, including health services.

One way to picture this continuum is to imagine that the child or adolescent is surrounded by different “circles of support.” Each of these circles offers opportunities to reinforce the well-being of the child/adolescent. Although, unfortunately, these circles can be broken or disrupted, other circles can provide support. Children and adolescents are best cared for by committed and affectionate adults, who occupy the innermost circle of support. When the caregiving capacity of this circle is broken, extended families can step in; however, if this is not possible, community initiatives need to fill the gap (Figure 12.1). Finally, if the community circle of care is broken, external agencies must intervene. The collective efforts of different providers of PSS can strengthen each child and adolescent’s support circles and help prevent them from breaking down. At times, the child or adolescent and his or her caregiver will require specialised care and support from professionals to maintain the circles.

Figure 12.1. Circles of Support, Gaps, and Alternatives



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>

## 12.3. THE FAMILY AS A SUPPORT SYSTEM

HCPs must understand that in all cultures, the family is the agent of human development, an institution for child-rearing, and a means to transfer cultural and social norms, values, and practices from one generation to the next. Most children and adolescents living with and affected by HIV are cared for in the family support system. Thus, it is important for HCPs to work to maximise the strengths within the families caring for HIV-positive children in order to help them meet their needs best. Two key concepts are important to know:

- » While the structure of families may vary, their functions with respect to nurturing, rearing and protecting children remain similar.
- » Children in different family systems face different types of vulnerabilities, so each child must receive individualised care that suits his/her context.

## DEFINITION OF FAMILY AND TYPES OF FAMILIES

Families are social groups connected by kinship, marriage, adoption, or choice. Family members have clearly defined relationships, long-term commitments, mutual obligations and responsibilities, and a shared sense of togetherness. Families are the primary providers of protection, support, and socialisation for children and adolescents (Irwin, Adams, and Winter 2009). In the context of HIV, families were the first to respond and continue to provide care and support for children affected by the virus.

A family can be nuclear (consisting of parents and children) or extended (consisting of parents, children, and other relatives). In many sub-Saharan African settings, the extended family system structure is common, although there are indications of this system weakening due to HIV, poverty, conflict, and urbanization (Mathambo and Gibbs 2009). Families are dynamic entities that have adapted their systems of childcare in response to the HIV epidemic and other challenges. Other family structures, such as those headed by children, single parents, and elderly caregivers (mainly grandparents), as well as those of non-kin community members, provide care to children and adolescents living with HIV.

Families can also be categorised on where they are located (urban and rural). Children and adolescents living with HIV in rural and urban areas may face different challenges to access and remain in care. For instance, most centres of excellence for paediatric and adolescent HIV care tend to be in urban areas. Children in those areas often have better access to HIV diagnosis, care, and support services than their rural counterparts; in remote areas, specialised HIV care and psychosocial support services are often too far away to attend regularly, and are associated with high transport costs.

Children in different family settings may have different opportunities and challenges. For instance, children in nuclear families may have better care if their parents are healthy and living with them, but may have limited circles of support to fall back to in the absence of parents, or when their biological relatives are unable to provide. By contrast, children in the extended family setting may be able to tap from the wider family networks for their care and protection—but they may be at a higher risk of dropping out of school, child labour, missing clinic visits, or stigmatisation in comparison to those in nuclear families. Similarly, such vulnerabilities may be more pronounced for children living in child-, elder-, and single parent-headed households (see below). It is important for HCP to understand and help to address the varying vulnerabilities of children and adolescents living with HIV in different family settings (Table 12.1). Due to many biologic and psychosocial factors, vulnerabilities may also be more pronounced for girls than boys.

**Table 12.1. Family Care Arrangements and Likely Vulnerabilities\***

LIKELY VULNERABILITY	NUCLEAR FAMILY	EXTENDED FAMILY	CHILD-HEADED	ELDERLY CAREGIVER-HEADED	SINGLE PARENT	NON-KIN COMMUNITY MEMBER
<b>Poverty</b>	X	XX	XXX	XXX	XXX	XX
<b>School dropout</b>	X	XX	XXX	XXX	XXX	XX
<b>Domestic violence</b>	X	XX	X	X	XX	XX



LIKELY VULNERABILITY	NUCLEAR FAMILY	EXTENDED FAMILY	CHILD-HEADED	ELDERLY CAREGIVER-HEADED	SINGLE PARENT	NON-KIN COMMUNITY MEMBER
Child labour	X	XX	XXX	XXX	XXX	XXX
Food security	X	XX	XXX	XXX	XX	XX
Inadequate medical care	X	XX	XXX	XXX	XXX	XXX

**X= low vulnerability; XX = increased vulnerability; XXX high vulnerability**

*\*Mathambo and Gibbs 2009; Evans 2010; International HIV/AIDS Alliance and HelpAge International 2003*

## ORPHANS AND OTHER VULNERABLE CHILDREN

Absent or weakened family connections lead to increased risk. Orphans and other vulnerable children (OVC) who have lost one or both parents are more likely to be HIV-positive. Orphaned children are at an increased risk of HIV from vertical transmission. Due to their economic vulnerability, they may also be at risk for horizontal HIV transmission through sexual abuse, early sexual debut, or transactional sex. In Zimbabwe, for instance, 18 percent of orphaned children attending a community-based OVC programme tested HIV-positive (U.S. Centers for Disease Control and Prevention and USAID 2013). Integrating HTS or referrals into OVC programmes can help identify orphaned children living with HIV. Thus, HCPs should tailor HTS to orphans and other vulnerable children to ensure early diagnosis and linkage to care if needed. Because such children are common in countries with high HIV prevalence, providers should be aware of the kinds of organisations and agencies that provide specialised services for them. It is advisable that HCPs and OVC care and support organisations establish functional bidirectional referral systems in order to increase OVC access to HIV testing, care, and treatment services as well as social services and support.

## CHILD-OR ADOLESCENT-HEADED FAMILIES

Some children and adolescents living with HIV have no surviving adult figures and reside in families that they or their siblings head. These types of families may experience multiple forms of deprivation—including food, clean and safe water, sanitation, medical care, shelter, and education—that directly affect children/adolescents’ psychosocial well-being and initiation/retention in HIV care. The experiences of children and adolescents in child-headed families vary by age, gender, and the amount of external support available to the family. For instance, girls from these types of families may often be absent or withdraw from school because of their caregiving roles, and may feel stigmatised or isolated.

Thus, it is important for HCPs to identify children and adolescents living in child-headed families and link them to appropriate support agencies to meet their needs. While the types of support agencies may vary from one place to another, they may usually include government departments (such as probation, social welfare, community development), civil society and nongovernmental organisations with activities on care for OVC in health, education, and family economic strengthening.

Because caring for minors living in these “broken circles” is complex, it is also important for HCPs to have information and training to help these patients to cope. Providers must have essential

knowledge on available HIV care and support services, child friendly and adolescent-friendly services, along with training on effective communication with children/adolescents, age-appropriate HIV status disclosure, drug adherence, nutrition, and preventing HIV. They also must be familiar with and able to link patients (through functional referral systems) to child protection (probation and social welfare, community development, and police) and family economic strengthening service, including governmental and nongovernmental community development programmes.

## FAMILIES HEADED BY ELDERLY/GRANDPARENTS

Many children live in households with older caregivers, such as grandparents. Studies show that about 40 percent of orphaned children in South Africa and Uganda, and more than half in Zimbabwe, live with their grandparents (von Braun, Vargas Hill, and Pandy-Lorch 2009). Unfortunately, elderly caregivers are often among the poorest in their communities. Consequently, children, particularly girls, often take on earning responsibilities and care for their elderly grandparents and siblings. Such children miss school and are vulnerable to abuse and exploitation. They also have trouble meeting their basic needs such as food, transport to health care facilities (for drug refills and routine assessments), shelter, and water. These difficulties can keep children from HIV treatment, retention, and adherence.

Children and adolescents living in families headed by grandparents urgently need to be identified and linked to a range of support interventions. These may include economic strengthening interventions such as cash transfers, income generation projects, village savings and loans groups, education support for children as well as to social, psychosocial and legal protection programmes. It is also important to provide information to grandparents on the children's needs and building skills to meet them.

While the structure of families may vary, their functions with respect to nurturing, rearing, and protecting children remain similar. It is important to note that children in different family systems face different vulnerabilities and thus the support they receive needs to be contextualised. For instance, those living in extended families may be at a higher risk of dropping out of school, child labour, missing clinic visits or stigmatisation in comparison to those in nuclear families. Similarly, such vulnerabilities may be more pronounced for children living in child, elderly, and single parent-headed households. It is important for HCP to understand and help to address the varying vulnerabilities of children and adolescents living with HIV in different family settings (Table 12.1). Due to many biologic and psychosocial factors, vulnerabilities may also be more pronounced for girls than boys. It is important for HCPs to identify and support families of children that do not fit into the conventional definition of a family in a particular setting. The types of families identified influence the type of interventions and support services needed.

### Family Functioning

Beyond assessing the type of family, HCPs need to understand the functionality of the family—functional or dysfunctional. Many families are varied and have a mix of traits, but understanding the range of diversity can help HCPs deliver care that builds upon existing strengths and minimises unhealthy traits. Box 12.1 further highlights some functional characteristics, while Table 12.2 highlights dysfunctional traits.

Traits that contribute to family functioning include:

1. Providing resources to meet the basic needs of children (such as food, clothing, shelter, and medical care)
2. Nurturing and supporting children and adolescents to grow and reach their full potential
3. Providing support with HIV testing, enrolling and remaining in HIV care, and adherence on HIV treatment

### **BOX 12.1. FUNCTIONAL TRAITS WITHIN FAMILIES**

- » Members (including children) are able to express emotions and get support
- » Members able to seek and receive attention
- » There are clear and consistent rules
- » Boundaries are honoured
- » Children are treated with respect
- » Children are given age-appropriate responsibilities
- » Mistakes are made and corrected
- » Authority is present

Functional actions allow for families to facilitate children learning, receiving, and offering love and care; they also take part in age-appropriate household activities, and uphold family norms and values. When families are functional, children are more likely to attend school and to perform well. Education has multiple short- and long-term benefits to children, families, and communities. For girls, education is protective against HIV.

Families that function well are an optimal place for the care of children and adolescents. However, some families also exhibit traits that contribute to dysfunctionality. These may include:

- » Substance abuse
- » Death of parents/relative
- » Disease
- » War and conflict
- » Domestic violence
- » Divorce and separation
- » Untreated mental illness
- » Poverty
- » Poor parenting practices
- » Sexual abuse

Care for children and adolescents living with HIV can strain families and cause them not to function optimally (see Table 12.2). Regardless of the type of family in which children and adolescents live, the functionality of the family is important, and HCPs should assess and contribute to strengthening all families maximising strengths and minimising dysfunction.

**Table 12.2. Dysfunctional Traits within Families and Effects on Children and Adolescents**

CHARACTERISTICS OF DYSFUNCTIONAL WITHIN FAMILIES	EFFECTS OF FAMILY DYSFUNCTION ON CHILDREN AND ADOLESCENTS
<ul style="list-style-type: none"> <li>» Inconsistent behaviours</li> <li>» Unresolved conflicts</li> <li>» Isolation</li> <li>» Unclear boundaries</li> <li>» Lack of empathy for others</li> </ul>	<ul style="list-style-type: none"> <li>» Low self-esteem</li> <li>» Distrust of others</li> <li>» Difficulty expressing emotions</li> <li>» Difficulty forming healthy relationships</li> <li>» Feeling angry, anxious, depressed</li> <li>» Poor access to education, health care, and other services</li> </ul>

Dysfunction patterns can have immediate and long-term effects on children and adolescents; and growing up and living in families with unhealthy habits can negatively affect children's lives in the short, medium and long term. Indeed, some negative consequences are irreversible, and have been associated with psychological, physical, and social ill health.

When working with children and adolescents living with HIV and their caregivers, HCPs should aim to strengthen or restore family functioning. This may require linking families to other service providers within and outside the health sector. Providers within the health sector may include medical social workers, counsellors, community extension/outreach workers, and psychologists, among others. Services outside the health sector may include governmental and nongovernmental actors, including probation and social welfare officers, police, and other agencies involved in addressing the education, health, nutrition, legal and economic needs of vulnerable children.

In some cases, services are not available; and existing families do not always prioritise the needs of children. In these cases, other community institutions (national government, the health sector, schools, faith-based organisations, and nongovernmental organisations) may also be required to fill family gaps when families are unable to respond.

It is also important to note that families are ever-changing. Changes in families' and individual members' roles may be due to sickness, death of an adult/sibling, loss of income, or migration. These changes may be abrupt or gradual, and they affect the family's ability to care for children and adolescents living with HIV. HCPs must be able to recognise when such changes occur in families and find ways to help the family (or other institutions) meet the needs of children, adolescents, and their caregivers in the context of HIV care. While children's caring situations may be very fluid, it is critical to establish and support a strong relationship with the child or adolescent's primary caregiver (whether biological parent, extended family member, or other caregiver) as this can help improve the child or adolescent's access to HIV and other services as well as their retention in care.

## FAMILY CULTURE

Family culture encompasses the values, beliefs, attitudes, and practices shared by members of a family. Family culture can be a resource or a barrier in caring for children and adolescents living with HIV. HCPs should help families strengthen these elements of family culture:

- » **Self-awareness (parents/caregiver):** HCPs can help caregivers to identify and use their own strengths (including individual abilities and resources within the environment) and minimise their weaknesses as they relate to their support for children/adolescents with HIV.

- » **Permanence planning:** This entails anticipating and meeting the current and future needs of children and adolescents living with HIV—for example, making wills, writing memory books, and identifying and linking children to other relatives or friends who can continue their care if the current caregiver is unable to.
- » **Economic strengthening:** HIV causes and worsens poverty at family and community levels. Poor families have trouble meeting the medical, nutritional, educational, and other needs of children and adolescents living with HIV. Children in low-income families have difficulty accessing and staying in HIV care; they are likely to drop out of school, and may be malnourished. Interventions to strengthen families' economic capacity to meet the needs of their members are becoming an increasingly important part of the HIV response. Economic strengthening interventions include support for formal and vocational skills education, financial literacy and money management skills building, cash transfers, income generation projects, savings and loans groups, and food security, among others. Most of these interventions are designed and implemented by nongovernmental organisations and government departments outside the formal health sector. HCPs should be aware of such initiatives in their areas of operation, so that they can help to link and refer families to access economic strengthening support (see a brief description of economic support groups later in this chapter).

## GENDER AND POWER CONSIDERATIONS IN A FAMILY SUPPORT SYSTEM

Gender and power are important elements of family dynamics; they affect interactions between family members and influences expectations of individual family members. Gender shapes roles and expectations for boys and girls and influences intra-family decision-making within families, especially around the allocation of resources or access to economic and educational opportunities. HCPs should need to be aware of and respond to the varying needs and constraints for boys and girls, because they affect access to and use of HIV services.

Girls of all ages are more likely to be removed from school to take on caregiving roles. In poor households, resources for education are more likely to be allocated to boys. The impact of social gender norms can mean that women and girls have limited participation in community decision-making, but also in the case of HIV, caregivers may miss clinic appointments when these appointments compete with care responsibilities. Girls are also more vulnerable to violence and abuse within the family. This has a direct impact on their ability to make informed decisions about their health care, including if, when, and where to test for HIV and access care. Boys, like men, are less likely to seek care early and are more likely to use drugs and alcohol, which can negatively affect adherence and retention in care. It is important for HCPs to understand and challenge negative gender norms in their environments.

## 12.4. COMMUNITY SUPPORT

A community is a group of people who share common beliefs and values whose members reside in a given location (such as a village or neighbourhood), with the same governance structures, common culture, and sometimes a common origin. Community members have diverse characteristics, are linked by social ties, share common perspectives, and engage in joint actions in geographical

locations or settings. The communities in which children and adolescents living with HIV live may have positive or negative effects on their care, growth, and development. Communities can provide psychosocial, medical, education, information, economic, and other forms of support. Communities can consist of:

- » Extended families, friends or other community members
- » Community-based groups such as peer support groups, savings and loans groups, faith groups
- » Formal community structures such as schools, hospitals, and other government and nongovernmental organisations.

On the other hand, in some situations communities can have adverse impacts on children and adolescents living with HIV. These may include communities with high rates of:

- » Stigma, discrimination, and isolation of HIV-positive persons
- » Drug and alcohol abuse
- » Child abuse, exploitation and neglect
- » Poverty
- » Domestic violence
- » Untreated mental illness
- » Death of caregivers

## ROLE OF HCPs IN COMMUNITY SUPPORT

HCPs can play vital roles in strengthening community support through referrals to, or interactions with, the numerous resources that communities can offer (Box 12.2).

### BOX 12.2. 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.

## PEER SUPPORT GROUPS

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.

Peer support groups help members with treatment and present opportunities to learn about healthy decision-making. HIV peer support groups help HIV-positive children/adolescents, and their caregivers to deal with a wide range of concerns that accompany their HIV diagnosis, and are important allies in the fight against stigma and discrimination. It is important that the HCPs support these groups and establish and maintain effective linkages with other institutions to ensure that peer groups meet the needs of members.

**Peer support groups** for children, adolescents, and caregivers meet to:

- » Exchange information and skills
- » Discuss and help one another address positive and negative experiences
- » Provide extra support to manage symptoms, side effects, and the challenges of lifelong treatment adherence
- » Improve self-esteem of children and adolescents living with HIV and help them become self-supporting.

Other health services can be integrated into peer support groups to increase efficiencies. For example, child support groups can integrate immunisation clinics; nutrition education, demonstration and support; and adherence support. Adolescent support groups can integrate SRH education and linkages to family planning services.

HCPs will need to examine variations and approaches for peer interventions (Box 12.3). It may be best to consider separate peer support groups for different vulnerable groups. These may be for women, men, children, adolescents in and out of school, girls, boys, those disclosed to, those undisclosed to, key populations, and single or married individuals. Each of these groups may require different approaches, based on varying needs. It is helpful to ensure that people are comfortable with, and prepared to take advantage of, the benefits offered by the peer support process. Peer support can also include identifying and training peers to provide individualised support within and outside the clinical setting.

HCPs should also take advantage of the growing opportunities provided by information communication technology to provide support to children and adolescents. While taking national privacy protection guidelines into consideration, electronic support systems such as telephone calls, SMS, and other social media platforms can help to disseminate educational information on HIV prevention, care, and treatment; identify HIV testing, care, and treatment locations; provide appointment reminders and follow-up for missed appointments; and support adherence.

### BOX 12.3. ROLE OF HCPs IN 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

## SCHOOLS

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. 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.

For example, HIV-positive children need time off to visit health facilities for drug refills, and to access routine health services. They also need additional support to help them adhere to treatment and overcome stigma in school settings. Schools can also offer additional counselling to these children. HCPs can improve access to treatment and enhance adherence by taking medications to schools so that they do not have to leave school. However, providers should always be careful that their interventions in schools do not lead to unintended disclosure or increase stigma and discrimination (Box 12.4).

### BOX 12.4. ROLE OF HCPs IN SCHOOLS\*

- » 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

*\*[Note: HIV interventions provided in schools should be in line with country-specific HIV and school policies and guidelines.]*

## FAITH-BASED AND OTHER COMMUNITY SUPPORT ORGANISATIONS

Faith-based and other community support organisations can complement health facility efforts to meet the needs of HIV-positive children and adolescents by providing information, guidance,



counselling, and practical support—including food, education, transport, and clothing. However, some spiritual beliefs may hinder HIV testing, care, and retention. HCPs should dispel negative influences of faith-based agencies while building their positive influences. They should also educate faith leaders on HIV, so that these leaders can in turn play an active role in educating and mobilising their congregations and the community on the importance of HIV testing and care for children and adolescents living with HIV.

## ECONOMIC STRENGTHENING GROUPS

These tend to be target group-specific; for instance, youth or women's groups. HCPs should use such groups to promote health literacy and facilitate referral of community members to benefit from these initiatives and other services for economic strengthening.

## ROLE MODEL AND SUPPORT NETWORKS

Both peers and members of wider networks of people living with HIV can be a source of motivation and support for children, adolescents, and their caregivers. Role models and networks draw on their own experiences to empower others in similar situations. HCPs should identify and build the capacity of these organisations and use their skills to help meet the psychosocial needs of their patients.

## 12.5. HCP SUPPORT

As caregivers, HCPs require support to be able to provide effective care to their patients, especially HIV-positive children/adolescents and their families. HCPs with heavy workloads face both personal and professional risks from stress and burnout. *Stress* is a physical and emotional response to new or difficult situations that, if not addressed through skill-building and other types of support, can lead to physical and mental collapse known as *burnout*.

These risks are very real for all types of HCPs who provide care for HIV-positive children/adolescents and their caregivers—including medical doctors, clinical officers, nurses, counsellors, and social workers, among others. Support for HCPs is often neglected in HIV policy and programming, which compromises the care that children and adolescents receive. This section stresses the need to provide support to HCPs caring for children and adolescents living with HIV and their caregivers; highlights common challenges, and suggests ways to support HCPs and prevent burnout.

## CHALLENGES WORKING WITH CHILDREN AND ADOLESCENTS LIVING WITH HIV

HCPs who work with these complex patients face multiple challenges along the care continuum, some of them related to the individual and the care context (see Box 12.5).

## BOX 12.5. KEY HCP CHALLENGES

- » Inadequate skills and knowledge to effectively provide care for children and adolescents, including counselling and social support
- » Limited training/education/supervision opportunities
- » Lack of tools/equipment and supplies (e.g., toys, drugs)
- » Heavy workload
- » Lack of motivation and recognition
- » Lack of proper working environment (e.g., child-friendly environment)
- » Inadequate health care support systems
- » Lack of a functional referral and support system to meet the needs of children, adolescents, and their caregivers
- » Personal issues getting in the way of appropriate treatment delivery
- » Limited reference materials and guidance
- » Death of children, adolescents, and caregivers, resulting in emotional impacts
- » Stress
- » Burnout

In resource-poor settings, many providers struggle with heavy workloads and a shortage of necessary materials, recognition, training, and supplies (Uebel, Nash, and Avalos 2007; Rujumba, Mbasalaki-Mwaka, and Ndeezi 2010). When these challenges are not addressed, they lead to stress and ultimately to burnout. Certain situations are more stressful than others, and these vary from one to person. Additionally, different people cope with stress differently. Exposure to prolonged periods of unrelieved stress can lead to burnout. The drivers of stress can be from internal and external factors (see Box 12.6).

## BOX 12.6. CAUSES OF STRESS

- » Inadequate skills and knowledge on HIV care for children/adolescents
- » Inability to work as team/lack of support
- » Inability to accept uncertainty
- » Poor life-work balance
- » Poor self-motivation
- » Unrealistic expectations
- » Perfectionism
- » Lack of assertiveness
- » Inadequate supportive supervision
- » Heavy workloads
- » Poor motivation
- » Dysfunctional teams
- » Regular change in policies and guidelines
- » Relationship difficulties
- » Financial problems
- » Other tasks/responsibilities
- » Poor working environment

Effective stress management first requires the ability to recognise stress. Several indicators can help in early identification of stress (see Box 12.7).

## BOX 12.7. INDICATORS OF STRESS

- » **Physical:** Feeling tired, being exhausted and restlessness
- » **Emotional:** Anxiety, depression, mood changes
- » **Cognitive:** Problems with thinking, lack of concentration and forgetfulness
- » **Behavioural:** Frequent absenteeism from work, failure to meet deadlines
- » **Spiritual:** Increased or decreased interest in religion.

There is limited information in resource-limited settings on evaluation and management of stress and burnout among HCPs. Some approaches for relieving stress take place at the individual (see Box 12.8).

## BOX 12.8. INDIVIDUAL STRESS MANAGEMENT STRATEGIES

### Your body

- » Know your stress triggers
- » Recognise early warning signs and symptoms and act on them
- » Practice relaxation techniques such as deep breathing, meditation, rhythmic exercise, and yoga
- » Eat a balanced, healthy diet
- » Exercise regularly
- » Get enough sleep
- » Change environments

### Thinking

- » Worry less about things you can't control, make plans and deal with the things you have control over
- » Set realistic goals
- » Apply problem-solving techniques
- » Have a positive attitude
- » Think positively about yourself

### Behaviour

- » Plan and organise ahead to allow enough time to get tasks done
- » Set priorities
- » Be open and honest with people
- » Seek guidance and support when you are feeling stressed
- » Allow time for recreation and relaxation
- » Reward yourself when you achievement your goals
- » Avoid/limit use of alcohol, caffeine, and other drugs

### Group activities

- » Organise and take part in sports
- » Engage in singing/dancing
- » Participate in joint team visits, meetings, discussions, community, and other social activities

Preventing and managing stress among HCPs requires making adjustments in their working environments. Such interventions can include use of peers, team-building events, mentorship, supportive supervision, continuous professional development, professional associations, conferences, and electronic learning sources (see Box 12.9). Clinical and organisational managers should encourage and develop these opportunities to support and build HCPs' skills and resilience.

Peers can help to identify stress among their colleagues and support them to reduce and manage it through individual and team-building activities. Supportive supervision, training, and mentorship can help to enhance providers' knowledge and skills, which can increase their confidence in carrying out their work properly and thus reduce stress and prevent burnout. Professional associations, conferences, and continuous professional development activities allow HCPs to interact, share experiences, and enhance their knowledge and skills.

HCPs should also take advantage of existing electronic learning and support opportunities to learn and obtain support. These include online courses, online discussion groups, and internet- and telephone-based mechanisms that include call-in support centres, email, and social media platforms. As much as possible, options that allow physical human-to-human interaction should be encouraged. Ensuring that the critical supplies and appropriate environment are in place is key to prevent and manage HCP stress and burnout (see Box 12.9).

## **BOX 12.9. INSTITUTIONAL STRATEGIES TO PREVENT STRESS**

### **Individual work strategies**

- » Attend regular supportive supervision meetings and discuss challenging cases
- » Participate in regular team meetings and share challenging cases and events with colleagues
- » Recognise when you are feeling stressed and find ways to decrease stress (talking with colleagues, taking breaks during day, exercise, relaxation techniques)
- » Attend continuing education activities to increase your knowledge/skills
- » Request assistance in handling challenging situations and cases
- » Find ways to make work fun, and ways to make interactions at work fun

### **Identify and implement administrative measures to prevent stress**

- » Organise regular team meetings/events
- » Know your team and act when you recognise members getting stressed
- » Provide opportunities for continuing education
- » Promote job rotation
- » Provide constructive feedback on work performance
- » Offer performance-based incentives
- » Focus on problem-solving communication (vertical and horizontal)

## **HCPs AS PEER SUPPORTERS**

HCPs themselves have a role to play in ensuring that their fellow providers receive support if they need it. They can:

- » Map out and develop a referral directory of community resources to support HCPs
- » Develop and strengthen interventions geared at meeting HCPs' needs
- » Link stressed HCPs to external resources
- » Continuously monitor and evaluate interventions geared at improving HCPs' capacity and functionality

## Preventing Burnout

Institutions and HCPs can monitor and provide education to prevent burnout in colleagues or in themselves. Burnout—a state of chronic stress that leads to physical and emotional exhaustion, doubt, and detachment—has serious effects on HCPs and on the quality of care that they and the clinic provide.

**Clinical presentation of burnout:** Burnout does not occur suddenly; it builds up slowly, which makes it very difficult to recognise. However, it is important to note that our bodies and minds give us warnings. If one knows what to look for, they can recognise it before it is too late. The following are common features of burnout.

- » **Chronic fatigue:** Lack of energy; feeling tired most days of the week, leading one to feel drained and depleted. One may feel a sense of dread when facing or anticipating work.
- » **Insomnia:** One may have trouble falling or sustaining sleep. As burnout continues, sleep becomes much more difficult to obtain.
- » **Impaired concentration attention and forgetfulness:** Lack of focus and subsequent forgetfulness eventually results in piling up of work with minimal achievements.
- » **Physical symptoms:** These can include increased heartbeat, chest pain, abdominal pain, headache dizziness, chest pain, and fainting.
- » **Loss of appetite:** One may not feel hungry and may miss meals and lose weight.
- » **Anxiety:** Symptoms of tension, worry, and problems in personal life.
- » **Depression:** One may feel sad, hopeless, guilty, or worthless. This at times may lead to impulses towards self-harm. At this point, some HCPs or caregivers can resort to substance use as a way of self-treatment.
- » **Anger:** When interpersonal tension and irritability progresses to outbursts and serious arguments, with eventual potential for violence.
- » **Loss of enjoyment:** May be expressed as reluctance to work and eagerness to leave early. One can totally withdraw from any form of socialisation and eventually become isolated.
- » **Pessimism:** Negative outlook and self-talk, which may lead to trust issues in dealing with workmates and family members.
- » **Detachment:** A general feeling of being disconnected from others or from the environment.
- » **Apathy and hopelessness:** Presents as a general sense that nothing is going right or nothing matters, then deteriorate to helplessness. This can destroy relationships and careers. Some people end up making erratic decisions about retirement or just abandoning work.
- » **Increased irritability:** Feelings caused by ineffectiveness, unimportance, and uselessness.

- » **Lack of productivity and poor performance:** Chronic stress prevents one from being as productive as before and leads to incomplete projects and an ever-increasing to-do list.


Strategies for managing burnout are similar to those for managing the lesser challenge of stress. One should establish normal routines including eating healthy, drinking enough water, and sleeping sufficient amounts. Regaining a sense of normality and recovery is gradual.

HCPs should teach themselves to recognise burnout and the symptoms before further compromise occurs. Also, they should speak with trusted individuals, including counsellors, friends, and family members. Reconnecting with nature through nature/forest walks, viewing wild animals, and observing landscapes and waterfalls can also be productive. It is important to note that stress reduction approaches are unique to each individual.

### **Gender Issues among HCPs**

Gender concerns are an essential element in supporting HCPs. For instance, female HCPs may experience stress from the dual roles and expectations from domestic care roles and the stressors from their health care roles. HCPs, like their patients, may also face gender-based violence. Women may face limited opportunities to advance professionally, given that many occupy lower-level positions in health service provision; this may be a demotivating factor, since these positions command less pay and provide less responsibility, among other limitations. Health care administrators should ensure that policies are in place and implemented so that female providers have the same employment, salary, and promotion opportunities as male providers in order to promote gender equity and a gender-sensitive work environment.





# **CHAPTER 13.**

## **MONITORING AND EVALUATION OF PSYCHOSOCIAL SUPPORT OUTCOMES FOR CHILDREN AND ADOLESCENTS**



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## SUMMARY

- » Monitoring and evaluation (M&E) is critical to developing evidence-based PSS programmes; monitoring programme outputs, outcomes and impact; and adapting programmes based upon data.
  - » M&E is the basis for reporting on results achieved by PSS programmes.
  - » Often, the most effective means of measuring psychosocial well-being is through qualitative measures.
  - » Patient psychosocial assessments can form the basis for identifying psychosocial gaps and service needs and serve as a tool to identify progress over time.
-

## 13.0. INTRODUCTION

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. In this way, information reporting becomes an opportunity to learn from our programmes, to inform decisions, and to assess the impacts of what we do. M&E addresses the following questions when implementing psychosocial interventions:

- » What is the PSS intervention meant to change?
- » Whom is it benefitting?
- » Is the PSS intervention on track?
- » How do I know if there is something wrong in a PSS intervention?
- » What do I need to adjust to improve it?
- » How do I know if the PSS intervention is bringing about the change I want?

## 13.1 MONITORING AND EVALUATION

Monitoring and evaluation are two different processes that are interconnected and complementary:

- » **Monitoring** is a continuous process of collecting and analysing information to compare how well a project or programme is being implemented against expected results. Monitoring aims to provide managers and other stakeholders with regular feedback and early indications of progress (or lack of progress) in the achievement of intended results. It generally entails collecting and analysing data on implementation processes, strategies and results, and recommending corrective measures.
- » **Evaluation** is the systematic and objective assessment of an ongoing or completed project or programme, its design, implementation, and results. Evaluation determines the relevance and fulfilment of objectives, efficiency, effectiveness, impact, and sustainability. An evaluation should provide credible, useful information, leading to the incorporation of lessons learned into the decision-making process of both recipients and donors.

M&E of most psychosocial interventions tends to largely remain at *output* level (for example; counting number of adolescents/children who received PSS services) rather than measuring *outcomes* (i.e., changes in attitude, skills or practices. For example; reduced troubling thoughts or increased ability of a child to cope with stress) or *impacts* (for example, improved social and emotional well-being of a child). It is important for HCPs to assess whether or not their interventions are leading to the expected change for children, adolescents, and their families and/or communities within the core psychosocial domains. When data show that the expected change is not occurring, early intervention is needed to address PSS care gaps and move towards more favourable outcomes.

### Psychosocial Well-Being Indicators

Indicators measure changes related to implementation of an intervention. They can be either quantitative or qualitative. More details on these indicators appear in Table 13.1. Qualitative

indicators provide the best opportunity to collect in-depth information about psychosocial well-being. There are three typical psychosocial response outcomes indicators, which all contribute to the measurement of psychosocial well-being.

- » **Emotional well-being is improved:** Children have trust, hope for the future, a sense of control and are less stressed.
- » **Social well-being is improved:** Children gain the ability to interact with and assist others and solve problems actively.
- » **Skills and knowledge are improved:** Children learn to resolve conflicts and gain other new skills from their participation in psychosocial activities.

**Table 13.1. Psychosocial Domains and Key Indicators (Southern African Development Community 2011)**

PSYCHOSOCIAL DOMAIN	OUTCOMES	INDICATORS
<p><b>Emotional well-being (intrapersonal)</b></p> <p>Refers to an individual's capacity to live a full and creative life and the flexibility to deal with life's inevitable challenges. The intrapersonal area concerns people's ability to know and manage themselves and what they are doing in their lives. This includes self-awareness and a sense of self-worth, control over one's behaviour, realistic beliefs, spiritual appreciation or belief in one's purpose, independence, feeling safe and happy, and having hope for the future.</p>	<ul style="list-style-type: none"> <li>» Reduced troubling thoughts and feelings.</li> <li>» Children show more self-confidence.</li> <li>» Increase of children's ability to cope with stress.</li> </ul>	<p><b>Measures of improved emotional adjustment</b></p> <ol style="list-style-type: none"> <li>1. Reduced number of bad dreams/nightmares as reported by children, adolescents and parents.</li> <li>2. Children/adolescents can name things that they are good at and proud of about themselves.</li> <li>3. Number of daily life (social, cultural, recreational) activities that children enjoy as reported by children/adolescents and parents.</li> </ol>
<p><b>Social well-being: improved social engagement</b></p> <p>Concerns the ability to interact and get along with others. Social well-being refers to the extent and quality of social interactions. This includes relationships with caregivers, family members and peer groups, developing social networks, sense of belonging to a community, ability to communicate, social responsibility, empathy, and participation in social and cultural activities.</p>	<ul style="list-style-type: none"> <li>» Improved social relations in home.</li> <li>» Improved social relations at school.</li> <li>» Improved social relations in the community.</li> </ul>	<p><b>Measures of improved social functioning</b></p> <ol style="list-style-type: none"> <li>1. Reduced number of negative (verbal and physical) interactions at home as reported by children and parents/caregivers.</li> <li>2. Cooperative behaviour with peers as reported by children.</li> <li>3. Child seeks for help to solve his/her problems in the community.</li> </ol>

PSYCHOSOCIAL DOMAIN	OUTCOMES	INDICATORS
<p><b>Skills and knowledge or competencies</b></p> <p>The ability to cope with life's demands and stresses and to manage relationships well. This includes skills like problem-solving, planning and decision-making, stress management, negotiation, assertiveness, using culturally appropriate coping mechanisms, and the ability to assess their own abilities and strengths in relation to their needs. It also includes the capacity to detect, refer, and manage mental illness alongside specialised mental health services.</p>	<ul style="list-style-type: none"> <li>» Increased positive self-expression among children.</li> <li>» Increased problem-solving skills.</li> </ul>	<p><b>Measures of acquisition of skills</b></p> <ol style="list-style-type: none"> <li>1. Number of children able to share feelings and opinions with other children, parents and teachers as reported by children and parents.</li> </ol>
<p><b>Service delivery</b></p> <p>The programme shows the number of children and adolescents screened for PSS, referrals made, the number of children and adolescents who received PSS (disaggregated by age and sex). Also: recording the number of children and adolescents with positive psychosocial outcomes during a specified period.</p>	<ul style="list-style-type: none"> <li>» Increased number of children and adolescents referred for PSS and achieve positive psychosocial outcomes.</li> </ul>	<p><b>Measures of coverage of PSS interventions</b></p> <ol style="list-style-type: none"> <li>1. Number of children and adolescents screened for PSS.</li> <li>2. Number of children referred for PSS</li> <li>3. Number of children who received PSS, disaggregated by age and sex.</li> <li>4. Number of children with positive psychosocial outcomes during a specified period.</li> <li>5. Number of children with negative psychosocial outcomes during a specified period</li> </ol>

## 13.2. BASELINE ASSESSMENTS

A psychosocial assessment should be conducted with each child and adolescent patient before the psychosocial intervention using an assessment/screening tool (Table 13.2 provides an example). HCPs should 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. Providers should also make sure that the patient and/or parents/caregivers have time to ask questions, allows time to summarise the session, and agree upon next steps.

The psychosocial assessment tool provided in this Handbook was developed to support HCPs with assessing and responding to the patient's psychosocial needs. It explores key aspects of their life including moods, activities, alcohol/substance abuse, sexual health, disclosure, stigma, friends and support, living situation, and adherence and retention in care. This format encourages the adolescent to ask questions as well as to identify areas of concern.

HCPs may want to conduct a follow-up psychosocial assessment or revisit specific psychosocial issues when a patient's situation changes in a significant way, such as when a patient reaches a new developmental stage or starts to show signs that he or she is facing new challenges. Key information from the psychosocial assessment should be recorded on the form, which should be kept in the patient's file for reference during follow-up visits.

**Table 13.2. 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](http://files.icap.columbia.edu/files/uploads/Intro_TM_Adolescent.pdf).*

## 13.3. ROUTINE DATA RECORDING AND ASSESSING PSYCHOSOCIAL OUTCOMES

During every psychosocial visit, HCPs should record the patient's progress in dealing with the causes of psychosocial distress using a psychosocial monitoring tool for children (an example is in Table 13.3). Providers should document other patient concerns that require additional support and follow-up during subsequent psychosocial support visits.

**Table 13.3. 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?

At the end of the agreed psychosocial support period, an assessment of the outcomes of the intervention should be done using the Psychosocial Evaluation Tool for children (an example is in Table 13.4).

**Table 13.4. Psychosocial Evaluation Tool**

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

*Interpretation of the total scores of each psychosocial domain \* (3-6 No change, 7-11 Moderate positive change, 12-15 Significant positive change).*



## 13.4. REPORTING

Psychosocial outcomes should be reported based on the baseline/outcome indicators, comparing baseline indicators and outcome indicators to assess progress at the end of the psychosocial intervention in keeping with national data collection guidelines/practices.

The report should cover the major psychosocial issues identified at baseline, and quantitative and qualitative results of the psychosocial support intervention (see Assessment Guide in Table 13.2). A psychosocial intervention report consists of the following:

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

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# ADDITIONAL RESOURCES

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Resources for the Clinical Management of Children and Adolescents Who Have Experienced Sexual Violence: <https://aidsfree.usaid.gov/collections/resources-clinical-management-children-and-adolescents-who-have-experienced-sexual>

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# **APPENDIX I.**

## **MINIMUM PACKAGE FOR HIV-EXPOSED AND HIV-POSITIVE CHILDREN<sup>II</sup>**



SERVICE	KEY ELEMENTS TO CONSIDER WHEN OFFERING THE SERVICE PACKAGE	DOCUMENTS TO GUIDE IMPLEMENTATION	TOOLS AND EQUIPMENT
<b>Early determination of exposure and infection status</b>	<ul style="list-style-type: none"> <li>» Identify HIV-exposed and –infected infants at entry points (maternity ward, OPD, YCC, nutrition wards, paediatric wards, TB clinic, ART clinic)</li> <li>» Provide PITC for children at entry points (consider appropriate tests for those &lt; or &gt; 18 months)</li> <li>» Provide HTS to family members</li> <li>» Offer pre-test counselling messages</li> <li>» Offer post-test counselling messages for both HIV-negative and HIV-infected breast feeding infants</li> <li>» Refer to mother-baby care point or ART clinic and physically escort patient to point of care</li> <li>» Document in appropriate data tracking tools accurately, consistently and completely</li> <li>» Schedule for EID sample transportation</li> <li>» Follow-up HIV results from laboratory; return to health facility in real time; document results accurately, consistently and completely; return to mother-baby pair for clinical follow-up.</li> </ul>	<ul style="list-style-type: none"> <li>» National guidelines</li> <li>» HCT policy</li> <li>» Screening tool for HIV testing in children and adolescents</li> </ul>	<ul style="list-style-type: none"> <li>» EID register</li> <li>» HCT register</li> <li>» HCT patient cards</li> <li>» Triplicate referral forms</li> <li>» Exposed infant register</li> <li>» DBS kit</li> <li>» Mothers' health passport</li> <li>» HIV-exposed Infant Card</li> </ul>

SERVICE	KEY ELEMENTS TO CONSIDER WHEN OFFERING THE SERVICE PACKAGE	DOCUMENTS TO GUIDE IMPLEMENTATION	TOOLS AND EQUIPMENT
<p><b>Growth and development monitoring for HIV-exposed/infected children</b></p>	<ul style="list-style-type: none"> <li>» Assess growth and development parameters at every visit</li> <li>» Put a growth chart in every child's file</li> <li>» Monitor growth and provide appropriate care and referral (nutrition, HIV care)</li> <li>» Counsel on growth/development monitoring</li> </ul>	<ul style="list-style-type: none"> <li>» Consolidated job aid</li> <li>» Exposed infant care guideline</li> </ul>	<ul style="list-style-type: none"> <li>» Growth charts/ Mothers' health passport</li> <li>» Outpatient therapeutic care register</li> <li>» MUAC tapes</li> <li>» HC tapes</li> <li>» EID/HIV clinical chart</li> <li>» Infantometer</li> <li>» Stadiometer</li> <li>» HIV-exposed infant card for unknown status</li> <li>» Paediatric care and treatment file for confirmed HIV+ children</li> </ul>
<p><b>Nutritional counselling and support</b></p>	<ul style="list-style-type: none"> <li>» Age-appropriate vitamin A supplementation</li> <li>» Deworming as per national recommendations</li> <li>» Counsel on optimal infant feeding: breastfeeding, weaning, complementary feeds with maternal ART</li> <li>» Conduct a nutritional assessment at each visit</li> <li>» Continuous monitoring of nutritional status</li> <li>» Provide appropriate nutritional support: counselling, in-patient care, therapeutic feeds, referral where necessary</li> </ul>	<ul style="list-style-type: none"> <li>» Consolidated job aid</li> </ul>	<ul style="list-style-type: none"> <li>» Growth charts</li> <li>» Outpatient therapeutic care register</li> <li>» MUAC tapes</li> <li>» HC tapes</li> <li>» EID/HIV clinical chart</li> <li>» Infantometer</li> <li>» Stadiometer</li> </ul>

SERVICE	KEY ELEMENTS TO CONSIDER WHEN OFFERING THE SERVICE PACKAGE	DOCUMENTS TO GUIDE IMPLEMENTATION	TOOLS AND EQUIPMENT
<b>Routine health maintenance (immunisation, safe water, ITNs)</b>	<ul style="list-style-type: none"> <li>» Check status of immunisation at every clinic visit,</li> <li>» Immunise as required/refer for the service</li> <li>» Provide basic care kit</li> <li>» Educate on use and importance of the basic care package kit</li> </ul>	<ul style="list-style-type: none"> <li>» Exposed infant care guidelines</li> </ul>	<ul style="list-style-type: none"> <li>» Mothers' health passport</li> <li>» Child health card</li> </ul>
<b>Early identification and treatment of acute infections</b>	<ul style="list-style-type: none"> <li>» Screen for common childhood illnesses at each visit</li> <li>» Classify and treat infection</li> <li>» Refer for specialised care if needed</li> </ul>	<ul style="list-style-type: none"> <li>» IMCI algorithm</li> <li>» Exposed infant care guideline</li> <li>» National clinical guidelines</li> </ul>	<ul style="list-style-type: none"> <li>» Exposed Infant Card</li> <li>» HIV care clinical cards</li> <li>» EID register</li> </ul>
<b>OI screening, prophylaxis and treatment</b>	<ul style="list-style-type: none"> <li>» Screen for common OIs at each visit (PIP and cryptococcal disease)</li> <li>» Provide cotrimoxazole prophylaxis</li> <li>» Provide fluconazole when indicated</li> </ul>	<ul style="list-style-type: none"> <li>» National clinical guidelines</li> <li>» National guidelines</li> </ul>	<ul style="list-style-type: none"> <li>» EID and HIV care clinical cards</li> <li>» EID register</li> <li>» ART register</li> </ul>
<b>TB: TB screening, prophylaxis and treatment</b>	<ul style="list-style-type: none"> <li>» Screen for TB at each clinical visit</li> <li>» Provide isoniazid preventive therapy after ruling out active TB</li> <li>» Provide anti-TB medication and DOT for patients on treatment</li> <li>» MDR-TB</li> </ul>	<ul style="list-style-type: none"> <li>» ICF guide for PLHIV</li> <li>» National HIV guidelines</li> <li>» TB/HIV policy guidelines</li> <li>» Health workers guide on INH preventive therapy</li> <li>» MDR-TB treatment guidelines</li> </ul>	<ul style="list-style-type: none"> <li>» Presumptive TB register</li> <li>» TB Unit register</li> <li>» MDR-TB register</li> </ul>
<b>MDR-TB: surveillance, diagnosis and treatment with second-line drugs</b>	<ul style="list-style-type: none"> <li>» Use of GeneXpert testing following the National algorithm to detect rifampicin-resistant patients and confirmatory diagnosis of MDR-TB by culture and sensitivity</li> <li>» Referral to MDR-TB treatment sites</li> <li>» Management and treatment of MDR-TB using second-line drugs (mixed model—both ambulatory and inpatient care)</li> <li>» DOT for patients on treatment</li> </ul>		

SERVICE	KEY ELEMENTS TO CONSIDER WHEN OFFERING THE SERVICE PACKAGE	DOCUMENTS TO GUIDE IMPLEMENTATION	TOOLS AND EQUIPMENT
<b>ARV prophylaxis, treatment and monitoring (preparation and initiation)</b>	<p><b>HIV-exposed infant</b></p> <ul style="list-style-type: none"> <li>» Provide NVP prophylaxis at birth or earliest opportunity thereafter</li> </ul> <p><b>HIV-infected infant</b></p> <ul style="list-style-type: none"> <li>» Initiate ART according to national guidelines</li> <li>» Conduct accurate, consistent and timely documentation into appropriate data tools</li> <li>» Provide adherence counselling and support at every visit</li> </ul>	<ul style="list-style-type: none"> <li>» National guidelines</li> <li>» National adherence strategy</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care clinical cards</li> <li>» EI clinical cards</li> <li>» EID register</li> <li>» ART register</li> </ul>
<b>Psychosocial support and palliative care</b>	<ul style="list-style-type: none"> <li>» Provide adherence counselling and support at every visit</li> <li>» Establish family clinic days</li> <li>» Enrol and engage mothers in family support groups</li> <li>» Establish children support groups</li> <li>» Facilitate disclosure of HIV status to child by 10 years</li> <li>» Link to other community support structures and OVC programmes</li> <li>» Link to palliative care programmes</li> <li>» Pain management</li> <li>» Bereavement support</li> <li>» Provide preventive interventions (oral care, bed sores, pain relief)</li> <li>» Manage key symptoms (pain, weight loss, vomiting)</li> <li>» End-of-life care</li> </ul>	<ul style="list-style-type: none"> <li>» Consolidated guidelines</li> <li>» Family Support Groups manuals</li> </ul>	<ul style="list-style-type: none"> <li>» FSG register</li> <li>» HIV care card</li> <li>» Family planning register</li> </ul>

SERVICE	KEY ELEMENTS TO CONSIDER WHEN OFFERING THE SERVICE PACKAGE	DOCUMENTS TO GUIDE IMPLEMENTATION	TOOLS AND EQUIPMENT
<b>Adherence and retention support for HIV-exposed infants and infected children</b>	<ul style="list-style-type: none"> <li>» Provide care for mother and baby together for infants under 18 months</li> <li>» Voluntary family planning counselling and service delivery</li> <li>» Use the appointment book to track appointments</li> <li>» Generate weekly lists of missed appointments</li> <li>» Follow-up missed appointments using phone calls, home visits</li> <li>» Conduct district inter-facility meeting to track lost patients</li> <li>» Community engagement by the health facility: Community sensitisation, radio talk shows, community outreaches</li> <li>» Mobile technology: SMS reminders, social media support such as WhatsApp groups</li> <li>» Innovative approaches to appointments, such as family clinics and whole family appointments</li> </ul>		<ul style="list-style-type: none"> <li>» Patient appointment book</li> <li>» Clinic Appointment registers/ Clinic diaries</li> <li>» Mobile phones</li> </ul>

# **APPENDIX II.**

## **MINIMUM CARE PACKAGE FOR ADOLESCENTS LIVING WITH HIV<sup>12</sup>**

SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<b>HIV counselling/testing as the entry into care</b>	<ul style="list-style-type: none"> <li>» Active identification of ALHIV</li> <li>» Stigma elimination surrounding testing</li> <li>» Support sensitisation and demand creation for HCT</li> <li>» Provide PITC in school settings, youth-friendly centres, and communities and PITC at health facilities</li> <li>» Refer and link all positives to care and refer HIV-negative to prevention follow-up, preferably active linkage through patient escort or youth peer navigator where possible., escort, referral forms</li> </ul>	<ul style="list-style-type: none"> <li>» HCT policy</li> <li>» HCT implementation guidelines</li> <li>» PITC job aids</li> </ul>	<ul style="list-style-type: none"> <li>» HCT register</li> <li>» HCT patient card</li> <li>» ANC register</li> </ul>
<b>HIV prevention services</b>	<ul style="list-style-type: none"> <li>» Provide health education and information on ABC</li> <li>» Provide PEP</li> <li>» Positive health, dignity and prevention service (risk-reduction counselling, partner testing, STI screening, family planning, condoms, adherence support)</li> <li>» Provide safe male circumcision services</li> </ul>	<ul style="list-style-type: none"> <li>» HIV prevention strategy</li> <li>» PEP guidelines</li> <li>» VMCMC guidelines</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> <li>» SMC register</li> <li>» Family planning register</li> </ul>
<b>Growth and development monitoring and counselling</b>	<ul style="list-style-type: none"> <li>» Assess growth and development parameters at every visit (Tanner's staging)</li> <li>» Put a growth chart in every adolescent's file</li> <li>» Monitor growth and development and provide appropriate counselling</li> <li>» Documentation of menarche for girls</li> <li>» Counselling regarding personal adolescent hygiene practices</li> </ul>	<ul style="list-style-type: none"> <li>» Growth reference charts</li> </ul>	<ul style="list-style-type: none"> <li>» Growth charts</li> <li>» Outpatient therapeutic care register</li> <li>» HIV clinical chart</li> <li>» Stadiometer</li> </ul>

SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<b>Nutritional assessment, counselling and nutritional support</b>	<ul style="list-style-type: none"> <li>» Nutrition assessment using anthropometry measures (i.e.,: weight, height, MUAC)</li> <li>» Categorise</li> <li>» Nutrition counselling and education</li> <li>» Nutritional supplements, i.e., iron or folate</li> <li>» Food by prescription: inpatient/outpatient nutritional care</li> <li>» Follow-up</li> <li>» Community linkages to OVC programmes</li> <li>» Nutritional demonstrations of a balanced diet</li> <li>» Referral for nutritional services</li> </ul>	<ul style="list-style-type: none"> <li>» National HIV guidelines</li> <li>» Growth reference charts</li> <li>» Guidelines for Nutritional Care and Support for People Living with HIV/AIDS.</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> </ul>
<b>Opportunistic infection (OI) screening, prevention, and treatment</b>	<ul style="list-style-type: none"> <li>» Screen for common OIs at each visit (PJP and cryptococcal disease)</li> <li>» Provide cotrimoxazole prophylaxis</li> <li>» Provide fluconazole when indicated</li> <li>» Document stage on clinical charts</li> <li>» Provide basic care kit which includes insecticide-treated bednet, safe-water vessel and chlorine-water treatment</li> </ul>	<ul style="list-style-type: none"> <li>» National HIV guidelines</li> <li>» National policy guidelines for cotrimoxazole prophylaxis</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> </ul>



SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<p><b>TB: TB screening, prophylaxis and treatment</b></p>	<ul style="list-style-type: none"> <li>» Screen for TB at each clinical visit</li> <li>» Provide isoniazid preventive therapy after ruling out active TB</li> <li>» Provide anti-TB medication and DOT for patients on treatment</li> <li>» Screen for MDR-TB</li> </ul>	<ul style="list-style-type: none"> <li>» National HIV guidelines</li> <li>» National TB guidelines</li> <li>» TB/HIV collaborative policy guidelines</li> <li>» Health workers' guide on INH preventive therapy</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> <li>» ART register</li> </ul>
<p><b>MDR-TB: surveillance, diagnosis and treatment with second-line drugs</b></p>	<ul style="list-style-type: none"> <li>» Use of GeneXpert testing following the national algorithm to detect rifampicin-resistant patients and confirmatory diagnosis of MDR-TB by culture and sensitivity</li> <li>» Referral to MDR-TB treatment sites</li> <li>» Management and treatment of MDR-TB using SLDs (Mixed model- both ambulatory and inpatient care).</li> <li>» DOTS for patients on treatment</li> </ul>		

SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<b>SRH</b>	<ul style="list-style-type: none"> <li>» Conduct sexual health and activity assessments</li> <li>» Sexuality education (provide accurate and age-appropriate information on SRH, counsel on menstruation hygiene, provide BCC materials)</li> <li>» Screen and treat for STIs (syphilis test)</li> <li>» Counsel and provide voluntary and informed dual Family planning services.</li> <li>» Immunise against tetanus, HPV, hepatitis B</li> <li>» Pregnancy test</li> <li>» Provide emergency contraception with informed consent</li> <li>» Reproductive life planning and counselling to assess pregnancy desires</li> <li>» Preconception planning and discussion regarding family planning method and safe pregnancy</li> <li>» Provide maternal and child health services (ANC, PAC, delivery )</li> <li>» Screen and provide SGBV services</li> <li>» Provide eMTCT services referral system (information, contraception services, family planning, SGBV, ANC, PNC, PAC, legal services)</li> <li>» Screen for cancer (cervical and breast) and refer where applicable</li> <li>» Link to psychosocial support groups and active community tracking of mother-baby pairs</li> </ul>	<ul style="list-style-type: none"> <li>» The national adolescent health policy guidelines and service standards</li> <li>» Adolescent health strategy</li> <li>» National training curriculum for health workers on adolescent</li> <li>» Participants manual for ASRH for training VHTs</li> <li>» A handy desk reference tool for health workers-a step-by-step guide for ADH provision</li> <li>» USG/PEPFAR care and treatment consultation report, Dec 2010</li> <li>» HCT policy</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> <li>» ANC, Maternity, PNC, family planning, FSR registers</li> </ul>

### Counselling and psychosocial support

#### Counselling:

- » Prevention of HIV transmission (positive health prevention and dignity)
- » Safer sex and condom use
- » Disclosure and partner testing
- » Positive living and treatment adherence
- » STI education
- » Family planning and safer pregnancy
- » Alcohol and other risk reduction

#### Disclosure:

- » Counsel and support parents/caregivers to disclose to adolescents (both vertically infected and horizontally)
- » Support and empower adolescents to disclose their HIV status to significant others.
- » Link to peer support groups

#### For newly enrolled, initial counselling includes:

- » Benefits of ART and adherence
- » HIV infection, treatment and prognosis
- » Importance of routine follow-up with the health care system
- » Importance of family HIV counselling and testing
- » Importance of TB screening and prevention
- » Disclosure
- » Stigma
- » Enrol and engage support groups.
- » Use peers to give health education and counselling.
- » Link and refer to community support structures (self-coordinating entities, networks of people living with HIV) and OVC programmes
- » Link to IGAs
- » Mobilise and sensitise for demand creation
- » Education on navigating the clinic and health system including services available in the clinic, expected number of visits, medication pick up, ancillary services (mental health, social work, SRH), as well as problem-solving regarding transportation to the clinic.
- » Link to peer mentors/navigators/expert clients
- » Counselling using the HEEDSSS framework (see **Appendix III**)

- » National ART guidelines
- » National Psychosocial support guidelines

- » HIV Care Card

SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<b>ART preparation, initiation and monitoring</b>	<ul style="list-style-type: none"> <li>» Psychosocial preparation</li> <li>» Educate on benefits of ART and adherence.</li> <li>» Develop a care and treatment plan with patients</li> <li>» Monitoring</li> <li>» Assess ART adherence and offer ongoing counselling and support at each visit</li> <li>» Assess and manage side effects and toxicities at each visit</li> <li>» Assess for treatment failure</li> <li>» Hold switch meeting before switching patients' treatment</li> <li>» *For lab tests, refer to laboratory services above</li> </ul>	<ul style="list-style-type: none"> <li>» National ART guideline</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> <li>» Pre-ART and ART register</li> </ul>

SERVICE PACKAGE	KEY ELEMENTS TO CONSIDER WHEN PROVIDING A SERVICE	DOCUMENTS GUIDING THE IMPLEMENTATION	TOOLS
<p><b>Adherence and retention into care</b></p>	<ul style="list-style-type: none"> <li>» Counsel caregivers and adolescents on the benefits of good adherence</li> <li>» Link adolescents with adherence support groups</li> <li>» Employ use of adherence reminders</li> <li>» Schedule appointments using appointment book.</li> <li>» For clinically stable patients, at least every 3 months For clinically unstable patients: as and when indicated</li> <li>» Generate weekly lists of missed appointments</li> <li>» Follow-up missed appointments using phone calls, home visits</li> <li>» Conduct district inter-facility meeting to track lost patients.</li> <li>» Provide peer-led counselling (both individual and group)</li> <li>» Transition</li> <li>» Sensitisation of care givers and adolescents</li> <li>» Preparation, planning, orientation of caregivers and adolescents on transition</li> <li>» Build skills for self-management of adolescents</li> <li>» Develop and document a transition plan with key timelines</li> <li>» Establish transition clinics</li> </ul>	<ul style="list-style-type: none"> <li>» National ART guideline</li> </ul>	<ul style="list-style-type: none"> <li>» HIV care card</li> <li>» ART register</li> <li>» MOH appointment book</li> </ul>
<p><b>Mental health support</b></p>	<ul style="list-style-type: none"> <li>» Provide information on risk/harm reduction</li> <li>» Screen for alcohol and substance abuse</li> <li>» Screen for mental illnesses and disorders (anxiety, stress, depression, conversion disorders, etc.)</li> <li>» Referral for mental health services</li> <li>» Sensitisation of staff on mental illness symptoms</li> <li>» IEC distribution on mental health</li> </ul>		<ul style="list-style-type: none"> <li>» HIV care card</li> </ul>

**APPENDIX III.**  
**HOME-**  
**EDUCATION/EMPLOYMENT-**  
**EATING-ACTIVITIES-**  
**DRUGS-SEXUALITY-**  
**SUICIDE/DEPRESSION-**  
**SAFETY (HEEADSSS)**  
**TOOL FOR ADOLESCENTS<sup>13</sup>**

COMPONENT	AREA OF ASSESSMENT (TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMIZE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCP).	ASSESSMENT RESULTS
<b>Home, Situation, Family</b>	<ul style="list-style-type: none"> <li>» Who lives with the young person? Where?</li> <li>» Do they have their own room?</li> <li>» What are their relationships like at home?</li> <li>» What do their parent and relatives do for a living? Ever institutionalised? Incarcerated? Recent moves? Running away?</li> <li>» New people in the home environment?</li> <li>» Have they disclosed their HIV status? If yes, to whom? If not, what are the reasons?</li> </ul>	
<b>Education and Employment</b>	<ul style="list-style-type: none"> <li>» School/grade performance—any recent changes? Any past dramatic changes?</li> <li>» Favourite subjects—worst subjects? (include grades)</li> <li>» Any years repeated/classes failed?</li> <li>» Suspension, termination, dropping out?</li> <li>» Future education/employment plans?</li> <li>» Any current or past employment?</li> <li>» Relations with teachers, employers—school, work attendance?</li> </ul>	

**COMPONENT**

**AREA OF ASSESSMENT**

(TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMIZE SHARING OPPORTUNITIES AND MINIMIZE CONCERNS REGARDING JUDGEMENT FROM THE HCP).

**ASSESSMENT RESULTS**

**Activities**

- » On own, with peers (what do you do for fun? where? when?)
- » With family?
- » Sports—regular exercise?
- » Religious attendance, clubs, projects?
- » Hobbies—other activities?
- » Reading for fun—what?
- » TV—how much weekly—favourite shows?
- » Favourite music?
- » Does the young person have a car, use seat belts?
- » History of arrests—acting out—crime?

**Drugs/Tobacco/  
Alcohol**

- » Use by peers? Use by a young person? (include tobacco, alcohol)
- » Use by family members? (include tobacco, alcohol)
- » Amounts, frequency, patterns of use/abuse, and car use while intoxicated?
- » Source—how did they pay for the substance?

**Sexuality**

- » Do you like boys, girls, both or neither?
- » Have you had sex? Vaginal sex? Anal sex? If yes, did you use a condom?
- » The number of partners?
- » Masturbation? (normalise)
- » History of pregnancy/abortion?
- » Sexually transmitted diseases—knowledge and prevention?
- » Contraception? The frequency of use? Comfort with sexual activity, enjoyment/pleasure obtained?
- » History of sexual/physical abuse?



COMPONENT	AREA OF ASSESSMENT (TAKE CARE TO NORMALISE THE QUESTIONS TO MAXIMIZE SHARING OPPORTUNITIES AND MINIMISE CONCERNS REGARDING JUDGEMENT FROM THE HCP).	ASSESSMENT RESULTS
<p><b>Suicide/ Depression</b></p>	<ul style="list-style-type: none"> <li>» Sleep disorders (usually induction problems, also early/frequent waking or greatly increased sleep and complaints of increasing fatigue)</li> <li>» Appetite/eating behaviour changes</li> <li>» Feelings of 'boredom'</li> <li>» Emotional outbursts and highly impulsive behaviour</li> <li>» History of withdrawal/isolation</li> <li>» Hopeless/helpless feelings</li> <li>» History of past suicide attempts, depression, psychological</li> <li>» History of suicide attempts in family or peers</li> <li>» History of recurrent serious 'accidents'</li> <li>» Psychosomatic symptomology</li> <li>» Suicidal ideation (including significant current and past losses)</li> <li>» Decreased affect at the interview, avoidance of eye contact—depression posturing</li> <li>» Have you thought of harming yourself or others?</li> </ul>	

## **APPENDIX IV.**

# **POSITIVE HEALTH, DIGNITY, AND PREVENTION**

Positive health, dignity, and prevention (PHDP) is a dynamic package of services that facilitates leading a lifestyle by people living with HIV (PLHIV) that is complete and healthy with reduced risk of transmission of the virus to others. The primary goal of PHDP is to improve PLHIV resiliency, dignity, quality, and length of life of people living with HIV; if achieved, this will, in turn, have a beneficial impact on their partners, families, and communities, including reducing the likelihood of new infections. PHDP is characterised by its systematic delivery of a range of combination, behavioural, and sociocultural services within local communities. PHDP highlights the importance of placing the person living with HIV at the centre of managing their health and well-being. It also emphasises the leadership roles of people living with HIV in responding to policy and legal barriers within the sociocultural and legal contexts in which they live, and in driving the agenda forward towards better health and dignity. PHDP stresses the importance of addressing prevention and treatment simultaneously and holistically

Interventions that constitute the PEPFAR minimum package of services for PHDP include:

1. Consistent condom use and risk-reduction counselling
2. Assessment of partner status and provision of partner testing or referral for partner testing
3. Assessment for STIs and provision of or referral for STI treatment (if indicated, and partner treatment if indicated)
4. Assessment of family planning needs and provision of contraception or safer pregnancy counselling or referral for family planning services
5. Assessment of adherence and support or referral for adherence counselling
6. Referral or enrolment of PLHIV to community-based programmes, such as home-based care, support groups, and post-test clubs.

Based on context and sociocultural environment PHDP package of services may vary, adding to or adapting the above list to fit. However, most importantly these services must be delivered in a manner agile enough to address any forms of stigma and discrimination that acts as barriers to PLHIV resiliency and ability for living life to the fullest.

# **APPENDIX V.**

## **OTHER IMPORTANT CHILDHOOD AND ADOLESCENT MENTAL HEALTH DISORDERS**

*These disorders are not more likely to occur among children and adolescents living with HIV, but may be noted as possible comorbid conditions. This information is provided in addition to that in Chapter 4.*

# I. AUTISM

**Definition:** Autism is a disorder of development portrayed by delays and deviations in communication and socialisation. Affected children either have delayed or odd speech pattern of using one word to communicate, enjoy playing alone (don't enjoy playing with fellow children), flap their fingers and appear to be in a world of their own. Table VI describes the clinical features of autism.

**Management;** Autism alone is incapacitating, especially in achieving personal independence. Autism worsens the HIV morbidity among children or adolescents with HIV. The care of an autistic child is already demanding enough for the caregiver, and adding a HIV infection can worsen stigma and increase isolation. Any intervention tries to achieve near normal development in the affected areas, minimising the impact of the co-morbidity. The pillar of autism management is a special education programme and behavioural modification.

**Role of HCPs:** The HCP should recognise symptoms of autism and make appropriate referrals to a paediatrician or psychiatrist for further intervention. HCP can also educate the parent or caregiver on maintaining clear structure and routine activities to reduce agitation. HCP can also refer the patient to the special education system as this serves as a pillar of their management.

**Table VI. Diagnosis and Management of Autism**

AUTISM	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Infants and Older Children</b>	<ul style="list-style-type: none"> <li>» Do not develop social smile</li> <li>» Older ones lack the anticipatory posture of being picked up by a caregiver</li> <li>» Poor eye contact is common</li> <li>» May not explicitly acknowledge or differentiate the most important person in their life</li> <li>» Feel and display extreme anxiety when their routine is disrupted</li> <li>» Social behaviours is awkward and inappropriate</li> <li>» Developmental exploratory behaviour is restricted and muted</li> <li>» Toys and objects are often manipulated in a ritualistic manner without symbolic features</li> <li>» Their activities and play are rigid repetitive and more monotonous</li> <li>» They commonly have associated problems such as difficulties in language development, intellectual disability, irritability, insomnia, hyperactivity, and inattention</li> <li>» Precautionary skills and odd response to stimuli, e.g., covering their ears in response to particular sounds</li> </ul>	<ul style="list-style-type: none"> <li>» Early intervention is always the best</li> <li>» Once identified, enrol the child in a kindergarten/nursery school to facilitate interaction with fellow verbal children for speech stimulation and socialisation</li> <li>» In centres with adequate resources, daily speech therapy is advocated</li> <li>» Referral for occupational therapy</li> <li>» Those with severe associated hyperactivity will require medication hence referral to a psychiatrist</li> </ul>

AUTISM	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Early and Middle Childhood</b>	<ul style="list-style-type: none"> <li>» In addition to the above symptoms, ritualistic and compulsive behaviours are common</li> <li>» Enjoy spinning, banging, and watching water flowing</li> <li>» They exhibit compulsive behaviours such as lining up objects and strong attachment to particular inanimate objects</li> <li>» Those who are severely intellectually disabled have increased rates of self-stimulatory and injurious behaviours</li> <li>» They are frequently skilled in visual-spatial tasks than those requiring skills in verbal reasoning</li> <li>» Impaired ability to infer feelings of emotional states of others round them</li> <li>» They have difficulties making attributes about the intentions or motivations of others</li> </ul>	<ul style="list-style-type: none"> <li>» May need medication to control the rituals and self-aggression</li> </ul>
<b>Adolescents</b>	<ul style="list-style-type: none"> <li>» Exhibit fewer gestures in a conversation for those who have speech</li> <li>» Social impairment may be manifested in the lack of initiation and maintenance of a conversation</li> <li>» Exhibit more of absentmindedness and daydreaming</li> <li>» More of inattention and less of restlessness</li> <li>» They find transition or change very intimidating</li> <li>» Affected adolescents often desire relationships and for some, their increase in social competency and skills over time enables them to develop long-term friendship</li> </ul>	<ul style="list-style-type: none"> <li>» Referral to a psychiatrist for medication and advice on behaviours management</li> </ul>

## II. ATTENTION DEFICIT HYPERACTIVITY DISORDER

**Definition:** Attention deficit hyperactivity disorder (ADHD) is a neuropsychiatric disorder affecting preschoolers, children, adolescents, and adults around the world. It is a pattern of sustained inattention, and increased impulsivity or hyperactivity. The symptoms usually appear by the age of twelve years. Table V2 summarises the signs and symptoms, as well as the management of ADHD.

**Role of HCPs:** The HCPs should be able to recognise the affected child/adolescent, explore how the family is coping with the problem and recommend reinforcement of discipline, consistency and order. Once recognised the HCPs should refer to the paediatrician or psychiatrist who is more conversant with medical intervention of ADHD. It is important to note that ADHD can interfere with ART adherence and contribute significantly to family stress.

**Table V2 Diagnosis and Management of ADHD**

LIFE STAGE	SIGNS AND SYMPTOMS	MANAGEMENT
<b>Toddler</b>	<ul style="list-style-type: none"> <li>» Sleep little and cry a lot</li> </ul>	<ul style="list-style-type: none"> <li>» Constitutes a combination of drug therapy and behavioural management</li> <li>» Central nervous system stimulants such as methylphenidate are the first choice of agents because they have the greatest efficacy with generally mild tolerable side effects</li> <li>» Behavioural interventions include psychoeducation, academic organisation skills remediation, and parent training and behaviour modification, both at home and school, and social skills training</li> <li>» It is important to note that when children are helped to structure their environment, their anxiety diminishes</li> </ul>
<b>Preschoolers</b>	<ul style="list-style-type: none"> <li>» More restless and energetic than their peers</li> <li>» Often unable to await their turn in play</li> <li>» Impulsive; unable to delay gratification</li> <li>» Susceptible to accidents</li> </ul>	
<b>Schoolers</b>	<ul style="list-style-type: none"> <li>» Unable to wait for their turn in class setting</li> <li>» Susceptible to accidents</li> <li>» Destructive, fail to finish tasks, lack organisation, forgetful, and jumpy in class</li> <li>» Lose equipment required for day-to-day class work, e.g., pencils, erasers, etc.</li> </ul>	
<b>Adolescents</b>	<ul style="list-style-type: none"> <li>» Absentminded and prone to daydreaming</li> <li>» Inattentive, but less restless</li> <li>» May have specific learning disabilities, speech and hearing deficits</li> <li>» May show behavioural problems (aggression and defiance)</li> <li>» Impacts the child/adolescent's ability to follow instructions and follow through on interpersonal relationships</li> </ul>	

### III. SERIOUS MENTAL ILLNESS

**Definition:** Serious mental illnesses, or SMIs, include schizophrenia, schizoaffective disorder, psychotic disorders, major depressive disorders, bipolar disorders, and borderline personality disorder. Many of these describe a condition in which a person thinks and functions separately from reality. S/he experiences disturbance of perception characterised by hallucinations and disturbances in thinking represented by delusions or odd beliefs not shared by others.

**Clinical presentation:** Patient experiences auditory, visual, tactile, and olfactory sensations that are not present for an observer. Thought disorder shows itself as strange beliefs not shared by others or explained by religion or cultural beliefs. The affected person is out of touch with reality. An example of a common psychosis is schizophrenia.

**Management:** SMIs require the care/treatment from a high-level mental health specialist, such as a psychiatrist. A diagnosis of a SMI may require the introduction of psychotropic medication by a psychiatrist along with supportive care for the family in the form of education and reassurance. SMIs can be very frightening for the family, so the patient must be initiated on medication as soon as possible. Culturally some communities associate SMI with witchcraft; religion associates SMI with demonic forces. These kinds of beliefs can act as an obstacle to health-seeking behaviour and interfere with adherence both to psychotropic and antiretroviral therapies.

**Role of HCPs:** To identify a patient exhibiting symptoms consistent with SMI, and refer to a psychiatrist for care.

**APPENDIX VI.**  
**CATEGORIES OF LIFE SKILLS**



## KNOWING AND LIVING WITH ONESELF

- » **Self-awareness:** This skill includes the recognition of one's self-esteem, identity, internal locus of control, likes, and dislikes. If an adolescent is able to recognise them, then he/she starts believing that they can make a change in the world. Therefore, they start looking at themselves and the world more positively.
- » **Self-esteem:** Self-esteem is how we value ourselves; it is how we perceive our value to the world and how valuable we think we are to others. Self-esteem affects our trust in others, our relationships, our work; nearly every part of our lives. Positive self-esteem gives us the strength and flexibility to take charge of our lives and grow from our mistakes without the fear of rejection.
- » **Making effective decisions:** Refers to the ability through which alternatives are selected and then managed through implementation to achieve objectives. Effective decisions result from a systematic process, with clearly defined elements, that is handled in a distinct sequence of steps.
- » **Assertiveness:** Being assertive means being able to stand up for your own or other people's rights in a calm and positive way, without being either aggressive, or passively accepting "wrong."
- » **Coping with emotions:** Coping with emotions means involving, recognising emotions within us and others, being aware of how emotions influence behaviour and being able to respond to emotions appropriately. Intense emotions like anger or sadness can have negative effects on our health if we do not respond appropriately. Intense emotions, like anger or sorrow can have negative effects on our health if we do not react appropriately.
- » **Coping with stress:** Adolescence is a vulnerable period of development and the rapid developmental changes can cause stress. If proper direction is not given, then the adolescent may feel stressed. Therefore, it is important to empower adolescents with the capacity to recognise the sources of life stress and direct an individual to choose a way that can control the heightened stress level.
- » **Focus and self-control:** To support focus and self-control, we can encourage children to pretend and to make up stories. Give them time to get lost in their imaginations! While pretending, children often use themselves to represent different people, use objects to represent something else, and adapt to changed circumstances. Each of those actions requires "cognitive flexibility," an important skill.

## KNOWING AND LIVING WITH OTHERS

- » **Interpersonal relationships:** Teamwork is required for the successful completion of a project. For example, if one wants to organise an exhibition at school, then one considers who would provide help. It could be the principal, colleagues or teachers. Working with other people towards a common goal like this is known as an “interpersonal” skill. This skill helps an individual to positively relate to other people. Development of this skill enables an individual/ adolescent to be accepted in the society. He/she also develops the acceptance of positive social norms, which is essential to prevent an adolescent developing delinquent behaviour.
- » **Friendship formation:** As a part of growing up, adolescents redefine their relationships with parents, peers and members of the opposite sex. Adults have high expectations from them and often do not understand their feelings. Adolescents need social skills for building positive and healthy relationships with others including peers of the opposite sex. They need to understand the importance of mutual respect and socially defined boundaries of every relationship.
- » **Empathy:** It is an ability to imagine and understand what life is like for another person, even in a situation that you may not be familiar with. It is important for an adolescent to develop a positive outlook towards others and feeling of cooperation, which is necessary for preparing the foundation for adulthood.
- » **Peer pressure/resistance:** Adolescents find it difficult to resist peer pressure. Some of them may yield to these pressures and engage in experimentation. Aggressive self-conduct; irresponsible behaviour and substance abuse involve greater risks with regard to physical and mental health. The experiment with smoking and milder drugs can lead to switching over to hard drugs and addiction at a later stage.
- » **Negotiation:** Sometimes, an individual is put in a situation where he/she does not want to remain for a long time. This induces lot of dissatisfaction in an individual. For example, a child is bullied or abused by his/her classmates. This can put him/her in a state of depression or detachment. Here negotiation skills will help that child/adolescent to negotiate, without getting aggressive towards them and thus helping him/her to become more acceptable.
- » **Effective communication:** Communication is an important process which is used by an individual to transfer ideas, information or feelings to others. Unless the communication is effective, the purpose of communication fails. Effective communication skills help one to express oneself both verbally and non-verbally through gestures, in way that messages are not distorted and it is appropriate to one's culture and situation. Therefore, effective communication includes active listening, ability to express feelings and giving appropriate feedback.

## MAKING EFFECTIVE DECISIONS

- » **Decision-making:** Decision-making is a process to determine alternative and constructive solutions about problems.
- » **Critical thinking:** Critical thinking skills help one to analyse information and experiences in an objective manner. It also helps us to evaluate the influence of decisions taken on our own values and values of people who are near to us. Adolescents are most often influenced by media and peers. This skill can assist them to assess the pros and cons of the situation and help them to evaluate their actions and resulting consequences.
- » **Creative thinking:** Ability to think differently and out of the box; looking beyond our direct experience; responding adaptively; having flexibility to situations in daily life; and achieving the objectives in daily life situations. By thinking creatively, we can find the solutions when it seems that there is no way out. Critical thinking promotes creativity. Just generating new ideas may not work. One needs to generate new ideas which are useful and relevant, and creative thinking helps us in improving ourselves after self-reflection.
- » **Problem-solving:** Ability to identify a problem correctly; understanding its sources and causes constructively. These causes have to be reduced or eliminated. This skill also assists in choosing the best alternative from many to solve the problem.

**APPENDIX VII.**  
**LOPINAVIR/RITONAVIR (LPV/R)**  
**PELLET INFORMATION SHEET<sup>14</sup>**

<sup>14</sup> Resource available at: <http://www.aidsfree.usaid.gov/lpv/>.

## What is the current Paediatric Optimal HIV Formulary? (Interagency Task Team (IATT), World Health Organization, and UNICEF 2016)

	0–2 WEEKS	2 WEEKS–<3 MONTHS	3 MONTHS–36 MONTHS
<b>Preferred</b>	AZT + 3TC + NVP	(ABC or AZT) + 3TC + <b>LPV/r Solution</b>	(ABC or AZT) + 3TC + <b>LPV/r Pellets</b>
<b>Alternative</b>	AZT + 3TC + NVP		(ABC or AZT) + 3TC + <b>LPV/r Pellets</b>

### What are LPV/r pellets? Why are they recommended for young children?

In 2015, the United States Food and Drug Administration tentatively approved a new formulation: *LPV/r 40 mg/10 mg heat-stable pellets in a capsule*.

- » The pellets are approved **only** for use in children above 3 months old **and** weighing more than 5 kilograms.
- » Caregivers should give infants and young children pellets two times each day. **See Weight Band Dosing Table.**
- » For younger children, the pellets are easier to swallow than tablets.
- » The pellets' taste can be masked by breast milk, infant formula, or age-appropriate soft food\*.
- » The pellets do not require refrigeration.

### How do I know if a child I am treating is eligible to take pellets?<sup>15</sup>

LPV/r pellets are appropriate for infants and children who:

7. Weigh 5 kilograms or more, *and*
8. Are 3 months of age or older, *and*
9. Are able to swallow pellets that are taken with expressed breast milk, infant formula, or age-appropriate soft food such as porridge\*.)

\*Mixed feeding is discouraged and complementary feeding starts at 6 months.

### How do I determine the appropriate LPV/r formulation for my patient?

The table below provides a side-by-side comparison to help you determine the appropriate LPV/r formulation.

	PELLETS (40MG/10MG)	SOLUTION (80MG/20MG/ML)	TABLET (100 MG/25MG)
<b>Who should get this formulation?</b>	Patients weighing 5 kilograms or more. Patients 3 months or older. Patients who are able to swallow pellets.	Patients weighing 3 kilograms or more. Patients who are 14 days old or older.	Patients weighing 10 kilograms or more. Patients who are able to swallow the whole tablet without splitting, crushing, or chewing the tablet.
<b>What are the advantages of this formulation?</b>	The pellets do not need to be stored in a refrigerator. The pellets can be taken with soft food or liquid to ease administration.	The solution can be taken with or without food. The solution may be used in patients with a body surface area less than 3 kilograms.	The tablets do not need to be stored in a refrigerator. Tablets can be taken with or without food.
<b>What are the disadvantages of this formulation?</b>	The drug burden for older children might be high. Caregivers may not be familiar with the required way to administer pellets.	The solution has a very unpleasant taste. The solution should be stored in a refrigerator until given to the patient.	Tablets must be taken whole. They cannot be broken, crushed, chewed, or dissolved.

<sup>15</sup> Inter-Agency Task Team (IATT) for Prevention and Treatment of HIV Infection in Pregnant Women, Mother and Children Fact Sheet on Lopinavir and Ritonavir (LPV/r) Oral Pellets.  
[http://apps.who.int/iris/bitstream/handle/10665/193543/FactsheetIATT\\_WHO\\_UNICEF\\_lopinavir\\_eng.pdf?sessionid=544F0E43008A321A3F9169DAF816F7CC?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/193543/FactsheetIATT_WHO_UNICEF_lopinavir_eng.pdf?sessionid=544F0E43008A321A3F9169DAF816F7CC?sequence=1)

# APPENDIX VIII.

## DENVER DEVELOPMENTAL ASSESSMENT TOOL

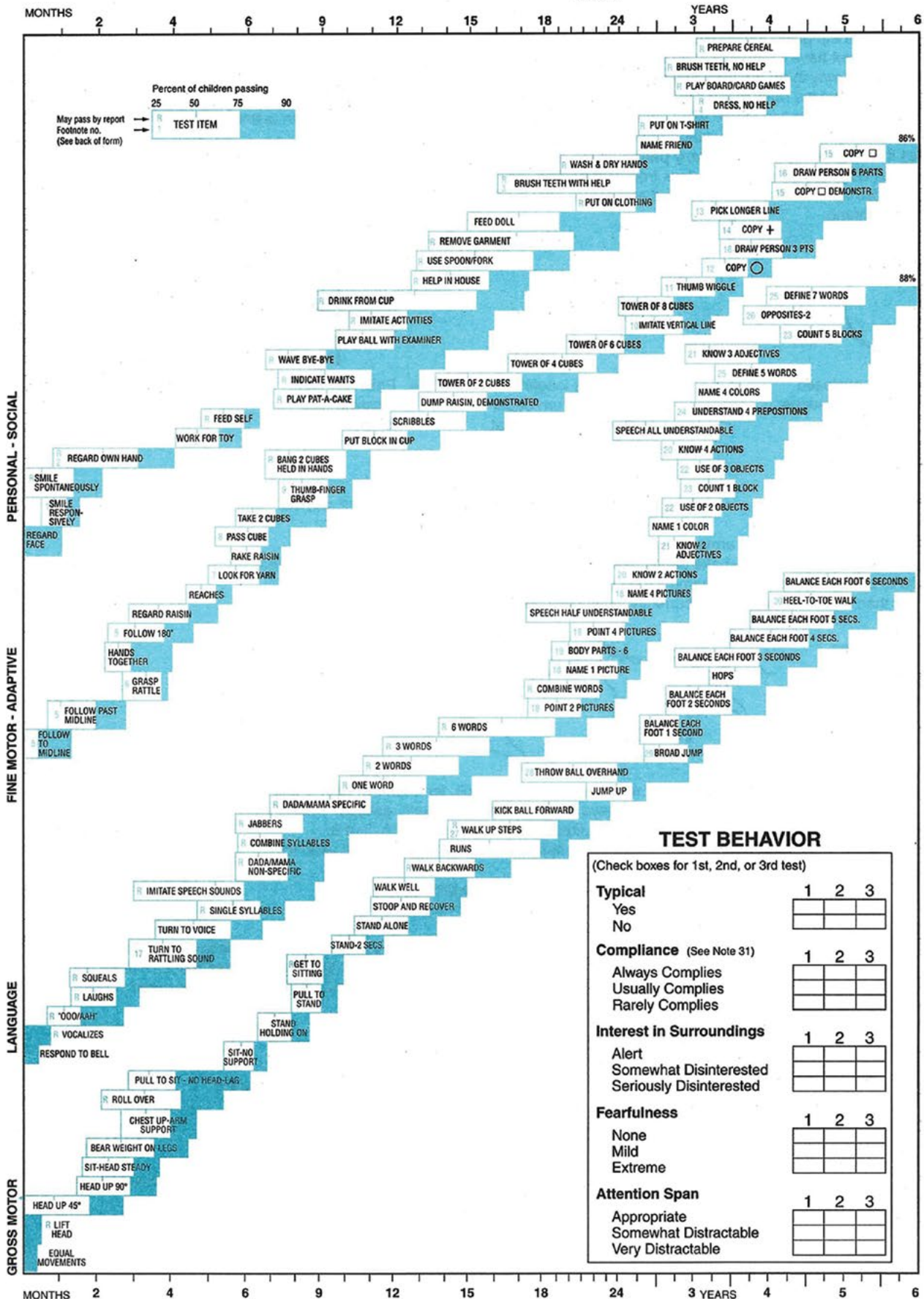
[**Note:** This tool assesses development along 4 domains; *gross-motor; language; fine motor/adaptive; and social/personal*. This assessment is done by taking a detailed history from the mother/caregiver and carrying out specifically planned examinations. One needs to use locally appropriate items or language in both the history taking and the examination. The following open source study details adaptation of the tool to the Ethiopian context.]

Abessa, T.G., B.N. Worku, M.W. Kibebew, J. Valy, J. Lemmens, H. Thijs, W.K. Yimer, P. Kolsteren, and M. Granitzer. 2016. "Adaptation and Standardization of a Western Tool for Assessing Child Development in Non-Western Low-Income Context." *BMC Public Health*, no. 16:652. doi: 10.1186/s12889-016-3288-2.  
Available at: <https://bmcpublikealth.biomedcentral.com/track/pdf/10.1186/s12889-016-3288-2>.

# DENVER II

Examiner:  
Date:

Name:  
Birthdate:  
ID No.:



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**APPENDIX IX.**  
**SAMPLE REFERRAL DIRECTORY**



<b>Name of organisation/institute</b>	
<b>Physical location</b>	
<b>Postal address</b>	
<b>Phone</b>	
<b>Contact person name</b>	
<b>Position</b>	
<b>Phone</b>	
<b>Email</b>	
<b>Type of institution</b>	
<b>Area of operation</b>	
<b>Target population</b>	
<b>Major PSS interventions/services</b>	

## **APPENDIX X.**

**PIERCE SUICIDE INTENT SCALE:  
TO BE COMPLETED AFTER  
SUICIDE ATTEMPT\***

**Patient's Name:**

**Assessor:**

**Date:**

<b>Circumstances</b>			
<b>1</b>	Isolation	<b>0</b>	Someone present
		<b>1</b>	Someone nearby or on telephone
		<b>2</b>	No one nearby
<b>2</b>	Timing	<b>0</b>	Timed so intervention probable
		<b>1</b>	Intervention unlikely
		<b>2</b>	Intervention highly unlikely
<b>3</b>	Precautions against rescue	<b>0</b>	None
		<b>1</b>	Passive (e.g., alone in room, door unlocked)
		<b>2</b>	Active precautions
<b>4</b>	Acting to gain help	<b>0</b>	Notifies helper of attempt
		<b>1</b>	Contacts helper, doesn't tell of intent
		<b>2</b>	No contact with helper
<b>5</b>	Final acts in anticipation	<b>0</b>	None
		<b>1</b>	Partial preparation
		<b>2</b>	Definite plans (e.g., will, insurance, gifts)
<b>6</b>	Suicide note	<b>0</b>	None
		<b>1</b>	Note torn up
		<b>2</b>	Presence of note
<b>Self-report</b>			
<b>7</b>	Lethality	<b>0</b>	Thought would not kill
		<b>1</b>	Unsure if lethal action
		<b>2</b>	Believed would kill
<b>8</b>	Stated intent	<b>0</b>	Did not want to die
		<b>1</b>	Unsure
		<b>2</b>	Wanted to die
<b>9</b>	Premeditation	<b>0</b>	Impulsive
		<b>1</b>	Considered less than 1 hour
		<b>2</b>	Considered less than 1 day
		<b>3</b>	Considered more than 1 day
<b>10</b>	Reaction to act	<b>0</b>	Glad recovered
		<b>1</b>	Uncertain
		<b>2</b>	Sorry he/she failed
<b>Risk</b>			
<b>11</b>	Predictable outcome	<b>0</b>	Survival certain
		<b>1</b>	Death unlikely
		<b>2</b>	Death likely or certain
<b>12</b>	Death without medical treatment	<b>0</b>	No
		<b>1</b>	Uncertain
		<b>2</b>	Yes

\* Pierce, D.W. 1977. "Suicidal Intent in Self-Injury," *British Journal of Psychiatry*, 130(4); 377-385, doi: 0.1192/bjp.130.4.377

Items (1 + 2 + 3 + 4 + 5 + 6) = "circumstances score" = \_\_\_\_\_

Items (7 + 8 + 9 + 10) = "self-report score" = \_\_\_\_\_

Items (11 + 12) = "medical risk score" = \_\_\_\_\_

Total score 0-3 = low intent; 4-10 = medium intent; >10 = high intent

# **APPENDIX XI.**

## **EFFECTIVENESS OF COMMON CONTRACEPTIVE METHODS, AND THEIR SAFETY IN HIV INFECTION**

METHOD	FAILURE RATE/100 WOMAN –YEARS	IMPACT ON DISEASE PROGRESSION	INCREASE HIV TRANSMISSION TO PARTNER	IMPACT ON ART OR TUBERCULOSIS TREATMENT
<b>Oral combined Oral contraceptive</b>	0.2–3	No conclusive evidence of harm: can use	No conclusive evidence of harm: can use	Drug interaction with some NNRTIs*: do not use Drug interaction with rifampicin and related TB drugs: do not use
<b>DMPA and NET – EN (Injectable progestin)</b>	0–2	No conclusive evidence of harm; can use	No conclusive evidence of harm; can use	HAART: can use, no need to increase dose or injection frequency TB drugs: can use, no need to increase dose or injection frequency
<b>Male condom</b>	Careful use: 0.4–8 Typical use: around 10	None; may prevent re-infection	Barrier method protect partner	N/A
<b>Female condom</b>	Careful use: 5 Typical use: around 21	None; may prevent re-infection	Barrier method protect partner	N/A
<b>Copper IUCD</b>	0.1–0.3	Evidence on safety reassuring; can use	Little evidence but extrapolating from Cu IUCD can use	No interactions
<b>Levonorgestrel IUCD 20</b>	0.1–0.3	Limited evidence of safety reassuring; can use	Little evidence but extrapolating from Cu IUCD can use	No interactions
<b>Male and female sterilisation</b>	Female 0–0.5 Male 0–0.2	No evidence but unlikely; can recommend	No evidence but unlikely; can recommend	N/A

\*NNRTI = non–nucleoside reverse-transcriptase inhibitor

# **APPENDIX XII.**

## **WHAT SHOULD BE COVERED IN PRECONCEPTION COUNSELLING?**

Preconception counselling should ensure an informed choice about reproductive options, including the inherent risks and costs of each treatment and the likely chances of success.

It must include:

- » Summary of the available data on safety for each method together with advice on additional methods of reducing risk, such as limiting intercourse to the fertile window, or early initiation of ART
- » The benefits of maternal ART in reducing transmission of the virus to the baby (i.e., “U=U” (undetectable viral load = Untransmittable HIV)
- » Regular screening for sexually transmitted infections
- » The need to identify evidence of reduced fertility or sterility at an early stage in either or both partners
- » The possible use of pre-exposure prophylaxis (PrEP).
- » If the woman is on a dolutegravir-based regimen, the need to consider switching to an alternate first-line regimen (WHO, 2018).

The discussion should balance the risk of natural conception with that of more established risk-reduction methods such as sperm washing or risk-free options such as donor insemination. Although timed unprotected intercourse may be the only option for discordant couples in resource-limited settings, this has risk.

Preconception counselling should also address:

- » The possibility of treatment failure and how the couple would cope if they successfully had a child but the infected parent became more seriously ill or died.
- » Those electing to have assisted conception with sperm washing have to understand that this is a risk-reduction method and not a risk-free method.
- » When the female partner is HIV-infected they need to understand the risks of MTCT and the methods used.
- » They should plan and agree to attend an antenatal clinic once pregnant to ensure that they receive the best possible advice to minimize MTCT risk.

# **APPENDIX XIII.**

# **CERVICAL CANCER**

# **FACTSHEET**



### **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 SSA where cervical cancer screening and treatment is suboptimal (Ghebre et al. 2017). 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 progression 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 STI, such as herpes simplex, chlamydia, and gonorrhoea
- » Having had many births (the more births, the greater the risk)
- » Who were young when she first gave birth
- » Smoke tobacco
- » Have used combined oral contraceptives (COCs) 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 women of any age 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).
- » 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.



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