

## THE UNITED REPUBLIC OF TANZANIA MINISTRY OF HEALTH, COMMUNITY DEVELOPMENT, GENDER, ELDERLY AND CHILDREN ADOLESCENT HIV SERVICES: A GUIDE FOR HEALTH CARE WORKERS



Ministry of Health, Community Development, Gender, Elderly and Children

National AIDS Control Programme (NACP)

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### Table of Contents

ABBREVIATIONS	1
FOREWORD	1
ACKNOWLEDGMENT	2
GLOSSARY OF TERMS AND CONCEPTS	3
CHAPTER 1: INTRODUCTION	6
1.1. Rationale	6
1.2. Target Audience	7
1.3. Goal	7
1.3.1 Specific objectives	7
1.4. HIV Acquisition — Modes and Implications for HIV Care and Treatment	7
1.4.1. Perinatally-infected adolescents	7
1.4.2. Adolescents who acquired HIV during childhood or adolescence	8
CHAPTER 2: HIV SERVICES FOR ALHIV	9
2.1. Components of HIV Services for Adolescents	9
2.2. Organization of Adolescent Friendly Services	
2.3. Rights and Obligations of ALHIV	11
2.4. Bioethical Consideration for ALHIV Services	11
2.4.1. Bio-ethical care to survivors of GBV	12
2.5. Guiding Ethical Principles for HCWs	12
2.6. Effects of HIV on Adolescents	
2.6.1. Effects of HIV infection on growth of adolescents	13
2.6.2. Effects of HIV infection on cognition of adolescents	13
2.6.3. Effects of HIV infection on psychosocial aspect of adolescents	13
2.7. Important Messages to Share with Adolescents and Caregivers/parents	14
2.7.1. Adherence to medicines	14
2.7.2. Adherence to care	14
2.7.3. Stigma and discrimination	14
2.7.4. Counselling adolescents	
2.7.5. Safe sex	15
CHAPTER 3: HIV PREVENTION SERVICES FOR ADOLESCENTS	16
3.1. Behavioral Interventions	16
3.2. Bio Medical Interventions	17
3.3. Structural Interventions	17
3.4. Management of GBV among ALHIV	18
3.4.1. GBV in Tanzanian adolescents	

3.4.2. Steps for management of GBV	18
3.4.3. The role of HCWs in managing adolescent victims of GBV	19
CHAPTER 4: COMMUNICATION, COUNSELLING, AND LIFE SKILLS FOR ALHIV	20
4.1. General Principles of Communication with ALHIV	20
4.1.1. Building trust in communicating with ALHIV	20
4.1.2. Empowering the parent/caregiver in communicating with ALHIV	22
4.1.3. Social and behavioral change communication for risk reduction among	
4.1.4. Principles HCWs should follow in designing and implementing SBCC in facilities	
4.2. Counselling ALHIV	26
4.2.1 Common counselling mistakes	27
4.3. Life Skills	27
CHAPTER 5: DISCLOSURE SUPPORT FOR ALHIV	
5.1. Issues to Consider in Adolescent Disclosure	
5.2. Disclosure Process	
5.3. When to Delay Disclosure	31
5.4. Preparing Parent/Caregiver for Disclosure	32
5.4.1. Ongoing disclosure support to caregivers	
5.4.2. Strategies parent/caregivers may use in the disclosure process	
5.5. How to Help Adolescents who Know their HIV Status to Disclose	33
5.5.1. Post-disclosure support to adolescents	34
5.6. Special Cases	34
CHAPTER 6: CLINICAL CARE FOR	
6.1 Comprehensive Clinical Care for ALHIV	
6.1.1. Entry into adolescent care	
6.2. Service Delivery Models (SDMs) for Differentiated Care for Adolescents	37
6.2.1. Service delivery models (SDMs) for differentiated care	37
6.2.2. Building blocks of service delivery models	
6.2.3. Differentiated ART delivery for stable ALHIV	
6.2.4. Differentiated ART delivery for unstable clients	
6.3. Components of HIV Care Package for ALHIV	40
6.3.1. Enrolment visit (initial visit) - clinical assessment and management of	0Is40
6.3.2. Follow-up visits	41
6.4. Prevention of Common OIs	41
6.4.1. Cotrimoxazole (CTX) prophylaxis in adolescents	41
6.4.2. Prevention of tuberculosis with IPT	42

6.5. ART Regimens	42
6.5.1. ART regimens for ALHIV	42
6.5.2. Observations during the first 6 months of ART	43
6.5.3. ARVs toxicities	44
6.5.4. Treatment failure	44
6.5.5. Switching to new regimens	45
6.5.6. Treatment considerations in adolescents with TB and HIV co-infection	
CHAPTER 7: PSYCHOSOCIAL SUPPORT SERVICES	47
7.1. Psychosocial Support Needs of ALHIV	48
7.1.1. Reasons for having psychosocial support	
7.1.2. Psychosocial assessment	49
7.1.3. Ways to provide PSS to the caregiver	50
7.2. Peer Support Groups	50
7.3. Adolescent Support Group Entry Criteria	51
7.4. Stigma and Discrimination	51
7.4.1. Effects of stigma and discrimination to ALHIV	51
7.4.2. Individual strategies of dealing with stigma	
7.4.3. Strategies for dealing with stigma and discrimination within health care	
settings	
7.5. Psychosocial Support to Most-at-Risk ALHIV	
CHAPTER 8: ADHERENCE SUPPORT	
8.1. Adherence Preparation Support to ALHIV and Caregivers	
8.1.1. Treatment supporters	
8.1.2. Adherence counselling for treatment in adolescents	53
8.1.3. First adherence counselling session for adolescents	
8.1.4. Second adherence counselling session for adolescents	55
8.1.5 Third adherence counselling session for adolescents	55
8.1.6. Follow-up visits after initiating ARV medicines to adolescents	55
8.1.7 Assessing adherence and providing ongoing adherence support	56
8.1.8. Ongoing adherence support	
8.2. Ways of Improving Adherence and Retention to Care	57
CHAPTER 9: MENTAL HEALTH IN ALHIV	59
9.1. Psychosocial Factors to Consider in ALHIV	
9.2. Basic Mental Health Support to ALHIV	61
9.3. General Assessment of Common Mental Illness in ALHIV	
9.4. Basic Management of Common Mental Illness in ALHIV	62
9.4.1. Neurocognitive disorders	62

9.4.2. Depression	62
9.4.3. Suicidal or self-harming adolescents	63
9.4.4. Anxiety	64
9.4.5 Trauma/post-traumatic stress disorder (PTSD)	64
9.5. Management of Mental Health Emergencies in ALHIV	
9.6. Drugs/Alcohol Abuse in ALHIV	
9.6.1. Predictors of alcohol/ substance abuse	66
9.6.2. Consequences of adolescent alcohol and other substance use	
CHAPTER 10: NUTRITIONAL CARE AND SUPPORT AMONG ALHIV	69
10.1. Nutritional Requirements for ALHIV	70
10.2. Importance of Good Nutrition in ALHIV	71
10.3. Factors Affecting Adolescents' Nutrition	
10.4. Nutritional Care and Support for ALHIV	72
10.4.1. Nutritional assessment for ALHIV	
10.4.2. Nutritional counselling and education among ALHIV	73
10.5. Dietary Recommendations for Common Signs and Symptoms Associated	
HIV	74
10.5.1. Management of MAM and SAM	74
10.5.2. Food support to ALHIV and caregivers	74
10.5.3. Food and water safety and hygiene	74
10 .6. Drug-food Interactions and Drug Side Effects	75
CHAPTER 11: ADOLESCENT SEXUAL AND REPRODUCTIVE HEALTH SERVICES	77
11.1. Information on Adolescent Sexuality and Sexual Risk Screening and Coun	0
11.1.1: Sexual risk screening and counselling	
11.1.2. Conducting risk assessment	
11.1.3. Risk reduction counselling	
11.2. Adolescent Reproductive Health Services	
11.2.1. SRH values clarification	
11.2.2. Counselling for pregnancy and PMTCT services among ALHIV	
11.2.3. Risks of adolescent pregnancy	
11.2.4. Considerations when offering PMTCT services in adolescents	
11.2.5. ALHIV and STIs	
11.2.6. Diagnosis and treatment of STIs	
11.3. Cervical Cancer Screening for ALHIV	
11.4. Comprehensive Post Abortion Care (cPAC)	
11.4.1. Components of cPAC	
A	

11.5. GBV and Violence Against Children	83
11.5.1. Messages to be shared with adolescents and caregivers	84
CHAPTER 12: LINKAGES AND REFERRALS	86
12.1. Strategies to Improve Linkages and Referrals	87
12.1.1 Facility level strategies	
12.1.2 Community level strategies	87
12.1.3 Schools/institutions in the facility catchment areas	88
12.2. Development of a Community Resource Directory	88
12.3 Roles and Responsibilities of CBHS Providers	89
12.4 Adolescent Participation	89
12.5 Peer Education Programs	90
12.5.1 Peer educators	90
12.5.2 Qualification of peer educators for ALHIV	90
12.5.3 Role of HCW in coordinating the work of adolescent peer educators	90
CHAPTER 13: SUPPORTING THE TRANSITION OF ALHIV TO ADULT CARE	93
13.1. Goal of Transition from ALHIV to Adult Care	93
13.2. Barriers Influencing Transitioning Process of ALHIV	94
13.3 Roles of the HCW in Transitioning ALHIV to Adult Care	
13.4. Transitioning Approaches	96
13.4.1. Empowering adolescents to transition into adult care	96
13.4.2 Innovative strategies that HCWs and programs can undertake to suppor transition	
13.4.3 HCWs and ALHIV Peer Educators shall help ALHIV prepare for the trans process	
13.4.4 Support older ALHIV be more involved in their own care	97
13.5. Transition Tools for ALHIV	97
CHAPTER 14: MONITORING, EVALUATION AND QUALITY IMPROVEMENT	99
14.1. Monitoring	100
14.1.1. Disaggregating data	
14.1.2. Indicators	101
14.1.3: Targets	101
14.1.4. Data collection and analysis tools	101
14.2. Evaluation	102
14.3. Quality Improvement and Supportive Supervision	102
14.3.1: Methods to assess quality	103
14.3.2. QI activities might examine/evaluate	103
14.3.3: Overview of supportive supervision	104

APPENDICIES	
Appendix 1: Common Counseling Scenarios	
Appendix 2: Psychosocial Assessment Tool	
Appendix 3: ALHIV Psychosocial Assessment Guide and Recording Form <sup>3</sup>	
Appendix 4: Adherence Support Tree	
Appendix 5: Adherence Preparation and Support Guides	115
Appendix 6: Nutritional Management of Common Symptoms Related to A HIV Infection	
Appendix 7: BMI chart	125
Appendix 8: Contraception Considerations for People Living with HIV	126
Appendix 9: ALHIV Transition Checklist for HCWs	



## ABBREVIATIONS

AIDS	- Acquired Immune Deficiency Syndrome
ALHIV	- Adolescent Living with HIV
ANC	- Ante-Natal Clinic
APE	- ALHIV Peer Educators
ART	- Anti-Retroviral Treatment
ASRH	- Adolescent Sexual and Reproductive Health
BMI	- Body Mass Index
CBHS	- Community-Based HIV and AIDS Services
CECAP	- Cervical Cancer Prevention
CIN	- Carcinoma Intraepithelial Neoplasia
COC	- Combined Oral Contraceptive
cPAC	- Comprehensive Post Abortion Care
CSO	- Civil Society Organization
СТС	- Care and Treatment Clinic
СТХ	- Cotrimoxazole
DSM-V	- Diagnostic and Statistical Manual V
EC	- Emergency Contraception
EGPAF	- Elizabeth Glaser Pediatric AIDS Foundation
EPT	- Expedited Partner Therapy
FGM	- Female Genital Mutilation
FP	- Family Planning
GBV	- Gender Based Violence
HCW	- Health Care Worker
HFA	- Height for Age
HIV	- Human Immunodeficiency Virus
HPV	- Human Papilloma Virus
НТС	- HIV Testing and Counselling
HTS	- HIV Testing Services
IDCC	- Infectious Disease Control Centre
IGA	- Income Generating Activity
INH	- Isoniazid
IPT	- Isoniazid Preventive Therapy
IRIS	- Immune Reconstitution Inflammatory Syndrome
IUD	- Intra Uterine Device
LTFU	- Lost to Follow Up
M&E	- Monitoring and Evaluation
MAM	- Moderate Acute Malnutrition
MDMA	- 3 Methylenedioxymethamphetamine (commonly known as ecstasy)
MISSAP	- Missed Appointment

MOHCDGEC	-	Ministry of Health, Community Development, Gender, Elderly and Children
MUAC	-	Mid-Upper Arm Circumference
NACP	-	National AIDS Control Programme
NNRTI	-	Non-Nucleoside Reverse-Transcriptase Inhibitors
OIs	-	Opportunistic Infections
OPD	-	Out-Patient Department
PHDP	-	Positive Health Dignity Prevention
PI	-	Protease Inhibitors
PLHIV	-	People Living with HIV
РМТСТ	-	Prevention of Mother to Child Transmission of HIV
POP	-	Progestogen-Only Pill
PSS	-	Psycho-Social Support
PTSD	-	Post-Traumatic Stress Disorder
PWID	-	People Who Inject Drugs
QA	-	Quality Assurance
QI	-	Quality Improvement
RCH	-	Reproductive and Child Health
RH	-	Reproductive Health
RPR	-	Rapid Plasma Riagin
RTI	-	Reproductive Tract Infections
RUTF	-	Ready to Use Therapeutic Food
SAM	-	Severe Acute Malnutrition
SDMs	-	Service Delivery Models
SOC	-	Standards of Care
SOP	-	Standard Operating Procedures
SRHR	-	Sexual and Reproductive Health Rights
STI	-	Sexually Transmitted Infections
ТВ	-	Tuberculosis
UNICEF	-	United Nations Children's Fund
UPT	-	Urine for Pregnancy Test
VAC	-	Violence against Children
VAC	-	Violence against Children
VDRL	-	Venereal Disease Research Laboratory
VL	-	Viral Load
WFH	-	Weight for Height
WHO	-	World Health Organization

## FOREWORD

In Tanzania, adolescents, persons aged 10-19 years, constitute 23 percent of our total population. Worldwide, adolescents (10 – 19 years) represent a growing share of people living with HIV (PLHIV). Despite the presence of various interventions, the infections pattern among adolescents shows an increase. In 2016 alone, 610,000 young people between the ages of 15 to 24 were newly infected with HIV, of whom 260,000 were adolescents between the ages of 15 and 19. To compound this, most recent data indicate that only 13 percent of adolescent girls and 9 percent of adolescent boys aged 15-19 in sub-Saharan Africa – the region most affected by HIV – have been tested for HIV in the past 12 months and received the result of the last test (UNICEF data, 2016). With the new global strategy of ending the HIV epidemic by 2030 there is a need to accelerate efforts to address the epidemic among adolescents.

This guide will assist HIV service providers, programme managers, stakeholders and decision makers to address and accelerate adolescents' HIV services.

The MOHCDGEC will ensure the provision of adolescent-friendly HIV services and information at all levels of health care. We call upon regional and district authorities to ensure that this *Guide for ALHIV Services* is referred and adhered to in order to provide high quality and friendly adolescent HIV services in the health facilities offering HIV services. We hope that all stakeholders involved in adolescent HIV services will be committed to implementing adolescent HIV services in accordance with this guide.

Dr. Mpoki M. Ulisubisya

#### **Permanent Secretary**

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Prof. Muhammad BakariKambi

**Chief Medical Officer** 

### **GLOSSARY OF TERMS AND CONCEPTS**

For the purpose of this document, these terms and concepts shall have the following meanings.

**Access:** The extent to which a person can obtain appropriate services at a cost and effort that is both acceptable to them personally and within the means of a large majority in a given population.

**Adolescents:** Young men and women aged 10-19 years. These persons are in transition from childhood to adulthood during which they experience physiological and psychological developmental changes that significantly influence their behaviour. They are generally dependent upon others for guidance and support. This group is recognized to be heterogeneous and that different strategies are required to meet the specific needs of different adolescents e.g. rural and urban adolescents, in school and out-of-school, sexually experienced and those without sexual experience, married and unmarried, etc.

- *Young Adolescents:* In this guide, this is a group of adolescents aged 10 and 14 years.
- *Older Adolescents:* In this guide, this is a group of adolescents aged 15 to 19 years.

**Adolescent Friendly Health Services (AFHS):** Services adolescents identify with because the services meet their expectations, needs and set national standards for provision of health services to adolescents. In a broader context, AFHS are services that:

- Are available and accessible
- Meet the needs of adolescents in a holistic manner
- Adolescents feel welcome in obtaining them
- Are provided by competent service providers
- Ensure client comfort, privacy, confidentiality and respect
- Are provided in a safe and clean environment
- Are provided efficiently and without any discrimination
- Have social, parental and community support
- Adolescents are actively involved in planning for and implementing.

**Abuse:** Misuse of power through which the perpetrator gains control or advantage of the abused, using and causing physical or psychological harm or inflicting or inciting fear of that harm. Abuse prevents persons from making free decisions and forces them to behave against their will.

**Child:** Someone who is not yet an adult or someone who has not yet reached puberty; a person who is younger than age 18 years.

**Coercion:** Forcing, or attempting to force, another person to engage in behavior against her/his will by using threats, verbal insistence, manipulation, deception, cultural expectations or economic power.

**Consent:** Making an informed choice to freely and voluntarily to do something. There is no consent when agreement is obtained through the use of threats, force or other forms of coercion, abduction, fraud, deception, or misrepresentation. Threatening to withhold, or promising to provide a benefit in order to obtain the agreement of a person constitutes an abuse of power. Any agreement obtained in such a way, or from a person who is below the legal (statutory) age of consent, or is defined as a child under applicable laws, is not considered consensual.

**Gender:** The term used to denote the social characteristics assigned to men and women. People are born female or male (sex); they learn how to be girls and boys, and then become women and men (gender). These are constructed based on different factors, such as age, religion, national, ethnic and social origin. They differ both within and between cultures and define identities, status, roles, responsibilities and power relations among the members of any culture or society. Gender is learned through socialization. It is not static or innate, but evolves to respond to changes in the social, political and cultural environment. Gender refers to what it means to be a boy or a girl, woman or man, in a particular society or culture. Society teaches expected attitudes, behaviours, roles, responsibilities, constraints, opportunities and privileges of men and women in any context.

**Gender-based Violence (GBV):** GBV is an umbrella term for any act, omission, or conduct that is perpetuated against a person's will and that is based on socially ascribed differences (gender) between males and females. In this context, GBV includes but is not limited to sexual violence, physical violence and harmful traditional practices and economic and social violence. The term refers to violence that targets individuals or groups on the basis of their being female or male.

**Female Genital Mutilation (FGM):** Cutting of genital organs for non-medical reasons, ranges from partial to total cutting, removal of genitals, stretching or stitching whether for cultural or non-therapeutic reasons; often undergone several times during life-time, after delivery or if a girl/woman has been survivor of sexual assault.

**An incidence of Violence:** An act or a series of harmful acts by a perpetrator or a group of perpetrators against a person or a group of individuals. It may involve multiple types of and repeated acts of violence over a period of time, with variable durations. It can take minutes, hours, days, or a lifetime. It may occur at home (domestic) or elsewhere.

**Perpetrator:** A person, group, or institution that directly or indirectly inflicts, supports and condones violence or other abuse against a person or a group of persons. Perpetrators are in a position of real or perceived power, decision-making and/or authority and can thus exert control over their survivors.

**Physical Violence or Physical Assault:** Beating, punching, kicking, biting, burning, maiming or killing, with or without weapons; often in combinations with other forms of sexual and gender-based violence.

**Rape:** The invasion of any part of the body of the survivor by the perpetrator with a sexual organ, or of the anal or genital opening of the survivor with any object or any other part of the body by force, coercion, taking advantage of a coercive environment, or against a person incapable of giving genuine consent (1998 Rome Statute of the International Criminal Court (ICC).

**Reproductive Health:** A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes. It also includes sexual health, the purpose of which is the enhancement of life and personal relations, and not merely counselling and care related to reproduction and sexually transmitted diseases.

**Rights, Human:** Basic rights and freedoms that all people are entitled to regardless of nationality, sex, national or ethnic origin, race, religion, language, or other status.

**Service Provider:** A skilled HCW who can offer services based on health needs of adolescents.

**Sexual Violence:** Includes sexual exploitation and sexual abuse. It refers to any act, attempt, or threat of a sexual nature that result, or is likely to result, in physical, psychological and emotional harm.

**Standards:** Minimum accepted levels of practices on performance, based on environmental situation, knowledge, resources and statements of expected quality. Standards assist in guiding the development, implementation, monitoring and evaluation of services.

**Support Groups:** Community-based organizations that have incorporated adolescent sexual and reproductive health (ASRH) issues in their activities. These include individuals who are actively working together to enhance ASRH activities in their communities.

**Survivor:** In this context is someone, a child or an adult male or female, who has been physically and /or psychologically violated because of his/her gender and continues to live with varying levels of problems after violence.

**Violence:** Control and oppression that can include emotional, social or economic force, coercion or pressure, as well as physical harm. It can be overt, in the form of physical assault or threatening someone with a weapon; it can also be covert, in the form of intimidation, threats, persecution deception or other forms of psychological or social pressure. The person targeted by this kind of violence is compelled to behave as expected or to act against her will out of fear.

### **CHAPTER 1: INTRODUCTION**

The Guide on HIV Services for Adolescents Living with HIV (ALHIV) describes organization of adolescent-friendly services to guide heath management teams and health care workers (HCWs) on their roles. It also outlines important aspects to consider when offering comprehensive care to adolescents and their parents/caregivers at health facilities and in the community. Comprehensive care should include the provision of quality clinical and psychosocial support (PSS) services with clear linkages to the community. These services need to be adolescent-friendly at any health facility with clear prescription of minimal standards, and has to be integrated into existing services at the health facility.

HCWs should assess each adolescent's care, treatment, and support needs individually as they differ from one another in many ways. Aspects to be considered include stage of development, gender, sexual orientation, education level, financial situation and geographical location. Furthermore, culture, religion, marital/family situation and experience with stigma and discrimination should be assessed to ensure that the adolescent's care and treatment plan is tailored to meet his/her unique needs.

Worldwide, adolescents (10 – 19 years) represent a growing share of people living with HIV (PLHIV). Despite the presence of various interventions, the infection pattern among adolescents shows an increase. In 2016 alone, 610,000 young people between the ages of 15 to 24 were newly infected with HIV, of whom 260,000 were adolescents between the ages of 15 and 19. To compound this, most recent data indicate that only 13% of adolescent girls and 9% of adolescent boys aged 15-19 in sub-Saharan Africa – the region most affected by HIV – have been tested for HIV in the past 12 months and received the result of the last test.<sup>1</sup> With the new global strategy of ending the HIV epidemic by 2030 there is a need to accelerate efforts to address the epidemic among adolescents.

#### 1.1. Rationale

This Guide for HCWs on Adolescent HIV Services was developed to assist health care service providers in offering care and treatment to ALHIV. Adolescents have unique characteristics; judgemental altitudes of some HCWs and non-friendly environments can become substantial barriers to ALHIV accessing needed services. This guide is **not** expected to replace the National Guidelines for Management of HIV; rather it will guide health service providers on how HIV prevention, care and treatment services should be offered to adolescents. In the HIV epidemic era, adolescents are at the centre of HIV vulnerability due to several factors including social, economic, cultural, and biological reasons. Furthermore, successful HIV care services to perinatally-infected children has

allowed them to reach adolescence and adulthood. High levels of awareness of HIV among communities, reduced stigma, greater access and acceptance of testing has also led to a significant number of adolescents enrolling onto HIV care and treatment services. Due to these facts, availability of a document to describe what should be offered to ALHIV as a standard package in provision of HIV care and treatment services is of paramount importance.

#### 1.2. Target Audience

The Guide for ALHIV Services is intended to be used by HCWs on all aspects of HIV service provision which includes HIV prevention, HIV Testing Services (HTS), disclosure, clinical care for ALHIV, adherence support, PSS, sexually transmitted infection (STI) and TB screening and management, and transition to adult HIV care. HCWs, however, are expected to refer to other relevant guidelines or documents for detailed information or knowledge on HIV/AIDS-related services for management and coordination purposes not covered by this Guide.

#### **1.3. Goal**

This guide aims to ensure that ALHIV receive comprehensive clinical care including psychosocial support and appropriate linkages to community services.

#### 1.3.1 Specific objectives

- To guide HCWs on provision of comprehensive HIV services to ALHIV
- To ensure all services offered by all stakeholders to ALHIV are friendly and standardized in order to attract and retain adolescents
- To maximize HIV prevention service delivery within the HIV care and treatment setting

#### 1.4. HIV Acquisition — Modes and Implications for HIV Care and Treatment

ALHIV who acquired HIV:

- Perinatally (acquisition from their mother during pregnancy, delivery or breast feeding)
  - OR
- During childhood or adolescence (sexual intercourse, rape, injecting drug use, blood transfusion, sharing cutting/piercing instruments like traditional circumcision and Female Genital Mutilation (FGM))

Adolescents in these two groups have distinct features, which need to be observed for successful care program.

#### 1.4.1. Perinatally-infected adolescents

• May have been enrolled in HIV care since infancy, or identified later in life during an acute illness or through routine testing

- Some started ART in infancy and have taken various ART regimens by the time they reach adolescence
- Others may still be taking the initial regimen they started during early childhood
- May or may not have been fully disclosed (depending on their age and their caregivers)

#### 1.4.2. Adolescents who acquired HIV during childhood or adolescence

- May have recently learned their HIV status and have generally not had extended contact with the health system; often identified via HIV testing programs
- Some adolescent girls are identified when they seek ANC and receive routine testing



as part of PMTCT services.

## **CHAPTER 2: HIV SERVICES FOR ALHIV**

The standard for adolescent-friendly health services is that they are safe, effective and affordable, and that they meet the individual needs of adolescents and young people who return when they need to and recommend these services to friends.

ALHIV face unique issues when accessing health services, which can lead to poor adherence to medication, and often psychosocial needs are not addressed holistically.

Setting standards in the provision of HIV services to ALHIV requires well-organized and integrated health services that are adolescent-centred. This Chapter describes the minimum standards package for an adolescent accessing HIV care and treatment services.

#### 2.1. Components of HIV Services for Adolescents

HIV services should be integrated to attract and retain adolescents. The following are the components of adolescent-friendly services:

- HIV testing and counseling services
- Sexual and reproductive health (SRH) services (e.g. sexually transmitted infection (STI)/reproductive tract infection (RTI) services)
- Substance use prevention and counseling
- Mental health services
- Information and education on HIV prevention, care and treatment
- Parent/caregiver and community support
- Adolescent-friendly and competent providers
- Conducive, friendly environment
- Life skills development such as financial literacy, goal setting, communication skills, income generating initiatives, public speaking, writing skills, developing friendship networks, decision making and the like
- Adherence to human rights (equity and non-discrimination)
- GBV services
- Proper record-keeping
- Engagement of adolescents in service provision.

#### Appropriate package of services includes:

- HIV testing and counseling services
- HIV care and treatment
- SRH services (e.g. STI/RTI services)
- Substance use prevention and counseling
- Mental health services

#### 2.2. Organization of Adolescent Friendly Services

Ensure the services are accessible, equitable, acceptable, appropriate, comprehensive, effective and efficient:

- Arrange special days or outreach and times for services: conduct adolescent clinics on convenient days, hours and location according to availability of staff and clients to offer services and availability of resources
- Establish Clubs (pre-teen, teen): allocate adolescents in peer support Clubs, putting into consideration their age and cognitive maturity
- Involve peer educators in running the clubs: describe roles and responsibilities, and provide supervision
- Involve parents, caregivers and influential community leaders in ASRH and HIV care services
- Facilitate easy registration of adolescents coming monthly to care
- Ensure retrieval and storage of records
- Guarantee privacy and confidentiality
- Promote autonomy so that adolescents can consent to their own treatment and care
- Create an atmosphere that encourages adolescents to consult HCWs

#### Adolescent-friendly services should be:

- Affordable
- Short waiting times
- Non-discriminatory in line with policy and procedures
- Open and accessible without appointment
- Should offer integrated services (one stop shop)
- Address GBV which includes sexual, physical, emotional and negligence
- Address ASRH services including family planning and CECAP
- Fulfil the rights of the adolescents as outlined in the Law of the Child of Act 2009
- Ensure smooth networking and referrals
- Discuss risk factors for HIV/STI among adolescents including risk-taking behaviour, low self-esteem, environmental influences, and illicit drug use.

HCWs should assess each adolescent client's care, treatment, and support needs individually as they differ from one another in many ways. Aspects to be considered include stage of development, gender, education level, financial situation and geographical location. Furthermore, culture, religion, marital/family situation as well as experience with stigma and discrimination should be assessed to ensure that the adolescent's care and treatment plan is tailored to meet his/her unique needs.

#### 2.3. Rights and Obligations of ALHIV

The rights of adolescents align with general 'basic rights and duties' stipulated in the national constitutional from Article 12 – 29 as well as the HIV Prevention and Control Act 2008.

- Right to equality: ALHIV should be treated with recognition and respect for his dignity
- Right not to be discriminated against
- Right to live and to the protection of life: rights to highest attainable standard of physical and mental health, rights to treatment of opportunistic infection (OI)
- Right to live as a free person: voluntary HIV testing and disclosure
- Right to respect and protection of his/her privacy, privacy of his/her family and matrimonial life.

#### ALHIV are advised to:

- Inform spouse/sexual partner about HIV infection
- Take measures and precaution to prevent the transmission to others

#### 2.4. Bioethical Consideration for ALHIV Services

Referring to rights and obligation of ALHIV, the following bioethical issues should be considered:

**Adolescent's competence**: Each adolescent is independent when it comes to his/her decision making. All adolescents who have attained 18 years are considered competent unless when they are experiencing an episode of severe mental illness. Adolescents below 18 years are considered not competent in making their own decisions, thus requiring parent/guardian consent.

**Negotiating a decision**: All adolescents who are competent can make their own decisions, with the guidance of a HCW. If the adolescent is judged incompetent, then the decision depends on the parent/caregiver with the support of the HCW.

**Informed consent**: ALHIV who are competent have the right to make his/her own decisions around health care including HIV services and treatment. ALHIV who are considered incompetent still have the right to be informed with the guidance of the parent/caregiver and such information should be adapted to his/her level of understanding, however he/she cannot say no if the intervention is considered to be in his/her best interest.

**Confidentiality:** Competent ALHIV has the right to demand that the HCW does not disclose any information to any other person. HCWs should disclose only that information that is necessary to achieve the purpose of the disclosure and only to people required to have that information. All confidential client information must be

securely stored including hard and electronic copies and should only be accessible authorized individuals.

#### 2.4.1. Bioethical care for survivors of GBV

#### Safety and confidentiality

Many acts of violence to adolescents are socially acceptable and survivors rely on the family and/or HCWs for help. Survivors are exposed to different risks after violence hence HCWs should conduct conversations and assessments in a safe setting. Assess the safety of the survivor. Share information only when there is clear understanding and consent.

#### Rights and dignity of the survivor

The survivor has the right to make a choice s/he wants. The best interest of the adolescent should be a primary consideration. Allow adolescents to participate in decisions related to their lives. Take into account the adolescent's age and capacity.

#### 2.5. Guiding Ethical Principles for HCWs

HCWs should always be guided by ethical principles. The framework below ensure that the HCW has a set of ethical principles to work within as well as a systematic approach to decision making, which are essential to competent practice.

Ethical principle	What does this mean?	In the context of adolescent HIV services
Autonomy	Every individual is entitled to receive information about their condition and the treatment options in order for them to make an 'informed' decision.	Adolescents that need more information about their illness are entitled to know.
Justice	Every decision made regarding an individual's health care must uphold the existing legislation and be fair and justifiable.	Decision-making processes around adolescent HIV services must be documented to show how the decision was justified.
Beneficence	All decision-making should be aimed at the "best intent" of the client. HCWs should ensure best care for their clients.	Documentation should reflect how decisions were made in the best interest of the adolescent.
Non maleficence	A HCW must not do anything that will hurt, cause emotional, physical or psychological pain to the adolescent.	The short-term effects of adolescent HIV services should be well managed to minimise harm to the adolescent. Long-term follow up is required to ensure benefit to the adolescent.
Integrity	A HCW must handle themselves professionally, demonstrating trustworthiness and reliability.	A HCW must be trained in the correct procedures and skills.

When facing a difficult ethical problem, the HCW should identify all contributing factors, conflicts, role players and consequences for each decision made. All this information should be discussed and documented in the patient file.

#### 2.6. Effects of HIV on Adolescents

Based on the client status, the HCW should understand and communicate the following information clearly with adolescents and caregivers/parents to clear misunderstandings and enhance support to ALHIV.

#### 2.6.1. Effects of HIV infection on growth of adolescents

- HIV infection acquired during the perinatal period commonly affects the growth of adolescents. These adolescents may experience delays in physical development and may appear younger and smaller. Small stature may lead to a negative self-image with regard to how other people view the adolescent. Some ALHIV may experience drug-related side effects, including those that change physical appearance. Physical effects of HIV may be minimized through the use of effective ART.
- ALHIV who were infected as adolescents may not experience growth challenges as they have typically already reached their adult height by the time they are infected with HIV.

#### 2.6.2. Effects of HIV infection on cognition of adolescents

Adolescents who acquired HIV perinatally may experience neurological consequences of longstanding HIV infection. The result may be developmental delays and learning problems.

#### 2.6.3. Effects of HIV infection on psychosocial aspect of adolescents

- Emotional difficulties which may not necessarily be due to health status, but rather to the pressures of life and a history of loss (including the loss of parents and home)
- Failure to attend some activities that help define adolescents' identities due to illness
- Mental health problems
- Sense of fear and failure to fit in with peers
- Sense of isolation for adopted adolescents and those living with relatives
- ALHIV may experience peer problems, which can be exacerbated by the stigma associated with HIV
- ALHIV may have to regularly miss school to attend clinic appointments. Missing school may impact ALHIV educational attainment and their sense of fitting in with peers. It also suggests that the school environment is not supportive of ALHIV's needs.
- If adolescents feel different from their peers, they have a harder time bonding with both peers and caregivers.

#### 2.7. Important Messages to Share with Adolescents and Caregivers/parents

The HCW should revisit and discuss the following key information with caregivers/parents when managing ALHIV:

#### 2.7.1. Adherence to medicines

- Younger adolescents may still rely on a caregiver to take their medicines
- Older adolescents need to take some or all of the responsibility for taking their medicines every day
- Often, adolescents struggle with adherence at various points in their development, as they strive to form their own identity and to fit in with peers.

#### 2.7.2. Adherence to care

- Adherence to care may be more difficult for ALHIV because ALHIV:
  - $\circ~$  Often have less disciplined or structured lives and less stable relationships outside of the family
  - Are more likely to lack skills to negotiate health services and to understand side effects, treatment options, and regimen requirements
- Adolescents can become lost in the system when in transition from adolescent to adult HIV services
- Transition of adolescents from adolescent care to adult HIV care should be a slow process depending on the adolescent's readiness to move.

#### 2.7.3. Stigma and discrimination

- Blame is often placed on ALHIV because of an assumption that they voluntarily engaged in "risky behaviour"
- Stigma may hinder some ALHIV to disclose their HIV status when they decide to become involved in a sexual relationship.

#### 2.7.4. Counselling adolescents

- Adolescents' cognitive abilities and skills are different from adults and as a result they require different counselling sessions
- Conflicts between cultural or parental expectations and adolescents' emerging values can present serious challenges
- Adolescent clients often depend on their caregivers and cannot always make independent decisions
- Adolescents have a range of future decisions to make, like whether to have children, whether to get married, etc.
- Adolescents face strong peer pressure and tend to be dependent on peers for lifestyle guidance

#### 2.7.5. Safe sex

- ALHIV may not understand risk-taking behaviour or the importance of risk reduction making them more vulnerable to reinfection, unintended pregnancy and STIs
- There is a widespread belief that ALHIV are "not supposed" to be having sex and as a result, they often hide their sexuality
- Adolescents may have limited access to contraceptives and methods beyond condoms; they may also lack the skills to use them correctly and/or negotiate their use
- Gender inequality may further reduce female adolescents' ability to negotiate condom use.

## **CHAPTER 3: HIV PREVENTION SERVICES FOR ADOLESCENTS**

HIV prevention uses an integrated approach of behavioural, biomedical and structural interventions. This mix of interventions helps to meet the HIV prevention needs of the population to have the greatest possible impact on reducing new infections.

HCWs should remember that ALHIV are at increased risk of secondary HIV infection and have the right to access appropriate prevention services. Secondary prevention intervention should focus on people, places and programmes where there is maximum impact with the available resource. The health facility management team and HCWs should ensure that they design HIV prevention interventions specifically for ALHIV.

#### **3.1. Behavioral Interventions**

Risk behaviors among adolescents such as early sexual debut, multiple sex partners, cross-generational and transactional sex, unsafe sex practices, and alcohol and drug abuse can lead to serious long-term health consequences such as STIs, HIV and unintended pregnancy.

The main goal of behavioural interventions is to encourage safe behaviour to reduce new HIV incidence among adolescents by focusing on these priorities areas:

- Abstinence from sex
- Using condoms correctly and consistently at every sex act
- Avoiding multiple sex partners, especially concurrent sexual partnerships
- Discouraging cross-generational (older younger relationships) and transactional sex (something for something sex)
- Discouraging alcohol consumption and drug abuse, which could limit safe decision-making and increase risk.

Strategies that should be used to address risk behaviours for adolescents include:

- Providing health education to adolescents at health facility or in the community through outreach services.
- Risk reduction counselling messages include reduction of concurrent sexual partners; consistent and proper condom use; disclosure and knowing your partner's status; and reduced alcohol consumption. This can be done during Teen Club meetings or during counselling sessions at the clinic.
- Community mobilization through use different gathering of adolescents at schools, festivals and sport activities.
- Advocacy at National, Regional and District levels.
- Sexuality education in specialised adolescent clinics, use of cultural meetings like *jando* and *unyago* and use of parents and caregivers.

- Peer education programmes by targeting schools, health facilities, social activities and social gathering.
- Social marketing campaigns e.g. to promote condoms use.

#### **3.2. Biomedical Interventions**

The biomedical measures listed below aim at providing primary and secondary HIV prevention to adolescents. HCWs should provide the following services:

- Condom promotion and distribution
- Post exposure prophylaxis (PEP)
- PMTCT services
- FP services
- Voluntary medical male circumcision (VMMC)
- TB treatment and diagnosis
- STI/RTI diagnosis and treatment
- GBV screening and support
- If unknown HIV status or HIV negative, HTS

#### **3.3. Structural Interventions**

Facility management teams should promote an enabling environment to prevent/reduce HIV infections and increase access of HIV services to adolescents, as shown in the Table below.

	Structural intervention	Implementation approach
1.	Supportive policies	Ensure availability of guidelines and SOPs for
		HIV services to adolescents at health facility
		e.g. Standard of Care
2.	Reduction of stigma and	Empowering youth through provision of
	discrimination	health education and counselling on HIV
		services
3.	Integration of health services	Training HCWs from each service delivery
		point on HIV e.g. at OPD,TB and RCH clinic
4.	Addressing GBV issues	Integrate post-GBV care services in HIV
		services, and/or establish one stop centre
5.	Community mobilisation and dialogue	Participating community meeting, mass
		communication ( radio programs)
6.	Income generating activities	Collaborate with CSOs supporting IGA and link
		adolescents to these CSOs

Table 3.1: Enabling environment to prevent/reduce HIV infections and increase
access of HIV services to adolescents

#### 3.4. Management of GBV among ALHIV

Worldwide, GBV is a serious problem that limits the ability of men, women and children to enjoy their basic human rights and fundamental freedoms.

#### 3.4.1. GBV in Tanzanian adolescents

Tanzania has unacceptably high levels of GBV and Violence against Children (VAC). The TDHS 2015/16 shows that 40% of women ages 15-49 have ever experienced physical violence and 17% have experienced sexual violence. Three out of 10 girls and one out of seven males had experienced sexual violence before age of 18 years<sup>2</sup>. Three-fourths of females and males had experienced physical violence before the age of 18 years old<sup>3</sup>. Despite its high prevalence, GBV is often not adequately addressed. It is rooted in gender inequalities and gender norms, often serving to reinforce gender inequality at different levels.

Health facility management teams at all levels should establish links with the community and other stakeholders like social welfare and law enforcement (police and court) to provide effective GBV prevention among ALHIV.

#### 3.4.2. Steps for management of GBV

In addressing GBV, HCWs must be aware that adolescents' health problems may be caused or made worse by violence. Whenever violence is reported or suspected, the first line of support should be offered which includes:

- Listen closely with empathy and without judging
- Inquire about needs and concerns including emotional, physical, social and practical (e.g. childcare)
- Validate show that you understand and believe assure that s/he's not to blame
- Enhance safety discuss a plan to protect her/him from further harm or violence if it occurs again
- Support support her/him by providing information, services and other social support that might be required.

REMEMBER: This may be the only opportunity to help.

The HCW should be responsible for sharing the following key messages with adolescents and caregivers:

• GBV is a human rights violation in which a person is physically, sexually, or

<sup>2</sup> Violence against Children (VAC) Survey, 2009

<sup>&</sup>lt;sup>3</sup> United Nations Children's Fund (UNICEF) et. al 2011

psychologically harmed by another person who feels that he/she has more power and control over the other.

- Feelings of guilt and self-blame are common among survivors however GBV is never the fault of the survivor
- Survivors of GBV especially young adolescents may be intimidated and threatened so that they may fear reporting the incident. It is important for community, family and HCWs to create safe space for survivors of violence and have mechanisms with which to remove survivors from violent living situation
- Adolescents should be assessed for GBV at least once every six months as part of the HIV program
- GBV like rape has the potential to increase the risk of acquiring new HIV infections
- GBV can negatively affect retention and ART adherence of adolescents leading to poor treatment outcomes
- HCWs, caregivers and other stakeholders should teach life skills to ALHIV to empower them.

#### 3.4.3. The role of HCWs in managing adolescent victims of GBV

Health and social welfare services should ensure HCWs are equipped with relevant information regarding GBV issues. HCWs should be able to identify, refer and link adolescents with relevant services according to the needs.

- For adolescents who are raped and/or forced anal penetration with unknown HIV status, test for HIV and manage according to the national guidelines
- For ALHIV who are raped and/or forced anal penetration, review ART history and ascertain adherence to medication
- Screen for STIs and offer treatment
- Assess for risk behaviour
- Facilitate forensic interviews and examinations
- Give emergency contraception, according to national guidelines, if person is attended within the first 120 hours; female rape victims identified late should be offered pregnancy testing and/or linked to FP counselling. Offer a possibility of contraception for adolescents at risk of repeated sexual violence.
- Counsel the adolescent and assess mental health
- Identify, refer and link adolescents to other services including:
  - Long-term psychosocial support
  - Legal and/or Police (investigations, restraining orders)
  - Economic empowerment
  - Emergency shelters
  - Peer support groups.

## CHAPTER 4: COMMUNICATION, COUNSELLING, AND LIFE SKILLS FOR ALHIV

Communicating with ALHIV, their families and other/related users of health services will sustain clinical advances and strengthen the knowledge and skills of HCWs who counsel adolescents and their families. Families have the major responsibility for caring for adolescents during their growth and development. Emphasis is placed on interpersonal communication and listening skills. The principles of non-directive counselling are introduced with the aim of facilitating ALHIV's overall development by strengthening their self-understanding, and enhancing their abilities to personally manage and cope with present problems and prevent future difficulties.

#### 4.1. General Principles of Communication with ALHIV

These principles include:

**Trust** - Both the ALHIV and the parent/guardian/caregiver need to be able to trust those who are caring for them.

**Honesty** - Never lie to ALHIV. ALHIV's trust in those who are caring for them can be destroyed, and future care will be feared and anxiety increased.

**Respect** – Respect ALHIV for who they are with an non-judgemental attitude. Do not ignore the adolescent's viewpoint and feelings.

**Freedom to express** - Allow ALHIV to express their worries and anxieties through play, drawing, songs or other activities.

**Our own feelings** - Be careful of your own feelings; ALHIV are very perceptive to the attitude of those around them. They pick up on the distress and anxiety of those around them.

**Participatory approach** - Include them in care, teach them about their illness and encourage them to make decisions and appreciate their success.

**Unconditional care** - Treat ALHIV equally regardless of gender, background, or socioeconomic status.

**Touch** - Can convey more than words in terms of comfort and reassurance. Be conscious that it can also be misused.

**Family involvement** - Ensure that close family or other significant adults in the family are involved in the care of the ALHIV.

#### 4.1.1. Building trust in communicating with ALHIV

Trust is the starting point that paves way for effective communication and counselling. ALHIV may have concerns related to their diagnosis, disclosure of their HIV status, feelings of isolation, and coping with a chronic condition. HCWs should display desirable attributes of an effective care provider.

Building trust and rapport with adolescent clients starts with understanding their feelings and mind-set. Being able to understand the perspective of the adolescent will enable the HCW to respond appropriately and to create a positive and effective service experience. Adolescents may have feelings of discomfort, embarrassment, shyness, and uncertainty when communicating with HCWs about personal issues (for example, about sexuality, wanting to have sex, wanting to have a baby, etc.).

#### To effectively build trust to an adolescent, a HCW should:

- Reassure adolescents that anything they say will be kept confidential. This means that members of the multidisciplinary care team will not tell other people any information about clients, including what they say or that they are living with HIV.
- Describe to adolescents and caregivers circumstances in which information shared can be disclosed
- Not threaten to break adolescents' confidentiality
- Stress that information entrusted with them will not be shared even with caregivers unless the client gives his or her permission (Adolescents may be reluctant to disclose personal information if their parents or caregivers are present).

#### When communicating with adolescents, a HCW should:

- Create a safe, adolescent friendly environment
- Establish rapport
- Get to know client and help the adolescent feel comfortable
- Assess risks, including emergent psychological concerns
- Explore related issues by giving real-life examples through story telling
- Provide relevant information
- Repeat information back to clients in the form of a question to encourage them to re-think what they have just said.
- Facilitate peer support if necessary
- Discuss next course of action and reasons for referral
- Ask questions about the adolescent's home, family, school, and even hobbies before moving onto more sensitive topics like adherence to medication, disclosure, and sexual or reproductive health issues.
- Hang posters in common areas that communicate important messages.

#### Role of HCWs in building trust when communicating with ALHIV:

HCWs should encourage ALHIV to discuss issues with peers who are also infected with HIV — either one-to-one or in groups. Peer support helps adolescents recognize that they are not alone in dealing with the types of problems they have. HCWs should encourage initiation of peer support groups for ALHIV as well as supervise them regularly. ALHIV may not respond to adults who tell them to take their medication every day; but they might listen to a peer who tells them the same thing. Using other

adolescents who have struggled with the same problems related to care and treatment, like adherence challenges or disclosure, can be an extremely effective motivator for adolescent clients.

HCWs can take the lead in initiating and facilitating peer support groups, ensuring the involvement of adolescents in planning and setting up the groups, as well as serving as peer educators and supporters. However, it is also important to emphasize that while they are important sources of support, peer supporters do not replace the roles and responsibilities of health care professionals. Nevertheless, with appropriate training, mentorship and supervision, peer supporters can provide important linkage between adolescents and the community to HCWs and services (WHO).

### 4.1.2. Empowering the parent/caregiver in communicating with ALHIV

The HCW is responsible in assisting the parent/caregiver in communicating with the adolescent effectively. They should encourage appropriate support for the adolescent and take into account the perceptions, feelings and needs of the parent or caregiver.

HCW should explain to parent/caregiver:	During discussion HCW should:
<ul> <li>Parents/caregivers are expected to give continued support to adolescents</li> <li>Parents /caregivers are responsible to provide consent for adolescents when needed</li> <li>Adolescents still depend on their parents/caregivers</li> <li>It is part of the standard care to involve parents/caregivers</li> <li>Parents/caregivers should spend more time with adolescents.</li> </ul>	<ul> <li>Respect caregivers/parents views</li> <li>Demonstrate non-judgmental attitudes</li> <li>Reinforce the confidence of the caregiver to communicate with adolescents</li> <li>Appreciate their contributions and reinforce their strength</li> <li>Assist parent/caregiver to address their communication gaps</li> <li>Discuss with the caregiver the importance of good communication with adolescents</li> <li>Support the caregiver to appreciate the communication needs of adolescents</li> <li>Support the caregiver to use age appropriate language while communicating with adolescents.</li> </ul>

Table 4.1: Role of HCW for empowering parent/caregiver in communicating withALHIV

HCWs should ensure that the parent/caregiver is well informed on special considerations to observe when communicating with younger and older adolescents.

## Table 4.2: Special considerations to observe when communicating with younger andolder adolescents

Adolescents 10 - 14 years	Adolescents 15 – 19 years
<ul> <li>Need time to feel safe and to trust.</li> <li>Understand concrete things they can touch and see. Explain things in simple terms. Drawing, demonstration, or visual aids can be used to make information more concrete.</li> <li>They may feel scared and may fear being judged.</li> <li>They may feel anxious or embarrassed when asking for help.</li> <li>They may hesitate to respond to questions.</li> <li>Do not force adolescents to share. Positively reinforce their efforts to express themselves.</li> <li>If an adolescent is rude or aggressive, remember that this behaviour may not be directed at you. Be patient and do not take it personally.</li> </ul>	<ul> <li>When advising adolescents, do so from the perspective that they have not yet had the opportunity to learn what you are explaining to them.</li> <li>Ask adolescents about the things that are important to them.</li> <li>Try to understand the perspective of adolescent</li> <li>Never assume that they are not yet sexually active. Also never assume that they are sexually active.</li> <li>Do not assume that any adolescent has the same interests or issues as other adolescents you have met recently.</li> <li>Adolescents may be overconfident to matters to related to him/her</li> <li>Never make assumptions, use openended questions and always remain non-judgmental.</li> </ul>

Note: Some of the special considerations can apply for both groups.

#### 4.1.3. Social and behavioral change communication for risk reduction among ALHIV

Social and Behaviour Change Communication (SBBC) is the developmental practice of enabling individual and societal change through engaging with communities to determine what changes are necessary to address their specific challenges and identifying localized strategies to facilitate the required change. Communication is an essential element of HIV prevention and treatment and care efforts. It is the exchange of information, ideas or feelings.

Communication is the core components of SBCC that enables interactive process of engagement between SBCC practitioners and communities. This engagement is aimed at empowering communities to change their behaviours. SBCC interventions usually comprise a combination of advocacy, communication and social mobilization:

- **Advocacy** attempts to influence leaders at all levels from community right up to national and sometimes regional and international level to promote enabling legislation and remove barriers to change.
- **Communication** aims to enable and promote behaviour change that often uses multiple channels including inter-personal (provider-client), TV, radio, print, drama, peer education, storytelling, etc.
- **Social Mobilization** is directed to individuals, groups and communities to encourage grounds well support to address barriers to change.

#### For ALHIV, HCWs should communicate the following key messages:

- Delay onset of sexual debut (abstinence)
- Promote correct and consistent condom use and offer condoms as appropriate for adolescents who are sexually active
- Discourage multiple, concurrent sexual partnerships and promote faithfulness with a partner of known status for adolescents who are sexually active
- Discourage cross-generational and transactional sex for adolescents who are sexually active
- Assess for violence, (physical, emotional, or sexual); if an adolescent discloses sexual violence, assess if the adolescent was raped and act immediately

# *4.1.4. Principles HCWs should follow in designing and implementing SBCC in health facilities*

Understanding communication practices in health delivery settings is important for ensuring better behavioral and health outcomes. For HCWs, understanding and applying these key principles is essential for producing high-quality communication outputs and improving quality of adolescent services.

The types of communication activities you design will depend on the needs that exist along the continuum of care. For example:

- For needs in the '*before*' stage, you might design demand generation and outreach, normative change, or provider trust activities.
- For needs in the '*during*' stage, you might design counseling, provider behavior change, clinic environment, or adolescent empowerment activities.
- For needs in the *after* stage, you might design peer support, outreach, or followup activities.

All of these activities will be part of your larger service delivery efforts and linked to the same overarching behavioral and health outcomes.

Each health facility will have its own design process. The Table below summarizes some of the key challenges service delivery projects face, minimum service communication solutions, and the skills necessary to delivery those solutions.

#### **Minimum service communication Required service communication** Challenge skills solutions Getting clients to Strategically segment audiences • Audience analysis, including • services Seek to understand clients and effective segmentation, what matters to them prioritization, and profiling Identifying and selecting the Design activities based on an • most relevant determinants of understanding of what behavior change motivates client behavior

## **Table 4.3:** Challenges in service delivery projects, service communication solutions, and the skills necessary to delivery those solutions.

	<ul> <li>Address provider bias and how providers treat clients</li> <li>Tailor messages to different audiences</li> <li>Address underlying norms and attitudes</li> </ul>	<ul> <li>Addressing providers as an audience for behavior change</li> <li>Designing and tailoring messages for different audiences</li> <li>Community outreach and mobilization</li> </ul>
Helping clients adopt desired behaviors and use products	<ul> <li>Strategically segment audiences</li> <li>Seek to understand clients and what matters to them</li> <li>Offer clear benefits for adopting behaviors and using products, based on what the clients care about</li> <li>Address provider bias and how providers treat clients</li> <li>Design activities that address the true determinants of behavior</li> <li>Foster support systems</li> </ul>	<ul> <li>Audience analysis</li> <li>Determining key benefits</li> <li>Addressing providers as an audience for behavior change</li> <li>Identifying and selecting the most relevant determinants of behavior change</li> </ul>
Helping clients maintain desired behaviors and adhere to treatment regimens	<ul> <li>Foster support systems</li> <li>Design activities that address the true determinants of behavior</li> <li>Seek to understand clients and what matters to them</li> </ul>	<ul> <li>Community mobilization</li> <li>Identifying and selecting the most relevant determinants of behavior change</li> <li>Audience analysis</li> </ul>
Reaching the desired audience with messages	<ul> <li>Tailor messages to different audiences, based on a clear understanding of the audience</li> <li>Use appropriate communication channels</li> </ul>	<ul> <li>Designing and tailoring messages for different audiences</li> <li>Selecting an appropriate channel mix based on communication landscape and audience preferences</li> </ul>
Getting the audience to respond to communication efforts	<ul> <li>Seek to understand clients and what matters to them</li> <li>Tailor messages to different audiences, based on a clear understanding of the audience</li> <li>Offer clear benefits for adopting behaviors and using products, based on what the clients care about</li> <li>Use appropriate communication channels</li> </ul>	<ul> <li>Audience analysis</li> <li>Designing and tailoring messages for different audiences</li> <li>Determining key benefits</li> <li>Selecting an appropriate channel mix based on communication landscape and audience preferences</li> </ul>
Achieving positive client- provider interactions	<ul> <li>Address provider bias and how providers treat clients</li> <li>Create counseling and job aids</li> <li>Improve the work environment</li> <li>Empower clients</li> </ul>	<ul> <li>Address providers as an audience for behavior change</li> <li>Materials development</li> </ul>

#### 4.2. Counselling ALHIV

On counselling adolescents, HCWs are not responsible for solving all of the client's problems. Ultimately, it is the responsibility of the client to make his or her own decisions and to then carry them out. The role of HCWs is to support and assist the adolescent decision-making process by helping them:

- Talk, explore, and understand their thoughts and feelings
- Work out for themselves what they want to do, what choices are available and consequences of decisions, and how they want do it
- Make an informed personal decision and cope with stress.

#### *In the context of HIV, the counselling sessions should talk about:*

- Prevention: HIV counselling and risk reduction information helps to prevent HIV transmission and acquisition.
- Care: HIV counselling helps to ensure that ALHIV are taking care of their health, adhering to treatment and clinic services (labs, pharmacy, etc.)
- Support: HIV counselling helps to provide emotional, psychological and social support to adolescents affected by HIV
- Referral: HIV counselling helps to identify and facilitate referrals for other health or related HIV care, treatment and support services.

#### During counselling session with ALHIV, HCW should:

- Establish supportive relationships
- Conduct conversations with a purpose (not just chatting)
- Help ALHIV talk without fear of stigma or judgment
- Give correct and appropriate information
- Help ALHIV make informed decisions
- Explore options and alternatives
- Help adolescents recognize and build on their strengths
- Help ALHIV develop a positive attitude and become more confident
- Respect everyone's needs, values, culture, religion, and lifestyle
- Be willing to trust ALHIV feelings and decisions
- Involve them in their own care
- Assess their emotional and developmental level
- Be aware of the client's changing capacities and adapt accordingly
- Listen careful to ALHIV, reflect back feelings, offer empathy, and show that you care about what they are going through
- Encourage questions to check understanding
- Be aware of the client's attention span
- Watch the client's body language. If inattentive, stop and try again at a later time
- Schedule adolescents to see the HCW with whom they best get along/relate.
- Use the skills, strengths, and approaches of different HCWs on the multidisciplinary team to meet clients' needs
- Teach adolescents life skills i.e. skills of knowing and living with oneself; knowing and living with others; and making effective decisions.

Refer to national Guideline on Management of HIV and AIDS for details and guidance on counselling at various visits according to needs. Also refer to Appendix 1: Common Counselling Scenarios.

#### 4.2.1 Common counselling mistakes

HCW should n	ot deal with the following aspects during counselling sessions:
Solving anoth	her person's problems
Telling anoth	ner person what to do
Making decis	sions for another person
Blaming anot	ther person
Interrogating	g or questioning another person
Sympathizing	g with the person
Judging anot	•
0	or lecturing another person
01	nises that cannot be kept
	e's own beliefs on another person
Providing ina	accurate information.

### 4.3. Life Skills

WHO defines Life Skills as "skills and ability to adopt positive behaviour to avoid problems that are present in everyday life." Most ALHIV have knowledge about problems that abound their treatment, social and personal lives every day, but they do not have the skills to handle these problems. Hence, they fall victims of such problems. Teaching life skills is one amongst many strategies that are observed to effect individual behaviour change. Teaching adolescents' life skills is a continuous process that requires patience and understanding. Life skills cannot be imparted in one day and it is important to continually help adolescents to build life skills at any opportunity.

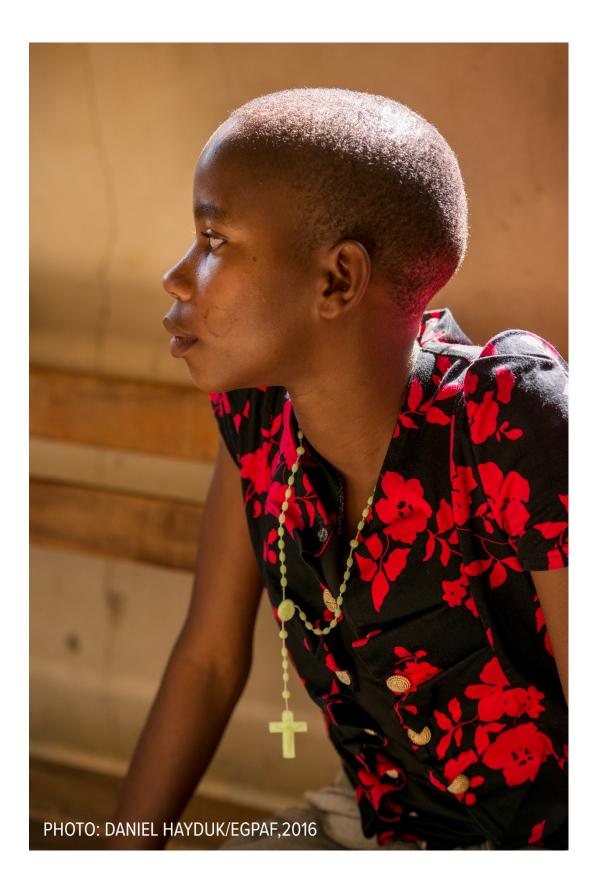
Life skills teachings should look at:

- Skills of knowing and living with oneself: Self-awareness, self-esteem, assertiveness, coping with emotions, coping with stress
- The skills of knowing and living with others: Inter-personal relationships, friendship formation, empathy, peer pressure/resistance, negotiation, non-violent conflict resolution, effective communication
- The skills of making effective decisions: Decision-making, critical thinking, creative thinking, problem solving.

Effective life skills enable adolescents to know who they are, understand and take responsibilities, take care of their health and cope with emotions and stress. It is very important for ALHIV to understand themselves, where they are, where they want to go

and how to get there. As an HCW, assist them to understand this. On the aspect of teaching adolescents' life skills HCWs should refer/link adolescents to various resources available in their localities. Adolescents should actively seek information and support as guided. If the facility has developed a resource directorate showing activities of all CSOs/CBOs/NGOs/ support groups and the like they may be useful to refer/link adolescents in need of the support.

Refer to "Life Skills: A Standard Guide for Training out of School Youth by Ministry of Labour, Employment and Youth Development 2018"



# **CHAPTER 5: DISCLOSURE SUPPORT FOR ALHIV**

This guide aims to assist HCWs involved in the disclosure process in empowering and equipping parents/caregivers and adolescents to be actively involved in the management of the HIV.

The goal of disclosure is to assist adolescents to understand:

- The diagnosis, infection, disease process and health changes that could occur
- Strategies to lead a healthy life and his or her responsibilities now and in the future
- How to cope with the possible negative reactions from others

Perinatally-infected adolescents should be fully disclosed to by adolescent age. The disclosure process should begin early, at 4 - 6 years, by addressing the adolescent's health status and his or her need for care and treatment. In the early stages, very simple terms should be used.

## 5.1. Issues to Consider in Adolescent Disclosure

- Cognitive ability
- Use of developmental approach
- Parent/caregiver or appropriate person to be involve based on the best interest of the adolescent
- Follow up plan to support and monitor adolescent's emotional adjustment
- Adolescent to disclose HIV status to parents or caregiver (for those who acquired non- perinatally)
- Risk reduction plan
- Document and storage of information
- Skills of HCW in conducting disclosure
- Wiliness and readiness of parent/caregiver to disclose
- Privacy and confidentiality
- Adolescent protection policy<sup>4</sup>

#### **5.2. Disclosure Process**

Disclosure should follow a plan, which should be handled as a cyclical process that is repeated as new information is shared with the adolescent. HCWs should assess when an adolescent needs partial or full disclosure.

Partial disclosure refers to giving information about health to client without using the word 'HIV' or AIDS and more information and details should be given as the child grows. Full disclosure is when an adolescent is told that he/she is HIV infected and is given

<sup>&</sup>lt;sup>4</sup> 2007, Ministry of Labour, Employment and Youth Development, National Youth Development Policy

further HIV related details, ensure full disclosure to the child is attained about 8 to 10 years of age. Full disclosure should be considered when the adolescent portrays a mature kind of thinking. The HCW should empower parents/caregivers to be able at each visit to start/continue disclosure systematically as follows:

## **Steps in disclosure process:**

**First step:** Encourage the parent or caregiver to explain to the adolescent how and when to take the medicine without mentioning the name ARV or HIV, name of the medicine and that treatment is not a cure but lifelong medicine to make your body healthy.

**Second step:** Encourage the parent/caretaker to explain to the adolescent that your medicines make you healthy by increasing the "soldiers of the body" hence, that your health problems are less and when your soldiers are strong, you can do whatever you want in life.

**Third step:** Encourage the parent/caretaker to explain to the adolescent that your soldiers ("kingayamwili") became weak because something was attacking them.

**Final step:** Encourage the parent/caretaker to explain to the child that 'something' attacking their bodies is an acquired virus.

In order to move from one step to another the HCW should be guided by adolescent's questions, age depending on maturity, and understanding. Use disclosure job aids/tools from step two to the final step. The process will be smooth if an adolescent has been partially disclosed to over time and has been supported throughout the disclosure process.

Note: Refer to Section 5.6 for special considerations.

## 5.3. When to Delay Disclosure

Disclosure may be delayed in case of the following conditions:

- Adolescent has severe cognitive and developmental delays
- Adolescent is serious ill or has mental health conditions
- One or both parents/the caregiver has an acute health problem or mental health crisis
- Parent/caregiver is not ready for disclosure.

Disclosure should not happen accidentally, carelessly, in anger, unplanned, when the child is dying or after child has already worked things out for him/herself, if one of this happen provide immediately supportive counselling.

## 5.4. Preparing Parent/Caregiver for Disclosure

Caregivers also undergo different phases of disclosure before been ready to disclose to their children/adolescents therefore it is important for the HCW to facilitate the caregivers through this phases until they are ready.

- Build trust by getting to know them; find out what HIV means to them
- Assess their psychosocial situation and ability to cope; answer their questions; identify their sources of support
- Discuss implications of disclosure and possible reactions
- Assess adolescent's readiness for disclosure and share impressions with the caregiver
- Help caregivers to develop a plan for disclosure
- Arrange follow-up visits
- Help them identify barriers and possible solutions
- If there is disagreement between family members, assess concerns and discuss benefits and risks
- Respect and try to understand their reasons for fearing or resisting disclosure.

Remember that if the caregiver is not ready to disclose, the process cannot be forced. However, the HCW should always advocate disclosure for easier access to health care and good adherence of adolescent.

## Different phases of disclosure:

- Secret phase where most caregivers want to keep it secret after diagnosis
- **Exploratory phase** where caregivers may disclose to one person close to them to test their reaction
- **Preparatory phase** where caregiver is now prepared to disclose, shares with others to learn experience
- **Disclosure phase;** ready and not avoiding confrontation.

## 5.4.1. Ongoing disclosure support to caregivers

Caregivers will need ongoing support from HCWs, family members, and peers as the disclosure process proceeds over time. At each visit, ask the parent/caregiver follow-up questions, such as:

- Have you noticed any changes in your adolescent behaviour since he or she learned about his or her HIV-status?
- Who else at home knows about the adolescent status?
- What kind of help, support, or information do you still need?
- What feelings or concerns do you have about the disclosure process with your adolescent?
- Who does your adolescent talk to if he or she has questions?
- What questions do you have?

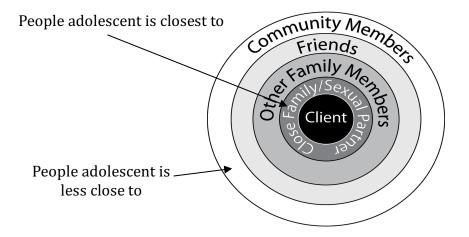
• When will we meet again?

#### 5.4.2. Strategies parent/caregivers may use in the disclosure process

- Probe by giving scenarios
- Show pictures
- Ask related questions

#### 5.5. How to Help Adolescents who know their HIV Status to Disclose

Adolescents should always make their own decisions about disclosure. Assist them to decide whom to disclose to, to decide when and where to disclose, to weigh the advantages and disadvantages of disclosure, and to anticipate likely responses. Support them to develop a disclosure plan and guide them throughout the process. Create a disclosure circle that can help adolescents decide who to disclose to; each level represents a process in itself:



#### Illustration of the above disclosure cycle:

- Centre of the circle is the adolescent
- The next circle out is a person or people the adolescent is very close to, such as his or her mother, siblings, or partner (give the adolescent a piece of paper so that he or she can write the names of the people at this and the next layers of his or her own disclosure circles).
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- Each level of disclosure represents a process in itself preparing for disclosure, the actual disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure there will likely be ongoing discussions over time between the client and the person to whom he or she disclosed.

The goal is NOT to disclose to all of the people included in the circles. Instead, the circles provide a way of discussing the disclosure process, considering the risks and benefits of disclosing to different people, and helping to prioritize disclosure activities.

## 5.5.1. Post-disclosure support to adolescents

- Assess emergent psychological symptoms regularly, particularly during and postdisclosure process
- Offer continued support and availability; discuss the importance of having continued counselling sessions on a regular basis
- Discuss the pain and distress after disclosure at each visit, over time otherwise pain will become internalized
- Address the adolescent's self-perception/esteem and their outlook on life
- Encourage the adolescent to draw on inner-strength and support from his/her parent/caregivers/community/friends to help bring about change in self-perception and outlook on life
- Give the adolescent current information on HIV treatment in a manner which he/she can understand
- Identify sources of support and refer adolescent
- Link adolescent with peer support groups for positive testimonials
- Support the adolescent to identify his/her talent and abilities this will make him/her confident hence positive living
- Provide information on hygiene, SRH, self-awareness and how to deal with stress in order to improve their wellbeing
- Allow adolescent to ask questions and discuss their fears, challenges and how to overcome them.

# At each visit, ask the adolescent follow-up questions, to understand how they are coping up, such as:

- Who else knows about your HIV-status? What do you think about disclosing your status to (other) people you are close to?
- What are some of the ways you are taking care of yourself? How do you think you can live positively with HIV?
- How are you doing with your medications?
- What other questions do you have?
- When should we meet again to talk more?

## 5.6. Special Cases

In situations where an adolescent is head of the household, living with sexual partner or married, homeless, coming to the clinic alone; the HCW (and if possible, more than one member of the multidisciplinary team) may have to take a more active or "parental" role in the disclosure process. This includes deciding when and how to begin and move forward with the disclosure process according to the adolescent unique situation and developmental stage.

For adolescents living in institutions like orphanages, foster homes, or education- or employment-related housing programs HCWs should identify the person who is legally responsible for the child or adolescent and, if possible, invite that person (with the consent of the adolescent client) to the clinic for an educational and counselling session.

# **CHAPTER 6: CLINICAL CARE FOR**

Clinical care for ALHIV requires that both the facilities and communities where the care is being provided, and the HCWs providing care, are sensitive to the particular developmental needs of adolescents. The services should be adolescent-friendly as described in Chapter Two.

## 6.1 Comprehensive Clinical Care for ALHIV

Comprehensive clinical care for ALHIV is supposed to be:

- Integrated (provision of HIV and other related health services)
- Age, sex, and developmentally appropriate
- Responsive to the needs of perinatally and newly-infected adolescents and their caregivers/parents
- Empowering to adolescents to take responsibility for their own health and transition to adult care
- Focusing on differentiated HIV care, to improve adherence and retention

## 6.1.1. Entry into adolescent care

The Table below summarizes entry point into adolescent care, clinical package and type of service delivery model.

Comprehensive Clinical Care for ALHIV		
Entry	Adolescent clinical package	Categories of client according to differentiated HIV care
Existing client transitioning from paediatric care at about age of 10 years	Follow-up visits Integrated health services including PSS services Review and strengthen referral and linkage with support services	Stable or unstable
Newly-diagnosed adolescent	Enrolment visit Initiation of ART Establish, review and strengthen referral and linkage with support services Follow up visits	Early disease or advanced disease Reassess at six months on ART and categorize to stable or unstable client

## Table 6.1: Comprehensive clinical care for ALHIV

## 6.2. Service Delivery Models (SDMs) for Differentiated Care for Adolescents

Service Delivery Models for differentiated care is a client-centred approach that simplifies and adapts HIV services across the treatment cascade in order to reflect the preferences and expectations of various groups of PLHIV. It reduces unnecessary burden on the health system and enables the health system to refocus resources to most in need clients.

The treatment cascade entails steps from initial HIV diagnosis, linkage to care, receiving ART, retention in care and achieving viral suppression. (Refer to 6<sup>th</sup> Edition *National Guidelines for Management of HIV and AIDS 2017).* 

## 6.2.1. Service delivery models (SDMs) for differentiated care

With "treat all", HIV services face an increasing number of clients on ART. Due to that, four groups of clients with different specific needs are categorized through the differentiated service delivery models as follows:

- **Clients with Early Disease**: These are the clients who present with WHO Stage 1 or 2, and CD4 count ≥350cell/ mm<sup>3</sup>
- **Clients with Advanced Disease**: These are clients who present with low CD4 count ≤200 cells/mm<sup>3</sup> or WHO Stage 3 and 4
- Stable Clients on ART
- Unstable Clients on ART

#### Stable Clients on ART for at least six months and:

- Age above 5 years
- Have no adverse drug reactions that require regular monitoring
- No current illnesses (OIs and co-morbidities)
- Have good understanding of lifelong adherence of 95% and kept clinic visit appointments for the past six months
- On first line ARV with recent undetectable viral load of below 50 Copies/ml.
- In the absence of viral load monitoring, rising CD4 counts  $\geq$  350 cells/mm<sup>3</sup>.

This group represents the majority of people on ART. The clients on this group should be offered less frequent clinical visits and extended drug refills.

**NOTE:** Stable clients should meet ALL of the above criteria.

#### Unstable Clients on ART have ANY of the following:

- Age below 5 years
- Presence of an active OIs (including TB) in the past 6 months
- Poor or questionable adherence to scheduled clinic visits in the past 6 months
- Recent detectable VL above 50 copies/ml
- In absence of viral load monitoring decreasing CD4 cell count or  $CD4 \le 200 \text{ cell/mm}^3$
- People Who Inject Drugs (PWID)

- Pregnant women
- Clients on second or third line regimens

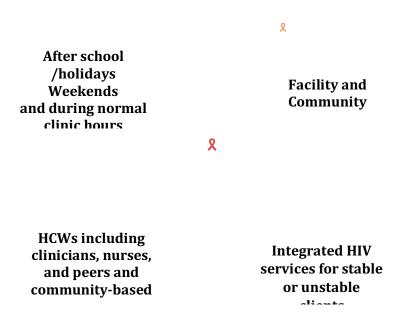
These clients require additional clinical care, adherence support and timely switch to alternative treatment.

#### 6.2.2. Building blocks of service delivery models

Delivery models are designed using the building blocks approach with four delivery components:

- The types of services delivered; What care or services are provided?
- The location of service delivery; Where is care provided?
- The provider of services; **Who** is providing care?
- The frequency of services. When is care provided?

#### Figure 6.1. Service delivery model for ALHIV<sup>5</sup>



#### 6.2.3. Differentiated ART delivery for stable ALHIV

#### WHEN:

• Clients should have a clinical review twice a year

<sup>5</sup> Adapted from International AIDS Society (IAS). Differentiated Care for HIV: A decision framework for antiretroviral therapy delivery. July 2016.

- ART refills for stable clients should be provided for two months depending on supply
- Clients should choose a blocked appointment time (AM /PM) as well as an appointment date
- Clinics should provide extended opening hours (weekends, after school hours, during holidays) and during normal clinic hours. Frequency of extended hours should be determined based on local demand and client volume.

## WHERE:

- ART refill should be provided to all existing facilities
- Clients should receive ART at the health facility of their choice
- ART may be offered in a group refill approach led by HCW in Teen Clubs
- In hard to reach areas, ART refills through a mobile outreach strategy by HCWs

## WHO:

• Follow-up on ART should be performed by a trained HCW (clinician or nurse), adolescent peer, and/or community-based provider for tracing MISSAP, LTF clients and strengthening adherence.

## WHAT:

- Full clinical review should be done during clinical consultations
- ART refills should be provided to clients according to service delivery model in use
- Adherence support
- Psychosocial support
- Nutritional support
- Referral and Linkage according to the needs

## 6.2.4. Differentiated ART delivery for unstable clients

## WHEN:

- Clinical review should be monthly
- Additional visits as required to address any medical or psychosocial concerns
- The decision to switch to 2<sup>nd</sup> line should preferably take no longer than two weeks from the receipt of the second high viral load >1000 copies/ml

## WHERE:

- At all health facility levels
- Management of client is done at any ART service delivery point
- Second line initiation should be decentralised to all sites who have a qualified HCW to switch
- Consider referral to higher facility or linkage to other services as required

## WHO:

- All levels of HCWs who have received training should be able to prepare a VL sample
- All HCWs who have been trained and assessed as competent to assess clients with treatment failure should be able to switch adolescents to second or third line
- Adolescent peers and community-based providers for tracing MISSAP, LTF clients and strengthening adherence

## WHAT:

Case management to address reason/s for not meeting stable eligibility criteria:

- Enhanced adherence counselling should be available both at facility and community level
- Viral load monitoring according to the national algorithm
- Appropriate switch to second or third line ART
- Screening and management of OIs and co-morbidities
- Screening, counselling and management of malnutrition
- Adherence support
- Psychosocial support
- Referral and linkage according to the needs

## 6.3. Components of HIV Care Package for ALHIV

- Enrolment visit
- Follow up visits
- Laboratory monitoring, to confirm treatment success and if no switch to 2<sup>nd</sup> or 3<sup>rd</sup> line regimens
- ART initiation
- Prophylaxis (Cotrimoxazole, Isoniazid Preventive Therapy and Fluconazole)
- Integrated services for TB, nutrition, GBV, mental health, and SRH

## 6.3.1. Enrolment visit (initial visit) - clinical assessment and management of OIs

Enrollment visit for adolescents is not different from the general population; however, there are special considerations for ALHIV as follows:

- Assess readiness to transition from pediatric to adolescent care
- Screening for STIs, UPT, mental health problems and GBV
- Determine disclosure status
- Identify committed treatment supporter
- Screening for TB and other OIs
- Link to adolescent peers
- Assess for risky behaviours and provide counselling and support accordingly
- Provide SRH services as required

Ensure privacy and confidentiality throughout when dealing with adolescents and services provided should be friendly.

Adolescents transitioning from paediatric services have been in care prior to age 10 and they will have undergone an enrolment assessment as infants or children. HCWs are recommended to use the enrolment visit to adolescent care to review the client's file, history, and current status to assess if they are eligible for the Fast Track (stable) service package or Main Track (unstable) service package.

## 6.3.2. Follow-up visits

- Assess adherence and conduct counselling accordingly
- Follow-up on disclosure status and provide appropriate support
- Follow up if have joined PSS groups
- Review results from past laboratory investigations and perform other investigation as needed
- Screen for OIs including TB in each visit
- Continue with CTX prophylaxis according to eligibility criteria
- Assess for Risky behaviours and provide counselling and support accordingly
- Provide SRH services as required

## 6.4. Prevention of Common OIs

ART reduces HIV related morbidity and mortality by reversing the HIV induced immune depletion, which is responsible for occurrence of different OIs. Provision of prophylaxis drugs helps to prevent infections, which may destroy the health of ALHIV.

## 6.4.1. Cotrimoxazole (CTX) prophylaxis in adolescents

Give Cotrimoxazole to adolescents including adolescent pregnant women with CD4 counts of <350 cells/ml **Dosage:** Give one double strength tablet of CTX (160/800 mg) or two single strength tablets (80/400mg) once a day for those with  $\geq$ 60kg. For ALHIV  $\leq$  60Kg find CTX dose on the ARV dosing chart under CTX dosage.

Note: Perform Baseline Haemoglobin test before long term administration of CTX.

## Stop Cotrimoxazole:

- With occurrence of severe drug and cutaneous reactions
- If ART is initiated and CD4 count is above 350 cells/ml and virological suppression is below 50 copies/ml.
- If use of ARV agents causes renal and/or hepatic insufficiency or severe haematological toxicity.

## 6.4.2. Prevention of tuberculosis with IPT

The following should receive IPT:

- ALHIV with no evidence of active TB disease and no contraindications to IPT
- ALHIV who do not have any TB symptoms (should be offered IPT for at least 6 months)
- ALHIV who have been successfully treated for TB disease for the past 2 years (should be offered IPT for 6 months, unless MDR or XDR TB)
- ALHIV who have had contact with a TB case and do not have active TB disease (should be offered IPT for 6 months).

## **IPT DOSE**

- The recommended dose of isoniazid (INH) for preventive therapy in ALHIV is 300mg daily for 6months to complete 1 cycle of IPT
- Should only be given in 1 cycle in lifetime no repeat cycle is needed
- In case of neuropathy due to INH, Pyridoxine 25mg daily should be used for treatment of neuropathy.

## 6.5. ART Regimens

All HIV infected individuals regardless of age, WHO clinical stage, CD4 count HIV risk group, pregnancy status, associated comorbidities and degree of immunosuppression are eligible for ART.

## 6.5.1. ART regimens for ALHIV

#### Table 6.2. First line ARV regimens for adolescents under 15 years

Patient Group	Preferred 1 <sup>st</sup> Line Regimen	Alternative Regimens
Adolescents ≤ 15 years	ABC+3TC+LPV/r	AZT+3TC+EFV ABC+3TC+EFV TDF+3TC+EFV AZT+3TC+LPV/r AZT+3TC+NVP
TB co-infected ALHIV ≤ 15 years already on LPV/r based regimen	ABC+3TC+LPV/r	ABC+3TC+LPV/r but the dose of LPV/r should be doubled due to the interaction between ritonavir and rifampicin

TDF may only be given to children >2 years and above 35 kg. Adult formulation ATV/r can be used as an alternative to LPV/r in adolescents >40 kg.

Table 6.3. Recommended first line ARV regimens for adolescents above 15 years

Patient Group	Preferred (Default) Regimen	Alternative Regimens
Adults and adolescents (≥15 years), pregnant/lactating mothers	TDF/3TC/EFV600mg	TDF/FTC/EFV600mg TDF/ (3TC or FTC) +DTG ABC/3TC+EFV600 or DTG AZT/3TC+EFV600 or DTG AZT/3TC/NVP
TB co-infections	TDF/ (3TC or FTC) /EFV600mg	TDF/FTC/EFV600mg TDF/ (3TC or FTC) +DTG AZT/3TC+EFV600 or DTG ABC/3TC+EFV600 or DTG
People who inject drugs (PWID)	TDF/(FTC or 3TC) +DTG	TDF/ (FTC or 3TC) +ATV/r

## Note:

- Efavirenz should be taken with or without food, but NOT with a high-fat meal. Preferably before bedtime.
- Atazanavir should be taken with food
- Plan with the client a daily routine for taking drugs and meals to maximise the effectiveness of the drugs.

## 6.5.2. Observations during the first 6 months of ART

The first six months on ART are critical.

- Most adolescents respond well to ART initiation, with increases in CD4 cell count; however, some fail to respond as expected
- Complications in the first few weeks following ART initiation (IRIS) are most common in those with severe immunodeficiency
- Failure to improve does not necessarily reflect a poor response to ART

- It takes time for viral replication to be controlled by ART
- It may, however, reflect inadequate adherence

**Remember:** Immune Reconstitution Inflammatory Syndrome (IRIS):

- Often occurs in the first weeks to months after ART initiation
- Is a complication caused by reactivation of the immune system
- Can present as a flare-up of symptoms when the recovering immune system begins to respond to an existing infection (e.g. TB)
- Is NOT due to failure of ART, but rather its success (and the resulting immune reconstitution)

#### **Responses to successful ART are:**

- Improvement in growth or weight gain in adolescents who have been failing to grow
- Decreased frequency of infections (bacterial infections, oral thrush, and/or other OIs)
- Feeling stronger, more energy, ability to focus, interest in play, friends, and fun

#### 6.5.3. ARV toxicities

Adolescent clients may not have much experience taking medication that has side effects, especially every day. They should be educated on mild (common and normal) side effects of ART that will diminish over time. They should also know when side effects are moderate or severe and be advised to return to the clinic.

#### Three categories of drug toxicities:

- 1. **Mild toxicities** do not require discontinuation of ART or drug substitution. Reassure the client and manage side effects.
- 2. **Moderate or severe toxicities** may require drug substitution, but do not require discontinuation of all ART. Continue with ARVs as long as feasible, substitute if the reaction persists or the client cannot tolerate and refer for adherence counseling.
- 3. **Severe life-threatening toxicities** require stopping all ARVs immediately. Initiate supportive therapy until the patient is stabilized and the toxicity is resolved. Restart ARVs when the patient is stable.

## 6.5.4. Treatment failure

Treatment failure is when the ARV regimen is unable to control HIV infection. Failure can be clinical, immunologic, virologic or any combination of the three. Assess for correctable causes (drug-drug interaction, food-drug interaction, poor adherence, inappropriate dosing schedules) of treatment failure and take appropriate measures.

Virological failure is the most accurate method. If not available, use immunological criteria (i.e. CD4 cell count). Once treatment failure has been detected, select a new regimen (refer to 6<sup>th</sup> Edition National HIV/AIDS Guidelines).

#### **Confirmation of Treatment Failure**

#### Things that should be reviewed to confirm treatment failure include:

- Level of detectable viral load (Refer to 6<sup>th</sup> Edition National Guidelines for the Management of HIV and AIDS)
- Adolescent has been on ART for at least 24 weeks (6 months)
- Adolescent has been adherent. If not, keep ALHIV on same regimen and provide Enhanced Adherence Counselling and support (Refer to 6<sup>th</sup> Edition National Guidelines for the Management of HIV and AIDS).
- CBHS providers can also provide home visits if the adherence issue is a social one
- Any inter-current infection or major clinical event has been treated and resolved
- IRIS has been excluded
- Adolescent is receiving adequate nutrition (if not consider nutritional support for SAM and MAM clients and appropriate meal planning).

#### 6.5.5. Switching to new regimens

Whenever an adolescent client is switched to a new regimen:

- Counsel him or her on reasons for the change in regimen, differences in drug types, dosages, and timing of administration
- Review possible side effects of the new regimen
- Reassess for social issues that could negatively influence adherence and review the importance of adherence especially at home, school, work as appropriate
- Provide ongoing adherence counselling and support

**Note:** Switch client to a new regimen within two weeks of confirming treatment failure.

Patient Group	Preferred (Default) Regimen	Alternative Regimens
Adolescents (≥15 years) and pregnant women/lactating mothers	AZT/3TC+ATV/r: if TDF was used in first line. TDF/FTC+ATV/r: if AZT was used in first line	AZT/3TC+LPV/r in Case of TB ABC/3TC+ATV/r ABC/3TC+LPV/r TDF/FTC+LPV/r
HIV and TB co-infection	AZT/3TC+LPV/r ABC/3TC+LPV/r TDF/FTC+LPV/r	Note: double dosage of LPV/r to 800/200mg for Rifampicin based TB treatment
PWID	ABC/3TC + ATV/r	DTG+(ABC/3TC)+ATV/r

Patient Group	Preferred (Default) Regimen	Alternative Regimens
Adults, adolescents (≥15 years)	DTG+DRV/r+ ETV	DTG+ATV/r+ ETV
Pregnant women/lactating mothers	(DTG or RAL)+DRV/r+ ETV	DTG+ATV/r+ ETV
HIV and TB co-infection	DTG+ ETV+ (3TC or FTC)	
PWID	DTG+DRV/r+ ETV	DTG+ATV/r+ ETV
<b>Note:</b> For second and third line regimens which are non TDF based, in case of new Hepatitis B co-infection, TDF with FTC should be added to the new regimen as treatment of Hepatitis B.		

Table 6.5. Recommended third line regimens for adults and adolescents

## 6.5.6. Treatment considerations in adolescents with TB and HIV co-infection

ALHIV with active TB disease should begin TB treatment immediately and should start ART as soon as possible - within 2-8 weeks. Co-management of TB and HIV is complicated by drug interactions, particularly between rifampicin and the PI classes of ARVs such as LPV/r where doubling the dose is required. NNRTI such as EFV is preferred in patients starting ART while on TB treatment. Offer ALHIV and caregivers' adherence counselling and monitoring at every clinic visit, and adherence support for IPT or anti-TB therapy should be included in the ART adherence discussion.

#### Each adolescent should be screened for TB at each visit.

#### ART Switching for ALHIV Who Develop TB While on 1<sup>st</sup> Line ART:

ART should continue in ALHIV already on 1<sup>st</sup> line regimen who are subsequently diagnosed with TB. The ART regimen should be reviewed and may need adjustment to ensure optimal treatment of both TB and HIV, also to decrease the potential for toxicities and drug-drug interactions (Refer to ART dosage tables above).

Where TB is being considered as a sign of treatment failure of the 1<sup>st</sup> line regimen, consider switching to a 2<sup>nd</sup> line regimen if the adolescent has taken ART for more than six months; and has not responded to anti-TB treatment.

#### Plan for Follow up visits

- Schedule monthly appointments for the first six months for clinical, laboratory evaluation and medicine refill
- Provide appointment at two month intervals after the patient is clinically stable

## **CHAPTER 7: PSYCHOSOCIAL SUPPORT SERVICES**

Psychosocial support (PSS) addresses the ongoing psychological and social problems of HIV infected individuals, caregivers, family and their partners (WHO). Providing PSS to ALHIV is essential as it helps adolescents to cope with developmental issues, such as taking more responsibility for themselves, wanting to be accepted and to fit in with peers, and learning to navigate their HIV needs among emerging sexuality and new intimate relationships. ALHIV will benefit from additional PSS at the facility and in community. PSS therefore should be included in all aspects of treatment, care and management of ALHIV.

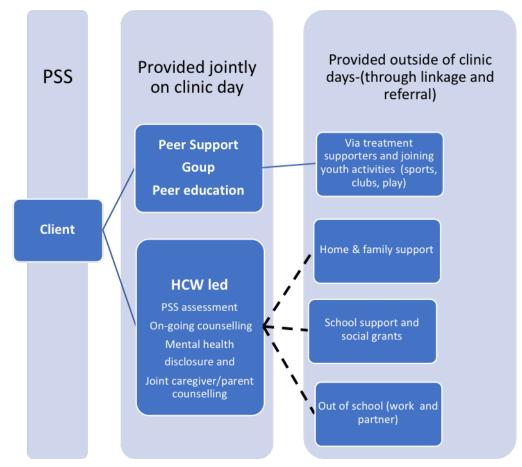
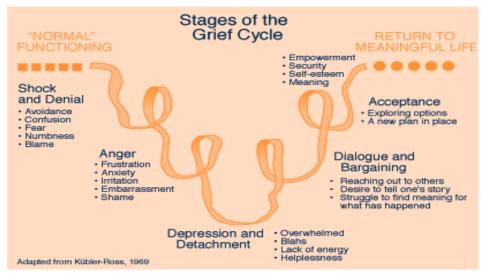


Figure 7.1. Approaches in providing psychosocial support

## 7.1. Psychosocial Support Needs of ALHIV

Adolescents' psychosocial needs change over time. HCWs should assess ALHIV needs, ensure confidentiality, build rapport and find out more about his/her support structure to provide ongoing counselling and support at every clinic visit. ALHIV needs may include:

• Coping with the stages of grief to accept HIV diagnosis and live positively



#### Figure 7.1. Stages of the grief cycle

- Understanding and coming to terms with own and family member's' HIV status
- Coping with cycles of wellness and poor health
- Long-term adherence
- Disclosure
- Normal development in puberty and SRH
- Anxiety over physical appearance and body image
- Developing self-esteem, confidence, and a sense of belonging
- Dealing with stigma, discrimination, and creating social support networks
- Accessing education, training, and work opportunities
- Managing mental health issues

*Remember:* It is useful for the HCW to understand that any simple interaction with the child or adolescent, and their primary caregiver, should include some aspects of PSS.

## 7.1.1. Reasons for having PSS

PSS addresses the ongoing psychological and social challenges of ALHIV, their families and caregivers.

#### Why psychosocial support is important:

- HIV infection affects all dimensions of adolescent's life: physical, psychological, social and spiritual. Counselling and social support can help adolescent and their carers cope more effectively with each stage of the infection and enhances quality of life. With adequate support, ALHIV are more likely to be able to respond adequately to the stress of being infected and are less likely to develop serious mental health problems. Assessment and interventions may be aimed at the acutely stressful phase following notification of HIV infection, the ensuing adjustment period, and the process of dealing with chronic symptomatic HIV infection and disease progression through to death.
- HIV infection often can result in stigma and fear for ALHIV, as well as for those caring for them, and may affect the entire family. Infection often results in loss of socio-economic status, employment, income, housing, health care and mobility. For both adolescents and families, PSS can assist people in making informed decisions, coping better with illness and dealing more effectively with discrimination. It improves the quality of their lives, and prevents further transmission of HIV infection.
- For ALHIV who must adhere to TB treatment, long-term prophylaxis or ART, ongoing counselling can be critical in enhancing adherence to treatment regimens.

Holistic care requires collaborative, inter-sectoral networking and the development of partnerships with other organizations, programmes and service providers to enhance capacity.

#### 7.1.2. Psychosocial assessment

A psychosocial assessment should be conducted at enrolment and at every follow up visit (use assessment tools shown in Appendices 2 and 3). Use psychosocial assessment findings to support the ALHIV with coping strategies for him/her and his/her caregivers to help them reduce stress, deal more effectively with challenges, and promote their psychosocial well-being. During emergencies HCWs should focus on the adolescent's immediate safety.

# Coping strategies that can be suggested to adolescents in absence of emergency include:

- Talking about problems with someone trusted
- Seeking help from clinic staff, especially if sad, depressed, or anxious
- Joining a support group
- Creating an "escape" by taking a walk or listening to music
- Seeking spiritual support
- Participating in recreational activities or cultural events
- Returning to a daily routine
- Doing something to feel useful

## 7.1.3. Ways to provide PSS to the caregiver

HCWs should be aware that in early adolescence, caregivers and parents play an important role in treatment success, especially when the needs of caregivers are also addressed.

## HCWs can support caregivers/parents PSS needs by:

- Explaining the basis of HIV infections, diagnosis, treatment and prevention
- Explaining normal emotional responses in the HIV care process
- Answering questions about HIV treatment support at home, at school and in the family
- Reinforcing that clients can achieve their hopes and dreams with treatment success and viral suppression
- Facilitating a good relationship between parents/caregivers and adolescents by advising the following:
  - Spend time with and listen to adolescents
  - Allow each other to express feelings
  - Communicate unconditional love
  - Help the adolescent plan activities
  - Involve the adolescent in family activities
  - Get enough rest and eat well
  - Get help from counsellor or social worker
  - Be aware of changes in behaviour or mood
  - Talk to someone if they need help
  - Get help from a community-based support organization
  - Continue regular religious or spiritual practices.

## 7.2. Peer Support Groups

Peer support can also be a good source of practical information, motivation and positive reinforcement for adherence to treatment, disclosure, SRH issues, and addressing mental health and substance use concerns<sup>6</sup>.

Adolescents generally depend on peers for information, approval, and connection. HCWs have a role in initiating and facilitating peer support groups and in linking ALHIV with existing support groups.

Types of support groups that can be established at the facility include:

- Adolescent support groups
- Playgroups for younger adolescents
- Young mothers support groups
- Couples support groups
- Groups for other specific populations

## 7.3. Adolescent Support Group Entry Criteria

HCWs should consider the following criteria before enrolling ALHIV in adolescent support groups:

- Interest and willingness to attend
- Age of adolescent: 10+ years depending on the maturity of adolescent
- Adolescent knows his/her status (disclosed)
- Parents/caregivers consent (filled consent form)
- Adolescent attending the particular CTC clinic

## 7.4. Stigma and Discrimination

Stigma can affect an adolescent's ability to live positively with HIV. It can be linked with discrimination, social isolation and loneliness. Adolescents from key populations often are more vulnerable to stigma and discrimination than others, as they are more likely to be blamed for their status. Many not only face stigma related to their behaviours but also possible prosecution if these activities are illegal.

## 7.4.1. Effects of stigma and discrimination to ALHIV

Stigma and discrimination can affect the following:

- Individual's sense of self-worth and self-esteem
- The ability to seek emotional and psychosocial support through disclosure to others
- Adherence to treatment at school or in the workplace
- Anxiety, stress, and/or depression
- Social isolation and loneliness
- Ability to negotiate safer sex
- Access to PMTCT services i.e. not disclosing pregnancy
- Prevents people from caring for PLHIV

#### 7.4.2. Individual strategies of dealing with stigma

The HCW should communicate the following key strategies with adolescents to support them in dealing with **s**tigma:

- Attend peer support groups
- Stand up for yourself
- Educate others

- Be strong and focus on your dreams
- Talk to people with whom you feel comfortable and support you
- Ignore or avoid people who stigmatize you

#### 7.4.3. Strategies for dealing with stigma and discrimination within health care settings

HCWs are all responsible for challenging stigma and discrimination. They should all play a role in:

- Educating other HCWs and clients and advocating for new attitudes and practices
- Involving ALHIV in care team, on committees and in implementation
- Ensuring adolescents are given opportunities to evaluate clinical services and that feedback is formally reviewed
- Supporting linkages to community-based groups for ALHIV
- Supporting each other to discuss attitudes, feelings, fears, and behaviours (to avoid burnout)
- Challenging any discrimination you see in the health care setting and report it to the manager
- Listening to clients' concerns about stigma and discrimination
- Working with the entire multidisciplinary team to identify and reduce stigma and discrimination in the clinic.

## 7.5. Psychosocial Support to Most-at-Risk ALHIV

Most-at-risk ALHIV are among society's most marginalized groups, such as those in extreme poverty, displaced, with disabilities, using illegal drugs, and highly vulnerable. They generally have few connections with social institutions like schools and organized religion, where many support services are traditionally provided. Most-at-risk adolescents often have greater, more complex psychosocial and mental health needs.

#### Strategies to support most-at-risk ALHIV:

- HCWs should utilize their community-facility directories (see Chapter 12) for available services to meet these client's unique needs
- HCWs must make sure that vulnerable adolescent for any reason know their rights to health, protection and self-determination
- Facilitate access to services so that they can advocate for themselves and seek the types of support they are entitled to.

# **CHAPTER 8: ADHERENCE SUPPORT**

This Chapter describes guidelines on adherence and retention to care for ALHIV.

#### 8.1. Adherence Preparation Support to ALHIV and Caregivers

Adherence preparation may include 1-3 individual sessions. Ongoing adherence assessment and support is necessary. Depending on disclosure level and age of the adolescent, group sessions are useful for giving many adolescents information at once. Individual sessions can be used to find out what the adolescent learned from previously attended group sessions and to identify support needs, and develop an individual adherence plan. Discuss potential adherence challenges and make an individual adherence plan.

Ideally, adherence preparation counselling should begin early in HIV care. While providing as much support as possible, the HCW should be flexible when addressing ART readiness. The preparation process should always facilitate ART initiation and should never act as a barrier. All newly diagnosed adolescent should go through adherence sessions. During adherence preparation sessions, HCWs should have a separate session with the adolescent alone.

## 8.1.1. Treatment supporters

A treatment supporter is someone chosen by an adolescent to provide him or her with ongoing support for adherence to HIV care and treatment. HCWs should explain the importance of having a treatment supporter to ALHIV. The treatment supporter is usually an adolescent's parent, caregiver, friend, family member, or another ALHIV who is also enrolled in care. HCWs should make sure treatment supporters have the needed information and skills.

**Remember**: not having a treatment supporter should not act as a barrier to any adolescent initiating ART. HCWs should encourage treatment supporters to support and accompany ALHIV on clinic visits when needed.

## 8.1.2. Adherence counselling for treatment in adolescents

Adherence counselling is support given to an adolescent and treatment supporter in order to help the adolescent take right medicine, at the right dose, at the right time, in the right frequency, in the right way, every day and exactly as agreed between the HCW, adolescent and treatment supporter. Adherence counselling after initiation of ART is a multidisciplinary approach involving clinicians, nurse counsellors, pharmacists and CBHS providers.

## **Important Adherence Issues before Initiating ART to Adolescents:**

- Identify a primary committed treatment supporter and counsel them fully
- Provide counselling on administration of ARVs
- Discuss with parent/caretaker about disclosure of HIV status of an adolescent as mentioned in Chapter 5
- Counsel the adolescent properly about HIV and its transmission, and encourage positive prevention strategies
- Discuss issues of safe sex with adolescents
- Discuss contraceptive use to prevent unintended pregnancies in adolescent girls
- Confirm availability of support services
- Assess for stable family environment
- Ensure access to primary care for nutrition support
- Assess caregiver and adolescent's readiness to start ARVs
- Have an agreement with a caregiver/adolescent that ART should be taken as prescribed

## 8.1.3. First adherence counselling session for adolescents

- Review socio-demographic data on the CTC 1 & 2 card
- Use Counselling Session II Checklist
- Review the parent/caregiver/adolescent's understanding on how HIV is transmitted and how ARV drugs work, and correct any misconceptions
- Discuss with the adolescent the importance of treatment adherence and the consequence of failing to take ART as prescribed
- Provide information on the role of CD4 count and HIV viral load tests in monitoring treatment
- Discuss with parent/caretaker about disclosure of HIV status of an adolescent as mentioned in Chapter 5
- Counsel the adolescent properly about HIV and its transmission, and encourage positive health dignity prevention such as safe sex and prevention of unintended pregnancies
- Discuss adolescent's access to HIV care, treatment, support and follow up
- Provide information on OI prophylaxis and treatment
- Address the key barriers to adherence and suggest how to alleviate them (Use Table 4.1)
- Assess treatment supporter and adolescent readiness and willingness to start ARV
- Agree with the treatment supporter and adolescent that ARVs should be taken as prescribed
- Use and document adherence information in the checklist. If not ready or not willing to start ART, schedule the client an early appointment (within 7 days for the 2<sup>nd</sup> counselling session with the treatment supporter).

## 8.1.4. Second adherence counselling session for adolescents

- At this visit, prepare the parent/caregiver/adolescent for assessment of readiness to start ART
- Review the previous counselling session and answer the client's and caregiver's questions
- Use Counselling Session II Checklist and document the information in the CTC2 card; provide enough time for questions and respond accordingly
- Assess client's willingness and readiness to start ART
- Discuss potential barriers and lifestyles that might influence ART adherence and assist the client to make a plan to overcome the barriers
- If not ready and willing to start ART, schedule the client an early appointment (within 7 days) for the 3<sup>nd</sup> counselling session.

## 8.1.5 Third adherence counselling session for adolescents

- At this visit, confirm parent/caregiver and adolescent readiness to start ARV drugs and initiate the patient on ARV drugs
- Use Counselling Session III checklist
- Assess barriers to adherence and address them
- Change plans with the parent/caregiver adolescent as needed
- Review the implementation of risk reduction, lifestyle, and use of traditional herbs
- Document successes and revisions in plans
- Let the parent/caregiver and adolescent demonstrate ARV administration
- Encourage parent/caregiver and adolescent to return as soon as possible to the clinic with any side effect before deciding to stop ARVs
- Identify parent/caregiver and adolescent-appropriate adherence helpers such as alarm clocks, cell phone alarms, pill boxes and dose schedule cards and advise accordingly. Encourage parent/caregiver and adolescent to have two or more methods to remind him/her on the time to take their medications.
- Provide time for questions, respond and refer the client accordingly
- Emphasize the importance of adherence to care and ART
- Schedule the next appointment with parent/caregiver and adolescent
- Remind parent/caregiver and adolescent to bring the remaining pills at every appointment visit to the clinic.

## Refer to Appendix 4. Adherence Support Tree

## 8.1.6. Follow-up visits after initiating ARV medicines to adolescents

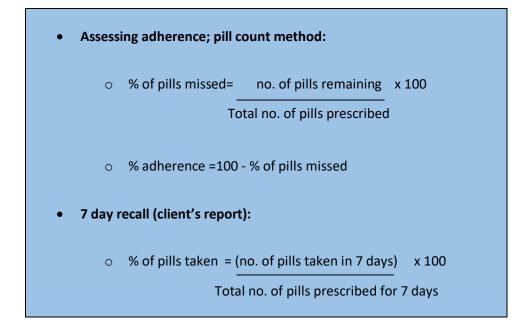
• Assess the mood of the caregiver/adolescent; observe for any signs of stress or burnout.

- Review and document the parent's/caregiver's/adolescent's understanding of the prescribed ARVs and the dosing.
- Ask caregiver/adolescent to demonstrate dose administration of ARVs
- Review the implementation of disclosure plans
- Review elements of positive health dignity prevention
- Fill follow-up visit checklist after ART initiation form
- Facilitate linkage of ALHIV to CBHS for easy follow up and support
- Use the formula below to understand adherence status
- Explore missed doses and document the number of missed doses since the last visit
- Use seven-day recall to assess adherence.

#### 8.1.7 Assessing adherence and providing ongoing adherence support

The following are the procedures to assess adherence:

- Assess adherence at every visit
- Conduct separate sessions with ALHIV and their caregivers
- Discuss differing answers with the adolescent and caregiver together
- Use tools to help assess and improve adherence, such as:
  - Pill counts tables (BD and OD) see count method below
  - Review clinical findings and lab tests
  - Review the 'seven-day recall' and follow-up adherence form



For ALHIV, missing pharmacy refills or clinic appointments is a **RED FLAG** indicating poor adherence that should be addressed immediately. Always follow national guidelines and use national tools to assess adherence. Do not be judgmental.

## 8.1.8. Ongoing adherence support

When providing adherence support, build on previously established trust and rapport, maintain a safe space to discuss any problems, and give ongoing encouragement.

If the adolescent seems to be adhering well:

- Praise the adolescent (and the caregiver, if present) for good adherence
- Remind the adolescent to come back if there are any problems
- Talk about how important it is to be open with HCWs and solve challenges together
- If the adolescent seems to be experiencing challenges with adherence, provide individual counselling
- Praise the adolescent for sharing his or her challenges
- Identify the adolescent 's specific challenges
- Help adolescent resolve each challenge
- Discuss importance of adherence
- Refer adolescent to an Adolescent Peer Educator (APE), adolescent support group, etc.
- Refer difficult cases to other support services according to need
- Plan for next steps
- Record the session on the patient record
- Follow up at the next visit
- Share observations with the health facility team

## 8.2. Ways of Improving Adherence and Retention to Care

- Ensure services are adolescent-friendly and convenient
- Use a developmental approach in counselling and education
- Ensure 5 Rs right (drug, time, dose, frequency, route)
- Establish good relationship of trust and respect with adolescents
- Make time for private counselling, ensure confidentiality
- Ensure appointment systems are in place, and that adolescents receive reminders (via phone, SMS, or home visit) for missed appointments or pharmacy refills
- Check in with adolescents often after they start or change medicines
- Review each adolescent's drug regimen to assess whether changes can be made to facilitate adherence
- Use fixed dose combinations of ARVs to reduce pill burden
- During enrolment and each visit make sure personal information like addresses and phone number are updated
- Ensure linkages to Adolescent Peer Educators and adolescent support groups
- Advise adolescents to join teen clubs/adolescent support groups
- Obtain adolescent feedback (exit interview, suggestion box, SMS and community dialogue)

Ensure that each adolescent has a laboratory monitoring test schedule which is adhered to (follow-ups viral load, CD4).

*Refer to National Guideline for Management of HIV and AIDS* 6<sup>th</sup> *Edition (2017) for more information on ongoing adherence support and barriers to treatment adherence and how to alleviate them.* 

## **CHAPTER 9: MENTAL HEALTH IN ALHIV**

Healthy development during childhood and adolescence contributes to good mental health and can prevent mental health problems. However, a proportion of children and adolescents suffer from overt mental health disorders. A mental illness or disorder is diagnosed when a pattern of signs and symptoms are identified. These are associated with impairment of psychological and social functioning, and that meets criteria for disorder under an accepted system of classification such as the International Classification of Disease, version 10 (ICD-10, WHO, 1992) or the Diagnostic and Statistical Manual V (DSM-V, American Psychiatric Association, 2013

Adolescence is a dynamic time in which many changes occur. It may be difficult to identify the emerging signs of mental health problems. Management of adolescents living with mental health problems includes history taking, physical examination, screening and proper treatment of the identified mental illnesses. This may involve prescription of psychotropic drugs.

## 9.1. Psychosocial Factors to Consider in ALHIV

- Adolescents who acquired HIV during the perinatal period may experience neurological consequences due to longstanding HIV infection. The result may be developmental delays and learning problems.
- Pregnant and breastfeeding adolescents have the dual pressures of living with HIV and preventing transmission to their unborn/infant child at an early age
- Emotional difficulties may not necessarily be due to health status, but rather to the pressures of life and a history of loss (including the loss of parents and/or home)
- Failure to attend some activities that help define adolescents' identities due to illness, or perceived lack of fitness
- Pre-existing mental health problems
- Sense of fear and failure to fit in with peers
- Sense of isolation for adopted adolescents and those living with relatives
- Peer problems, which can be exacerbated by the stigma associated with HIV
- Missing school to attend clinic appointments, which may affect an ALHIV's educational attainment and their sense of fitting in with peers. It also suggests that the school environment is not supportive of the ALHIV's needs.
- If adolescents feel different from their peers, they have a harder time bonding with both peers and caregivers.

Adolescent pregnant girls living with HIV are more likely to develop mental health problems, therefore HCWs should prioritize screening them and offer mental health support.

## 9.2. Basic Mental Health Support to ALHIV

The HCW should use the following strategies to improve mental health of ALHIV:

- Recognize that ALHIV are at risk for mental illness and know the array of mental illnesses that are seen in adolescents
- Conduct regular psychosocial assessments, assess a client's mental health needs, check in with caregivers about changes they have observed
- Use clinical skills and observation during routine visits to identify possible signs of mental illness
- Use simple mental health screening tools (Appendices 2 and 3) and refer clients for further assessment and care
- Identify urgent mental illness like self-harm and address them immediately
- Provide appropriate mental health referrals and follow-up care and support
- Consider the impact of mental illness on an adolescents' HIV care, including adherence
- Respect and listen to adolescent's and caregiver's/treatment supporter's (peer, relatives etc.) beliefs about the origin and treatment of mental illness
- Discourage the use of alcohol, tobacco and drugs among adolescents, who may use as coping methods that increase harmful effects and decrease ART effectiveness.

## 9.3. General Assessment of Common Mental Illness in ALHIV

Diagnosing a specific mental illness can be difficult and requires specialized training. However, all HCWs should know the signs that a serious mental illness may present and know how to manage simple conditions and to refer adolescents with complicated condition for further assessment and care.

## Assessment of mental health:

- 1. Review client's recent and past history (somatic/bodily symptoms, clinical and ART history)
- 2. Make observations (appearance and presentation, attitude and behaviour, mood and emotions, speech, thinking, and perception, level of alertness and orientation, social and intellectual skills)
- 3. Conduct regular psychosocial assessments or refer for expert support (refer to Annex 7A). It is important to ask every adolescent how things went on in his/her life since the last visit. Questions should be tailored according to the adolescent's response rather that flowing with check lists.

## If the history and observations reveal possible problems:

Ask a few simple follow-up questions that are specific to the problems reported or observed, such as:

- Why are you crying?
- You look frightened today are you scared?
- You look different today, why are you angry?

- You are usually so nicely dressed is something wrong?
- Have you noticed how quickly you are speaking?

## 9.4. Basic Management of Common Mental Illness in ALHIV

Common mental illnesses in ALHIV include neurocognitive disorders, depression, alcohol and substance use disorders, anxiety, trauma/post-traumatic stress-related disorders and behavioural disorders. Suicide is the most severe consequence of mental illness. While severe depression is most commonly associated with suicide, other mental illnesses may also increase an adolescent's risk of suicide.

#### 9.4.1. Neurocognitive disorders

- Adolescents with neurocognitive disorders may be slower at processing information.
- Effects may be seen in concentration, attention, memory, learning and higher level functioning such as planning, judgement and organisation
- There may be abnormal motor skills or sensory perception
- School difficulty and learning problems may arise because of these effects.

There are no screens validated for identifying neurocognitive disorders in this age group. It is advisable to regularly enquire about school performance, and to take a careful history where these are reported. Management consists of ART (ensuring viral suppression), rehabilitation, and appropriate schooling.

#### 9.4.2. Depression

Depression is a feeling of intense sadness, including feeling helpless, hopeless, and worthless; and loss of interest in activities that usually give pleasure that last for at least two weeks. It is one of the most common illnesses in outpatient clinics but it is often overlooked; it is the largest cause of the burden of disease among adolescents.

Very few adolescents will present with a straightforward complaint of depression. The majority of adolescents will present with other complaints and may never mention depressed mood unless questioned specifically for the symptoms. If presents with vague somatic (body) complaints or numerous complaints that do not fit any clear clinical pattern, consider depression as a diagnosis.

S	Sleep disturbance
Ι	Interest/pleasure reduction
G	Guilt feelings or thoughts of worthlessness
Е	Energy changes/fatigue
С	Concentration/attention impairment
А	Appetite/weight changes

#### **Common Symptoms of Depression**

Р	Psychomotor disturbances	
S	Suicidal thoughts; including not taking ART	
Plus depressed mood or agitation		
*Five of these nine symptoms must be present to make a diagnosis		

Remember many ALHIV may not present with these symptoms; instead they may demonstrate behavioural changes. Behaviour changes that may indicate depression include non-adherence with ART regimen, difficulty making life choices, ruminating thoughts, inability to perform daily activities, academic difficulties, somatic complains (like headache, stomach upset, chest tightness, burning sensation, changes in menstruation, changes in weight and appetite) and acting-out behaviours (like impulsiveness, anger outburst, and temper tantrum).

# Treatment

Counselling is essential in all age groups but often access is limited. Conduct counselling in routine clinical visits; this may require more time. Refer the adolescent if this does not seem to yield expected results. Adolescents who may not respond to psychotherapy/counselling can be referred to a psychiatric hospital, psychologist or experienced medical doctor/trained HCW in managing mental illnesses.

# 9.4.3. Suicidal or self-harming adolescents

Adolescence is considered a high-risk parameter for self-harm, including suicide; therefore, regular screening should be done for all ALHIV.

- Evaluate whether the adolescent has attempted a medically serious act of self-harm or suicide
  - Ask about past self-harm attempts
  - Look for signs of poisoning, intoxication, and self-injury
  - Medically treat as necessary with the advice of a mental health expert
  - Closely monitor the person to prevent further self-harm
  - Do not leave the person alone or unsupervised
- Evaluate whether there is an imminent risk of self-harm or suicide
  - Ask about current thoughts or plans to commit suicide or self-harm, including stopping treatment
  - Look for signs of severe emotional distress, hopelessness, agitation, uncommunicative behaviour, or social isolation

# Treatment

Suicidal attempt is a psychiatric emergency. Assess level of risk and manage accordingly (see Appendices 2 and 3).

- Treat or refer the adolescent to a psychiatric hospital, psychologist or medical doctor experienced in managing clients in need of mental illness
- If risk of suicide or self-harm is imminent:
  - Remove access to means of self-harm
  - Create a secure and supportive environment and ensure that the person is not left alone
  - Transfer the adolescent to a psychiatric hospital, with accompaniment by a family member or other reliable escort, including, if available, a HCW
  - Adolescents with suicidal thoughts may still be at risk of suicide even after treatment has begun.

# 9.4.4. Anxiety

Adolescents may report feeling anxious, and may be able to identify the source of their anxiety. The presenting complaint may be of physical symptoms, especially chronically unwell patients (or those who perceive themselves so). An important area for inquiry is if they feel they are able to cope with their anxiety, as well as if their anxiety is affecting their daily functioning.

ALHIV are at risk to develop anxiety if they:

- Are newly diagnosed
- Become symptomatic
- Are faced with difficult in disclosure of their HIV status
- When dealing with relationship implications

Anxiety may also be a manifestation of medication side effects or a symptom of illness associated with HIV disease.

# Common anxiety symptoms

- Physical (nausea, abnormal heartbeat, reported breathing disturbance, insomnia)
- Cognitive (difficulty concentrating, overwhelming fear, panic disproportional to the cause)
- Behavioural (social withdrawal, avoidance, restlessness)

# Remember the possibility of associated substance use/abuse.

# Treatment

Treatment of anxiety disorders includes counselling and/or psychotherapy sessions. However, in severe cases, benzodiazepines may be used.

# 9.4.5 Trauma/post-traumatic stress disorder (PTSD)

- Common in ALHIV, these may include loss of family member, rape and violence
- Caused by exposure to a traumatic event, usually involving threatened or actual death, harm or injury (to self or others)

- Symptoms may occur soon after the event or be delayed
- Symptoms include hyper-arousal, avoidance, and intrusive recollections/memories of the event
- PTSD has been associated with diminishing immune system and increasing the risk of infections
- Psychological effects of PTSD may be manifested as increased risk-taking behaviours such as substance abuse, poor eating habits and unsafe sexual behaviours
- The condition may take the form of denial, followed by nightmares or as intrusive thoughts regarding the stigma of being sero-positive and/or death.

When you suspect PTSD, refer client to psychiatric facility for specialized trauma-focused care.

# 9.5. Management of Mental Health Emergencies in ALHIV

Each health facility should develop standard operating procedures (SOPs) on the management of psychiatric emergencies, should train all HCWs on these procedures, and should ensure that they are implemented. Common psychiatric emergencies in adolescents are attempted suicide, substance abuse, depression, psychosis, violence and rapid changes in behaviour.

# Management of an adolescent who is violent or very agitated:

- Protect the adolescent from harming him- or herself, you, or others
- Ensure that you are in a quiet area where there is no audience
- Use space to protect yourself
- Get help from other colleagues, security, or family members
- Approach the adolescent in a calm and confident manner
- Speak in a calm and reassuring way
- Be non-confrontational, non-judgmental, and deflect criticism
- Keep your own emotions in check
- Be aware of potential weapons and remove unsafe objects
- Consider sedation with diazepam or haloperidol.

It was previously customary practice to restrain violent or agitated patients, such as by using hand and feet restraints. The global community recognizes such extreme restraint as both cruel and unnecessary. HCWs should not restrain patients in this way unless it is necessary to protect the patient.

#### Regular psychosocial assessments can:

- Reveal things about the client's mood, mood changes, coping, daily habits, alcohol and drug use, and support systems
- Identify areas for additional follow-up and support and possible signs of mental health problems that require further assessment.

# 9.6. Drugs/Alcohol Abuse in ALHIV

Adolescents often face challenges and temptations related to drug and alcohol use. People sometimes drink or use drugs to take away their worries; however, this will make them feel worse in the long term. Early drug and alcohol use may lead to addiction, which may lead to improper nutrition, missed ART doses, and affects ART absorption and effectiveness in the body.

HCWs can help adolescents avoid alcohol and other substance use by:

- Discussing use openly and making adolescents aware of the effects of use on the mind, body and possible future plans
- Advising adolescents to avoid peer pressure groups that use alcohol, and connect them with peer support groups
- Ensuring addicted adolescents are referred to rehabilitation centres within the facility or outside the facility e.g. methadone clinics
- Providing psychosocial support.

# 9.6.1. Predictors of alcohol/ substance abuse

The common predictors of substance abuse include:

Response to stress	Feeling out of control, feeling hopeless, having a lack of direction in life.
Family factors	Observing parents or family members using or abusing drugs or alcohol; genetic risk factors; parental absence; inconsistent discipline; lack of communication within family; conflict between parents and adolescents; death of parents due to HIV, family breakup.
Peer factors	Spending time with peers who use alcohol and drugs is perhaps the strongest predictor of substance use and abuse.
Mental health problems	There is a strong link between mental health problems and substance abuse.

# 9.6.2. Consequences of adolescent alcohol and other substance use

The HCW should note that not everyone who uses drugs becomes addicted, but alcohol and other substance use may lead to:

- Poor adherence to ART
- Engagement in risky sexual behaviour
- Violence
- Delinquent behaviour and juvenile crime/breaking the law

- Developmental problems
- Certain substances may interact with ART:
  - Alcohol: theoretically may increase Abacavir levels
  - Benzodiazepines (midazolam, clonazepam, alprazolam): can cause increased sedation with PI use
  - Cannabis: may reduce serum PI levels
  - MDMA and amphetamines: when used with Ritonavir may cause toxicity

# Physical and mental consequences include:

- **Short-term:** memory loss with poor school performance
- **Long-term:** cancers, heart and respiratory failure, stomach ailments, central nervous system damage, and sexual impotence
- May interact with depression and contribute to suicide; may accelerate HIV disease progression; may increase risk of violence and accidental death

The use of alcohol and other substances can become severe enough to constitute the diagnosis of a mental disorder. HCWs should watch for signs of alcohol and other substance use and screen when indicated. HCWs should counsel, support, and refer adolescents who have alcohol and substance use problem.



# **CHAPTER 10: NUTRITIONAL CARE AND SUPPORT AMONG ALHIV**

Adolescence is a time of rapid change and growth that increases the need for macro and micronutrients, hence the need for balanced diet. A balanced meal is a meal that contains all five food groups:

- i. Carbohydrates: cereals, green bananas, roots (cassava, ming'oko etc.) and tubers (yams, potatoes etc.)
- ii. Proteins: pulses (peas, beans) and animal-source foods (fish, milk, meat, senene etc.)
- iii. Fruits
- iv. Vegetables
- v. Sugar, honey, fats and oils

Other important food substances are dietary fibre and adequate amount of water (at least 8 glasses of clean water equivalent to 1.5 liters). Please refer to the figure below, which emphasizes the food groups and their relative proportions within a balanced meal.

# Figure 10.1. Food pyramid for adolescents



This Food pyramid guide serves as a general guide to food choices for adolescents. It is a healthy guide divided into sections to show the recommended intake for each food group.

# **10.1. Nutritional Requirements for ALHIV**

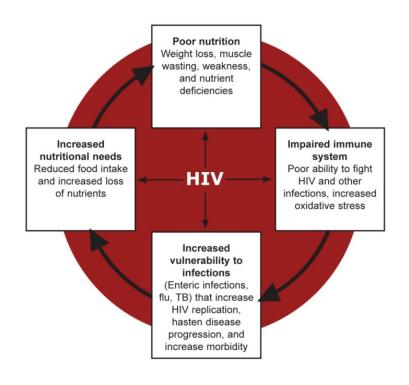
ALHIV need additional energy because of the altered metabolism and nutrients malabsorption.

- ALHIV with no AIDS-related symptoms (WHO Stage I) need 10% more energy (about 210 additional kcal/day, equivalent to 1 cup of porridge).
- HIV-infected adolescents with AIDS-related symptoms (WHO Stages II, III and IV) need 20-30% more energy (420-630 kcal/day, depending on severity of symptoms).
- The requirements may even be higher if the HIV-infected adolescent is treating OIs or is pregnant or lactating, and might need multiple micronutrient supplements (containing iron/folate, Ca, Iodine, Zinc, Selenium, vitamins A, B, C, etc.). Good nutrition for pregnant and lactating ALHIV improves health and infant survival.
- For breastfeeding ALHIV, identify safer infant feeding practices and demonstrate proper breastfeeding techniques.

*Note: Requirements will vary from one client to another depending on the regular weight and nutrition monitoring.* 

#### The Cycle of Malnutrition and HIV:

This cycle illustrates weight loss and wasting seen in some ALHIV clients. Decreased food intake (due to poor appetite or lack of food) is the most important cause of malnutrition and wasting. Other causes are malabsorption of nutrients and changes in metabolism. HCWs should ensure access to nutrition education and food supplements to improve health and treatment success among ALHIV. Emphasize the relationship between malnutrition and HIV, and that if the cycle is not broken, immune function and clinical status continue to deteriorate, contributing to repeated illness and eventual death.



Source: Food and Agriculture Organization of the United Nations (FAO). 2002. Living Well with HIV/AIDS: A Manual on Nutritional Care and Support for People Living with HIV/AIDS. Rome.

# **10.2. Importance of Good Nutrition in ALHIV**

During counselling and health education sessions, the HCW should explain the importance of good nutrition to ALHIV, as good nutrition:

- Improves and speeds up recovery from HIV related illnesses
- Strengthens the immune system, thus enhancing the body's ability to fight diseases
- Prevents wasting and malnutrition
- Improves effectiveness and tolerance to drug treatments
- Improves the quality of life

# **10.3. Factors Affecting Adolescents' Nutrition**

HCWs should help ALHIV understand why it is important to avoid "junk foods" like soft drinks, sweets, and potato chips/crisps, as they have little nutrition value. Recommend adolescents eat fresh, natural foods as they are nutritious, affordable and locally available.

#### Common nutritional issues among adolescents are:

- Food insecurity
- Bad eating habits, such as eating a lot of "junk food," skipping meals, and having erratic eating pattern
- Loss of appetite due to ARV intake.

#### **10.4. Nutritional Care and Support for ALHIV**

Nutritional care and support for ALHIV is a package that includes:

- Nutrition assessment
- Nutrition counselling and education
- Guidance on ART and food or nutrient interactions
- Nutritional management of MAM and SAM
- Micronutrient supplementation (if needed)
- Food support (if needed)
- Food and water safety and hygiene
- Psychosocial support
- Referral to other relevant services if needed

#### 10.4.1. Nutritional assessment for ALHIV

The goal of nutritional assessment is to determine if the adolescent is taking the proper ART dose for the size and growth, to understand nutritional challenges, and if present, the severity and probable causes. The HCW should perform nutritional assessment of ALHIV during every clinic visit and document in the client file/record.

#### Nutrition assessment involves:

- 1. **Anthropometric nutrition assessment**: the measurement of body size, weight and proportions. Commonly used anthropometric measurements for assessment of nutritional status include:
  - Weight (Kg)
  - Height (Cm)
  - Height for Age (HFA) to measure stunting
  - Weight for height (WFH) to measure wasting
  - Mid-upper arm circumference (MUAC) measures wasting

- BMI for age measures wasting in 5-18 years (Use this measure for adolescents) see Appendix 7. Body mass index (BMI) measures wasting in 18 years and above. A normal BMI is 18.5 24.9kg/m<sup>2</sup>. A BMI <18.5 denotes underweight; that between 25.0 and 29.9kg/m<sup>2</sup> is overweight, and > 30.0kg/m<sup>2</sup> is obesity. For patients with BMI <18.5 nutritional education is required and food supplementation to be recommended if any.</li>
- 2. **Clinical nutrition assessment:** confirm that the ART dose meets the weight band criteria and find out whether a client has any signs/symptoms of nutritional deficiencies because of medical complications and or medicine side effects. Clinical nutrition assessment includes history taking and examination; bilateral pitting oedema, wasting, anorexia/poor appetite, persistent diarrhoea, nausea, vomiting, dehydration, anaemia and checking for signs of nutrient deficiencies (hair colour changes, pallor, lack of fat under the skin).
- 3. **Biochemical nutrition assessment:** Laboratory tests to assess nutritional status; for example iron deficiency anaemia, blood sugar, lipid profiles, and haemoglobin levels.
- 4. **Dietary nutrition assessment: I**nformation on the quantity and quality of food a client has eaten including eating habits, food preferences, food taboos, food allergies, intolerances, food availability and accessibility, and reasons for inadequate food intake during illness.

Please refer to BMI chart in Appendix 7.

# 10.4.2. Nutritional counselling and education among ALHIV

HCWs should provide counselling and education to ALHIV on:

- Adequate food intake (3 main meals and 2 snacks between meals)
- Consumption of a variety of foods (from all five groups)
- Increasing energy intake by eating more food more often during illness
- Preventing and seeking early treatment of infections and advice on managing symptoms through diet; and iron and folic acid supplements for girls to compensate for the loss during menses
- The need for additional energy and nutrients for pregnant adolescents to support their growth and that of the developing fetus
- Drinking plenty of boiled or treated water (clean water)
- Avoiding habits that can lead to poor nutrition and poor health such as junk foods, sweetened drinks (soda), alcohol, smoking, etc.

Refer to the National Guidelines for Management of HIV and AIDS 2017 for more information on nutritional monitoring and assessment.

# **10.5. Dietary Recommendations for Common Signs and Symptoms Associated** with HIV

It is important to counsel ALHIV to seek prompt treatment for all OIs and other diseases. Manage symptoms with dietary practices, especially for illnesses that may interfere with food intake, absorption and utilization. Common signs and symptoms associated with HIV are anorexia, diarrhea, fever, nausea and vomiting, anaemia, wasting, mouth sores and oral thrush. All of the recommendations for nutritional support and management of symptoms should be combined with routine clinical care and treatment. For more details on nutritional management of common symptoms related to advanced HIV infection, see Appendix 6.

# 10.5.1. Management of MAM and SAM

- Management of Moderate Acute Malnutrition (MAM): HCWs should always counsel ALHIV to eat a varied diet using traditional local foods on an outpatient basis – the aim is to prevent severe acute malnutrition. In times of food shortage, provide supplementary foods like fortified blended foods (FBF), which can be used to prepare smooth, ready-to-eat porridges, and lipid-based nutrient supplements.
- Management of Severe Acute Malnutrition (SAM): In managing severely malnourished ALHIV, the HCW should start with checking the presence of medical complications in order to decide on whether will be treated as inpatient or outpatient. Promote a health and suitable diet and encourage adolescents to eat. Provide therapeutic and or supplementary foods if available e.g. Ready to Use Therapeutic Food (RUTF).

#### 10.5.2. Food support to ALHIV and caregivers

The goal of food support to ALHIV and caregivers/households is to:

- Provide practical counselling and education on good nutrition, gardening, purchasing locally available foods, and how to store and prepare food
- Recommend multivitamins according to national guidelines
- Identify partners to be involved in food assistance at the community
- Work with the care team to link the clinic to agricultural and food support organizations in the community
- Link clients to community-based agricultural, nutrition, animal husbandry, and other programs.

# 10.5.3. Food and water safety and hygiene

Food and water safety are important for ALHIV because their low immunity can put them at higher risk of infection. They also experience more severe symptoms of foodand water-borne illness such as meningitis, which affect nutrient intake and absorption and increase the need for nutrients to fight infection and takes time recovering from illness. Food- and water-borne illness can cause weight loss and further lower the body's resistance to other infections.

# HCWs should tell adolescents to observe:

- Personal hygiene through:
  - Hand washing with clean water and soap or ashes before, during and after preparing food or eating, and after visiting the toilet
  - Using safe and clean water from protected sources. If the water is not from a protected source, it should be boiled for ten minutes and filtered
- Cooking and storage of food by:
  - Cooking food thoroughly, but do not overcook vegetables
  - $\circ$   $\,$  Covering food to keep flies and dust away  $\,$
  - Keeping rubbish in a covered bin and empty regularly
- Maintain clean environment by:
  - Using latrine and keep it clean, free from flies and cover with a lid
  - Keeping the surroundings clean
  - Washing their clothes, bedding and surfaces that might have been contaminated with faeces in hot water with soap.

# **10.6. Drug-food Interactions and Drug Side Effects**

ARVs can negatively change the way the body uses fats, proteins and energy. Some ARVs affect nutrient availability, absorption and utilisation. Some foods affect the effectiveness of certain ARVs and other medications by affecting their absorption, metabolism, distribution and excretion. ARV side effects can reduce food intake, absorption of nutrients and adherence to the medications.

The HCW should have updated information on medications clients are taking in order counsel them that:

- AZT should be taken with or without food, but NOT a high-fat meal, and should avoid alcohol.
- EFV should be taken with or without food, but NOT with a high-fat meal as it worsens side effects. Advised to take just before bedtime and avoid alcohol.
- Atazanavir should be taken with food.
- Isoniazid and Rifampicin should be taken on an empty stomach, 1 hour before or 2 hours after a meal.

• DTG may be taken without regard to meals but should be taken 2 hours before or 6 hours after taking food or medicines containing antacids or laxatives, sucralfate, oral iron supplements, oral calcium supplements, or buffered medications.

# CHAPTER 11: ADOLESCENT SEXUAL AND REPRODUCTIVE HEALTH SERVICES

**Reproductive Health:** is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to reproductive system and to its function and processes of women and men.

**Reproductive Rights (for adolescent >18yrs or mature minor):** The basic right of all couples and individuals to decide freely and responsibly the number and spacing of their children, and to have the information and means to do so; the right to attain the highest standard of sexual and reproductive health; and the right to make decisions concerning reproduction free of discrimination, coercion and violence.

**Sexual and reproductive health rights (SRHR)** can be understood as the right for all, whether young or old, women, men or of different sexual orientation, HIV positive or negative, to make choices regarding their own sexuality and reproduction, providing these respect the rights of others to bodily integrity. These definitions also include the right to access information and services needed to support these choices and optimize health.

Integration of ASRH and HIV services is essential to support realization of global and National goals. ASRH and HIV intersect in many ways, which creates opportunities to efficiently address the increased HIV burden, unmet need for family planning, STIs, cervical cancer and high prevalence of GBV. Integration of services will also include PMTCT services.

Encourage sexually active ALHIV to use contraceptive services as they are at risk of unplanned pregnancy. Ensure there is confidentiality, positive attitude and privacy. *Refer to Appendix 8 for Contraception Considerations for ALHIV.* Always follow the national family planning guidelines when providing counselling, support and when prescribing contraceptives to ALHIV.

The National Health Policy (2007) outlines that reproductive health care services for adolescents and youth should be friendly. The range of services for adolescents including ALHIV should include the following:

- Information and counselling on reproductive health, sexuality and safe sex
- Family planning services including condom and emergency contraception
- Testing services: HTS, STI and pregnancy
- Management of: STIs, PMTCT, and HIV/AIDS
- Focused antenatal care; care during childbirth; and postnatal care
- Post-abortion care
- GBV and Violence Against Children prevention and response services
- Reproductive cancer screening and treatment.

# **11.1. Information on Adolescent Sexuality and Sexual Risk Screening and Counseling**

HCWs should talk about sex and sexual behaviours with adolescents and deliver information, skills, and supplies they need to protect themselves and their partners.

**Sexual Health** is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

**Sexual Rights:** The fulfilment of sexual health is tied to the extent to which human rights are respected, protected and fulfilled.

**Health and human rights** is the right to "the highest attainable standard of health" requires a set of social criteria that is conducive to the health of all people, including the availability of health services, safe working conditions, adequate housing and nutritious foods.

# 11.1.1: Sexual risk screening and counselling

**Sexual risk screening:** HCWs can assess if a client is sexually active and, if so, with whom and what risks he or she is taking.

**Risk reduction counselling** focuses on reducing clients' risk of HIV, other STIs, and unplanned pregnancy by helping them choose a strategy that is right for them. These may include abstinence, delayed sexual debut, reducing the number of sexual partners, and contraceptive use, including condoms.

Sexual risk screening should start before the adolescent is sexually active. By the time adolescents are 12 years old, begin meeting with them separately from their caregivers for at least part of each appointment. This should be done with the caregiver's consent. Counselling sessions should also include information about early treatment of STIs, adherence to the ART regimen, and secondary prevention for HIV infection.

The following information should be considered:

• Create trust between you and the adolescent client to make him or her feel comfortable to ask questions and raise concerns

- Keep the information confidential unless there is an emergency or a health risk that requires intervention
- Use good communication and counselling skills
- Avoid making assumptions or judgments about the adolescent client, and about his or her knowledge, behaviours and sexual orientation
- If a discussion is awkward, respect a client's cues that further talk is unwanted.

Explain to adolescents and caregivers what information can and cannot be kept confidential, emphasizing that HCWs will protect client confidentiality unless there is an emergency like mental illness or a health risk that requires intervention like pregnancy. HCWs should avoid using any labels not first used by the client. Local law may require disclosure under some circumstances e.g. child sexual abuse.

HCWs should remember to observe non-verbal communications cues such as crying, silence, awkward smiles, and also should consider the environment where screening and counselling is happening, and to consider postponing the discussion; change of venue/time; or referral to other counsellors.

# 11.1.2. Conducting risk assessments

Possible questions that can be used to guide risk assessment in adolescents of unknown or negative HIV status include:

- Where do you live? (probe: school, home, ghetto)
- Who do you live with?
- Who is your closet relative and why?
- Do you have a male or female friend?
- What kind of relationship do you have with your male or female friend?
- Have you ever indulged in sexual activity with your male or female friend?
- Are you currently having sexual relationship with males, females or both?
- How many partners do you have right now? How many partners have you had in the past year?
- How do you practice your sexual activities?
- Did you use a condom last time you had sex? Do you use a condom every time you have sex?
- Are you currently taking any contraceptives? Which ones? Did you use other contraceptives last time you had sex?
- Have you had any abnormal discharge (colour, amount or smell), pain when urinating or any sores or bumps in or around your genitals or anus?
- Have you ever experienced sexual contact against your will?
- For girls have you had your first menstrual period?
  - If yes, when was your last period?
- For girls, have you ever been pregnant? What were the pregnancy outcomes?

- Do you know your own HIV status?
  - If so does your partner know? Do you know the HIV status of your partner(s)?
- Have you ever used alcohol or illicit drugs? If so, how often in the last week have you used alcohol or illicit drugs?

# 11.1.3. Risk reduction counselling

Risk reduction counselling is an important role of a HCW. It is important to explore and understand if the adolescent has correct knowledge and discuss options for sexual risk reduction. Risk reduction counselling happens in HTS, and should be part of routine care for ALHIV. Topics to be discussed include:

- Adherence and undetectable viral load
- Knowledge about HIV and risk behaviour
- Options for sexual risk reduction
- Abstinence
- Condoms and contraceptives
- Disclosure (applicable to ALHIV)

Abstinence means not having sex - tell adolescents that abstinence is the only way to completely avoid getting STIs/HIV and pregnancy.

# **11.2. Adolescent Reproductive Health Services**

# 11.2.1. SRH value clarification

Value is defined as a person's principles or standard of behaviour; and one's judgement of what is important in life. The purpose of SRH value clarification is to encourage teens to clarify and explore their personal attitudes and values and to become comfortable with listening to and understanding opinions different from their own.

All members of multidisciplinary teams caring for ALHIV should:

- Explore their own attitudes, values, and prejudices related to adolescent sexuality
- Assess how these attitudes, values, and prejudices could affect their ability to provide effective HIV care and treatment services to adolescent clients

HCWs should be sensitive to the emerging feelings of their adolescent clients and support them to talk openly and honestly in the clinic setting. An important part of adolescent HIV care and treatment is assessing and responding to the SRH needs of clients. To be able to do this, HCWs must be comfortable talking about sexuality and SRH with ALHIV. They must also be knowledgeable about the common SRH issues adolescents face and the SRH services and information adolescents need.

# 11.2.2. Counselling for pregnancy and PMTCT services among ALHIV

Key consideration HCWs should clarify to their clients (and their sexual partners) are about the ways and times PLHIV can safely have children.

- Educate adolescent on the risks of pregnancy during adolescence, it is recommended that girls to wait until they are 18 years to have their first pregnancy. Child spacing should be at least 2 years.
- Counsel ALHIV boys and girls on fertility, pregnancy and PMTCT services before they become pregnant
  - For ALHIV, it is better if their CD4 is above 500, with undetectable viral load and without co-infections.
- It is important for female ALHIV to adhere to ART throughout pregnancy

Remember that you should follow the recent national PMTCT and ART guidelines when providing services to pregnant ALHIV, their partners, and their families.

# 11.2.3. Risks of adolescent pregnancy

#### Health Risks for girls:

- Pregnancy complications (obstructed delivery, prolonged labor)
- Pre-eclampsia
- Anemia
- Complications associated with unsafe abortion
- Premature birth and low birth weight
- Spontaneous abortion and stillbirth, especially among adolescents < 15 years of age
- Mother-to-child transmission

Adolescents are not fully developed and their bodies may not be prepared to handle childbearing. Pregnant adolescents have a greater risk of obstructed delivery and prolonged labor, which increases their risk of haemorrhage, infection, and fistula.

# 11.2.4. Considerations when offering PMTCT services in adolescents

ALHIV have extra needs when in pregnancy, breastfeeding and supporting an HIV exposed infant.

Some challenges of adolescents include:

- Hiding pregnancy, especially if in school, and may be expelled
- Stigma for having HIV and becoming pregnant, and for being pregnant at a young age (especially if unmarried)
- Failure to disclosure the HIV status to caregiver/sexual partner
- Inadequate knowledge with safe infant feeding after delivery

• Lack of emotional and financial support from family and/or the child's father

ALHIV need more time and counselling to understand the expectations for care and use of services throughout the process. Services for pregnant ALHIV should follow the national guidelines for PMTCT.

# 11.2.5. ALHIV and STIs

HCWs should assume that all adolescent clients are sexually active or will be sexually active soon and conduct regular screening for STIs. HCWs should conduct thorough physical examination. Ensure there is privacy and follow medical ethics. Give feedback in a non-judgemental manner, for example, *"I see you have a sore here does it hurt"*?

Adolescents who are sexually active may not practice safer sex and as such are at increased risk of contracting STIs. At every visit, ask adolescents about STI symptoms:

Girls	Boys
Painful urination	Painful urination
Lower abdominal pain	
Sores/bumps around the genital	Sores/bumps around the genital/anus
Abnormal vaginal discharge	Urethral discharge

# 11.2.6. Diagnosis and treatment of STIs

Information from the physical examination in combination with the client's history should be used to make a syndromic diagnosis and manage the client as per the National STI treatment guidelines.

- Client history and physical examination should be used to make syndromic diagnosis
- Management of cases should follow National STI Treatment Guidelines (2017)
- Counsel adolescents to avoid sex until they are cured and advise their partner to seek medical care treatment
- Counsel adolescents to complete medication even if they feel better
- Conduct risk reduction counselling, ensure correct understanding of use of condoms, and access to free condoms.

#### **11.3. Cervical Cancer Screening for ALHIV**

Cervical infection with HPV is common and occurs primarily through sexual transmission<sup>7</sup>. Penetrative sexual intercourse is not strictly necessary for HPV transmission, but it is the primary risk factor for HPV infection, and HPV prevalence is low in young women who report only non-penetrative sexual contact. Cervical cancer screening should be conducted to female ALHIV according to recent National Guidelines for Prevention and Management of Cervical Cancer.

*Offer HPV vaccine to adolescent according to National Guidelines.* 

# **11.4. Comprehensive Post Abortion Care (cPAC)**

Comprehensive Post Abortion Care is an intervention that reduces maternal morbidity and mortality. cPAC provides care to females, including adolescent girls, who suffer any complications resulting from spontaneous (miscarriage), unsafe induced abortion, missed abortion, molar pregnancy, and termination of pregnancy on medical ground. Full guidance can be found within the National Guidelines for Post Abortion Care (2016.)

#### 11.4.1. Components of cPAC

The HCW should provide the following to services to all females presenting with indication of post abortion care needs:

- Counselling and psychosocial support
- Clinical exam and treatment, including the emergency management and removal of products of conception
- During follow-up appointments, Family Planning (FP) counselling and provision of FP methods
- Referrals for other FP and RH/HIV services
- Community involvement

# **11.5. GBV and Violence Against Children**

Tanzania marriage law allows girls to be married at 15 years old; 4 out of every 10 girls is married before their 18<sup>th</sup> birthday<sup>8</sup>. Three out of 10 girls and one out of seven males had experienced sexual violence before age of 18 years<sup>9</sup> Three-quarters of females and males had experienced physical violence before the age of 18 years old<sup>10</sup>. Despite its prevalence in most countries, GBV is often not addressed. It is rooted in gender

<sup>7</sup> 

<sup>&</sup>lt;sup>8</sup> National Bureau of Statistics Tanzania and ICF Macro 2011

<sup>&</sup>lt;sup>9</sup> 2009 Violence against Children (VAC) Survey

<sup>&</sup>lt;sup>10</sup> UNICEF 2011

inequalities and gender norms, often serving to reinforce gender inequality at different levels.

Health facility management teams at all levels should establish links with the community and other stakeholders like social welfare and law enforcement (police and court) to provide effective GBV prevention among ALHIV. Refer to the National Management Guidelines for the Health Sector Response to and Prevention of GBV 2011 for more information.

General principles when handling adolescent GBV cases:

- Ensure privacy and confidentiality at all times
- Be respectful and empathic at all times
- Non-judgmental
- Enhance safety and do no harm
- Obtain informed consent in all steps.

HCWs should carry out the following steps when handling GBV cases:

- Screen for life threatening or urgent needs and respond immediately
- Obtain medical history and conduct thorough physical examination in line with the do no harm principle
- Collect forensic evidence where indicated this includes proper documentation (consult laboratory personnel on how this can be done)
- For known HIV negative survivors, offer HIV PEP for rape cases involving oral, vaginal or anal penetration with a penis presenting within 72 hours. Offer emergency contraceptives for peno-vaginal penetration cases presenting within 5 days /120 hours. *Refer to Appendix 8 for Contraception Considerations for PLHIV.*
- Carry out STIs screening and offer treatment when indicated. Presumptive/prophylactic treatment for gonorrhea, chlamydia and syphilis should be provided for adolescents who have been sexually abused involving oral, genital or anal contact with penis or oral sex.
- Offer HPV vaccination as indicated in the Tanzania Service Delivery Guidelines for Cervical Cancer Prevention and Control (2011)
- Refer and link survivors to other required services such as legal and psychosocial support through treatment and following completion of the clinical package of care, Police (investigations, restraining orders), economic empowerment, emergency shelters and peer support groups.

# 11.5.1. Messages to be shared with adolescents and caregivers

The HCW should communicate the following key messages to adolescents and caregivers:

- GBV is a human rights violation in which a person is physically, sexually, or psychologically harmed by another person who feels that he/she has more power and control over the other.
- Feelings of guilt and self-blame are common among survivors however GBV is never the fault of the survivor.
- Survivors of GBV especially young adolescents may be intimidated and threatened so that they may fear reporting the incident. It is important for community, family and HCWs to create safe space for survivors of violence and have mechanisms with which to remove survivors from violent living situation.
- Adolescents should be assessed for GBV at least once every six months as part of the HIV program.
- GBV like rape has the potential to increase the risk of acquiring new HIV infection.
- GBV can negatively affect retention and ART adherence of adolescents leading to poor treatment outcomes.

# **CHAPTER 12: LINKAGES AND REFERRALS**

ALHIV spend most of their time out of the facility and in the community – at home, in school and in local settings. Community engagement improves the quality HIV services for adolescents to reinforce and enhance treatment adherence and success. Quality HIV care and treatment should actively link clients from facility to communities and back to facilities to maximize the continuum of care.

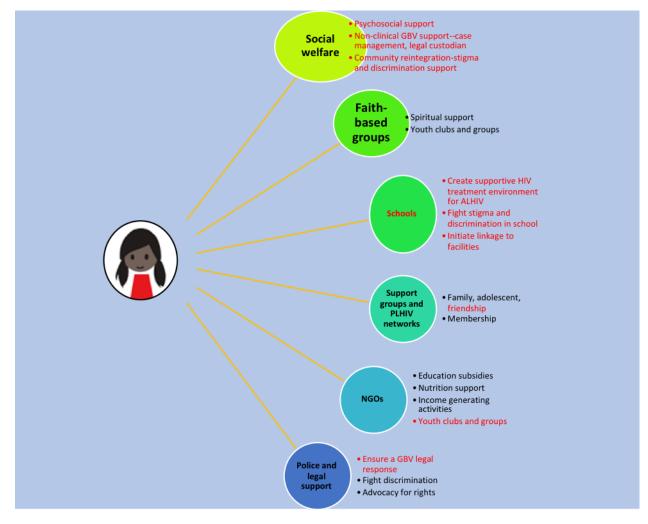


Figure 12.1. Linkages and referrals for ALHIV

To facilitate this linkage, the HCW should identify the community services, community groups or CBHS in the catchment area. It is the responsibility of the HCW to be culturally sensitive and continuously update resources, in collaboration with the facility-based social welfare officer and CBHS providers. When available, the Community Health Worker (CHW) is an important cadre that can implement HIV care services for ALHIV working collaboratively with HCWs.

ALHIV and their affected families and households have needs beyond the clinic, such as spiritual, food security, educational, economic and legal support. CBHS can support

these needs at community level and link patients to available social support systems. CHBS can work with communities by:

- Raising awareness and sharing information to increase access to HIV services and support
- Endorsing ART and adherence to improve treatment outcomes at home visits and through community outreach
- Facilitating facility-community linkages to local groups and resources that can improve the quality of life for the client and family affected by HIV.

# **12.1. Strategies to Improve Linkages and Referrals**

There are many ways to enhance the relationship between the facility and the surrounding community.

# 12.1.1 Facility level strategies

- Understand and document available services and serving organizations in the community relevant to ALHIV
- Meet with community leaders to talk with them about ALHIV and the importance HIV care and treatment services
- Start support groups for ALHIV that plan for transition to adulthood
- Facilities should facilitate regular meetings with stakeholders/community organizations to:
  - $\circ$   $\;$  Share information about the broad needs of ALHIV beyond the clinic  $\;$
  - Discuss available health services
  - Discuss how to facilitate linkages and referrals
  - Visit these organizations to find out what services they offer and record in the directory tool
  - Set up formal or informal "two-way" referral systems.

# 12.1.2 Community level strategies

Work in collaboration with the District Community Development Office/CHAC and Social Welfare Office to:

- Participate in community meetings to raise awareness of HIV, specific needs of ALHIV, availability and importance of HIV care and treatment
- Work with existing and newly trained community-based peer educators, youth group members, and community HCWs
- Involve young community members openly living with HIV in strengthening facility-community linkages advocating for support from community leaders and stakeholders

- Develop a directory of available ALHIV services and establish referral/linkage systems and networks
- Visit organizations to find out what services they offer relevant to ALHIV
- Set up formal or informal "two way "referral system.

# 12.1.3 Schools/institutions in the facility catchment areas

- Inform the District Education Office about facility-school activities, they can help organize more effective outreach and sensitization about ALHIV
  - Sensitize and orient teachers about HIV in their community and schools
    - Support each school to identify a focal person teacher from among the oriented teachers, to support ALHIV
  - Share with schools/institutions the directorate of available services and support groups in the area for ALHIV
  - Facilitate the elimination of stigma and discrimination in school settings
- Establish a referral and linkage system between schools and facility
- Establish facility school arrangements for disclosed ALHIV clinic visits i.e. specific clinic hours for adolescent students or holiday services.

# 12.2. Development of a Community Resource Directory

HCWs should:

- Be informed about organizations providing adolescent services at the community level that can enhance care for ALHIV clients.
- Work with facility leadership to organize meetings on a routine basis with community-based services at facilities to identify, coordinate and enhance the available package of care for adolescent clients in the community.
- Ensure there is an identified focal person (could be a peer educator, CBHS provider) for newly identified ALHIV for retention and reduction of loss to follow up; establish two-way referral systems to and from the organizations in the directory.
- Work with adolescents and stakeholders, such as peer educators, to map available resources in the community for ALHIV and their families.
- Regularly update the community resource directory.

The directorate should include location, days/times services are offered, types of services, fees, documentation required at the initial visit, address, phone number, contact person. Post copies in the clinic waiting room and make copies available in examination and counselling rooms. Designate one person (preferably CBHS provider) to be responsible for keeping up to date with any changes and adjusting the directory accordingly.

# HCW should document community services that could be accessed including: ALHIV support groups Life skills education

- Nutritional and food support
- Home-based care and adherence support
- Psychosocial support and counselling
- Social grants
- Support accessing supplies
- Condom distribution outlets
- Support for child-headed households and OVC

# **12.3. Roles and Responsibilities of CBHS Providers**

This guide recognizes the contribution of CBHS providers both at facility and in the community in supporting ALHIV. CBHS providers follow national guidelines for CBHS.

#### *The roles of CBHS provider in relation to ALHIV, include:*

- Intensify early identification of ALHIV
- Promptly link ALHIV to care and treatment clinics
- Support ART adherence and retention for ALHIV
- Track ALHIV who have missed appointments
- Facilitate effective community and facility referral and linkages for ALHIV
- Community sensitization and mobilization of ALHIV to access adolescent friendly services
- Identify and refer ALHIV to heath facilities for further management
- Facilitate ALHIV support groups and support them to have leadership and basic group constitution.

# **12.4. Adolescent Participation**

Successful and meaningful adolescent involvement is critical to ensure that services are designed and implemented to acknowledge and mobilize the value, strengths, contributions and talents of adolescents rather than concentrating solely on their needs or challenges. This requires commitment from every member of the multi-disciplinary team. Involvement of adolescents and affected communities in clinical services help people to draw on their own experiences, increase effectiveness and appropriateness of services.

ALHIV should be given opportunities, empowered and trained as effective peer educators, counsellors, trainers and advocates in clinical services from planning, implementation, and evaluation stages.

HCWs should:

- Work with and for ALHIV as beneficiaries
- Engage with ALHIV as partners
- Support ALHIV to take initiatives and to serve as leaders.

89

- Job preparation and placement
- Spiritual support
- Income-generating programs
- Legal support
- Alcohol and drugs rehabilitation programs/ support groups.

#### **12.5 Peer Education Programs**

#### 12.5.1 Peer educators

ALHIV Peer Educators (APE) can complement the work of HCWs and they play an important role in improving client adherence and service quality through peer education. Peer education refers to sharing of information and experiences among individuals with something in common. Peer education is an effective tool for promoting healthy behaviours among ALHIV and providing health talks on clinic days.

HCWs should support ALHIV Peer Educators to:

- Assist with planning, monitoring, evaluation of ALHIV facility activities
- Participate in quality assurance activities at the facility for ALHIV
- Give meaningful feedback to health care programs
- Offer insights into the best ways to retain young people in care
- Support ALHIV adherence to ART.

# 12.5.2 Qualification of peer educators for ALHIV

Expected qualities of a peer educator for ALHIV are:

- Older adolescent (15 19 years old)
  - Exceptions can be made for cognitively strong young ALHIV with strong facilitation skills
- Living positively with HIV
- Adherent to care and medication
- Open minded and non-judgmental
- Respectful and tolerant of different perspectives
- Basic literacy and numeracy skills
- Good interpersonal and communication skills
- Committed to work with other ALHIV
- Available to work at the clinic (no conflict with school/work)
- Represent ethnicity, social economic status, gender language and other features of ALHIV in the clinic
- Willing to volunteer their time and expertise to support other ALHIV
- Able to attend peer educators training and use training information and skills with peers.

#### 12.5.3 Role of HCW in coordinating the work of adolescent peer educators

• HCW should take the lead in initiating and facilitating peer support groups, ensuring the involvement of ALHIV in planning and setting up the groups, as well as serving as peer educators and supporters.

- Keep expectations and assigned responsibilities and tasks realistic (e.g. an APE should not be expected to provide professional-level counselling)
- Provide follow-up training and ongoing mentoring and on-the-job support
- Make boundaries very clear to APE
- Make sure that the program has explicit rules and that APE are coordinated and supported to adhere to them.

In involving ALHIV peer educators, avoid:

- Having adolescents present but with no clear role, training, support, or supervision
- Asking adolescents their opinions but not taking these opinions as they are.
- Assigning tasks to adolescents, like filing of CTCs cards/data or cleaning



**Note:** Peer Education curriculum used for training should be a National Peer Educators' curriculum for SRH or evidence-based ALHIV curriculum.

# **CHAPTER 13: SUPPORTING THE TRANSITION OF ALHIV TO ADULT CARE**

As ALHIV grow into adulthood, they will take responsibility for their own health and HIV management and it may become necessary for them to transfer to adult care settings, especially in high volume clinics where there are unique paediatric and adolescent services. Transition is an active process that attends to not only HIV care and treatment needs, but also developmental, psychosocial, needs of adolescents as they move from more supported - to more care that is independent. The transition process requires flexibility, interaction and prior planning by the adolescent health team, ALHIV, their treatment supporter, and the adult care providers. The timing of the transition should not be determined by age alone, but by the preparedness, maturity of the ALHIV, which can be assessed individually using specific parameters.

Health care transition should include health and other areas of life such as employment/work, community, and school/institute. This transition process should ensure that adolescents are well equipped to manage their own care, continue adhering to treatment and services (exams, PSS, labs, pharmacy), and to advocate for their HIV needs.

#### Planned and organized health care transition helps ALHIV to:

- Establish new relationships with care providers while developing the knowledge and skills necessary to manage their health
- Reduce any risk-taking behaviour that can interfere with treatment adherence and retention in adult HIV care settings
- Take on the psychological responsibility for when and if to disclose
- Manage their own treatment and nutrition
- Be linked to effective livelihoods, nutritional, mental health and psychosocial support to improve the quality of life and well-being of ALHIV

#### HCWs should take into account that:

Adherence can be significantly affected as adolescents try to accommodate into new adult care settings. Adherence includes clinic visits, ART refills, PSS, lab schedules and contraceptive access.

#### 13.1. Goal of Transition from ALHIV to Adult Care

The goal of transitioning adolescents to adult care is to ensure there is provision of *uninterrupted, coordinated, developmental, age-appropriate, and comprehensive care* before, during, and after the transition. Adolescents are eligible to use adult services from age 15 years and should be transitioned to adult services between 20-24 years. ALHIV may face challenges in transitioning to adult care. These challenges affect ALHIV,

their parents/caregivers/treatment supporter, and HCWs in adolescents' and adult clinics.

Key definition of the following terminologies should be communicated clearly by HCWs:

- **Uninterrupted**: The longevity and quality of life of ALHIV depends on the continuous and uninterrupted supply of ARVs and other medications, especially for OIs.
- **Coordinated:** Have a transition plan before the transition takes place. The transition plan should address any special care needs of ALHIV, such as the need for psychosocial support, counselling, appointment reminders, social support and income generation support.
- **Developmental:** Developmental issues for adolescents to be considered in transition include taking more responsibility for themselves, wanting to be accepted and to fit in with peers, and learning to navigate their emerging sexuality and new intimate relationships.
- **Age-appropriate:** Access to age-appropriate care and support for ALHIV helps sustain effective treatment.
- **Comprehensive care:** A multidisciplinary team approach involving paediatricians, adult care providers, physicians, social workers, peer educators and counsellors, tailored to individual specific needs.

# **13.2. Barriers Influencing Transitioning Process of ALHIV**

Barriers influencing the transitioning process may be related to adolescents, parents/caregivers, or HCWs:

- Adolescent:
  - ALHIV may feel reluctant to leave the comfort of a familiar care setting, where their privacy is maintained and they understand the systems and schedule.
  - ALHIV may feel uncertain about how to manage a new clinic setting with new providers.
- Caregiver:
  - Parents may feel unsure about their child's capacity for autonomy and ability to understand their illness, especially for those perinatally infected.
  - Parents may be fearful of the impact of ALHIV disclosure to others.
- Health Care Settings:
  - Adult clinics typically lack specific, adolescent-friendly services, and maybe crowded compared to adolescents or paediatric care settings.

- Staff shortages and increased workload in health facilities that they pay no attention to ALHIV specific needs e.g. not starting the transition process early as recommended.
- Unfriendly infrastructure e.g. lack of adolescent-friendly corners in health facilities to provide adolescent friendly services.

This is why the HCW must manage, plan and start the transition process early (three years before transitioning), with good communication between ALHIV, parents/caregivers, treatment supporters, and HCWs, and involving the adolescent in all the decisions taken around his or her ongoing care.

# 13.3 Roles of the HCW in Transitioning ALHIV to Adult Care

HCWs should help ALHIV set and achieve goals for independence and self-management of care and encourage ALHIV to develop as much independence as possible. It is recommended that providers plan to take **at least three years** to prepare patients for the transition to an adult practice setting. The transition plan, together with individual goals and achievements, should be reviewed and modified annually. In establishing transitioning plan, the HCW should:

- Develop a transition plan several years prior to transition and update it at regular intervals
- Ensure that ALHIV understand their chronic illness and its management, and provide them with skills to negotiate care in an adult clinic setting
- Assess patients, in an individualized manner, for development of sufficient skills and understanding for successful transition
- Address the individual barriers for each patient that may be preventing him/her from acquiring skills, such as developmental delays, anxiety, post-traumatic stress disorder, transient living conditions
- Include discussions around transition within peer support and education so that cohorts who know each other can move to adult care together
- Prepare and discuss a current medical history with the patient so that he/she is aware of previous hospitalizations or allergies that may have occurred during infancy or childhood
- Provide adequate and correct information to ALHIV and caregiver about transitioning to adult care
- For adolescents who do not yet know their HIV status, disclosure should be a primary goal of the transition plan
- Link ALHIV to income generating activities and other age-appropriate services such as family planning, etc.

# **13.4. Transitioning Approaches**

#### 13.4.1. Empowering adolescents to transition into adult care

HCWs shall ensure that the ALHIV is well prepared for transitioning:

- Begin the process early at least three years before, working as a team with the adolescent client, his or her caregivers, and other members of the multidisciplinary team. Appendix 9 includes a transition checklist.
- Enhance the adolescent's autonomy independence or freedom, as of the will or one's actions
- Promote a sense of personal responsibility Adolescents choose, start, or otherwise cause their own actions.
- Facilitate self-reliance reliance on one's own efforts and abilities
- Facilitate self-efficacy confidence in one's own ability to achieve intended results
- Boost the adolescent's capacity for self-care and self-advocacy.

In each of these stages, HCWs should consider each adolescent's developmental stage and readiness.

# 13.4.2 Innovative strategies that HCWs and programs can undertake to support transition

- Bring adult HCWs to the adolescents' clinic for a joint weekly clinical session so they can get to know more about adolescent clients and their unique needs
- Have peer educators (youth and adult) lead visits to adult care clinics to explain the systems and answer questions peer-to-peer
- A provider from the adolescents' clinic attend the adult clinic on a regular basis for "transition sessions"
- Identify and orient adult providers on the necessity of adolescent-friendly services and the needs of ALHIV through meetings, orientations, and trainings
- Transfer the client's medical records to the new clinic and hold a case conference to discuss key issues
- Accompanying the adolescent to the adult clinic for an orientation.

# 13.4.3 HCWs and ALHIV Peer Educators shall help ALHIV prepare for the transition process

- Review the ALHIV's medical history with him/her and encourage them to ask questions
- Ensure that the ALHIV understands his/her diagnosis, medications, adherence, and how to live positively
- Link ALHIV to peer support groups and support groups at the adult clinic
- Transition ALHIV to adult care in cohorts or groups
- Organize health talks for transitioning ALHIV

- Involve ALHIV Peer Educators, social workers, and counsellors when planning for ALHIV's transition, especially for most-at-risk ALHIV
- Connect ALHIV to other community-based services.

# 13.4.4 Support older ALHIV be more involved in their own care

Ideally, they should be able to:

- Make, cancel, and reschedule appointments
- Arrive to appointments on time
- Call ahead to schedule urgent visits
- Request prescription refills correctly
- Know when to seek care for symptoms or emergencies
- Identify symptoms and describe them
- Accept and Interact with different service providers and different types of clinic visits, such as ANC, CECAP
- Establish a good working relationship with a case manager such as clinician, nurse, nutritionist
- Ask questions and ask for help
- Have a full understanding of their care and treatment plan, including the medicines they are taking
- Get the results of every test and understand the results
- Join an ALHIV Association (if available in their locality) and support group
- Follow up on all referrals and document within the patient file.

#### **13.5. Transition Tools for ALHIV**

It is possible for ALHIV to have a smooth transition to adult care and to receive adolescent-friendly services in the adult clinic. Transition tools can help HCWs and ALHIV to prepare for and carry out the transition to adult care. HCWs should be familiar with and use the Transition Checklist when supporting ALHIV to transition to adult care as shown in Appendix 9.



PHOTO: ANDREW MARINKOVICH/EGPAF, 2017

# CHAPTER 14: MONITORING, EVALUATION AND QUALITY IMPROVEMENT

Monitoring and Evaluation (M&E) is an essential component of quality of HIV service delivery. It allows the program to follow the trends in HIV outcomes, utilize the program data for strategic planning and re-direction of resources and report on key indicators. M&E is the standardized process by which data related to the delivery of HIV services are collected and evaluated. These data can be used to monitor progress in the implementation of adolescent care and treatment services at the facility level, and can also be evaluated at the district and national levels. There is no a separate data collection and reporting system specific for adolescents. This is why it is particularly important that data are appropriately disaggregated by age. Health facilities should use regular national forms for HIV care and treatment.

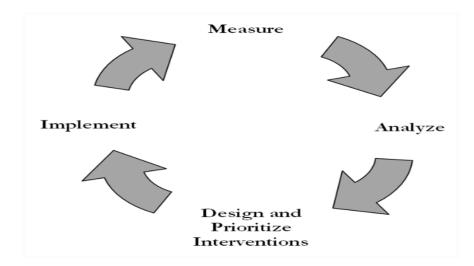
Effective M&E systems require record keeping that is:

- Accurate Correct and true
- Reliable Completed the same way every time
- Standardized Recorded using the same tools in every clinic in the country
- **Recorded** Following established guidelines

Important points to remember are that:

- Systems for documenting care and treatment activities must **maintain client confidentiality.**
- It is the responsibility of all staff members who complete registers or summary forms to ensure that data are accurate and complete and that data collection protocols are followed

#### **M&E is a CONTINUOUS process:**



#### 14.1. Monitoring

Monitoring is routinely tracking of HIV and AIDS programme interventions through collecting, analysing, and reporting of data to assess progress against set plans.

- It is a process that helps to identify problems early so that they can be corrected quickly and requires that data be collected, compiled, and analysed on a routine basis.
- It involves COUNTING what we are doing and routinely checking the quality of services.
- It also involves recording and reporting properly the various steps and events involved in implementing the activities. Monitoring should concentrate on key information in order to measure and report progress of the activities.
- It should also be standardized using well-designed formats for recording. The information collected should be analysed, interpreted and utilized to make decisions at the point of collection of information and at higher levels.

HCWs play a vital role in the monitoring process by regularly recording, compiling, and reporting data to determine, for example:

- Number of adolescents enrolled in HIV care
- Number of adolescents receiving ART
- Number of adolescents retained in care over time
- Types of clinical and support services offered to adolescents

#### M&E of HIV care and treatment programs can help to:

- Assess whether services are being provided according to national guidelines
- Identify successes and challenges in the implementation of adolescent services

Routine M&E is necessary to gather information on care and treatment program outcomes, such as:

- Is the program retaining adolescent clients in care?
- Are all eligible adolescents receiving ART?
- Are adolescents in care achieving treatment outcomes, such as viral load suppression?
- Are routine lab tests and clinical follow-up visits being conducted on schedule?
- Are the patients receiving test results in a timely manner (e.g. VL monitoring)?

#### 14.1.1. Disaggregating data

Disaggregation involves distributing collected data by age, sex, pregnancy and breastfeeding. Adolescent data should be disaggregated using the following age groups:

- Ages **10-14**
- Ages **15-19**

#### 14.1.2. Indicators

Indicators are summary measures used to help indicate the status of a services delivered and patient outcomes. Care and treatment indicators are established at the national level covering service delivery, quality of care, and management related information. Data measured by any indicators can be analysed, interpreted and utilised at the facility, district, Regional, and national level, depending on need and how these data will be used.

Health facilities can develop their own indicators to monitor progress towards national indicators and other gaps identified for specific health facility. Indicators may need to be revised periodically, especially to account for special needs or innovations in adolescent service delivery. Indicators reflect a certain timeframe (e.g., month, quarter). It is important to measure changes in indicators over time.

#### 14.1.3: Targets

Targets are specific goals established before a new program or service is implemented and on a regular basis to monitor performance of certain indicator. Performance can be measured by percentage, Ratio or number depending what is been measured. To calculate performance in percentage you must have numerator and denominator.

#### Example:

- "To ensure that 95% of eligible adolescent clients initiate ART."
- Numerator Number of adolescent clients initiated ART
- Denominator Number of eligible adolescent clients

#### 14.1.4. Data collection and analysis tools

- CTC 2 Card
- CTC 1 Card
- Pre-ART register
- ART register
- Cohort analysis register
- Appointment book
- Tracking register
- CBHS register
- Dispensing register
- HTC register
- Forms:
  - $\circ \quad \text{Report and Request forms}$
  - Referral form
- Reports:

- Cross-sectional reports
- o Quarterly
- HTC monthly summary forms
- Cohort analysis report form

For more explanation of the above tools, refer to the National Guideline for Management of HIV and AIDS 6<sup>th</sup> edition 2017, Chapter 17.

#### 14.2. Evaluation

Evaluation is an assessment of an ongoing or completed project or program. It measures outcome or impact of the program. Help to take a closer look at outcomes of interest and can help to answer questions about what these outcomes means. It is conducted at specific time periods (e.g. at the middle or end of project whereas monitoring happens on a more regular basis. Evaluation will demonstrate to what extent planned activities are actually realized, by comparing targets with indicator measurements (e.g. *What % of the target for ART initiation did the program reach last year?*)

Evaluation can also involve research methods to systematically investigate a program's effectiveness. One might use evaluation to answer the following program questions:

- Are adolescents enrolled in a peer support group more likely to return for scheduled appointments compared to adolescents who do not participate in peer support groups?
- Are adolescents enrolled in the program experiencing a better quality of life?
- Has the program reduced the number of adolescents hospitalized for HIV-related illnesses?

Evaluations should be conducted regularly to look at changes that occur as the adolescent HIV program is implemented and maintained. This will enable program staff to identify areas of program strength and weakness, and to respond to weaknesses by investigating and correcting problems. HCWs will be involved in collecting and reviewing evaluation data.

#### 14.3. Quality Improvement and Supportive Supervision

The term Quality Improvement refers to the routine evaluation of activities to check whether services are following established guidelines and standard operating procedures (SOPs). QI can also be referred to as quality assurance (QA). QI uses scientific principles and tools to understand and address system deficiencies in order to produce efficient and effective health care delivery processes, through redesign. QA is process of assessing whether services conform to specified standards (either be internal or external). QI is different from M&E. QI should be a routine, ongoing part of the normal functioning of health facilities, and should incorporate procedures in which all staff at all levels are involved.

**The purpose of QI is to identify problems** (in service delivery, in data, or in both) **so they can be corrected**, thereby improving services for adolescent clients and their families.

#### 14.3.1: Methods to assess quality

It is often necessary to use a variety of methods to assess program quality. Standard monitoring tools capture only a fraction of the services provided to adolescents and they provide no information on the quality of those services. For example, forms and registers do not give us information on the youth-friendliness of services or the quality of PSS, adherence, or counselling sessions.

#### 14.3.2. QI activities might examine/evaluate

- The quality and youth-friendliness of services
- Compliance with national guidelines, SOPs, and protocols for HIV care and treatment
- The adequacy of space and the attention to privacy and confidentiality
- Linkages to ongoing support and community-based services

#### QI Activities Might Include:

- Periodic reviews of records followed by staff feedback
- Direct observation of clinical procedures and counselling sessions
- Periodic assessments of the adolescent-friendliness of services, such as meeting standards for youth-friendly services
- Interviews with staff to obtain feedback on specific indicators
- Individual interviews or focus groups with ALHIV
- Individual interviews or focus groups with caregivers of ALHIV
- Exit interviews or surveys completed anonymously by clients
- Evaluation of physical space, client flow, and time concerns
- Meeting with representatives of services where ALHIV and caregivers are referred

#### **Frequency of QI**

It is important to set up an established time for health facility management teams to discuss QI findings and issues in their regular meetings, and to plan the way forward.

• **During initial implementation:** daily or weekly.

• As services become established: reviews should become a formal part of overall program monitoring activities at designated intervals (monthly progressing to quarterly reviews).

#### 14.3.3: Overview of supportive supervision

Supportive supervision is a process that promotes quality at all levels of the health system by strengthening relationships within the system, focusing on the identification and resolution of problems, optimizing the allocation of resources, promoting high standards, team work, and better two-way communication.

The **goal** of supportive supervision is to promote and maintain the delivery of highquality health services.

Supportive supervision is an important component of responding effectively to QI findings. Supportive supervision is an approach in which supervisors work with staff to:

- Establish goals
- Monitor performance
- Identify and correct problems
- Proactively improve the quality of services

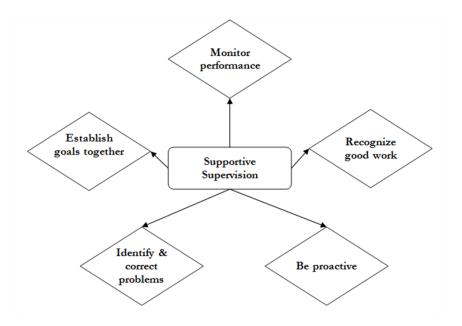
QI is most effective when the focus is on providing guidance and mentorship and using group problem solving to help HCWs correct problems and overcome barriers.

The aims of supportive supervision include:

- Obtain information on program functioning and quality
- Improve HCW performance by providing one-to-one support
- Acknowledge good practices by providing positive feedback
- Involve supervisors, HCWs, and volunteers to improve service provision
- Facilitate on-site, participatory problem-solving
- Involve youth in giving feedback and improving service provision
- Assure that the program is successful in meeting the needs of ALHIV/caregivers
- Motivate staff and volunteers

Once a deficiency in service provision is identified, supportive supervision must be established as quickly as possible to prevent poor practices from becoming routine.

#### Figure 14.1. Supportive supervision process



#### The processes of supportive supervision:

- **Monitor performance:** Involves routine monitoring of adolescent HIV services in the health facility through data collection and review.
- **Recognize good work:** There should be a system to appreciate and document success stories so that they can be applied to other health facilities.
- **Be proactive:** HCWs should be sharp in controlling any indication of failure in achieving set targets rather than complaining or waiting for somebody else to intervene.
- **Identify and correct problems:** This should be a routine process whereby issues arising from service delivery have to be identified and corrected very early. This is the role of every HCW in the clinic team.
- **Establish goals together:** The clinic team together with the supervisor should agree after every supportive supervision on the next steps for any issues identified.

### APPENDICIES

#### Appendix 1: Common Counseling Scenarios

Scenario	What the HCW can do
Silence	• Remember that silence can be a sign of shyness, embarrassment, anger, or anxiety.
	• If an adolescent client is silent at the beginning of a session, the HCW can say, "I
	realize it's hard for you to talk. Talking to someone you don't know can be scary. Many
	people are scared (or too embarrassed, too angry, too anxious) to share their feelings."
Anger	• Say, "You seem angry. It's OK to be angry, but would you like to talk about it?" Or, if
	the HCW thinks he or she knows why the client is angry, he or she can say something
	like: "Sometimes when someone comes to see me against his or her will and doesn't
	want to be here, it is difficult for him or her speak. Is that what is going on?"



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Shyness	<ul> <li>Legitimize the feeling by saying, <i>"I would feel the same way in your place. I understand that it's not easy to talk to a person you have just met."</i></li> <li>Use books, brochures, or posters to encourage discussion or refer to a story or anecdote so the adolescent can talk about others rather than him- or herself (see "Activities to promote expression with younger adolescents" on page 4-15). Some adolescents simply need time to feel comfortable with someone new.</li> <li>If the adolescent cannot or will not talk, the HCW should propose another meeting.</li> </ul>
Crying	<ul> <li>Try to evaluate what provoked the tears and assess if it makes sense in the given situation.</li> <li>If the client is crying to relieve tension, the HCW can give the adolescent permission to express his or her feelings by saying, <i>"It's okay to cryit's the normal thing to do when you're sad."</i></li> <li>If the client is using crying as manipulation, the HCW can say, <i>"Although I'm sorry you feel sad, it's good to express your feelings."</i></li> <li>The HCW should allow the client to freely express emotions and should not try to stop his or her feelings or belittle their importance.</li> </ul>
Threat of suicide	• Take all suicide threats very seriously! Refer the adolescent to a qualified counsellor, psychiatrist, or psychologist and accompany him or her to the appointment. Work together with relevant members of the multidisciplinary care team to form an appropriate plan of action.
Refusal of help	<ul> <li>Discreetly try to find out why the adolescent is refusing help. If the underlying feeling is anger, refer to some of the suggestions under "Anger" listed above).</li> <li>If the client has been sent against his or her will, the HCW can say, "I understand how you feel. I'm not sure I can help you but maybe we could talk for a minute and see what happens."</li> </ul>

Scenario	What the HCW can do
Difficulty dealing with short stature	• Reassure the ALHIV that most adolescents, without HIV, go through a period of feeling unhappy about themselves. Explain that everyone develops at different rates, this is normal.
(Many adolescents with perinatally- acquired HIV feel self-conscious about being	<ul> <li>Encourage ALHIV to reframe their difference as not making them "different," but rather as defining them as individuals. A young man who is shorter than the average might feel better about himself if he focuses on the skills and internal qualities that he sees as positive, e.g., if he is artistic, creative, or naturally outgoing.</li> <li>It is difficult for young people to reframe their differences as positive. Give them</li> </ul>
"different." These physical differences can interfere with their self-esteem).	<ul> <li>time and encourage them to talk about their differences with friends and within support groups. Support groups can also give adolescents tips on dealing with teasing.</li> <li>Encourage caregivers of ALHIV to support their children to feel good about</li> </ul>
then sen esteemy.	themselves. A caregiver's unconditional love and support is the core of self- esteem. Self-esteem is the armour adolescents need to ignore peer teasing.
Need to talk	• It can be a counselling challenge when a client is very vocal and wants an outlet

<ul> <li>to express concerns that the HCW does not perceive to be directly related to the client's immediate counselling needs. In this situation, the HCW should give the client the opportunity to express his or her needs and concerns. The HCW should then summarize the discussion so far and identify the key issues that need to be discussed further that day. This sets the agenda for the rest of the meeting and gives the HCW permission to pull the session back on track if the client starts discussing tangential issues.</li> <li>Sometimes the HCW simply does not have enough time to devote to a</li> </ul>
<ul> <li>particularly needy or talkative client. In this case, the HCW should get about partway through the session and should then summarize the session so far, identifying the key points that require further discussion. Assuming that the client agrees the summary is accurate, the HCW should then try to prioritize the client's issues. The HCW should suggest they talk about the first 2 or 3 issues in the time remaining during that day's session and that they tackle the other issues at the next session. Assuming the client agrees with this listing of priorities, the HCW should then make a note of the agenda items to be covered during the next session so they are not forgotten.</li> <li>Refer client to a peer support group; talkative clients tend to benefit greatly from opportunities to interact with their peers.</li> </ul>

#### Appendix 2: Psychosocial Assessment Tool

#### How to Use This Tool

This Psychosocial Assessment Tool was developed to support trained HCWs. Conducting a psychosocial assessment with each client (and caregiver, if applicable) helps providers learn more about the client's specific situation, helps them prioritize needs, and helps give direction to ongoing counseling and psychosocial support. This includes referrals for needed community- and home-based services.

A psychosocial assessment should be conducted with each adolescent client **both after enrollment in HIV care and treatment services and annually after that.** HCWs may want to conduct another psychosocial assessment or revisit specific psychosocial issues **when a client's situation changes in a significant way,** such as when a client reaches a new developmental stage or starts to show signs that he or she is facing new challenges or problems. Always respect client confidentiality and conduct sessions in a space that offers visual and auditory privacy. Information from the psychosocial assessment should be recorded on the form and the form should be kept in the client's file for reference during follow-up visits.

**Basic information:** Write down the client's name and file number. Be sure to sign and date the form at the end of each session.

**Questions to ask the client/caregiver:** These questions allow the HCW to discuss and assess the client's psychosocial issues and needs. It is important to allow time for the client to respond to each question. Clients should always be made to feel comfortable expressing psychosocial challenges and should never be judged or punished. Write down any important information from the client's responses in the right-hand column, as this will help you to decide on effective next steps, to decide on important areas for follow-up,

and in supporting the client's psychosocial wellbeing over the long term. Also make sure that the client has time to ask questions and that you have time to summarize the session and agreed upon next steps. Record key next steps in the space provided.

**Additional notes:** Write any additional notes about the session or the client's psychosocial needs in the space provided.

**Referrals made:** Linkages and referrals to psychosocial support services are an important element of HIV care and treatment programs and the ongoing support of adolescent clients and their families. Each clinic should have an up-to-date list of community support services (such as Adolescent Peer Educators, adherence counselling, ALHIV associations, food support, education and job training programs, GBV services, legal support, etc.) and formal two-way referral systems to these organizations and services. Clients with severe psychosocial and psychological issues (such as depression, alcohol or other substance use disorders, suicidal feelings) will require careful follow-up and immediate referrals to ongoing professional counseling and other services. Record any referrals made to the client in the space provided. At the next session, follow up to determine if the client accessed these services.

**Date of next counseling session/clinic appointment:** Schedule a follow-up counseling appointment with the client and record this date, as well as any other clinic appointments, in the space provided.

#### **REMEMBER:**

- Do not talk down to an adolescent.
- Allow the adolescent to speak for him- or herself. Respect his or her opinions.
- Be patient! Allow the adolescent to express his or her views and to describe his or her experiences.

#### Appendix 3: ALHIV Psychosocial Assessment Guide and Recording Form<sup>3</sup>

Cli	ent Name:	Client File#:	Date:
1.		yourself, and give a short explation the set of the set	-
2.	your HIV-status (	ow things have been going sin or since we last met)? How ar <b>uss client's coping strategies</b>	re you coping?
3.	changes have you eating and sleepi	ur mood now. Do you feel sad 1 noticed in your mood? What ng habits? <b>pression and need for referr</b> e	about in your
4.	other drugs? <i>Assess for harm</i>	last week have you used cigar ful coping strategies, such as ling and referrals	
5.	•		
6.	support?	close to? Who can you go to for <i>rtance of social support</i>	or emotional
7.	•	a community/religious organ u be willing to join a support g a <b>s needed</b>	
	experienced. Has made unwanted unsel and discuss	y negative attitudes or treatme anyone caused you harm (e.g sexual advances)? <i>support services; consider</i>	
9.	having sex? It's in to do this safely. and the spread of	s have sex. Have you ever had nportant for you and your sex If so, what are you doing to pro STIs and HIV? I risk-taking and counsel on	xual partner/spouse revent pregnancy
	Let's talk about y How long have ye Assess living situ If not living with this happen? How	our living situation. Who are y ou lived with them? How well <i>lation</i> parents, ask: Where are your p v did this affect you?	do you get along? parents? When did
11.	or work outside t How is this going	do most days. Do you, for exa he home? Where do you go to for you? ork situation and adherence	o school/work?

<ul> <li>12. 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?</li> <li><i>Refer to social worker and community-level support</i></li> </ul>	
13. Other than coming to this clinic, where else do you go for health services (for example, other clinics, traditional healers, etc.)?	
14. 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? <i>Counsel on adherence to care</i>	
<ul> <li>15. 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?</li> <li><i>Counsel on adherence and briefly discuss:</i> <ul> <li><i>WHO will give or manage your medicines?</i></li> <li><i>WHEN will you take them?</i></li> <li><i>WHERE will you store them?</i></li> <li><i>HOW will you remember to take them (review use of reminders, like calendars, pill boxes, etc.)</i></li> </ul> </li> </ul>	
16. 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)?	
17. Summarize the session and review immediate plans and next steps, including the next clinic visit date.	

#### Notes:

**Referrals made:** 

\_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_

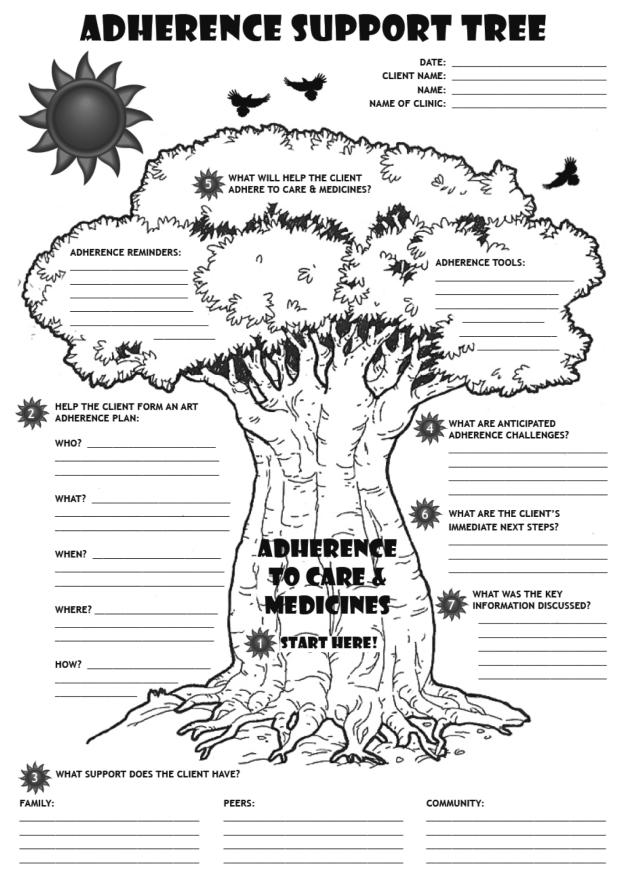
#### Appendix 4: Adherence Support Tree

#### Instructions for the Adherence Support Tree:

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

- 1. Start on the trunk. Begin by explaining what we mean by adherence to treatment and why near-perfect adherence is important.
- 2. Continue by helping the client make an ART adherence plan: address the ARE YOU COMMITTED question, and the WHO, WHAT, WHEN, WHERE, and HOW of the medicines. The lines to the left of the tree are spaces for writing down important information related to the client's adherence plan.
  - ✓ **ARE YOU READY TO TAKE YOUR MEDICINES?** If the response to this question is no, then consider delaying ART initiation.
  - ✓ WHO will help you remember to take your medicine every day at the same time? Is there someone who can help you come to the clinic for appointments?
  - ✓ WHAT medicines are you taking? What is the dose of each and how often will you take each medicine? What will you do when you are about to run out of your medicines? What will you do if you miss a dose of your medicine?
  - ✓ WHEN will you take your medicines? (Establish a routine.)
  - ✓ WHERE will you take your ART (e.g. at school, at home, at work, etc.)? Where will you store your ART?
  - ✓ HOW will you remember to take your medicines every day and at the same time? When you are at school or work? When you are away from home? When you are with your family? When you are with your friends? How will you know that you have taken your doses so you don't miss any or take them twice?
- 3. Ask the client to imagine him- or herself as a tree. His or her roots are "where you come from, your home, your family, and your community," they are "what support and ground you." Ask the client who will support him or her with the adherence plan and write this under "peers, family, and community" in the roots of the tree. Also write down if the client has a treatment buddy.
- 4. Discuss the possible challenges to adherence in the client's (and caregiver's) life. Write these under "what are the anticipated adherence challenges?"
- 5. The branches are the client's adherence strategies. These are things he or she can do to have perfect adherence, like using reminders, having routines, having a treatment buddy, etc. Give the client practical suggestions and help him or her plan ways of remembering to take medicines and to come to the clinic for appointments.
- 6. Always plan a follow-up session and record any action points under "immediate next steps." Tell the client that you will always be available to talk more with him or her. Adherence and follow up to the adherence plan should be discussed during every clinic visit.

7. Lastly, summarize the main points that were discussed during the adherence support session, talk about any necessary referrals, and arrange another time to talk (if necessary).



#### Appendix 5: Adherence Preparation and Support Guides

#### How to use these guides

These adherence preparation and support guides were developed to assist a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community health care workers, and others) who work with ALHIV and their caregivers. These guides can help providers work with their clients (and caregivers) to understand the importance of adherence to HIV care and treatment throughout their life; to ensure understanding of the care and medications plan; to identify potential adherence challenges; and to come up with practical solutions. The adherence guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used, including the age and situation of the individual adolescent client. It may be helpful to translate the guides into the local language.

Often, adherence preparation is not tailored to the specific needs and concerns of adolescents and, in some cases, adolescents are referred to adult ART clinics, which may not be youth-friendly, for adherence counselling and preparation. Many programmes stipulate that clients participate in a series of group and individual counselling and preparation sessions before starting ART.

Included is one adherence preparation and support guide to assess adolescents' readiness for ART and one to assess the readiness of caregivers. The forms should be adapted as needed and used during adherence counselling sessions, according to the client's (and caregiver's) needs and situation. Completed adherence assessment forms should be kept in the client's file and referred to during follow-up visits.

#### **Basic information:**

Write the client's name and file number at the top of the form. Be sure to sign and date the form at the end of each session and ensure that the form is kept in the client's clinic file.

#### **Questions to ask the client/caregiver:**

The questions in this section allow the HCW to discuss specific care, medication, and adherence issues with the adolescent client/caregiver. The questions should be used to identify areas where the client/caregiver may need additional information and support, but should not be used to "score" a client's knowledge and readiness to take ARVs. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable asking questions and expressing potential adherence challenges and they should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, important areas for follow up, and in supporting the client's adherence over the long term.

#### Client/caregiver requires more counselling and support in these areas:

Write down specific areas in which the adolescent client/caregiver needs ongoing adherence counselling and support. Refer to this section of the form during follow-up counselling appointments and clinic visits. Even if a client has questions about his or her care and medicines, or is facing specific adherence challenges, this is usually not a reason to delay initiation of ARVs/ART. Instead, these issues should be viewed as important areas for ongoing counselling and support.

## Adherence Preparation/Support Guide for Assessing Adolescents' Readiness for ART

Client's Name: Client's Age: Client's File#:					
Caregiver and/or Tr	eatment Buddy's Name:				
Questions to ask the	adolescent client:	Notes			
1. Can you tell me what	at peer support group or group				
education sessions you	u have attended here at the clinic?				
2. Can you explain why	y you need to take ARVs?				
3. Who have you spok	xen to/who knows about your HIV				
status?					
	from taking ARVs? 5. How do yo	u			
	icines every day for your lifetime?				
6. Can you tell me the	names of the ARVs you will be taki	ng			
	e them (how many pills, what time	S			
of day)?					
	ne possible side effects of your ARV	s?			
What will you do if you					
	at happens if you do not take all of				
your ARVs every day,					
	you come to the clinic for				
	s and help you take your medicines				
	hat is their name and contact				
information?					
	to the clinic with you?				
8	it difficult to come to this clinic for				
your appointments?					
5	ember to come for your clinic				
appointments?					
	ember to take your medicines the				
right way, at the same					
	medicines — other than the ones				
	he doctor or nurse (including				
traditional or herbal n					
<b>13.</b> Where will you sto					
	f you are about to run out of your				
	out if you are going to be away from	n			
home, such as when yo		<u> </u>			
	f you miss a dose of your medicine?				
-	you have about the plan for your				
care or your medicine					
<b>17.</b> Do you feel ready	to start taking these medications?				

Client requires more counselling and support in these areas (LIST): Signature of person completing assessment: \_\_\_\_\_ Date: \_\_\_\_\_ Adapted from: ICAP. 2010. Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for HCWs.

## Adherence Preparation/Support Guide for Assessing Caregivers' Readiness for ART

Caregiver and/or Treatment Buddy's Name:       Notes         Questions to ask the adolescent client:       Notes         1. Can you tell me what support group or group education sessions you and your child have attended here at the clinic?       Second Sec	Client's Name: Client's Age: Client'	s File#·				
Questions to ask the adolescent client:         Notes           1. Can you tell me what support group or group education sessions you and your child have statended here at the clinic?         .           2. Can you explain why your child needs to take ARVs?         .           3. Who knows about your child's HIV status?         .           4. What do you expect from your child taking ARVs?         .           5. How do you feel about your child taking medicines every day for his or her lifetime?         .           6. Can you tell me the names of the ARVs your child will be taking and when he or she will take them (how many pills, what times of day)?         .           7. Can you tell me some possible side effects of your child's ARVs? What will you do if your child has side effects?         .           8. Can you explain what happens if your child does not take all of his or her ARVs every day, at the same time?         .           9. Who will help your child come to the clinic for appointments and help him or her take his or her medicines every day? What is your contact information/other supporters' contact information?         .           9a. If someone other than the caregiver, has he or she been to the clinic with your child remember to cake his or her medicines the right way, at the same time, every day?         .           10. How will your child remember to take his or her medicines the right way, at the same time, every day?         .           11. How will your child remember to take his or her medicines prescribed to him or her by the doctor or nurse (including tra	5					
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17. Do you feel that you and your child are ready to start						
	taking these medicines?					

Caregiver requires more counselling and support in these areas (LIST): Signature of person completing assessment: \_\_\_\_\_ Date: \_\_\_\_\_ Adapted from: ICAP. 2010. Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for HCWs.

#### **Adherence Assessment Guides**

#### How to use these guides

These adherence assessment guides were developed to support a range of providers (trained counsellors, lay counsellors, Peer Educators, doctors, nurses, pharmacists, community health care workers, and others) who work with ALHIV and their caregivers. Routine adherence assessments help identify and solve specific adherence challenges in a timely manner. The adherence assessment guides should be adapted to reflect national HIV care and treatment guidelines, as well as the specific clinic, community, and cultural contexts in which they are used and for different ages of adolescent clients. It may be helpful to translate the guides into the local language.

Included is one adherence assessment guide for adolescents enrolled in HIV care and treatment and one to be used with caregivers. The guides should be used at every follow-up and refill visit to ensure that the adolescent client and caregiver understand the care and medication plan and that the client is taking his or her medicines the correct way, every day and/or that the caregiver is giving the client his or her medicines the correct way, every day. Completed adherence assessment forms should be kept in the client's file and referred to at follow-up visits.

#### **Basic information:**

Write the client's name, age, and file number, as well as the caregiver or treatment buddy's name, at the top of the form. Then, tick the box corresponding to the type of visit. Be sure to sign and date the form at the end of each session, and keep in the client's clinic file.

#### Questions to ask the client/caregiver:

The questions in this section allow the HCW to discuss and assess adherence. It is important to allow time for the client/caregiver to respond to each question. Adolescent clients and caregivers should always be made to feel comfortable expressing adherence challenges and should never be judged or punished. Remember to write down any important information from their responses, as this will help decide on next steps, know important areas for follow up, and support the clients' adherence over the long term. If possible, the HCW should meet with the client and caregiver separately to identify and address and discrepant responses. Meeting separately is especially important as young clients age into middle and late adolescence.

#### Other assessment measures and next steps:

This is the section where HCWs will plan with the adolescent client/caregiver to ensure that the client keeps up good adherence or develops strategies to improve adherence.

- **Other adherence assessment measures:** Depending on standard procedures at the clinic, the HCW may do a pill count and/or review the client's medicine diary or calendar. Record the results in the space provided.
- Specific adherence challenges identified by the adolescent client, caregiver, and HCW: Based on the answers to the questions asked in the first section of this form, discuss the specific challenges to adherence that the client is having. Together, discuss possible solutions to each challenge.
- **Referrals made:** If there is an outside organising, such as a youth support group or a home-based care programme, that could help support the client (and the caregiver and family) to overcome his or her challenges to adherence, refer the adolescent client

(and/or caregiver) to that organising or service and indicate the name and specific service in this part of the form. In some cases, the client (or caregiver) may need to be referred for other facility-based services, such as an appointment with a trained counsellor or a session with the pharmacist to explain dosing.

• **Next steps and follow-up plan:** Together with the adolescent client/caregiver identify which solutions and next steps he or she thinks are feasible and manageable. For each solution, list the necessary steps the client or HCW will need to take and a time line for each. Also, make an appointment for a follow-up visit and record the date on the form. This section of the form can be used as a starting point for the adherence assessment during follow-up visits.

#### Adherence Assessment for Adolescents Taking ART

Client's Name: Client's Age: Client'				s File#:	
Caregiver and/or Treatment Buddy's Name:					
	<b>ck one:</b> 2-week follow up	1-month follow up	mo	nthly refill	3-month
ref					
Qu	estions to ask the adolescent	t client:		Notes	
1.	Can you tell me more about he	ow you took your medicat	ions		
	this past month (or 2 weeks)?	(Do you know the names	of		
	the medicines? How many pil	ls do you take? At what tin	ne of		
	day do you take them?)				
2.	I would like you to think abou	t the last 7 days. How mar	y		
	pills did you take late in the la	st 7 days?			
	What were the main reasons	you took them late?			
3.	How many pills did you miss	in the last 7 days?			
	What were the main reasons	you missed them?			
4.	If we put all the pills you had	to take in the last 2 weeks	into		
	one cup, this is what you wou	ld see. If you took all of the	em		
	the cup would be empty. If yo	ou forgot to take all of then	1 the		
	cup would be full. Which of th	ese pictures best shows he	w		
	many of your doses you took	in the last month (or 2			
	weeks)? (circle one)				
5.	How did the medicines make	you feel?			
6.	Can you tell me about any cha	nges you noticed (such as	in		
	your health) or challenges you	u had with your medicines	?		
7.	What support or reminders d	o you have to help you tak	e		
	your medicines at the same ti	me, every day?			
8.	What questions do you have a	bout your care or your			
	medicines?				

Other assessment measures and next steps:	Notes
Results of pill count, if applicable:	
Review of medicine diary or calendar, if applicable:	
Specific adherence challenges identified by the adolescent	
client, caregiver, and HCW: (discuss possible solutions to each)	

Referrals made:	
Next steps and follow-up plan:	Next appointment date:

#### Notes:

**Signature of person completing assessment:** \_\_\_\_\_\_ **Date:** \_\_\_\_\_\_ *Adapted from: ICAP. 2010. Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for HCWs.* 

#### Adherence Assessment for Caregivers of Adolescents Taking ART

Client's Name: Client's Age: Client's F						0
Caregivers Name:						
Tic	ck one:	2-week follow up	hly refill	3-month refill		
Qu	estions	to ask the adolescer	nt client:		Notes	
1.	medicat the nam	tions this past month nes of the medicines?	now your child took his (or 2 weeks)? (Do you How many pills does h es he or she take them?	know e or she		
2.	pills dic	l your child take late i	ut the last 7 days. How in the last 7 days? he or she took them la	-		
3.			d miss in the last 7 day he or she missed them			
4.	weeks i took all to take pictures	nto one cup this is wh of them the cup woul all of them the cup wo s best shows how man	ild had to take in the la nat you would see. If he ld be empty. If he or sh ould be full. Which of th ny of your child's doses r 2 weeks)? (circle one	or she e forgot nese s he or		
5.	How die	d the medicines make	your child feel?			
6.	(such as with his	s in your child's healt s or her medicines?	anges you or your child h) or challenges your c	hild had		
	him or l day?	her take his or her me	loes your child have to edicines at the same tin	ne, every		
8.	What q medicir	-	about your child's care	or your		

Other assessment measures and next steps:	Notes
Referrals made:	
Next steps and follow-up plan:	Next appointment date:

Signature of person completing assessment: \_\_\_\_\_ Date: \_\_\_\_\_ Date: \_\_\_\_\_ Adapted from: ICAP. 2010. Improving Retention, Adherence, and Psychosocial Support within PMTCT Services: A Toolkit for HCWs.

## Appendix 6: Nutritional Management of Common Symptoms Related to Advanced HIV Infection

Note: All of the recommendations for nutritional support and management of symptoms should be combined with routine clinical care and treatment, including ART.

Sign/symptom	Nutritional recommendations and management
F	• Eat small meals often. Try to include "body building" foods (protein) with each
	meal.
	• Eat snacks during the day if possible (such as groundnuts, boiled eggs, and
	avocados).
	• Eat more "energy giving" foods (like rice, maize meal, bread, and porridge).
	• Eat more beans, lentils, peas, and groundnuts.
Mainmailalt	Try to eat more meat, fish, and eggs.
Major weight loss	• Use more fats and oils in food, especially "good fats" like avocados and nuts.
(sometimes	• Eat more dairy foods (like milk and yogurt).
called	• Add dry milk powder or pounded groundnuts to foods (like porridge and
"wasting")	cereals).
waseing j	Add sugar, honey, syrup, or fruit jam to foods.
	Try to eat more of your favorite foods.
	• Adhere to your care and treatment plan, including ART.
	• ALHIV may experience changes in their body shape. This is a long-term side
	effect that can be caused by ART. Some ALHIV may develop more fat on their
	stomach, breasts, or other areas and may lose fat in their face, arms, and legs.
	These side effects may be confused with weight gain or weight loss.
	• Eat soups and drink safe water, rice water, thin porridge, and weak tea to
	avoid dehydration.
	<ul> <li>Drink oral rehydration solution (ORS).</li> <li>Eat an all amounts of food mountained a dam</li> </ul>
	<ul> <li>Eat small amounts of food many times a day.</li> <li>Eat foods like millet bananas neas and lentils to beln retain fluids.</li> </ul>
	Eucrobus file filler, bullanas, peus, and felters to help retain natus.
	• Eat foods like rice, bread, millet, maize, porridge, boiled potatoes, sweet potatoes, and crackers, which are easy to digest.
	<ul> <li>Eat soft foods like bananas, squash, cooked and mashed green bananas, paw-</li> </ul>
	paws, mashed sweet potatoes, and mashed carrots.
	<ul> <li>Eat eggs, chicken, or fish for protein.</li> </ul>
Diarrhea	<ul> <li>Adhere to your care and treatment plan, including ART.</li> </ul>
	Stay away from:
	Strong citrus fruits (like oranges and lemons)
	• Dairy products, such as milk — try fermented products instead, like yogurt or
	sour milk
	Caffeine (coffee and tea)
	• Alcohol
	Fried foods
	Very sugary foods
	• Extra oil, butter, or lard
	Gas-forming foods (like cabbage, onions, and carbonated soft drinks)
N	Drink fluids (especially clean water) to prevent dehydration.
Nausea and	<ul> <li>Eat bland soups.</li> <li>Eat fruit such as hences</li> </ul>
vomiting	<ul> <li>Eat fruit, such as bananas.</li> <li>Eat lightly galty and dry foods (like graphers on broad) to salm the stomash</li> </ul>
	<ul> <li>Eat lightly salty and dry foods (like crackers or bread) to calm the stomach.</li> <li>Drink horbal toos and lomon jujies in hot water</li> </ul>
	Drink herbal teas and lemon juice in hot water.

Sign/symptom	Nutritional recommendations and management								
	Eat small amounts of food many times a day.								
	• Adhere to your care and treatment plan, including ART.								
	Stay away from:								
	Spicy or fatty foods								
	Caffeine (coffee and tea)								
	Alcohol								
	• Eat soft mashed foods, such as scrambled eggs, cooked carrots, sweet								
	potatoes, bananas, soup, paw-paws, and porridge.								
	Eat cold foods or foods at room temperature.								
	Drink liquids, such as beef broth or lentil/pea soup.								
	• Rinse the mouth with clean, warm salt water before and after eating.								
	Use cinnamon tea as a mouthwash.								
	Suck on clean ice, if available, to relieve pain.								
Mouth and	• For thrush, eat fermented foods (like plain yogurt and sour milk). Sucking on a								
throat sores or	lemon and eating garlic can also help.								
infection	• See the nurse or the doctor, and adhere to your care and treatment plan,								
	including ART.								
	Stay away from:								
	Spicy or salty foods, which can irritate mouth sores								
	Strong citrus fruits and juices, which can irritate mouth sores								
	Sugary foods and drinks								
	Rough foods like toast and raw vegetables								
	Alcohol								
	Eat small, frequent meals throughout the day.								
	Eat nutritious snacks between meals.								
	• Take walks before meals if possible — fresh air helps to stimulate appetite.								
	Avoid smoking — it reduces appetite.								
Loss of	• Add seasonings, especially herbs, to food to give it more flavor.								
appetite	• Try rinsing out the mouth after meals.								
	<ul> <li>Use lemon, raw tomatoes, or tonic water to stimulate the taste buds.</li> <li>Changing damage it around the mouth to stimulate to sta hade</li> </ul>								
	• Chew food well and move it around the mouth to stimulate taste buds.								
	<ul> <li>Avoid strong-smelling foods.</li> <li>Extruith others as much as reasible.</li> </ul>								
	<ul> <li>Eat with others as much as possible.</li> <li>A dhama ta annu and tractor out along in she ding ADT.</li> </ul>								
	<ul> <li>Adhere to your care and treatment plan, including ART.</li> <li>Change the superconductive conductive set for a data and divergence of the set of th</li></ul>								
Taste changes	• Change the sweetness, saltiness, or sourness of food by adding sugar, salt, jam,								
(can sometimes	<ul> <li>or lemon (which also increases the taste).</li> <li>Try different herbs and spices</li> </ul>								
be caused by	Try unter ent ner by und spices.								
ARVs and other	Lat more fish of effecter, as meat can often have a metallic taste.								
medications)	Lat rentris, beans, or spire peas.								
-	<ul> <li>Brush teeth after eating to remove any aftertaste.</li> <li>Address to seem and two tractors out along in alording ADT.</li> </ul>								
	Adhere to your care and treatment plan, including ART.								

## **BMI Chart**

Weight Ibs	100	105	110	115	120	125	130	135	140	145	150	155	160	165	170	175	180	185	190	195	200	205	210	215
kgs	45.5	47.7	50.0	52.3	54.5	56.8	59.1	61.4	63.6	65.9	68.2	70.5	72.7	75.0	77.3	79.5	81.8	84.1	86.4	88.6	90.9	93.2	95.5	97.7
Hight in/cm		Un	derw	reigh	t		He	althy				Ove	rwei	ght			Ob	ese			Extr	reme	ly of	bese
5'0" · 152.4	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42
5'1" - 154.9	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	36	37	38	39	40
6'2" · 157.4	18	19	20	21	22	22	23	24	25	26	27	28	29	30	31	32	33	33	34	35	36	37	38	30
6'3" · 160.0	17	18	19	20	21	22	23	24	24	25	26	27	28	29	30	31	32	32	33	34	35	36	37	38
5'4" · 162.5	17	18	18	19	20	21	22	23	24	24	25	26	27	28	29	30	31	31	32	33	34	35	36	37
5'5" - 165.1	16	17	18	19	20	20	21	22	23	24	25	25	26	27	28	29	30	30	31	32	33	34	35	35
5'6" - 167.6	16	17	17	18	19	20	21	21	22	23	24	25	25	26	27	28	29	29	30	31	32	33	34	34
5'7" - 170.1	15	16	17	18	18	19	20	21	22	22	23	24	25	25	26	27	28	29	29	30	31	32	33	33
5'8" · 172.7	15	16	16	17	18	19	19	20	21	22	22	23	24	25	25	26	27	28	28	29	30	31	32	32
5'9" · 175.2	14	15	16	17	17	18	19	20	20	21	22	22	23	24	25	25	26	27	28	28	29	30	31	31
5'10" - 177.8	14	15	15	16	17	18	18	19	20	20	21	22	23	23	24	25	25	26	27	28	28	29	30	30
5'11" - 180.3	14	14	15	16	16	17	18	18	19	20	21	21	22	23	23	24	25	25	26	27	28	28	29	30
6'0" - 182.8	13	14	14	15	16	17	17	18	19	19	20	21	21	22	23	23	24	25	25	26	27	27	28	29
6'1" - 185.4	13	13	14	15	15	16	17	17	18	19	19	20	21	21	22	23	23	24	25	25	26	27	27	28
6'2" · 187.9	12	13	14	14	15	16	16	17	18	18	19	19	20	21	21	22	23	23	24	25	25	26	27	27
6'3" · 190.5	12	13	13	14	15	15	16	16	17	18	18	19	20	20	21	21	22	23	23	24	25	25	26	26
6'4" - 193.0	12	12	13	14	14	15	15	16	17	17	18	18	19	20	20	21	22	22	23	23	24	25	25	26

#### Appendix 8: Contraception Considerations for People Living with HIV

(Including contraindications with ARVs and common OI drugs)

Essential Principles of FP Counselling in HIV	Key Messages for FP Counselling in HIV
Services:	Services:
<ul> <li>Every HCT, ART, and PMTCT client should be assessed for FP need.</li> <li>Quality FP counseling and services should reinforce clients' ability to limit HIV transmission to HIV-negative partners and infants.</li> </ul>	• Dual method use — using condoms as a contraceptive method for good protection from infection and unintended pregnancy — should be included in FP counseling for clients living with HIV.
<ul> <li>HCT, ART, and PMTCT clients have the right to make their own FP choice, including safer pregnancy for HIV-positive women (using risk reduction measures like ARVs and exclusive breastfeeding), if desired.</li> </ul>	<ul> <li>Generally, HIV-positive clients can use most contraceptive methods (even if on ART).</li> </ul>

		HIV-Related Treatments and Conditions										
FP Options	NNF	RTIS EFV	NRTIS (AZT, D4T, 3TC, ABC, TDF, DTG)	Ritonavi r or Ritonavi r- Boosted Protease Inhibitor s	Rifam picin (com mon for TB)	Certain Anti- Convulsants (Carbamaze pine, Phenytoin, Barbituates)	Systemi c Anti- Fungals (Azoles)	Untreated Chlamydi a and/or Gonorrhe a	Clinic al AIDS/ not doing well on ART			
Male/Femal e Condoms												
COCs				X	X	Х						
POPs				X	X	X						
Implants												
EC												
DMPA												
Injectables												
NET-EN Injectables												
IUD												
Insertion								Х	X			
Natural Family Planning												
Fertility Awareness												
Client Desires Safer Pregnancy		x				х	х	х	x			

#### Legend:

	Method appropriate for client; No reservation of drug interaction
	Possible reduced contraceptive effect or increased side effects of hormonal method;
	Recommend dual method use with condoms and perfect use of selected method
X	Do not use the method

#### Appendix 9: ALHIV Transition Checklist for HCWs

This checklist contains the key points related to preparing older ALHIV to transition to adult care. This checklist is meant to assist HCWs and all members of the multidisciplinary care team by outlining the basic steps involved in supporting ALHIV with the transition process. The checklist provides suggested subjects for discussion, although additional areas may be identified to meet an individual ALHIV's needs. In the 'Actions' section, the HCW should record major actions undertaken, referrals made, or information given to the adolescent or caregiver during the discussion.

CTC ID #	Facility Name		
Date			
Transitio		ESN	0
	Important steps and suggested activities to	A	ctions and comments
$\checkmark$	facilitate the transition process		
	Introduce the transition		
	scuss transition during clinical check-ups and		
	dividual counselling sessions with ALHIV clients.		
	scuss transition with caregiver during individual		
	ssions.		
2.	Encourage the ALHIV to assume increasing res	ponsibil	lity for his or her own
	health care management		
	ntly discuss with the ALHIV to make sure he/she		
	derstands his or her own their health condition,		
	re plan, and medications. lk about the transition and transfer to the adult		
	nic, discuss expectations, and answer any estions.		
	lk about general coping, positive living, and		
	ilding supportive relationships.		
	ve caregivers an opportunity to discuss their		
	elings about transition and any concerns.		
	Assess the ALHIV's ability to make independen	t health	care decisions, assess
	his or her readiness for the transition, and det		
As	sess the ALHIV's understanding of his or her own		
	re and the transition process.		
	sess the caregiver's understanding of the ALHIV's		
	re and the transition process.		
En	courage the ALHIV to make his or her own next		
cli	nic appointment and refill appointment.		
Ini	itiate any needed referrals, including to support		
	oups.		
	Provide anticipatory guidance		
Re	view plans for the client's continued adherence to		
car			
	view the client's adherence to medicines and		
	sure that he or she has a medicine calendar.		
	sure the client knows where to access help if he or		
sh	e has questions about the new clinic.		

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	5. Implement the transfer clinic	to an adult
Give copies of reports and tests to the ALHIV and his or her caregivers so they have their own copies.		
Transfer medical records to the adult clinic and ensure that the ALHIV also has a copy.		
Discuss the ALHIV's care with HCWs at the adult clinic.		
Provide orientation to the ALHIV or a small group of ALHIV, ideally together with a HCW at the adult clinic.		
Follow up after the transfer (for example, schedule a follow-up visit with the ALHIV, encourage ALHIV Peer Educators to visit the adult clinic, etc.).		
6. Other activities that may help HCWs and AL	HIV plan for the transition pr	ocess
Arrange for ALHIV to meet with young adult clients who have already transitioned to adult care.		
Schedule a visit to the adult clinic so ALHIV can learn more about the services and HCWs there before the transfer takes place.		
Invite adult providers to the specialized ALHIV clinic for a weekly session so they can get to know more about adolescent clients and their needs. And/or, have providers from the specialized ALHIV clinic hold regular transition sessions at the adult clinic.		
Refer ALHIV to attend a support group sessionwith other transitioning adolescents.Suggest that the adolescent start journaling or		
using a transition workbook.		

