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NEW HORIZONS
ADVANCING PEDIATRIC HIV CARE

Johnson & Johnson



Elizabeth Glaser
Pediatric AIDS
Foundation

*Until no
child has
AIDS.*

Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations

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Acronyms and Abbreviations

ALHIV	adolescents living with HIV
ARV	antiretroviral
ART	antiretroviral therapy
CAYA	Committee of African Youth Advisors
CHW	community health worker
CLHIV	children living with HIV
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HCT	HIV counseling and testing
HCW	health care worker
HQ	headquarters
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
PrEP	pre-exposure prophylaxis
PSS	psychosocial support
SRH	sexual and reproductive health
STI	sexually transmitted infection
WHO	World Health Organization
U=U	undetectable means untransmittable
USAID	United States Agency for International Development

Toolkit Overview

About This Toolkit

This toolkit was developed in response to an identified need by health care providers to have practical, abbreviated guidance on the process of disclosing an HIV-positive status with pediatric and adolescent populations, their caregivers, partners, and other relevant parties. It aims to complement existing national and global guidelines and to serve as an easily accessible reference within health care facilities.

Purpose of This Toolkit

The objective of this toolkit is to provide general guidance on disclosure of HIV status in the settings of pediatric and adolescent HIV care. This document contains tools for use in clinical practice to build the capacity of different parties—including health care workers (HCWs), caregivers, and pediatric and adolescent patients themselves—in assisting with and delivering successful and informed disclosure.

Target Audience: Who Should Use This Resource?

This toolkit is primarily for HCWs working with pediatric and adolescent populations living with HIV.

How to Use This Resource

The disclosure toolkit is divided into seven sections:

1. Background on the evidence base for disclosure, types of disclosure, and benefits and disadvantages of disclosure.
2. Guidance and checklists for HCWs on disclosing to a child or an adolescent.
3. Guidance and checklist for supporting caregivers on disclosing to a child or an adolescent.
4. Guidance and checklist on supporting horizontally-infected adolescents on disclosing their status to their parents and caregivers.
5. Guidance and checklist on supporting adolescents on disclosing their status to their peers, school, work, and community.
6. Guidance and checklist on supporting adolescents on disclosing their status to their partner.
7. Relevant appendices with various disclosure job aids, including disclosure algorithms, a generic readiness assessment checklist, references to additional disclosure resources, and role-playing scenarios.

Background

Introduction

Globally, many children living with HIV (CLHIV) are surviving into adolescence as a result of increased access to antiretroviral therapy (ART). With children and adolescents living longer with HIV on ART, the focus turns from survival to improving quality of life, treatment adherence, retention in care and treatment, viral suppression, and sustaining physical and mental well-being. Disclosure of HIV status among pediatric and/or adolescent patients and their families and support structures is a critically important component of the care and treatment cascade. However, despite the significance in disclosing an HIV diagnosis, the global prevalence of disclosure among children and adolescent remains low.¹⁻³

The process of disclosure is complex, emotionally and socially. Caregivers frequently experience uncertainty in revealing a HIV-positive status to their children, which stems from fears of negative consequences from disclosure, such as psychological problems, inability to comprehend and deal with the diagnosis and stigma, and unintended disclosure to others.^{4,5} Studies, however, suggest that the majority of children who have been told their HIV diagnosis do not experience long-term negative effects, but instead benefit from knowing their status, with a large percentage of children in one study reporting disclosure as a positive event for them.⁶⁻⁸

Studies also suggest that children who know their HIV status have higher self-esteem compared to children who are unaware of their status.^{9,10} Published data suggest that disclosure of HIV status may support the uptake of, and adherence to ART.¹¹⁻¹⁴ Furthermore, disclosure to children and adolescents may present an opportunity for increased access to adherence or psychosocial support (PSS).¹⁵

An improvement in outcomes and survival on ART among vertically infected children and adolescents living with HIV creates higher demand for the disclosure of an HIV status by their caregivers and care providers. Caregivers disclose the majority of diagnoses to their child and can experience a profound impact themselves from going through this process with their child.^{16,17} Parents who have disclosed the status to their child experience less depression compared with those who did not.¹⁸ Therefore, disclosure tends to have positive long-term impacts for all invested individuals: the child, the parents, and the family.¹⁹

Caregivers often prefer the active involvement of HCWs in the disclosure process, and they frequently play an integral role in the caregivers' decision to disclose.^{20,21} HCWs can provide crucially important and supportive discussions and education after disclosure by the caregiver. In the absence of an appropriate family member or at the request of the family or caregiver, the HCW needs to be ready to assume the primary role in disclosure. Outside of the health care system, other major stakeholders can be involved and can help coordinating the disclosure process and post-disclosure support of the child, adolescent, or their caregivers. More specifically, teachers and relevant school personnel represent an untapped resource and can provide great support, if provided with the proper education, counselling, and support to deal with stigma, self-esteem, and self-management.

Several factors influence the decision to disclose an HIV diagnosis to a child or adolescent. As with other chronic illnesses, age and developmental maturity are the most significant factors for determining whether a child or adolescent will be disclosed to; generally, the older the child, the more likely they are to know their status.^{22,23} World Health Organization (WHO) guidelines recommend that children

of school age be told of their HIV-positive status; younger children should be informed incrementally to accommodate their cognitive skills and emotional maturity, in preparation for full disclosure at an older age.²⁴ Other factors that may influence the decision to disclose include: caregivers wanting their child to improve or maintain a certain level of adherence, the caregiver's level of knowledge of HIV disclosure, and the child or adolescent's status on ART.²⁵⁻²⁸

HIV disclosure for children with vertically and horizontally acquired HIV differs based on several contextual factors. Caregivers of vertically infected children diagnosed at an early age are usually aware of the child's HIV status. The caregivers may choose to delay or postpone the disclosure process out of fear of stigma and being identified as a source of HIV infection and therefore feeling guilty, being blamed, or rejected.²⁹⁻³¹ In contrast, for horizontally infected adolescents, they require counseling on disclosing their status at home and to their peers, given that strong social support facilitates retention in care and adherence to treatment.³² There are a myriad of factors that can influence the decision of an adolescent to disclose to another person, be it their caregiver, a peer, or a teacher. Contextual differences, especially stigma, can profoundly impact an adolescent's decision to disclose.

Definitions and Types of Disclosure

In this tool, we use WHO definitions of adolescents as individuals from age 10- to 19-years-old.³³ This age range falls within WHO's definition of young people, which refers to individuals between the ages 10 and 24.³⁴ Children are defined as under age 10.

HCWs include both facility-based health care providers—such as doctors, psychologists, nurses—as well as social workers, community health workers (CHWs), and lay health workers.

Definition of disclosure: Disclosure of HIV status is not a one-time event, but rather a process, involving ongoing discussions about the disease as the child or adolescent matures cognitively, socially, emotionally, and sexually.

- **Full disclosure:** providing full information and knowledge about HIV.
- **Complete non-disclosure:** maintaining complete secrecy around diagnoses; not telling the truth or not providing any information about the diagnosis.
- **Accidental disclosure:** telling the child or adolescent about an HIV status without preparing them and disclosing to them by accident. It is usually done unintentionally when HIV diagnosis is being discussed among adults and a child or adolescent overhears. Accidental disclosure requires the HCW to act on at least partial disclosure of an HIV status to the child or adolescent. A readiness assessment and discussions with the parents or caregiver should be undertaken as soon as feasibly possible.
- **Deception:** ascribing the child's or adolescent's condition to a different illness or linking the child's or adolescent's behavior and appearance (e.g., for not eating enough); frequently coupled with non-disclosure.

The primary factors for deciding to disclose to a child or adolescent living with HIV are:

- Child’s age and cognitive development. In general, children under age nine and those living with HIV are less likely to know their status. This is guided by national guidance and policies, which recommend or instruct on full disclosure approaches and eligibility. Such guidance documents are listed in Table 1 below.
- The need for the child or adolescent to protect themselves and stay healthy.
- Child’s or adolescent’s adherence to their treatment regimen and ability to take responsibility for their care.
- Upcoming onset of sexual activity and the need for sexual and reproductive health (SRH) education. The various terminologies for disclosure include:

Table 1. Ages of Disclosure of HIV Status in Selected African Countries

Country	Reference	Age of Partial Disclosure	Age of Full Disclosure
Cameroon	National Guideline on the Prevention and Management of HIV 2015	7-11 years	12-13 years
Lesotho	2016 Test & Treat Guidelines	5-9 years	10 years
Malawi	National Guidelines for Clinical Management of HIV in Children and Adults 2016	5-7 years	11-13 years
Rwanda	National Guidelines for Prevention and Management of HIV and Sexually Transmitted Infections 2016	8-10 years	11-14 years
Tanzania	HIV Services for Adolescents 2018	4-6 years	8-10 years
Uganda	Uganda HIV Testing Services Policy and Implementation Guidelines 2016	None	12 years
Zambia	Zambia National Guidelines for HIV Counseling and Testing of Children	5-7 years	7+ years

HCWs should build up trust and establish rapport with children and adolescents and their caregivers from the start of providing services. It is important for a HCW to discuss the following points with the caregivers, which are described further in Modules A and B:

- Ask what the child or adolescent has been told about their health and medications.
- Highlight the benefits of disclosure.
- Inquire about potential barriers to disclosure.
- Offer support and **agree on a plan** to disclose the HIV status.
- Prepare the caregiver for handling questions from the child or adolescent.
- For horizontally infected adolescents and youth, discuss the need for a support network at home and evaluate the potential family members/partners for disclosure. This is discussed further in Modules C and D.

To initiate partial disclosure, a child or adolescent living with HIV needs to understand why he or she attends the clinic and takes medications. HCWs and caregivers can start by explaining that:

- Antiretroviral (ARV) medications help put germs to sleep.
- ARVs keep them healthy and strong.
- Medicines (including ARVs and cotrimoxazole) help to stop or prevent any new sicknesses.
- ARVs are not all the same and can change as you grow up.
- To use medicines well, blood tests every few months need to be drawn to check on the number of the body's "good cells."*

Benefits of Disclosure

What are the direct impacts of disclosure on children and adolescents?

According to the published data, positive impacts of disclosure from childhood through to adolescence include:

- Improved adherence among children, who are significantly less likely to experience disease progression and death.³⁵
- Significantly fewer missed ART doses compared with undisclosed children and adolescents.³⁶
- Experience with disclosure as a positive event among adolescents, reports of less frustration with taking medication, and disclosure seen as a motivating factor.³⁷
- Positive long-term psychological impacts and allowed for better self-care and treatment among adolescents.³⁸
- Significantly fewer emotional difficulties compared to undisclosed adolescents.³⁹
- Acceptance of diagnosis among majority of adolescents; children and adolescents also report relief after disclosure and felt disclosure was important.⁴⁰

What are the remote positive impacts after the disclosure of an HIV status to a child or an adolescent?

- Enables the child or adolescent to discuss and set their life and HIV treatment goals.
- May increase a child's or adolescent's willingness to adhere to treatment regimen.
- Helps children and adolescents to better participate in and understand their health.
- Avoids an accidental disclosure from occurring.
- May decrease behavioral problems by decreasing stress from an unknown source.
- May improve social functioning and school performance by decreasing stress from an unknown source.

What are the proven benefits of disclosure?

For children and adolescents:

- Feeling more in control of their health and body.
- Open involvement in medical care decisions.
- Allows for access to health education, SRH education, social support, and participation in adolescent peer support groups.
- Improves psychosocial well-being and mental health.
- Better school focus and performance

* AIDSFree. *How to Keep Healthy Booklet*. 2014. <https://aidsfree.usaid.gov/resources/booklet-1-how-keep-healthy>

For the parents and caregivers:

- Relief, no need to maintain secrecy, and reconciliation or acceptance.
- Ability to talk openly about the condition with the child or adolescent and others, and to provide support to the child.
- Better able to get treatment support for the child or adolescent at school and during changes in care (e.g., during holidays and with relatives).
- Potentially less behavioral problems with the child or adolescent.

For the HCW:

- Capacity to talk openly about HIV and treatment with the child or adolescent.
- Provision of SRH education, with emphasis on prevention of HIV transmission, including offering pre-exposure prophylaxis (PrEP) to partners of sexually active adolescents living with HIV (ALHIV).
- Capacity to provide more effective PSS referrals.

How does disclosure promote an adjustment to living with HIV?

- Provides developmentally appropriate and truthful explanations of the disease.
- Validates the child's or adolescents concerns for the unknown or fears for worse diagnosis (such as cancer and imminent death).
- Clarifies misconceptions about HIV and prepares the child or adolescent to deal with stigma.
- Provides ongoing support and openness to plan for life with HIV in a productive way.

Of note: After disclosure, even with good preparation, there still remains a possible, temporary surge in behavioral problems. While counseling and supporting disclosure, it is important for HCWs and caregivers not to raise expectations that all direct post-disclosure outcomes are easy, positive, and good. The caregivers and HCWs must be ready for a range of reactions and support children and adolescents in the period after disclosure. To effectively support the child or adolescent and caregiver during and after disclosure period, it is important for HCWs to coordinate with potential support systems for the child or adolescent outside of the health care and home settings, and involve school personnel or other community-based support, when feasible.

Challenges and Barriers to Disclosure

Remember that any disclosure of an HIV status may lead to stigmatization, discrimination, rejection of, and violence against individuals living with HIV of all ages, as well as their families and partners. HCWs can help minimize these negative effect by supporting the disclosure process.

The potential side effects or negative effects of disclosure include.⁴¹

- Emotional difficulties, such as sadness, anger, and rebellion.
- Blaming parents for infecting them (for vertically infected children and adolescents).
- Distress, fear, worry, and perceived or directly experienced stigma.
- Internalized stigma.
- Withdrawal from peers and friends.
- Perceived shortened future and fear of death.

- For adolescents with horizontally acquired HIV, fear of revealing their sexuality and being judged or rejected by their family, partners, or community.

It is important for the child or adolescent to accept family and social support to address these challenges and reinforce that HIV is one of many chronic health conditions that can be managed with medication and care.

What are the barriers to disclosure?

Health Facility Barriers

- Many ART cards or files do not require documentation of disclosure, therefore missing this important factor in a patient's physical and mental health.
- HCWs may feel uncomfortable about handling disclosure.
- Lack of standardized systems or approaches to disclosure.
- Lack of tools or clear guidance available for disclosure.
- Need for individualized approaches in addressing disclosure.
- Constraints for time, space, and confidentiality within health care settings.
- Lack of training on disclosure.
- Limited support (e.g., psychologist and social worker referrals who are available for engagement and follow up).

Community Barriers

Communities can play a critical role in expanding access to HIV care and treatment, but barriers to the disclosure at the community level persist, such as parental feelings of guilt, if vertical infection, and more. Examples of community level barriers include:

- Discomfort among caregivers or family around disclosing an HIV status to their child or adolescent.
- Desire to preserve innocence of childhood, or belief that the child or adolescent is not ready or is too young.
- Concern for child's or adolescent's emotional or physical health following disclosure.
- Fear of adverse consequences (e.g., psychological damage, poor self-esteem, etc.).
- Concern for being rejected, especially among HIV-positive parents.
- Belief that the child or adolescent may not be able to keep this information private and the child or adolescent and their family may be stigmatized.
- Need to protect the child or adolescent and their family from stigma and rejection.

Section I: The Process of Disclosure

General Principles of Disclosing HIV Status

- Both the health care team and caregivers should be involved throughout the process.
- The disclosure process should not be rushed, but instead needs to be flexible and remain sensitive to the family's feelings and needs as they evolve through the phases of disclosure.
- HCWs should support caregivers' decisions on whether to disclose an HIV diagnosis, and they should respect the family's timing and expectations.
- Use of clear and developmentally appropriate explanations of the disease and diagnosis is mandatory.
- Date of disclosure should not coincide with other important life events such as birthdays, holidays, graduation, etc.
- Disclosure should promote the sharing of feelings, but also should accept silence.
- HCWs should encourage the child or adolescent to ask questions during the disclosure process.
- When available, HCWs should use developmentally appropriate educational materials. Examples of such materials are included in Appendix C.

Special Issues in Disclosure of HIV status in Adolescents

HIV-positive adolescents generally fall under one of two distinct groups: those who acquired HIV in infancy and are highly ART-experienced, and those who acquired HIV horizontally, during their teenage years. Adolescence is a developmental period characterized by considerable social, biological, and physical change, during which young people gradually assume more autonomy and take on adult roles and behaviors.⁴² Adolescents with normal developmental milestones should be fully informed about their HIV status to address their health needs, and provided with anticipatory and preventive care to address aspects of their health, including SRH. HCWs should also encourage adolescents to involve their parents or caregivers in their care and support, where feasible.

Adolescents should be fully informed of their HIV status in a reasonable time frame and according to national guidelines (see Table 1). Caregivers who object to disclosing an adolescent's HIV diagnosis should receive intensive support and services from the clinical team to address their concerns. The HCW should assess what the adolescent already knows about their health or illness to guide future discussions and provide opportunities for the adolescent to discuss health care and SRH issues with their clinical team, in full confidentiality and independent of caregiver. This process is described further in Modules A and B.

When adapted for disclosure, the five Cs of adolescent HIV services⁴³ include:

- **Parental or caregiver CONSENT** to disclose HIV status to their child or adolescent until they reach the legal age of maturity or national threshold for independent disclosure. A horizontally infected adolescent can give consent to disclose their HIV status to their family members, partners, and any other parties, when relevant.
- **CONFIDENTIALITY in adolescent services.** What the provider and the individual discuss will not be disclosed to anyone else without the expressed consent of the adolescent.

- **Appropriate and high-quality COUNSELING** before any HIV services, ensured through quality assurance mechanisms and supportive supervision systems.
- Programs for adolescents should provide high quality testing services, and quality assurance mechanisms should be in place to ensure the provision of **CORRECT test results**.
- **Linkage to appropriate CARE** and follow-up services, as needed, including long-term treatment support and prevention services for HIV-negative sexual partners.

In addition, HCWs can support adolescents by identifying a supportive person from the clinical team, CHWs, or lay counselors with whom the adolescent can safely and comfortably discuss HIV-related issues. All adolescents should know of their HIV status because it:

- Is their right to know their diagnosis.
- Provides them with an opportunity to assume responsibility for their own healthcare and well-being.
- May increase adherence.⁴⁴⁻⁴⁹
- May prevent sexually active adolescents from unknowingly exposing their partners to HIV.
- Provides an opportunity for better counselling on SRH and risk reduction behaviors.
- Builds a trusting therapeutic relationship between clinicians and their adolescent patients.
- Helps adolescents develop self-management skills, and prepares them for transition of care between clinics and/or to adult health care facilities.

Stages of Disclosure

The stages of disclosure include:

- **Pre-disclosure:** The child has not yet been told about their HIV status.
- **Partial disclosure:** Telling the child the truth, but not the whole truth; usually withholding the name of HIV (can be a step in the full disclosure process).
- **Full disclosure:** This stage provides the child or adolescent with the name of the diagnosis and full information and knowledge about HIV.
- **Post-disclosure:** Period following disclosure, commonly described as early post-disclosure (first three to six months) and late post-disclosure (over six months) periods.
- **Complete non-disclosure:** Maintaining complete secrecy around diagnoses and the child or adolescent are not told the truth about their illness.
- **Deception:** Ascribes the child or adolescent's health condition to a different illness or links to their behavior for how they may appear. This is frequently coupled with non-disclosure.

Planning and Preparing for Disclosure

There are limitations and different methods to use when disclosing the status to a child or adolescent, depending on their age. They include:

- **Children <5 years:** These children are too young to understand that they have a chronic illness. They know they are unwell since they have to take medication regularly. They also require a caregiver to help them take medication, attend clinics, and take care of their health. They may dislike the hospital visits, but be unable to express their true

inner feelings freely. They may react by crying or just being uncooperative. They do not talk much about the future. They will not be able to keep a secret.

- **Children and adolescents 5-12 years:** These children and very young adolescents may realize that they are sick and feel that getting ill might be something bad. They ask more questions and want answers. They usually are tired of illness and going to the doctor. They may fault themselves for being ill and becoming a burden on others. They may not be able to keep a secret when younger, but those older than age 10 can usually be told about keeping things private.
- **Adolescents >12 years:** These adolescents have ways of getting answers to their questions. They can keep secrets and are more likely to keep an HIV diagnosis confidential. They usually understand the cause for the illness and frequent clinic visits, but may reject the idea of taking medication for life. They may have signs of self-stigma and are aware of how they look. They may be receptive to proper guidance and can become peer supporters, with proper direction and a supportive environment. They think about the future and want to have relationships with their peers. They understand death and may have experienced and remember the death of a family member.

When Should the Disclosure Process Begin?

- Discussions between the clinical team and caregivers should begin early in the patient's childhood, from the age of six with age appropriate information, and with the aim of full disclosure by age 12- to 14-years-old.
- For an adolescent who is not yet disclosed to, supported disclosure processes can speed up the process over a few months when working with caregivers or parents for their developmental stage. Under EGPAF-Zambia's Mbuya Daisy program, for example, parents attend three to five sessions on disclosure before fully disclosing an HIV status to their adolescent.⁵⁰
- Initiation of the disclosure process depends on:
 - Caregiver's acknowledgment and acceptance of the child's or adolescent's disease and caregiver's readiness to disclose to the child or adolescent.
 - Child's cognitive skills and emotional maturity (including ability to maintain confidentiality; usually done informally through discussion between HCWs and caregivers).[†]
- Among children and adolescents with mild to moderate development delays, it is important to use language the child or adolescent will understand. In addition, there should be suitable adherence support available for the needs of a developmentally impaired child or adolescent living with HIV. At times, the situation may call for a delay or withholding of disclosure, based on the extent of the developmental delay and cognitive function.^{51,52} These children or adolescents should be assessed periodically, in case their circumstances change.

The health care team should develop an individual plan for disclosure for each child or adolescent. This plan must include:

- Assessing the readiness and willingness of caregivers to disclose HIV diagnosis to the child or adolescent.

* An example of this kind of tool is the Malawi Developmental Assessment Tool, which is available here: <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000273>

- Discussing caregivers' concerns about disclosure.
- Working with caregivers to develop a disclosure plan that meets the individualized needs of the family and child or adolescent. Potential scenarios include: initiating disclosure at home and continuing at the health facility or conducting full disclosure at home and following up with HCWs, or carrying whole disclosure process at the health facility.
- Ensuring ongoing regular communications with the child or adolescent and their caregiver after disclosure.
- The disclosure process should not be rushed, but the timing of disclosure becomes more urgent as child nears adolescence and for adolescents in need of support services for their care and treatment.

Readiness Assessment

Prior to initiating the disclosure process, a readiness assessment should be undertaken that should gauge the readiness of the child or adolescent's readiness to be disclosed to as well as the caregiver's readiness to disclose to their child. Each module in this toolkit includes a readiness assessment. The HCW should assess the following with the child and adolescent prior to starting disclosure:

- Level of functioning at school.
- Family and peer relationships and support.
- Interests and activities at school and within the community.
- Moods and behavior patterns on daily bases (e.g., symptoms of mood swings, depression).

To proceed with the disclosure, the HCW needs to complete at least 2/3 of the steps in the readiness assessment checklist and have a majority of boxes checked. If a majority are not checked, the assessment for disclosure readiness should be repeated at another visit. If the assessment is repeated within six months, the HCW can use the points from the first assessment. If the HCW performs a repeated assessment six months or later, they should start a new assessment. If the HCW finds that the child or adolescent is not ready for disclosure, they should defer to another time and counsel the caregiver accordingly.

Developing a Disclosure Plan for a Child or Adolescent

The disclosure plan should be developed by the HCW together with their parents or caregiver. The objective of this plan is to outline the various steps that the team will go through during the disclosure. It states certain factors that must be considered for each child during the disclosure process.

The Process of Disclosure

The process of disclosure may take several visits with the disclosure counseling, and hence will not necessarily always be done on one visit. The intervention can involve the following steps:

- The HCW should ensure that private counseling room is available and that the environment is relatively peaceful.
- The HCW should block off a designated, uninterrupted amount of time (minimum 30 minutes).
- The HCW should make sure that the child is available all day so that the conversation

will not be cut short and that the family of the child being disclosed to is available for the rest of the day.

- The HCW should check in with the child or adolescent the next day.
- HCWs should support caregivers' decisions on whether to disclose an HIV diagnosis and to respect the family's timing. They should not rush the disclosure process, but instead stay alert and sensitive to the family's feelings and needs as they evolve through the phases of disclosure.
- HCWs should respect caregivers' reasons to fear and resist the disclosure process.
- Families should receive a detailed explanation of the disclosure model before full disclosure is carried out. The disclosure model may be in three forms including: started by family and continued by the HCW, carried out fully by family, or carried out fully by the HCW.
- During educational sessions, HCWs prepare family members to answer difficult questions that children are likely to ask following disclosure (e.g., "Who infected me?").
- When requested and agreed upon, the team of HCWs may also assist caregivers in revealing other family secrets, such as adoption.
- Staff members must consider the clinical stage of HIV and the child's or adolescent's other medical conditions, as fear, pain, and fatigue may further compromise the child's or adolescent's and their family's emotional state and energy levels during the disclosure process. Disclosure should be postponed during a time of acute illness or ongoing significant social changes (such as moving, divorce, changing schools).
- The HCW should emphasize confidentiality and engage the patient in a "partnership" based on confidence, privacy, and trust.
- Throughout preparatory sessions, the HCW should ensure that the child or adolescent remains engaged and actively learns about their medical condition.
- When the child or adolescent is ready to know more about his or her medical condition, they should be able to participate in the selection of which family and staff members they want present during the disclosure session.
- The HCW should express they are joining the child or adolescent and family members on their journey through the disclosure process (i.e., looking into their eyes, holding hands, and hugging, if the family and HCW are comfortable).
- Caregivers who have successfully disclosed to their child and agree to provide advice to others can serve as peer supporters/mentors to other caregivers.

Post-Disclosure Assessment and Support

The objective of post-disclosure evaluation and follow-up is to identify the feelings, perception, and degree of coping with the diagnosis and to prevent any complications after disclosure. It should be performed at the closest patient/caregiver encounter after disclosure and repeated regularly (at least yearly to ensure ongoing understanding and knowledge about HIV as the child grows and matures).

- After the HIV diagnosis has been disclosed, the HCW should make follow-up calls and/or visits to assess the child or adolescent understanding of the illness and emotional and psychological adjustment. They should reassess family's emotional and psychological adjustment.

- At every visit after disclosure, the HCW should assess the child's or adolescent's emotional well-being and functioning in the following areas:
 - School functioning.
 - Family and peer relationships and support.
 - Interests and activities.
 - Mood and behavior.
- The HCW should work closely with caregivers to monitor for changes in functioning that may signify poor adjustment.

Additional support may be needed for children who demonstrate significant post-disclosure changes in behavior. Patients and families who have a difficult adjustment to HIV disclosure without progress over time should be referred for mental health services and additional support (e.g., peer support, CHWs).

The post-disclosure support includes working with peers and being enrolled in an adolescent peer support group, if they are not yet part of one. As the child or adolescent grows and develops, their knowledge about HIV, life, sexuality, and SRH changes. It is very important to regularly reassess the child's understanding of the HIV diagnosis, laboratory results, HIV treatment, and related SRH issues and provide ongoing education and support.

Section II: Tools to Support Disclosure

The steps outlined in this guidance can each be done at different sittings, based on the availability of the caregiver. **Partial** and **full disclosures** can be done once the child is ready and has good family and social support systems in place.

Main Messages for Partial Disclosure:

- Explain the principles of the immune system working to protect an organism from infections.
- Identify the symptoms (current and past), if any can be linked to the disease.
- Explain the ability to living with a chronic disease and not feel sick.
- Explain the importance of taking treatments and their positive effect on microbes and viruses.
- Explain recovery from being sick or preventing becoming sick, as related to taking medicines.
- Identify the medicines that are being or to be taken (e.g., by shapes and sizes).
- Explain the need for regular checkups and living a healthy lifestyle.
- Explain the importance of sharing health information with the caregiver and provider.

Main Messages for Full Disclosure (in addition to the partial disclosure messages):

- Name HIV and explain modes of transmission.
- Discuss vertical transmission, respectfully addressing mother's role, and protecting the mother's status within the family and community.
- Distinguish between contradictory and poorly informed messages from different sources.
- Address stigma and confidentiality.
- Counsel on empowerment for living positively.

Module A: Guide for HCW on Disclosing Diagnosis of Vertically-Acquired HIV

Suggested Materials:

- At least one age-appropriate, child-friendly item available (such as drawing and coloring items, fun books, toys, Legos, soft balls, masks, etc.).
- Minimum of three seats (for the child or adolescent, caregiver, and HCW).
- Paper and pencils to use with visual aids, such as drawings.
- HIV educational cartoon book[†]
- Available printed or media disclosure materials.[§]

A1: Tool for Partial and Full Disclosures to a Child Aged 5-10 Years**

Disclosure for children aged 5-10 years should ideally be done in the presence of the main caregiver. HCWs must review the child’s file to ascertain whether there are major cognitive and developmental delays and whether the child is developmentally at least five to six years of age. They should assess the child’s clinical status to confirm that the child does not have active AIDS, non-controlled pain, or other concomitant severe illness that is accompanied by the significant physical and neurocognitive disability.

Readiness Assessment

The objective of the **readiness assessment** is to decipher how much the child knows about his or her condition, also how much the caregiver knows, and how much the caregiver has told the child. The readiness assessment needs to be conducted in two parts: 1) confidential discussion with the caregiver without the child and 2) discussion with the child in the presence of the caregiver. The caregiver might have told the child some partial or invented information, to hide the truth. For the readiness assessment, **complete these steps:**

Readiness Assessment Criteria: Partial and Full Disclosures to a Child Aged 5-10 Years	Check Mark
Assessment with the Caregiver	
Confirm with the caregiver that he or she agrees to initiate disclosure.	
Determine the caregiver’s knowledge about HIV and discuss the benefits and risks of disclosure.	
Assess what the caregiver has discussed, if anything, with the child regarding his or her HIV status or medications to date.	
Ascertain whether there other people living with HIV in the child’s household.	
Evaluate the child’s daily functioning in school.	
Identify whether significant events took place in the past six months such as a recent family death, divorce, separation, loss of friend, or distant relocation.	
Assess available family and/or community support for the caregiver and the child.	
If the mother is the caregiver, discuss any of her feelings of guilt and help her to address them.	

[†] K4health. Lukia’s Story. https://www.k4health.org/sites/default/files/HCP%20Paed%20ART-%20Lukia%20Story%20FINALAPPROVED_0.pdf ; Children and AIDS. Why I Take my Medicines. https://www.childrenandaids.org/sites/default/files/2018-05/Why%20I%20take%20my%20medicine_Namibia%20%282015%29.pdf

[§] Kimesh Naido. Step by Step Guide for Conversations with Children. http://www.kznhealth.gov.za/arv/Disclosure_Poster.pdf

**These are suggested age ranges only and need to be reassessed within each individual context.

Assessment with the Child and Caregiver	
Assess the information the child has about the medicines he or she has been taking.	
Determine the information child has about his or her health and HIV status.	
Assess whether the child has difficulties in building and maintaining friendships with peers at school and/or at home with siblings.	
Evaluate the child's daily mood at home and at school.	

Disclosure Encounter (30-60 minutes)

The objective of this step is for the HCW to disclose in the presence of the caregiver. For the disclosure encounter, **follow these steps:**

- The HCW should start by assuring to the child and caregiver that they are available to answer any questions at any time. Let them know they can interrupt to ask questions.
- Emphasize that there are no wrong questions to ask.

For **partial disclosure:**

- Explain to the child that there are viruses (can be referred to as bugs, disease particles, etc.) in the blood that can weaken the immune system, and explain that the medicines they are taking help to control the viruses and help him or her stay healthy.
- Use simple drawings when possible (no artistic skills required) to explain the concept of immune cells being attacked by the virus and medications stopping them.
- If **partial disclosure** is being done, skip the full disclosure steps and focus on adherence to medications and care and messaging on staying healthy.

For **full disclosure:**

- Build on the available knowledge about chronic illness and proceed with full disclosure, naming HIV and explaining how it damages the immune system and how it can be treated.
- Discuss modes of transmission and, more specifically, vertical transmission. Place an emphasis on protecting the mother's status within the family and the community, and explain that the transmission was not anyone's fault.

Following **full disclosure:**

- Provide concrete examples of living positively with HIV, openly discuss the stigma and its causes (ignorance, prejudice and fear), and provide empowering messages.
- Discuss issues of protecting the confidentiality of personal information and HIV status within the family and the community. Affirm your personal respect for the child and his or her caregiver.

Throughout and after disclosure:

- Pause periodically, and ask the child what he or she is feeling at the moment, without rushing answers; accept silence.
- Observe the caregiver's emotional response and provide support and reassurance.

After Disclosure:

- Take a pause to observe the child’s immediate reaction and be ready to support an emotional response with words of reassurance.
- Provide encouragement and reassurance and encourage the caregiver to be supportive of the child at home.
- Advise the child and caregiver to talk more at home and write up any questions that arise so they can discuss them at their next visit.
- Remind the child and caregiver of the benefits of disclosure, as discussed earlier in the toolkit.
- Provide enhanced adherence counseling reinforcing messages about the benefits of taking medications, seeing a medical provider regularly, and living healthy lifestyle.
- End the session by providing any available printed information to take home and showing respect to the child and the caregiver in a culturally appropriate way.

Post-Disclosure Evaluation and Follow-Up – 15-30 minutes

Post-disclosure evaluation should be conducted in two parts: one confidential session with the caregiver and without the child (while he or she waits outside of the room or is receiving other services) and one session directly with the child in presence of caregiver.

The aim of the post-disclosure evaluation and follow-up is to determine the effect of the disclosure done during the previous encounter and to address any unmet needs. The HCW will determine if the child or adolescent and/or their caregiver needs referral for any additional support. Throughout all of the steps below, the HCW should try to elicit responses, but also accept silence.

For post-disclosure assessment, **follow these steps:**

- Answer any questions in open and honest way, when possible.
- Ask the caregiver:
 - How they are coping with disclosure, while being receptive to their feelings.
 - How they are coping within the family and with providing support.
 - If the child or adolescent has had any changes interacting within the family and with their friends.
 - If they have any questions since the last encounter.
- Ask the child or adolescent:
 - How things are going and how they are doing in school.
 - If they disclosed their diagnosis to anyone else at home (place special emphasis on siblings) or at school. If the answer is yes, ask the child or adolescent how did the people react, and provide explanations and support.
 - If they have come up with any questions since last encounter.
 - How they have been feeling about themselves and their disease.
 - About their sleep pattern. Find out about the child’s mood at home and elsewhere.
- If necessary, repeat parts of disclosure and motivate the child to contribute their perspectives.

- Following **full disclosure**:
 - Reinforce concrete examples of positive living with HIV, discuss the stigma, and provide messages on empowerment.
 - Reinforce issues of protecting the confidentiality of personal information and HIV status within the family and the community.
- If the child requires any referral, such as psychosocial counseling and peer support, provide referrals with clear instructions.
- Provide enhanced adherence counseling, reinforcing messaging about the benefits of taking medications, seeing medical providers regularly, and living a healthy lifestyle.
- End the session by providing any available printed information to take home and showing respect to the child and the caregiver in a culturally appropriate way.

A2: Tool for Full Disclosure to the Adolescent (10-14 years or Older If Not Disclosed)**

Vertically infected adolescents with delayed diagnosis and initiation of ART may have stunted growth and cognitive and developmental delays, and therefore may require disclosure following the algorithm for children under age 10. Adolescents without significant development delays should have full disclosure by the age of 13- to 14-years-old.

Readiness Assessment: 15 – 30 minutes

*Readiness assessment needs to be conducted in two parts: one confidential session with the caregiver without the adolescent, and one confidential session with the adolescent without caregiver. Caregivers who object to disclosing an HIV diagnosis to the adolescent should receive intensive support and counseling to address their concerns. **SRH information shared by the adolescent needs to remain confidential with the counselor and can be shared with the caregiver only with the approval of the adolescent.***

In this section, the HCW will perform both the disclosure eligibility assessment and adolescent readiness assessment. The objective of the readiness assessment is to decipher how much the adolescent knows about their condition. The assessment will also determine the adolescent's cognitive ability, developmental stage, clinical status, and social circumstances. To conduct the readiness assessment, **follow these steps**:

**Age ranges are suggestions only and need to be reassessed within individual context.

Readiness Assessment Criteria: Partial and Full Disclosures to the Adolescent (10-14 years or Older)	Check Mark
Assessment with the Adolescent	
Review the medical file to confirm the adolescent’s age and assess whether there have been developmental delays.	
Assess what the adolescent already knows about his or her health and HIV status, and find out what information the adolescent has about the medicines he or she has been taking and about the illness.	
Find out about the adolescent’s relationship with their peers in school and/or at home or in the community. Find out about their mood and daily behaviors.	
Assess the sexual activity of the adolescent (i.e., sexually active, not in a sexual relationship, or ever had sex).	
Assessment with the Caregiver	
Review the caregiver’s knowledge about HIV and discuss the benefits and risks of disclosure.	
Confirm that the adolescent is psychologically stable (e.g., no recent family member’s death, divorce, or separation; loss of a friend; or distant relocation). Ask about the adolescent’s performance at school.	
Assess whether there are other siblings at home and their HIV status.	
Assessment with the Adolescent and Caregiver	
Independently confirm with the adolescent and caregiver that they are ready for disclosure.	
Assess from the caregiver and adolescent the available family, community, and peer support.	

If the HCW determines that this is not an appropriate time for the disclosure, defer to another time and counsel the caregiver and adolescent accordingly. If the HCW determines that disclosure can be initiated, they should ensure that there is an uninterrupted block of time in a private room.

Disclosure Encounter: 30-60 minutes

The adolescent must make the choice of whether to have the caregiver present or not during disclosure. Even when the choice has been made to have caregiver present, ask for private time to discuss issues related to sexuality and SRH directly with an adolescent, when appropriate. This is especially important for older adolescents.

The objective of this section is for the health worker to disclose the HIV status to the adolescent. For a disclosure encounter, **follow these steps:**

- Start by assuring the adolescent and caregiver that you are available to answer any questions at any time. Let them know they can interrupt to ask questions. Emphasize that there are no wrong questions to ask.
- Explain to the adolescent that there are viruses (can be referred to as bugs, disease particles, etc.) in their blood that can weaken their immune system. Explain the concepts of “good cells” (CD4 cells) and viruses (viral load).
- Proceed with full disclosure by naming HIV and explaining how it damages the immune system and how it can be treated.

- Use simple drawings, when possible (no artistic skills required), to explain the concept of immune cells being attacked by the virus and medications stopping them.
- Discuss modes of transmission and, more specifically, vertical transmission. Place emphasis on protecting the mother's status within the family and the community.
- Provide concrete examples of positive living with HIV, openly discuss stigma and its causes (ignorance, prejudice, and fear), and provide empowerment.
- Discuss issues of protecting the confidentiality of personal information and HIV status within the family and the community. Affirm your personal respect for the adolescent and their caregiver.

Throughout and after disclosure:

- Pause periodically and ask the adolescent what she or he is feeling at the moment without rushing them with answers. Accept silence.
- Observe the caregiver's emotional response and provide support and reassurance.
- Use simple, non-clinical language throughout the disclosure process with the adolescent and their caregiver (if present).
- Be empathetic; treat the adolescent as a person rather than patient. Listen to their concerns without judgement.
- Use positive, motivating language focusing on how their status does not define who they are and does not limit their ability to fulfill their life goals and dreams.

Advice About Accepting One's Status from ALHIV on EGPAF's Committee of African Youth Advisors (CAYA)



"HIV is just a virus that lives in the blood; it doesn't define who I am. I can accomplish all my goals and dreams that I want to achieve in life."

"What's important is accepting your status and realizing that what matters is your life. What people will say will never change your status — focus on making yourself who you dream to be."



"Bear in mind that having people knowing about your HIV status doesn't mean that your dreams are shattered, but instead you should use the situation as an opportunity to shine and reach your utmost potential."



After disclosure:

- Take a pause to observe the immediate reaction of the adolescent and be ready to support an emotional response with words of reassurance. Accept silence.
- Provide encouragement and reassure the caregiver about supporting the adolescent at home.
- Advise the adolescent to write up any questions that arise so they can discuss them at the next visit.
- Among older adolescents, discuss prevention of HIV transmission to a sexual partner and sexuality. Provide examples of positive parenthood, partnerships, and marriage.
- Provide enhanced adherence counseling, reinforcing messages about the benefits of taking medications, seeing a medical provider regularly, and living a healthy lifestyle.
- End the session by providing any available printed support information to take home, and showing respect to the adolescent and the caregiver in a culturally appropriate way.

Post-Disclosure Evaluation and Follow-Up – 15-30 minutes

Throughout all of the steps below, try to elicit responses, but also accept silence. Answer any questions in open and honest way when possible. For the post-disclosure assessment, **follow these steps:**

- Ask the adolescent how they are feeling since disclosure and how they are coping within their family and at home. Inquire about if they have had any changes interacting with their families and friends. Be receptive to his/her feelings.
- Ask the adolescent and their caregiver about any questions that have come up since the last encounter.
- Inquire with the adolescent about how the things are going at school.
- Ask the adolescent if they disclosed their diagnosis to anyone else at home (place special emphasis on siblings) or at school. If yes, ask them how these people reacted, and provide explanations and support.
- Find out about the adolescent's mood at home and elsewhere. Ask about sleep patterns.
- If necessary, repeat parts of the disclosure process initiated at the previous encounter. Motivate the adolescent to contribute his/her perspectives.
- Reinforce concrete examples of positive living with HIV, discuss stigma, and provide empowerment. Reinforce issues of protecting the confidentiality of personal information and HIV status within the family and the community.
- Among older adolescents, discuss again prevention of HIV transmission to sexual partner and sexuality. Provide examples of positive parenthood, partnerships, and marriage.
- If the adolescent requires any referrals, such as psychosocial counseling, and is interested in peer support, make the appropriate referrals. Provide enhanced adherence counseling to reinforce messages about the benefits of taking medications, seeing a medical provider regularly and living a healthy lifestyle.
- End the session by providing any available printed support materials to take home and showing respect to the child and the caregiver in a culturally appropriate way.

Module B: Guide for Preparing and Supporting Caregiver in Disclosing Diagnosis of Vertically Acquired HIV

Stakeholder Engagement

With increasing survival of CLHIV, parents face the challenges of disclosure to their child or adolescent. While most caregivers want to be involved in the process, many of them wish to have the support of the HCW. Caregivers mainly perceive disclosure as a single event rather than a process of gradual delivery of information about the child's illness, and this should be addressed in the process of disclosure support.⁵³ Caregivers can often feel overwhelmed with fear of negative outcomes of disclosure and may lack the ability to manage the full disclosure process. They need to be empowered with practical skills to recognize opportunities to initiate the disclosure process early, as well as supported to manage it in a phased, developmentally appropriate manner.

Reasons given by caregivers for non-disclosure:

- Inability of the child or adolescent to understand.
- Fear of disclosure to other children or disclosure to family members or friends.
- Fear of psychological disturbance of the child or adolescent.
- Fear of the child or adolescent blaming their parents.

Principles for Caregiver Disclosure to Patient

- The caregiver should to be asked if they have had a prior discussion with their child about their condition.
- Determine the caregiver's perception of their child's ability to understand the HIV diagnosis and keep it private.
- The caregiver must accept the disclosure process before it can continue.

Caregivers should be counseled on the benefits of disclosure so that they can foster social support from the family and address negative effects and related emotional difficulties that may follow disclosure. The benefits of disclosure can be found in Section I.

If the HCW finds that there is caregiver reluctance to disclose, some approaches include:

- Respecting the caregivers' reasons for fearing or resisting disclosure and attempting to understand the factors associated with their reluctance.
- Working with the caregivers to develop a plan that addresses their concerns and develop the timeline for future disclosure.

Caregivers can be referred for further counseling, if required.

B1. Readiness Assessment

Caregiver counseling can be conducted over one or two visits by HCWs. The readiness assessment counseling for the caregiver should be done separately from the child or adolescent.

Readiness Assessment Criteria: Caregiver Readiness	Check Mark
Assess caregiver readiness before the child or adolescent reaches the appropriate age of disclosure, per national guidance, typically between the ages of 6 and 12.	
Start by welcoming the caregiver to the session and make sure he or she is comfortable with discussing disclosure.	
Encourage the caregiver to start talking to the child or adolescent about their health to enable the caregiver to assess their child's or adolescent's perception of the illness.	
Review with the caregiver what he or she knows about the benefits and advantages of disclosure as well as some disadvantage.	
Assess the child's or adolescent's ability to understand an HIV diagnosis and keep it a secret.	
Explore the caregiver's fears about disclosing to the child. Discuss each fear objectively, while reassuring the caregiver of support from the health facility's team.	
Reassure the caregiver that, if well prepared, children and adolescents are usually able to avoid undue disclosure to others.	
Address key factors that influence disclosure by the caregiver, including the child's age; level of maturity or awareness; questions about health, disease, or HIV; and family situation, school situation, and overall health.	
Address key caregiver factors that influence disclosure by the caregiver, which are detailed below.	
Practice with the caregiver what they will say and how to support any emotional reaction from the child to the information. Attempt to involve the caregiver in role-playing, when feasible (see Appendix D).	
Before completing the session, find out from the caregiver if they think their child is ready for disclosure. Let them explain why they feel they are ready or not.	

Caregiver Factors Influencing Disclosure Include:

- Feeling worried about or unprepared for disclosure.
- Fearing negative effects of disclosure (such as disclosure will cause suffering for the child or adolescent).
- Fearing that child will tell others and face discrimination.
- Belief that knowledge of the status would create emotional stress, sadness, or depression for the child or adolescent.
- Stigma, abandonment, and negative reaction from family and partners.
- Belief that HIV should be kept concealed or private.
- Other caregiver- and family-related factors, such as caregivers believing that they do not know enough about HIV to be able to explain or answer questions that may arise during disclosure.

Strategies to enhance caregiver readiness to disclose HIV diagnosis to the children include:

If the caregiver is concerned that the child is too young or not emotionally ready for disclosure: HCW may advise partial disclosure, including telling the child that their medications help to keep them as healthy as possible and introducing the idea of an immune system as a part of the body that fights infections. Then, as part of disclosure plan, more information is given as the child matures.

If the caregiver is concerned that the child may mistakenly disclose status to other peers with negative effects: HCW may assess the child's cognitive and emotional ability to understand and maintain confidentiality and review the findings of this assessment with their caregiver.

If the caregiver is concerned that the child may react to the news in a negative manner (e.g. blame them, depression, contemplate suicide, abandon the home, stop school, etc.): HCW may reassure the caregiver that the health team will provide support for the family and child during the process of disclosure and after. This support includes PSS from peer and referral for additional PSS, as required.

If the parent is concerned that the child or adolescent will find out he or she transmitted the HIV infection, and will feel more guilt of that fact: HCW may offer continuous counseling to the parent to help alleviate guilt. The health care team should assist the parent to focus on the other benefits of disclosure, such as enhancing adherence to HIV care and empowering the child. Caregivers need to be assured of continuous support after disclosure to address any guilt and help to prepare answers in case the child asks any difficult or embarrassing questions. The HCW can help the caregiver prepare to answer questions that may be asked and may consider referring the caregiver to peer support groups and parental mentorship.

Remember: While supporting a parent to disclose to their child, HCWs needs to prevent the parents' feelings of guilt in by providing the child with a best possible explanation of HIV transmission to protect the privacy and maintain confidentiality of the parent. The provider should not perpetuate feelings of guilt that the parent may have and should support the caregiver in fining the language that helps avoiding the attribution of blame to the parent (in case of mother-to-child transmission of HIV).

If one or both caregivers refuse to disclose: HCW may discuss with the caregiver(s) and invite them to continue an open dialogue, reassessing regularly if the caregivers feel differently, and offer solutions for their concerns about the disclosure to the child. Based on these discussions, the HCW should work jointly with the caregiver(s) to develop and proceed with the plan. If required, the caregivers may be given additional counseling.

If one caregiver agrees to proceed with the disclosure, while another one refuses: In this scenario, the HCW should counsel the couple further and find out the concerns of the parent who wishes not to disclose. They should emphasize the benefits of disclosure and the impact of non-disclosure for the child. Based on the discussions, the HCW may schedule the disclosure for another date, as agreed by both parents. They should consider referral of the couple to an adult counselor to help reconcile their views on HIV and disclosure, when feasible.

Preparation of the Child or Adolescent for Disclosure by Caregiver

When the caregiver is ready to disclose, the HCW must make sure the child or adolescent is also ready for disclosure. This should be done in a manner not to raise suspicion or foreboding doom in the child or adolescent. It requires the HCW to gain the trust of the child and caregiver, so it is often best done by the HCW who has been handling the patient in the clinic. HCWs and the caregiver should then reconvene to determine if the child or adolescent is ready for disclosure, with a focus on reviewing the following topics:

- What the child understands about their own health.
- How they would cope with a stressful situation.
- The child's ability to keep a secret or maintain confidentiality.

After reviewing the above steps, invite the child or adolescent to the meeting to complete the readiness assessment described in Module A2:

- Greet the child or adolescent in a friendly manner and inquire about how they have been since the last time you saw them.
- Include conversation about school, playtime with friends, and chores at home.
- During the chat, ask the child or adolescent what they typically do when they need help. Use this chance to emphasize support structures that exist for the child, as identified by the caregiver.

If the assessment finds the caregiver and the child or adolescent are ready, advise the caregiver on the disclosure steps at home (see some tips above under HCW tool for disclosure) or offer to conduct both disclosure meetings at the health care facility. Help the caregiver establish the best timing (e.g., weekend, school break) and a realistic timeline for the disclosure (e.g., within few weeks or months, without significant delays).

B2. Disclosure Process

Once the caregiver(s) is ready for the disclosure, it may be done within the health care facility or at home. The caregiver should choose what they feel is best. The HCW should offer the caregiver an emergency contact number for any urgent questions or needs.

Inform the caregiver that the four main objectives of the disclosure are to:

1. Disclose the HIV status of the child or adolescent.
2. Provide correct information about HIV and self-care needs.
3. Assess and support the child's or adolescent's emotional reactions; they should feel free to reach out to the HCW team for support.
4. Share with HCW the disclosure progress and follow up on post-disclosure evaluations.

Below is a sample startup conversation tip the caregiver can use.

Hello dear (or use nick name). Let us have a talk together as grownups. There is something I want to share with you. I love you and will always be here to care for you. I want to talk to you about the reason you take medicines daily and why we have to visit the clinic regularly. Do you want to talk?



Points to be covered during the disclosure process by caregiver include the following:

- Assessing child's or adolescent's perceptions, concerns, and attitudes about their disease.
- Informing the child that they have HIV.
- Sharing relevant information on HIV, such as what it does to the body and how to fight it.
- Talking to the child about the difference between HIV and AIDS.
- Instructing the child how they can live with the virus, what they should do, and how to avoid transmitting HIV to others.
- Discussing how to keep their HIV status confidential; who to tell and what to tell.
- As with all adolescents, discussing safe sex, the potential for sexual relationships, and reproductive health (e.g., possibility of happy life, marriage and relationship with negative partner, having healthy children).
- Providing any further relevant information, depending on the age and cognitive ability and interest of the child or adolescent.
- Allowing the child or adolescent time to ask any questions. Reassuring them that they can ask questions in future.
- At the end of the conversation, the caregiver needs to summarize (repeat) the information they have shared with the child or adolescent.

B3. Post-Disclosure Evaluation and Follow-Up

Like adults, children may go through a period of denial, anger, or self-pity following disclosure of their HIV status. Once the HIV status has been disclosed to the child or adolescent, there should be monitoring and follow-up in the short- and long-term, providing support, additional information and evaluating for any adverse outcomes. The follow-up is meant to:

- Assess positive (such as improved self-confidence, self-awareness) any negative outcomes (such as stigma and depression) in both the caregiver and the child or adolescent.
- Review the understanding of the child or adolescent about their HIV status.
- Monitor how well they are coping with the diagnosis and treatment disease
- Identify needs for any further referrals and peer support.

Resource for Caregivers:

The Well Project. *Disclosure and HIV*.

Webpage: <http://www.thewellproject.org/hiv-information/disclosure-and-hiv>

Resources for Caregivers and Adolescents:

The AIDS InfoNet. *Telling Others You are HIV-Positive*.

Web page: http://aidsinonet.org/fact_sheets/view/204?lang=eng

Module C: Guide for Supporting Adolescents in Disclosing Their Status to Their Caregiver or Family

Stakeholder Engagement

The objective of this section is to help ALHIVs with disclosing their HIV-positive status to their parents or caregivers. Most of the ALHIV who need to disclose are likely to have acquired HIV horizontally. The experiences of the adolescent following disclosure to their parents or caregiver may not only affect their adherence to care and treatment, but also can affect how they continue to interact with their parents and other family and any existing and future support structures. It may deeply affect their self-respect, self-stigma, and self-management skills. Disclosure can also create opportunities for ALHIV to access adherence support and other forms of PSS from their family members. Major barriers for adolescents to disclose their HIV status to their parents or caregivers can include: a fear of revealing sexual activity, rejection, and reduced financial and/or emotional support.

Adolescents should be counselled on when, where, and to whom to disclose. They need to consider if they have come to terms with having HIV, if they feel prepared to talk about it, or whether there are other major stressors at the time, like starting HIV-related treatment or dropping out of school. It is also important to ensure a safe environment for the adolescent when disclosing and not to conduct it if there is any significant chance for harm or any form of violence. Some adolescents may prefer to disclose their status to their family members with the presence of a HCW or CHW.⁵⁴ With the adolescent's approval, HCWs may want to reach out to the CHWs to involve them in planning the disclosure to the family or caregiver.

Compulsory disclosure of HIV status in adolescents by HCWs (e.g., to authorities) can be a deterrent for adolescents to attend HIV testing services, particularly those from key populations. Disclosure needs to be handled sensitively, first and foremost with the adolescent's wishes being respected.

C1. Readiness Assessment

Readiness Assessment Criteria: Adolescent Disclosing to Caregiver/Family	Check Mark
Encourage the adolescent to understand why disclosure is important and decide who they plan to disclose to among their parents or family members.	
Review the potential benefits and disadvantages of disclosure with the adolescent..	
Determine whether the adolescent may be at any risk after he or she discloses their status to their parents or caregivers.	
Discuss the feelings or fears on disclosing with the adolescent freely and address each of their concerns.	
Provide the adolescent with some responses that they could use if questions are asked after disclosure.	
Once the adolescent is ready for disclosure, remind them that they have continued support and they can reach out to you for any help in the process.	
Provide with emergency access numbers and educate about how to handle violence and abuse.	
Practice role-playing for disclosing at home. See Appendix D for role-playing scenarios.	

The HCW should review the benefits of disclosure with the adolescent, such as:

- Avoiding the burden of secrecy and the feeling and practice of hiding the diagnosis at home.
- Avoiding anxiety about accidental or unwanted disclosure.
- Gaining access to emotional and practical support from parents and family members, including the freedom to talk about symptoms and concerns.
- Gaining easier (supported) access to health care and improved adherence.
- Gaining the ability to ask a friend or family member to be a treatment supporter/ treatment buddy.
- Getting facilitated access to other support (e.g. peer groups, PSS) with transportation and other available means.

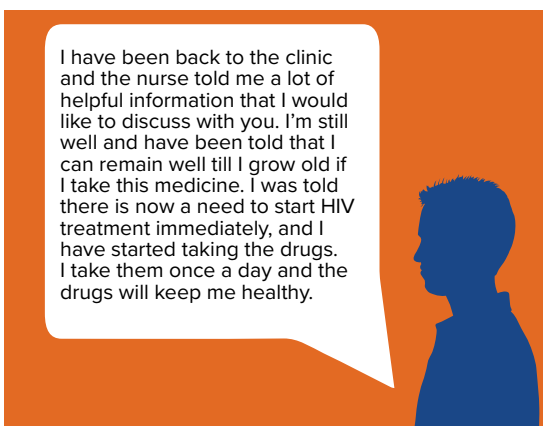
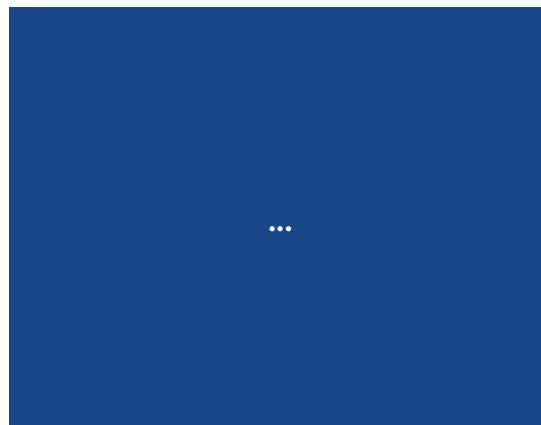
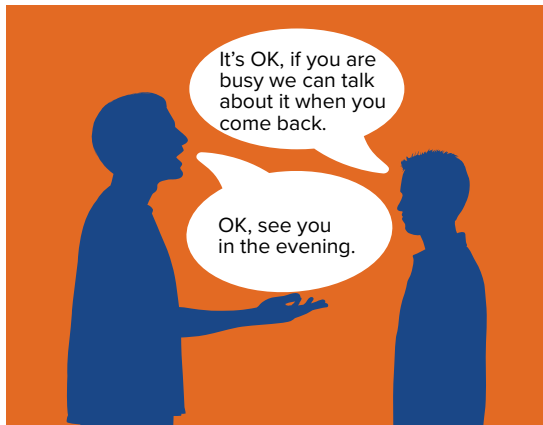
The HCW should also review the possible disadvantages of disclosing and how to deal with such challenges:

- Receiving blame by family for “being sexually active too early” and “bringing shame and HIV into the household.”
- Distancing, fear, rejection, or abandonment by parents and family members.
- Discrimination or rejection at school, the community, at work, including possible loss of job as a result of sharing their HIV diagnosis with others
- Making assumptions about their sexuality, promiscuity, or lifestyle choices.
- Real or perceived risk of physical violence.
- Self-stigma.
- Loss of economic or subsistence support from parents or family members. Lack of safety net support if hospitalized or ill.

C2. Disclosure Process

Consider including peer counselling and support ahead of the adolescent’s disclosure, as it can be a useful resource to support an adolescent preparing for the disclosure. The ALHIV needs decide where and when they want to have the disclosure to be done, such as at home or at the health care facility. The HCW can ask the adolescent if they wish to have a peer accompany them for the disclosure to their parents or caregiver; the HCW does not need to accompany the adolescent, but can offer to carry on disclosure at health care facility with their support.

The HCW should rehearse and role-play with the ALHIV. Consider the following sample script for role-playing:



From here, the HCW should work with the ALHIV to prepare how to answer all the questions and the address all the issues they think may be raised. They should allow their parent to take time to respond and ask questions. The adolescent should invite their parents and caregiver to come to the health care facility and get more answers from their HCWs. The adolescent should reassure their parents or caregivers of confidentiality and encourage an ongoing dialogue with HCW and willingness to work together to stay healthy.

After they disclose, the adolescent will need to give their parents or caregiver time to go through their reactions and be ready to deal with emotional reactions as well as many questions. The adolescent should also tell their parents or caregiver that they can provide more information or that a HCW is available to offer it. The discussions will continue after the actual disclosure and so the adolescent should be counseled on being patient and continuing these discussions with their parents or caregiver, as it arises.

C3. Post-Disclosure Evaluation and Follow-Up

- Once the adolescent has disclosed their status to their parents or caregivers, the HCW should closely follow up with them and assess their safety, emotional status, ART adherence and how the ALHIV is generally coping after the disclosure. They should monitor the adolescent to see if they have additional clinical, education, or other support needs.
- When feasible, a counselor, social worker, or CHW could do a home visit to assess the condition of the adolescent and their family members.
- It is important to sit down together with an adolescent to reflect on challenges and successes, and how they would do it differently the next time.
- Some adolescents may wish to bring someone they disclosed to with them to the clinic, so they also have an opportunity to ask any questions.
- Those adolescents and families who have gone through successful disclosure may be asked if they are willing to coach or mentor other adolescents and support their disclosure in the community.

Module D: Guide for Supporting Adolescents in Disclosing Their Status to Friends, Social Network, School, or Work

Disclosure of one's HIV-positive status to others is part of living with HIV. Disclosure to others needs planning and can be empowering for adolescents. It is important that disclosure is a positive experience for teens; it requires preparation prior to the actual disclosure event. When discussing who to disclose to, it is important for HCWs to be aware of relevant laws and national policies so adolescents are informed of their responsibilities and rights, especially to confidentiality.

Reasons for disclosing to others include to:

- Improve support for adherence at school, home, and in the community.
- Ensure sexual relationships are conducted in a way to reduce the chances of HIV transmission or reinfection.
- Gain social support for living with HIV with trusted peers, friends, and family members.
- Live openly with HIV without stress, secrecy, or shame.
- Empower others to disclose their status or get tested.
- Reduce the chance of unintended disclosure and control one's own information.

Key Talking Points

- Stigma is born by ignorance and fear. Encourage the adolescent to find people who are smart and knowledgeable.
- HCWs should find examples of people, including examples on the internet and media, who have HIV and live positively.
- The HCW should emphasize that those who love and care about the adolescent will be able to support them and make it easier for them to ask for help. Supportive loved ones will encourage them to achieve their treatment and life goals.
- Keeping a secret can be a burden on the mind and puts an additional strain on the body. This stress can be lowered as one shares their HIV status with others.
- As adolescents disclose their status to the people they trust and who love and care for them, they can work together to help them live a long, healthy, and fulfilling life. Loved ones can also support adolescents with processing emotions and feelings.
- When adolescents disclose their HIV-positive status within their community, they are helping to reduce secrecy, stigma, and discrimination surrounding HIV and opening doors for greater community support for other people living with HIV. **However, it should not be the responsibility of the adolescent alone to help reduce stigma and discrimination against people living with HIV and to encourage people to get tested for HIV. ALHIV should only disclose to individuals and communities when they are comfortable with sharing their status.**

- It is important to remember that disclosure is not a one-time event but rather a process that is often revisited over time. The person that is being disclosed to also needs to process the information. His or her initial reaction may change over time as he or she learns more information and processes the disclosure.
- The reaction may not be what the adolescent anticipates. They should be prepared for both a negative or positive reaction. It is important to realize that it may take time and support for community members to fully understand and be able to support the adolescent needs.

D1. Readiness Assessment

Readiness Assessment Criteria: Adolescents Disclosing to Friends, Social Network, School, and Work	Check Mark
Inform the adolescent that disclosing their HIV status is their personal decision and they have the right to choose to whom, how, and when to disclose their status.	
Encourage the adolescent to focus more on the positive outcomes as opposed to avoiding negative outcomes, such as rejection or conflict. This focus on the benefits will affect the way an adolescent approaches a disclosure event, the content of the disclosure, and the response they receive from their confidant by using effective communication strategies. However, the adolescent should be prepared for both positive or negative outcomes.	
Encourage the adolescent to learn all they can about HIV, positive living with HIV, and related issues so that they can feel empowered with the right knowledge to share with others.	
Encourage them to discuss their disclosure plans and practice scenarios with a HCW or counsellor as they make choices about who, why, and how to disclose their status to others.	
Counsel the adolescent that it is easier to disclose and share one's HIV-positive status with others when one has accepted one's own status, and to overcome any negative emotions such as fear, guilt, anger, self-pity or denial, which many people may feel when they first find out that they are HIV-positive. The difficulties one faces in accepting their status may stem from or result in self-stigma, where one stigmatizes one's own infection because of negative perceptions they have about HIV.	
Encourage the adolescent to join a peer support group for other ALHIV to share with and learn from their peers about their experiences with disclosure to others. Use disclosure within peer group as an exercise for future disclosure.	
Encourage the adolescent to talk with HCWs about any problems or anxieties they have about their health, their future, and the future of their loved ones.	
Rehearse (role-play) with the adolescent the words they will use to disclose so that they are prepared for positive or negative reactions and feel confident about the process. Role-playing scenarios are included in Appendix D.	
Discuss the adolescent's treatment status and review their most recent viral load results	

D2. Disclosure Process

Prior to Disclosure, HCWs Should Discuss with Adolescents to Whom to Disclose:

Once the adolescent feels that they are ready to disclose their status, think about who to disclose to, because the first time they disclose to someone may be the most difficult. It is important for adolescents to think about and discuss with HCWs how the person they choose to disclose to may react to the disclosure. The adolescent needs to discuss with the HCW why they wish to disclose to these specific people. Adolescents may decide to disclose their status to a variety of people and for a number of reasons, such as:

- Treatment supporters such as family/friends/teachers/faith community, so they can provide support and assistance as the adolescent grows up.
- A sexual partner, to enable them to discuss prevention strategies together and encourage their partner to get tested for HIV. The HCW should discuss that even if the adolescent and their partner are both HIV-positive, it is important to practice safe sex and avoid re-infection with a different strain of HIV.
- Service providers (facility- and community- based), to access prevention, treatment, support, and care services or contribute to outreach for services or providing testimony.
- Support groups for adolescents living with HIV, to share experiences, successes, and challenges, as well as provide support to one another.
- School, especially boarding school staff and teachers, who will play a role in access to medicines, adherence, and reducing potential of unintentional disclosure.
- For older adolescents, employers and workmates, to access workplace support and to be able to be excused from work for medical appointments.

Think carefully and ensure that adolescents have good support from his/her family and support network before disclosing his/her status publicly, as one cannot take the information back once it is out there.

HCWs should use simple questions to assist adolescents in determining the people they are thinking about disclosing to. The following questions can provide simple guidance to determine readiness.

Questions to assess readiness to disclose to an individual:

1. What is the age of the person that I intend to disclose to?
2. How long have I known them?
3. Is he or she trustworthy?
4. Do I know their status?
5. Determine whether the person has full knowledge of HIV, if not; first tell them about it.
6. Assess how they perceive people living with HIV.
7. How might they react when I disclose my status to them?
8. Identify on the most appropriate time and place to disclose to him/her your HIV status.
9. Evaluate your confidence and braveness. If not confident enough, ask for support from a HCW.

Table 2. Potential Benefits and Challenges of Disclosing in Different Settings

Setting	Benefits	Challenges
School	<ul style="list-style-type: none"> • Treatment support from friends/peers/teachers during school hours • Additional support for treatment refills and keeping appointments • Help with storing treatment at school • Living positively to focus on school performance and future success 	<ul style="list-style-type: none"> • Rejection by peers or friends • Discrimination by teachers • Self-stigma impacting school performance and treatment adherence • Possible wider knowledge of your status
Community	<ul style="list-style-type: none"> • Gain support from more people in your social network • Empowered to live freely and positively • Reduce the fear of accidental disclosure • Encourage others to disclose, get tested, or improve their adherence • Address/reduce stigma and discrimination • Reduce anxiety and stress from shame and secrecy 	<ul style="list-style-type: none"> • May encounter stigma and discrimination • People making assumptions (i.e., being sexually active early, parents not wanting their children to date the ALHIV, etc.) • Being blamed for action or life decisions • Self-stigma
Faith Community	<ul style="list-style-type: none"> • Improve awareness of transmission and reinfection • Promote acceptance and testing for those who haven't been tested • Act as a role model and helping others in the faith community • Gain additional support • Leverage on values of faith communities as caring communities 	<ul style="list-style-type: none"> • Rejection by some members (isolation, shunning, etc.) • Discrimination - labeled as not a true believer • Shamed or judged for "sinful" behavior • Negative attitudes towards HIV, such as a belief that HIV is not a virus but as a spiritual problem caused by demons • Misconceptions about HIV cure through prayer and alternative healing

Ways to Address Challenges

- HCWs should remind adolescents that some people don't have all the correct information to understand the full situation, so they need to be patient and link people with additional resources if they are willing; they should be prepared for both potential positive and negative reactions to disclosing.
- HCWs should prepare with adolescents beforehand to practice different scenarios in various role-play scenarios – both positive and negative reactions.
- HCWs should ensure adolescents have the resources they need and offer post-disclosure support.

During Disclosure

- Adolescents may find it easier to ask someone to accompany them when they decide to disclose, so that they can have support. This could be a HCW, a counselor, a member of their support group, a friend, or family member.
- Sometimes disclosure may be done on behalf of the adolescent, with their consent, by a parent or caregiver to a school leader to ensure adherence at school.

- When going to disclose to a person, it may be useful to bring along HIV-related informational materials. This will assist the adolescent in explaining facts and answering any questions the person being disclosed to might have. The adolescent can choose not to answer personal questions if not relevant or if uncomfortable.
- The adolescent can ask the person being disclosed to not to tell anyone else about their diagnosis and keep this information confidential.
- The adolescent should choose a time and place that is comfortable and safe for both them and the intended person for disclosure.
- Before the end of the disclosure, the adolescent should make sure to mention that they are HIV-positive and include the reason why they have decided to disclose and explain that you hope they will maintain the trust that was created prior to disclosure.
- HCWs should have the adolescent's contact information to ensure follow-up occurs.

D3. Post-Disclosure Evaluation and Follow-Up

Not all adolescents will want to discuss their disclosure experience. However, it is important for the HCW to try to meet with them after they have disclosed to someone for the first time. It is recommended to meet soon after the disclosure, while their thoughts and feelings are still fresh and to schedule an additional follow-up meeting within the next few days or week, after they had some time to process the experience.

Following the disclosure event, the HCW should:

- Find out how the overall experience of disclosure went.
- Ask what they thought went well and what was difficult for them.
- Ask about how the person they disclosed to reacted and if the reaction was what they had expected.
- Ask about how the reaction of the person they disclosed to made them feel and whether there were any adverse outcomes from disclosing.
- Monitor the effects of disclosing on the adolescent and refer to additional services, if needed.
- Note the event of disclosure in the adolescent's file and any additional referrals made.

Often the experience one has during their first disclosure will influence if and how they will disclose to others in the future. It is important for the HCW to ask the following questions:

- Did this experience affect if they will disclose in the future, to whom they will disclose to in the future, and how they will disclose?
- Keep in mind that an adolescent's initial reaction may change over time, as they process the experience, and as they have continue to have contact with the person to whom they disclosed.
- Did any questions come up that the adolescent did not know the answer to and they would like to discuss?

Module E: Guide for Supporting Adolescent to Disclose Their Status to Their Partner

E1. Stakeholder Engagement

ALHIVs need to be prepared to disclose their status to their partners. While being challenging and carrying the risks of stigma, rejection, violence, and isolation, disclosure to sexual partner also carries many benefits, such as trust, open negotiation of condom use, partner protection, safer conception, and HIV testing by partners. Successful HIV disclosure between partners leads to decreased HIV transmission within the community and improved self-awareness and mental health of those affected by HIV. Depending on the country's legal framework, non-disclosure to sexual partners may result in criminalization and adolescents from key populations may face specific legal consequences. HCWs must become familiar with the legal issues surrounding partner disclosure.

Disclosing one's HIV status to a sexual partner means talking about sex, sexual orientation, sexual acts, possible drug use, disease, and death. All of these are often taboo subjects that are difficult to talk about openly and honestly in most, if not all, societies and communities.⁵⁵ Even for the most self-affirming, confident person, these are difficult subjects to discuss. Furthermore, some people living with HIV believe they have a moral obligation to disclose their HIV status to all potential partners. Others may take a more situational or conditional approach, believing that disclosure is unnecessary if safer sex is practiced or disclose only if a relationship has the potential to progress beyond a casual stage.⁵⁶

E2. Talking Points

Key Terms:

U=U: Undetectable means untransmittable. People who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner. This, however, means a very consistent intake of ARVs by the HIV-positive partner. While beneficial for many couples, U=U also poses the challenge to disclosure to partners, as the PLHIV with an undetectable viral load may feel that he or she no longer needs to disclose his or her status to partners.

Condoms. Condoms are an effective way to prevent HIV transmission, when used correctly and consistently. In addition to the HIV, condoms prevent pregnancy and also prevent transmission of STIs, such as gonorrhea and syphilis.

Pre-exposure prophylaxis (PrEP). PrEP is a daily ARV that can prevent someone who is HIV-negative from acquiring HIV.

Key Messages:

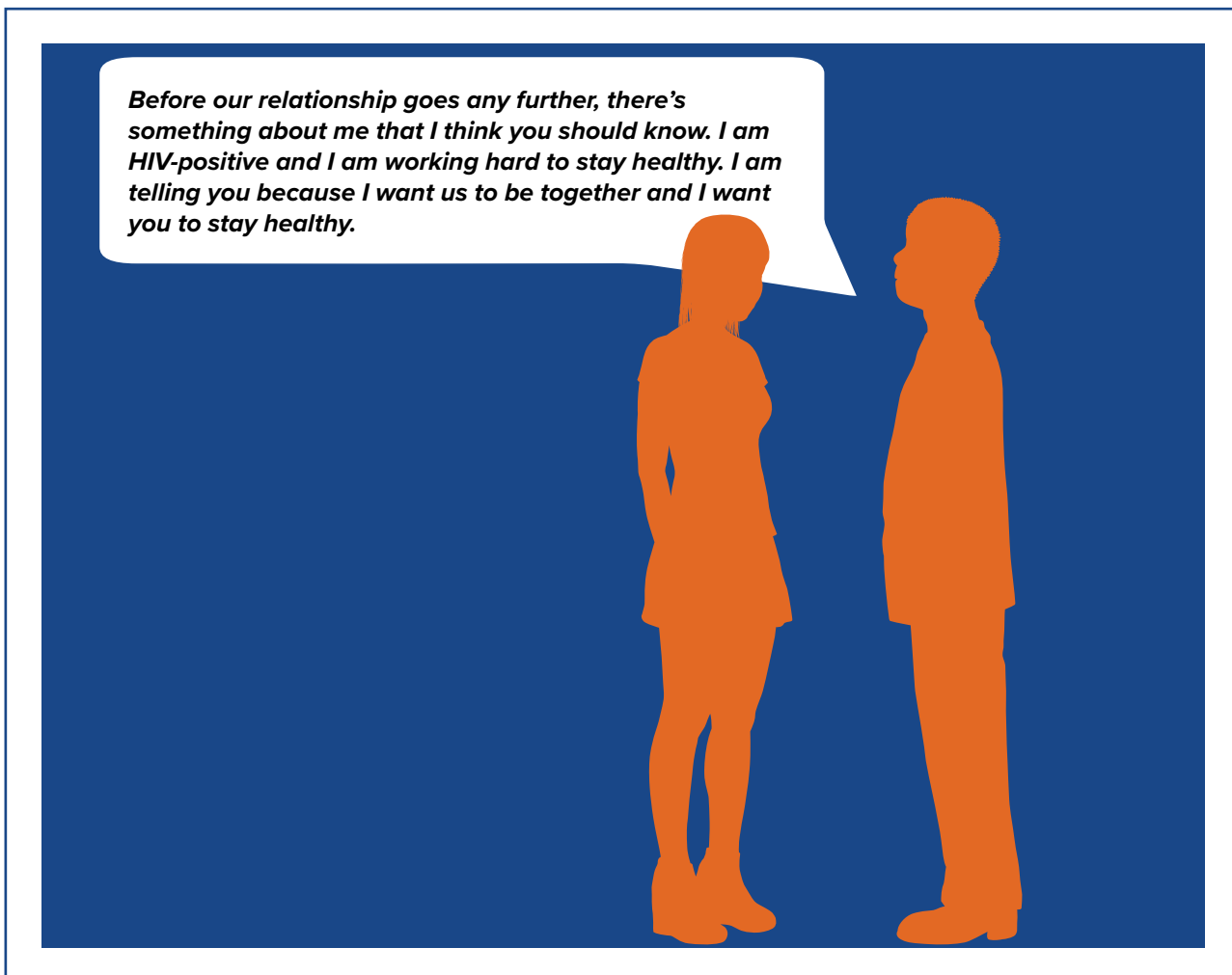
- In supporting an adolescent on how to disclose their HIV status to the partner, it is most important to equip them with information to ensure they can answer questions and manage the reactions of those they are disclosing to.
- Writing out a plan of what to say, and practicing possible questions and responses through role-play, can assist the adolescent to feel prepared.
- Before disclosing to sexual partner, ALHIV need to become familiar SRH health issues, HIV transmission risks, the concept of U=U, and PrEP, and they need to fully understand the role of the condoms in the transmission of HIV and STIs.
- Further support can be found through sharing of experiences with other ALHIV.

In many cases, due to fears of rejection and breach of confidentiality, disclosure to potential partners can be more difficult than disclosure to trusted friends or family. Disclosure may be less common with casual partners or in a commercial sex setting, especially if condoms are used. Disclosure in the context of a long-term or committed relationship is particularly difficult as the relationships may not always be based on trust, honesty, openness, safety, or good communication.⁵⁷ When counseling and preparing an adolescent for HIV status disclosure to their partner, potential talking points to discuss include:

- Telling someone you care about that you are HIV-positive is not easy.
- It is important that your partner knows of your diagnosis, especially in a committed relationship.
- You might be scared that he or she will no longer want to be with you or will be angry that you have kept it private. It is hard to know how a person will react.
- If you trust the person enough to be with him or her, then it's important to trust the person with your HIV status.
- Having to withhold information from someone you are close to can be exhausting.
- If the person accepts your diagnosis and would like to continue the relationship, you will probably feel relieved and closer to the person.
- Sharing the responsibility of protecting yourselves can make staying safe (and having safe sex) a lot easier.
- Working up the courage to talk about your diagnosis can be the hardest part.
- You may ask a counsellor or HCW to be present during the disclosure.
- Think about what you want to say, how you want to say it, and practice saying it before you do with HCW or counselor or peer.

E3. Disclosure Process

It is important for the adolescent to be honest with their partner about their status. The adolescent could start by telling their partner that they need to talk to him or her about a delicate private subject. A sample script to practice during the discussion can include:



- The HCW should counsel the adolescent that their partner may react with a lot of questions about how they became infected, medical information, and who else may know of their HIV-positive status. They should answer these questions to the extent that they feel comfortable. The adolescent should not feel pressured to disclose any more information than they would like.
- The adolescent's partner may be also living with HIV and may know or not know they are HIV-positive. It is important to discuss whether they were ever tested for HIV and know their status.
- The adolescent's partner may have very little information about what having HIV means. It would be a good idea for the adolescent to provide information about how one can and cannot transmit the virus. The adolescent should encourage their partner to try to find out more information on his or her own.
- The adolescent should be willing to give their partner space and time to reflect, and be open to more communication. For example, it is not advised to say, "I have HIV. Now you know, and I don't want to talk about it anymore."

- The HCW should remind the adolescent that their relationship does not have to be completely serious and only focused on HIV. While one’s HIV status is important, it does not define them.
- The adolescent should remind their partner that they are still the same person they were before they disclosed their diagnosis. They should discuss their feelings and how difficult it was for them to share this information. They should allow their partner to try to understand what they are going through.
- The adolescent may also want to ask their partner not to tell anyone else about their diagnosis, and to remind them that they have trusted him or her with this information.
- If the adolescent’s partner is at risk of having HIV, they should encourage him or her to get tested. If they begin or continue to have sex with their partner, protection must be discussed thoroughly.[#]
- The adolescent may fear that their partner will react violently to telling him or her about one’s HIV status. If he or she has been violent in the past, the adolescent should have someone else present who can protect them or at least tell the person in a public place. They should also take steps to get out of a violent relationship. The HCW should conduct a danger assessment and develop a safety plan with the adolescent, or refer the adolescent to health care providers trained on post-violence care services.^{§§}

E4. Post-Disclosure Process

Not all adolescents will want to discuss their disclosure experience, however it is important to meet with them after they have disclosed to their partner. Following the disclosure event, the HCW should:

- Find out how the overall experience of disclosure went.
- Ask what they thought went well and what was difficult for them.
- Ask about how the partner reacted.
- Ask about any adverse outcomes from disclosing.

Often the experience one has during their first disclosure will influence if and how they will disclose to others in the future. Keep in mind that an adolescent’s initial reaction may change over time, as they process the experience, and as they have continue to have contact with the person to whom they disclosed. The HCW will need to find out if any questions came up that the adolescent did not know the answer to and they would like to discuss.

It is important to remember that over-emphasis on disclosing one’s HIV status – especially to sexual partners – may discourage adolescents from engaging with health care services. On the other hand, successful disclosure to the partner may lead the partner to seek HIV testing and start treatment for those living with HIV and discuss prevention strategies such as voluntary male circumcision, PrEP, save conception, and condom use. HCWs should be open to have the ALHIV bring their partners for services, as supporting them means better retention in care and treatment of the index patients.

[#]K4health. Lukia’s Story. https://www.k4health.org/sites/default/files/HCP%20Paed%20ART-%20Lukia%20Story%20FINALAPPROVED_0.pdf ; Children and AIDS. Why I Take my Medicines. https://www.childrenandaids.org/sites/default/files/2018-05/Why%20I%20take%20my%20medicine_Namibia%20%282015%29.pdf

^{§§} Kimesh Naido. Step by Step Guide for Conversations with Children. http://www.kznhealth.gov.za/arv/Disclosure_Poster.pdf

Module F: The Power of Knowledge

Below are selected quotes from HCWs, caregivers, and young people living with HIV on their disclosure experiences.

Health care workers' perspectives on their role in the disclosure⁵⁸

We often use picture books to explain slowly to the child about the policemen (CD4 cells) in her/his body and their fight against the bad person (HIV virus). We tell the child, unless you take your medication, all the policemen in your body will be destroyed and you will become sick. (HCW)



Had we been adequately trained, we could have been able to cope with challenges that we face when dealing with parents/guardians of these children. We need more skills on how to deal with these parents/guardians during the disclosure process. (HCW)



Caregivers' experiences with disclosing the HIV status to the children⁵⁹

The first time [we disclosed] I wasn't sure if she understood. Now I know she knows. (Biological mother, 38 years old, HIV-positive, status disclosed at age 5)



If you tell the truth, and tell her that she will live longer with medication she won't lose hope. (Biological mother, 36 years old, HIV-positive, status disclosed at age 6)



I saw that she was mature, and she was asking why she was taking the medicines. (Biological mother, 38 years old, HIV-positive, status disclosed at age 10)



Perception of disclosure by children and adolescents

I think it's important [to disclose] because everybody must know about their status, and for me, knowing my status I see it as an important thing. (Male; 13 years old)



Children must be told about their HIV status, because if it is transmitted to children, you may find out that children do not know that they have HIV, and after that they get sick. (Female; 12 years)



It is better that they did not hide it from me..., they told me straight that I am HIV-positive so that I don't stop taking treatment. (Female; 13 years old)



Disclosed to by a family member, when told in adolescence after long treatment

I cried... I was very hurt, I was heartbroken. I was hurting and crying for five days. My aunt was trying to comfort me, but it was too painful. She kept talking to me. She was aware that I was hurting. (Female; 14 years old)⁶⁰



Actually, I did not understand anything, I didn't understand what HIV-positive was.... I was just taking the pills that they gave me. It never affected me. I just accepted. I just accepted. ...I didn't have problems. (Female; 13 years old)⁶¹



Disclosing to a close friend

I don't want them judging me, and I am afraid that my best friend will refuse to play with me. (Male; 14 years old)⁶²



When I first disclosed to my best friend, I first asked him how he was feeling about people living with HIV and his views were positive which made it easier for me to tell him. I did it by texting him a message and he gave me a good and clear reply which said, "You are not different from others, we are all the same." Oh my God, I felt so great and indeed he made me feel so normal for once in a lifetime. (Female; 18 years)



Disclosing at school

My status is my secret and will remain my secret until I am older. In most cases, it is a secret; the only people who need to know are your family. (Male; 17 years)⁶³



At (secondary) school, that is where I got hardships, but only a few knew about my status. It was a really critical time for me especially in my O-level, where I was afraid of disclosing. But what helped me was that the students confirmed I had sickle cells and really supported me to take medication but I didn't correct them to why I take my medicine—the same case with high school. I did that because I felt uncomfortable to tell them the truth. In university, I have not disclosed to anyone, because they don't really care about it and everyone minds their own business, which makes me fine not to disclose because not everyone has to know. It's of no use, even if they know.



Disclosing to a partner

When I had to disclose to my boyfriend because I had to tell him from my mouth, not him hearing me speak on different media channels. I only did this through a message (felt face to face was hard) then called him later to confirm what I had written down. It is then that I discovered that disclosure is hard, it's been easy for me on TV and other platforms to talk about my status, but it was hard for me to face my boyfriend and confirm what I always say on media platforms.



Appendix A: Disclosure Job Aids

General Disclosure Algorithm

STEP 1: ELIGIBILITY CRITERIA		
Developmental age of ~6 years or above	No severe physical or psychological illness	Caregiver is willing to disclose



STEP 2: READINESS ASSESSMENT COUNSELING				
Doing well in school	Family and peer relationships and support	Interests and levels of activity	Mood and behavior	Adherence Monitoring



STEP 3: DISCLOSURE COUNSELING (Guided by the caregiver and supported by the HCW)



STEP 4: POST-DISCLOSURE ASSESSMENT (Reduced interest and activity in the following indicators would suggest maladjustment after disclosure)				
Doing well in school	Family and peer relationships and support	Interests and levels of activity	Mood and behavior	Adherence Monitoring



STEP 5: REFERRAL AND SUPPORT		
Counsellor/ Psychologist	Psychiatrist	Child protection services

Major Steps in Disclosing Diagnosis to Child/Adolescent with Vertically-Acquired HIV

Readiness Assessment Counseling

Readiness Counseling for the Caregiver

- Find out from the caregiver if they think the child or adolescent is ready for disclosure.
- Assess what the caregiver has already communicated to the patient, especially on HIV.
- Explore with the caregiver some of their fears about disclosing to their child.
- Review with the caregiver what they know about the benefits and disadvantages of disclosure.
- Practice with the caregiver what they will say and how to support any emotional reactions.
- Assess from the caregiver the available family and community support.

Readiness of the Child or Adolescent

- Review what the child understands about their own health.
- Assess clinical status to confirm that the patient does not have severe illness.
- Find out what the child or adolescent knows about the medicines he/she has been taking and about their illness.
- Review the patient's mood and behavior.
- Review with the child how they cope with stressful situations.
- Review the child's ability to keep a secret or maintain confidentiality.
- Find out the patient's relationship with peers in school or at home.

Disclosure Process

- Start by assuring the patient and caregiver that you are available to answer any questions and there are no wrong questions to ask.
- If the patient has not had any disclosure discussions before, initiate discussion about health and immune system functioning.
- Build on previous information and basic understanding of health and immune function, and proceed with full disclosure, naming HIV.
- Take pauses to observe the patient's and caregiver's reactions. Be ready to support them.
- Ask the patient and caregiver what they are feeling at the moment without rushing them. Accept silence.
- Observe the caregiver and patient interactions and encourage them to be supportive of each other.
- Point to the benefits of disclosure and guide to continue discussions on future encounters. Encourage adherence to care and treatment.
- Instruct the child how they can live with the virus, and how to avoid spreading HIV further.
- For adolescents or children at risk for unsafe sex, discuss sexual relationships and safe sex.
- Discuss how to keep a secret.

Post-Disclosure Evaluation and Follow-Up

- Ask the patient and caregiver how they are feeling since disclosure. Be receptive to their feelings.
- Ask the patient and caregiver if they have any questions since the last encounter.
- Ask the patient if he/she disclosed their diagnosis to anyone at home or at school. If yes, ask them how did the people react, and provide explanation and support.
- Repeat parts of disclosure and motivate the child or adolescent to contribute his/her perspectives, as necessary.
- Provide enhanced adherence counseling reinforcing the message about benefits of taking medications, seeing medical providers regularly, and living a healthy lifestyle.
- If the patient requires any referral (e.g., psychosocial counseling) and is interested in peer support, make appropriate referrals.
- Review relevant options on how to cope when feeling down or depressed about the diagnosis.

Appendix B: Pediatric Disclosure Readiness Assessment Checklist (Kenya)

Pediatric Disclosure Checklist

Name of the child:	DOB:
Gender:	CCC Number:
Caregiver's Name:	Phone Contact:
Facility Name:	MLF Code:

Task 1. Assess the child for disclosure eligibility	Date task 1 executed:		Task Facilitator's Name:
Child has met the age criteria (between 6 and 10 years)	Yes	No	
Child and caregiver knowledge on benefits of disclosure	Yes	No	
Caregiver willing to disclosure to child	Yes	No	
Task 1 Comments:			
Task 2. Assess the child and caregiver readiness	Date task 2 executed:		Task Facilitator's Name:
Child and caregiver free from severe physical illness, trauma, psychological illness or psychiatric illness?	Yes	No	
Child has consistent family, peer support or social support	Yes	No	
Child demonstrates interest in the environment and playing activities	Yes	No	
Child already knows about the medicines and illness and addressed needs and concerns	Yes	No	
Functional school engagement by the child (consistent attendance, interacts well with the school community, able to freely discuss school activities)	Yes	No	
Caregiver ready for disclosure to the child	Yes	No	
Caregiver has communicated with the child to assess readiness	Yes	No	
Management of confidentiality of information regarding one's health discussed with the child and caregiver	Yes	No	
Task 2 Comments:			

Appendix B: Pediatric Disclosure Readiness Assessment Checklist (Kenya)

Task 3. Execute disclosure: to be guided by caregiver and supported by health care worker	Date task 3 executed:		Task Facilitator's Name:
Reassured the caregiver and the child	Yes	No	
Safety (environment and timing) assessed	Yes	No	
The depth of the child's knowledge assessed	Yes	No	
Caregiver supported to disclose using the simplest language the child can understand	Yes	No	
Immediate reactions of both the child and caregiver observed and addressed concerns or negative reactions	Yes	No	
Questions from the child invited	Yes	No	
Benefits of disclosure revisited/reviewed with the child and caregiver	Yes	No	
Care options available to the child and caregiver explained	Yes	No	
Concluded the session with reassurance to both child and caregiver. Reiterating importance of confidentiality of information of one's health with the child and the caregiver	Yes	No	
Task 3 Comments:			
Task 4. Post disclosure assessment (During the subsequent visits assess the post disclosure outcomes). This is usually a minimum of three sessions (every 3 months for 9 months). Focus on child's reaction to self and family, e.g. anger directed at self, siblings, parents.	Date task 4 executed:		Task Facilitator's Name:
Functional school engagement assessed	Yes	No	
Family, social, and peer relationship and support after disclosure assessed	Yes	No	
Child's interest and engagement in children's activities like playing assessed	Yes	No	
Questions from the child encouraged and assessed self-perception and outlook	Yes	No	
Negative body or self-image issues addressed	Yes	No	
Child's moods and negative behaviors assessed	Yes	No	

Referred appropriately for psychiatric and other complications developed post disclosure if indicated	Yes	No	
Given age appropriate adherence information	Yes	No	
Child's interest and engagement in children's activities like playing assessed	Yes	No	
Task 4 Comments: on self-perception and the child's fears (include if the child understands what is going on), concerns raised by caregiver, mood changes or reactions. Indicated any subsequent post disclosure session and concerns.			
Final comments: indicate overall disclosure comment, future plans, referrals, pending disclosure issues, support group enrollment and extended post disclosure support: more than three sessions for children with difficulties			

Appendix C: Additional Disclosure Resources

Resource	Author	Information
<p>Four Part Booklet:</p> <ol style="list-style-type: none"> 1. How to Keep Healthy 2. Knowing About Myself 3. Living a Life of Health 4. Teen Talk 	<ul style="list-style-type: none"> • PEPFAR • USAID • AIDS Free • BIPAI 	<ol style="list-style-type: none"> 1. Written for children from 2-6 years of age to answer questions surrounding reasons why they go to the clinic and take medications. 2. Written for children from 6 to 12 years to discuss the health of a child, getting more in depth about their condition and the reasons for taking their medications to stay healthy. 3. Written for children over 9 years of age to discuss HIV that builds on the information from the previous booklets. 4. A guide for positive living for teens providing information on all things HIV to allow for autonomous decisions and self-management
<p>Toolkit for Transition of Care and Other Services for Adolescents Living with HIV</p>	<ul style="list-style-type: none"> • PEPFAR • USAID 	<p>Module 1: Psychosocial Development</p> <ul style="list-style-type: none"> • Tool to assess the psychosocial stages of development to determine readiness to take on self-management • Timeline to assist with when/how to address topics for self-management • Psychosocial assessment tools for assessing needs of adolescents and caregivers in the context of disclosure and readiness for self-management • A psychosocial development journal entry for adolescents <p>Module 2: Mental Health Considerations</p> <ul style="list-style-type: none"> • Mental health symptom screener – adolescents • Additional mental health screening tools used among young people • Tool on recognizing and improving emotional health for adolescents and separate tool for caregivers • An emotional health journal entry for adolescents

Resource	Author	Information
<p>Toolkit for Transition of Care and Other Services for Adolescents Living with HIV</p>	<ul style="list-style-type: none"> • PEPFAR • USAID 	<p>Module 3: SRH</p> <ul style="list-style-type: none"> • SRH assessment tool for adolescents to determine needs and provide additional education as needed • A counselling guide on family planning and pregnancy for adolescents • A screening tool for STIs for adolescent girls/ young women and adolescent boys / young men • An STI fact sheet • A pregnancy and PMTCT fact sheet • A SRH journal entry for adolescents • A discussion guide for caregivers on sex and relationships <p>Module 4: Protection</p> <ul style="list-style-type: none"> • A protective services checklist • A screening tool for adolescent gender based violence and abuse • A journal entry on safety for adolescents <p>Module 5: Alcohol and Substance Abuse</p> <ul style="list-style-type: none"> • A system screener for substance abuse • A counselling guide on alcohol and abuse with adolescents • A journal entry on alcohol and substance use • A discussion guide for caregivers on engaging adolescents on alcohol and substance abuse <p>Module 6: Beneficial Disclosure</p> <ul style="list-style-type: none"> • A stepwise disclosure guide • A disclosure discussion guide for discussions with adolescents and family/caregivers • A guide on disclosing your HIV status for adolescents • A journal entry on disclosure for adolescents • A discussion guide for caregivers on disclosure <p>Module 7: Loss, Grief, and Bereavement</p> <ul style="list-style-type: none"> • Grief assessment discussion guide • Guide to counselling • Tips sheet for caregivers in supporting adolescents in the grieving process • Guided memory book for ill family members • Grief journal for adolescents

Resource	Author	Information
Toolkit for Transition of Care and Other Services for Adolescents Living with HIV	<ul style="list-style-type: none"> • PEPFAR • USAID 	<p>Module 8: Clinical Considerations</p> <ul style="list-style-type: none"> • Adolescent clinical transition document • Checklist for meeting key steps at baseline visit for adolescents • Checklist of key steps for adolescents not on ART • Checklist for key steps for follow-up visits and patients of ART • A guide on ART for providers concerning adolescents • A tool to prepare adolescents and caregivers to support adherence to treatment • An adherence readiness quiz for adolescents • A tool to assess adolescent adherence • The Tanner’s Guide for Pubertal Staging of Girls and Boys • Journal entries on daily medication adherence for adolescents, a medication worksheet, and on clinical considerations
Resources for caregivers	<ul style="list-style-type: none"> • South2South • AIDS Map 	<ul style="list-style-type: none"> • South2South Pediatric HIV Disclosure Series – created to assist caregivers in discussing HIV disclosure and other health-related topics with children ages 2-6 • HIV & Children – a resource to give information about HIV treatment and care for CLHIV
Resources for Health care workers	<ul style="list-style-type: none"> • BIPAI • Uganda Ministry of Health • Health Communication Partnership and Joint Clinical • Research Centre Uganda • Thailand Ministry of Public Health • Namibia Ministry of Health and Social Services • FHI, India Country Office, USAID • WHO • Baylor and UNICEF 	<ul style="list-style-type: none"> • Baylor International Pediatric AIDS Initiative (BIPAI) adherence curriculum – a resource for healthcare providers caring for CLHIV • Caring for Children Living with HIV • Lukia’s story – a picture book about a young girl living with HIV, a resource for pediatric HIV counsellors • Pediatric HIV Disclosure Manual • “Why I take my Medicine” – a cartoon book created to guide HCWs and caregivers in the disclosure process for children 6 years and older • Protocol for Child Counseling on HIV Testing, Disclosure and Support – guidance for counsellors working with children living with HIV and their caregivers in India • Guideline on HIV disclosure counselling for children up to 12 years of age • Disclosure Flipchart

Appendix D: Role-playing Scenarios

HCW Disclosure to Child and Adolescent – Two Scenarios

Case I

Chioma is a 32-year-old woman living with HIV, on treatment, and doing well. She is the mother of two daughters: 10-year-old Chika and eight-year-old Ezelia. Chika is HIV-positive and she does not know her status. She has been on HIV care and treatment since her diagnosis at four years of age and has done well. She is prescribed an ART regimen with one pill once a day and is responsible for taking it every day. Chika goes to primary school and has good friends. She recently went to the doctor because of the new white plaques in her mouth. Doctor Lucy talked with her mother about Chika's viral load test results and told her that last viral load for Chika was very high and her CD cell count is low. Mother wants the doctor to talk to her daughter about her treatment and the doctor has advised disclosing the HIV status to the daughter. He asks Chioma about her family and household members. Chioma's husband died in a car accident two years ago. The family lives in the same house with mother's older uncle Koji and younger sister Akuoma who is 23 years old. Koji knows about Chioma living with HIV; however, Akuoma does not. Akuoma is engaged and planning to get married in the summer. Chioma agrees to disclose Chika's HIV diagnosis and she asks the doctor to do it. She has her younger daughter with her at the appointment.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Mother Chioma
- Daughter Chika
- Young Daughter Ezelia
- Doctor Lucy
- Counsellor in Clinic

Case II

It is two weeks before the holidays and the clinic is very busy. Emmanuel brings his 13-year-old son Joshua to the clinic for his checkup. This is Joshua's first clinic visit. Joshua is HIV-positive, stable on ART, and his last viral load result was undetectable; however, he does not know his status. Emmanuel is also HIV-positive, is on treatment and doing well. There is an older brother, Moses, 16 years of age, who is also HIV-positive and at boarding school. It is unknown whether the older brother knows his own or his brother's HIV status; he never had this conversation with his father. Two months ago, Joshua and Moses' mother died and five years ago, the family lost a younger sibling at two years of age. Joshua has been recently in a bad mood and cries at home regularly. He doesn't have many friends and his grades at school have recently dropped. Emmanuel took Joshua to speak with his priest twice and Joshua keeps asking why his mother died. Moses will be coming home soon for the school break. Emmanuel feels overwhelmed, he now asks the nurse and another healthcare worker who lives in the same community to talk with Joshua and disclose Joshua's HIV status and explain that his mother died from HIV. However, Emmanuel does not want Joshua to know he and Moses also are HIV-positive.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Proceed with the disclosure and assign the roles:

- Father Emmanuel
- Son Joshua
- Healthcare Worker
- Nurse

Caregiver Disclosure to Vertically Infected Child or Adolescent – Two Scenarios

Case III

One week after the death of her 32 year old sister Nabila, Adisa returns home to her village. She brings back with her Nabila's two children – 11 years old Fahim and 13 years old Kaia. Nabila was not married and was raising her children alone while she worked at a travel agency in a big city. Adisa knew that her sister was not well and was losing weight, but she only now learned that her sister died from AIDS. When packing the children's belongings, she found several sets of bottles with medicines and asked children about them. Fahim and Kaia said they took them off and on and said mother took them as well. They did not know which bottles were theirs and which ones belonged to their mother. Kaia was crying when they talked about taking pills. Back home, Adisa asked her brother Babak, who works as a pharmacist in her village, about the pills. Babak explains to her that the pills are medicines for HIV. Both Babak and Adisa suspect that Kaia might know something about her mother dying from AIDS. They decide to have a conversation about HIV with her alone and talk to her on the day when Fahim is not home. Babak wants to invite nurse Lydia from the clinic where he works to help them talk to Kaia.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Aunt Adisa
- Uncle Babak
- Niece Kaia
- Nurse Lydia

Case IV

Abongo is a joyful nine-year-old boy, who was diagnosed with HIV at the nutritional clinic at the age of five. Abongo did not begin ARVs at the time of his diagnosis, but has done generally well. He goes to school, studies very well, and has earned several awards in math and science. His mother, Dabria, was diagnosed with HIV five years ago, and has been on treatment since then and is doing well. Abongo has two younger brothers, five years and two years old, and they are both HIV-negative. Dabria is married and her husband Michael is HIV-negative. At his most recent appointment, the doctor told Dabria that Abongo needs to start taking ARVs. Dabria picks up the pills and start giving them to Abongo, but he keeps asking why he takes them and when can he stop. He also asks if his pills are making him sleepy sometimes and why. Dabria is afraid to have these discussions with Abongo as she does not know what to say. Michael proposes to have a conversation with his son first alone and then inviting Dabria to join. Dabria asks Michael to talk to Abongo's doctor first and ask for an advice on what to say. Instead, Michael decides to invite his brother Darian to join their conversation with Abongo.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Mother Dabria
- Father Michael
- Son Abongo
- Uncle Darian

Adolescent Disclosure to Caregiver or Family – Two Scenarios

Case V

The family gathers for the holidays at the grandmother's Akumaa home. Seventeen-year-old Nelima comes in with her four-month-old baby boy, Baraka. Nelima is not married, and the biological father of Baraka is not involved. She lives with her mother Mulumba and she dropped out of school while pregnant. There are several family members in the room and many children. One of the nephews opens Nelima's bag and pulls out a bottle of pills in front of everyone. Akumaa asks Nelima about them in front of everybody; Nelima starts crying and runs out. People start talking about HIV and family shame and Akumaa forbids discussing the topic further. Nelima is comforted by her mother, admits that she had a positive HIV test while pregnant, and has been taking ARVs to protect her baby from HIV. Nelima leaves the family gathering and calls her clinic counselor for advice. The counsellor asks to share the information with the community healthcare worker.

Discuss first: How to deal with the family reaction, get support, and avoid rejection? What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Young Mother Nelima
- Mother of Nelima, Mulumba
- Grandmother Akumaa
- Counsellor
- Community Healthcare Worker

Case VI

Octavia is 16-year-old girl who lives her aunt Gabi, uncle Jordan, and their four children aged 4, 7, 8, and 12. She has been living since losing both of her parents in a car accident when she was seven. She is doing well in school and is on the honor roll. Three months ago, Octavia met a young man named Saburo at a friends' house and they started seeing each other. He is working and has treated her well, giving her presents and taking her out. She is in love with Saburo and they have had sex. On a recent night out together, he told her they needed to have a serious conversation. He told her he has been recently diagnosed with HIV and he tells her she should get tested too. Octavia is deeply saddened and scared. She has been crying a lot. She finally decides to go find out at the local clinic and finds out that she is HIV-positive as well. The healthcare workers and counsellor are very supportive and provide her with information, contraception, and initiate her on ART. She comes back with the box of pills and decides to hide them under her bed. One of the younger children finds the box and asks her about the pills. She tells him to keep it as a secret, but she worries he will still tell his mother. She decides to talk to her aunt Gabi alone. It is a difficult conversation as Octavia and her aunt never discussed her having sex. During their conversation, her uncle Jordan walks unexpectedly into the room.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Teenager Octavia
- Aunt Gabi
- Uncle Jordan

Adolescent Disclosure to Friends, at School, Work, or in the Community – Six Scenarios

Case VII – Disclosing at School

Hassan is a 16-year-old young man who has been on ART for the past eight years and is doing well. He takes one pill of fixed dose combination per day. He has not had any measurements of his viral load in the last year, but has been healthily and has had a stable CD4 count. His parents disclosed his HIV status to him when he was 14. He denies being sexually active but has drunk alcohol on a few occasions. Hassan is planning to leave for boarding school in two months. The other members of the household include: mother Fatuma (who is HIV-positive and on treatment); father Osman (HIV status unknown); 18-year-old brother Juma (in the same boarding school, HIV-negative, unknown if he is aware of brother's status); 12-year-old sister Aisha (HIV-positive but unaware of her or her family members diagnosis); and 10-year-old brother Musa (HIV-negative). At a clinic appointment, Hassan, who is accompanied by his mother and father, asks about his HIV care while in boarding school.

Discuss first: What advice would you give to Hassan and his parents on disclosing his HIV status at school?

Now assign the roles and proceed with the disclosure:

- Young man Hassan
- Mother Fatuma
- Father Mohammed
- Healthcare Worker

Case VIII – Disclosing at School

It has been three and a half months since Djibali started the school year at his new boarding school. Djibali is a young man living with HIV, who known his HIV status since the age of 10. He has been on treatment most of his life and his viral load is undetectable. His mother died from AIDS, and his adoptive mother and biological father have always been supportive and engaged in his care. Since Djibali moved to boarding school, he has been taking his medications regularly. He hides them among his personal items and takes them mostly at night when his roommate is asleep. Some kids observed him using a flashlight at night and the rumors started that he might be doing something secretive, like witchcraft. His roommate Benjamin decided to spy on him and pulled his pill bottle out of his hands at night. In the morning, Benjamin shared the news with the rest of the classmates. The kids in the class began mocking Djibali, asking him if he has AIDS and whether he did something “wrong” to get it. The teacher called for calm, but noticed Djibali crying and asked him to stay after class to talk. Djibali told his teacher his HIV status. The teacher proposes to have an open discussion in the classroom and pledges his support. He invites the school nurse to join the classroom conversation.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Djibali
- Teacher
- School nurse
- Benjamin

Case IX – Disclosing to Friends

Lavonia, James, Maria, and Fahima are all teenagers in the same village. They are good friends and hang out together, going to the beach, movies, parties and talking on social media. Over the holidays, James travelled to visit his family and had a short affair with the girl in the village he used to date. At the community health day last week, James learned he was HIV positive. He spoke to the counselor, began treatment, and was told to come back in one month for follow-up. Since then he has been depressed and hasn’t wanted to go out, and his friends are asking him questions. James has decided to tell Fahim, but is reluctant to tell Lavonia and Maria about his HIV. He believes that girls will not be able to keep the secret and will tell other girls in the community and nobody will ever go out with him.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- James
- Fahim
- Lavonia
- Maria

Case X – Disclosing to Community

Davie is 22-years-old and is studying to become a high school teacher. Davie is HIV-positive, stable on ART, and his last viral load undetectable. In his first year at college, Davie found out about his HIV status and was linked to care through a college HIV outreach program. On a college break, he visits his village to see his parents and young brother Tom, to let them know he will be taking a teaching position in a district far from his village. Unknown to him, Tom is also HIV-positive.

During this visit home, he learns that the HCWs will be conducting a community health day and providing HIV services. He wants to use the opportunity to disclose his status to his village community to encourage other young adults to get tested. Davie comes to the clinic to share his intentions to disclose his status at the community meeting.

Discuss first: As HCW, what else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Davie
- Parents
- Brother Tom
- Healthcare Worker
- Nurse

Case XI – Disclosing at Faith Community

Malaika is 15-year-old girl living with HIV, and has been on treatment since the age of four, and is doing well. She lost her mom when she was four and has been living with her Aunt Elizabeth who treats her like her own child. With the support of a health care worker, Aunt Elizabeth disclosed Malaika’s HIV status to her when she turned 12 years old. She is prescribed an ART regimen with one pill once a day and is responsible for taking it every day.

At 14, Malaika joined a boarding secondary school. She is doing well at school, and an active member of a church youth group. Malaika has many good friends in the youth group and is the favorite babysitter for the youth pastor’s family. She shares her boarding room with her best friend Jayne from the youth group. Malaika keeps her HIV status to herself and struggles to find a good time to take her medication when Jayne is not in the room. She sometimes skips taking her meds. On her last visit to the hospital, the doctor told Malaika and Elizabeth that her viral load is very high.

Malaika wants to tell her best friend and youth pastor about her status, and has asked the HCW for help disclosing her status.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Malaika
- Aunt Elizabeth
- Best Friend Jayne
- Youth Pastor James
- HCW/Counsellor in Clinic

Case XII – Disclosing at Work

Akua, a 19-year-old girl, recently began working as an assistant at the pharmacy in the nearby town. Akua is a hard working young woman, who also helps her mother raise her two younger brothers while her father is working overseas. At the age of 17, Akua was diagnosed with HIV. She used to date an older man who helped her through school, and she believes she contracted HIV from him. She has been on treatment and doing well. She has not had any steady relationship with the partner for over a year now. Her mother knows her HIV status and has been supportive of her care and treatment. The only other person who knows Akua's HIV status is her best friend Maria, who is also 19 years of age and is studying at university. While at the pharmacy, Akua was helping to organize some medicines and recognized some of her pills; she also saw other pills for HIV and asked pharmacist Dave about them. When he was telling her about the medication, she asked whether they worked better than the pills she took. Akua realized that by asking that question, she had accidentally disclosed her HIV status. Dave pretended that he did not hear her question, but she thinks he did. She texted Maria and asked for advice on what to do next. Maria suggested she do nothing and wait. The next day, Dave told Akua that he no longer needed her help and she can start looking for another job. She calls her friend Maria again for advice and tells her mother what happened at work.

Discuss first: What else would you like to know? How you would like to address this situation of accidental disclosure?

Now assign the roles and proceed with the disclosure:

- Akua
- Pharmacist Dave
- Maria
- Mother

Adolescent Disclosure to Partner – 2 scenarios

Case XIII

Jabir, 19 years old, and Lana, 17 years old, have been dating for three months. They are in love and recently started having sex. However, Jabir has not told Lana that he was diagnosed as HIV-positive four years ago. When he was told he has HIV, he did not believe it because he has never felt ill so he never began treatment. Since being with Lana, however, he has been thinking more about his status and whether he could put her at risk for getting HIV. He decides to get tested again and the result is positive. Jabir is prescribed one tablet per day and is told that he needs to come back in one month. He asks about his partner, the counselor advises to have partner tested as well. Jabir now considers telling Lana about his HIV and bringing her with him to get tested on his next appointment. He is worried, however, that she might break up with him.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Jabir
- Lana

Case XIV

After a school trip, 16-year-old Tabitha notices that her classmate Mohammed is a rather handsome young man. He has been looking at her too and has walked her home from school several times. They begin dating and Mohammed tells Tabitha he's never had a girlfriend before. Tabitha really likes Mohammed, but she is afraid that he will pressure her to have sex. Tabitha and her mother Jamila are both living with HIV. They are both doing well on treatment and have been in care for many years. Jamila told Tabitha that she should not marry anyone so she does not give her HIV to her husband and she should not have children. She also told her that if she has sex with someone, she should tell the person she has HIV. Tabitha decides to tell Mohammed her HIV status, but does not know how to do it. She also does not want her mother to know that she has a boyfriend. She decides to talk to her peer clinic counsellor Brian and asks him for an advice on how to talk to Mohammed.

Discuss first: What else would you like to know? How you would like to proceed with the disclosure?

Now assign the roles and proceed with the disclosure:

- Tabitha
- Counsellor Brian
- Mother Jamila
- Mohammed

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