

## Module 7

# Providing Disclosure Counseling and Support

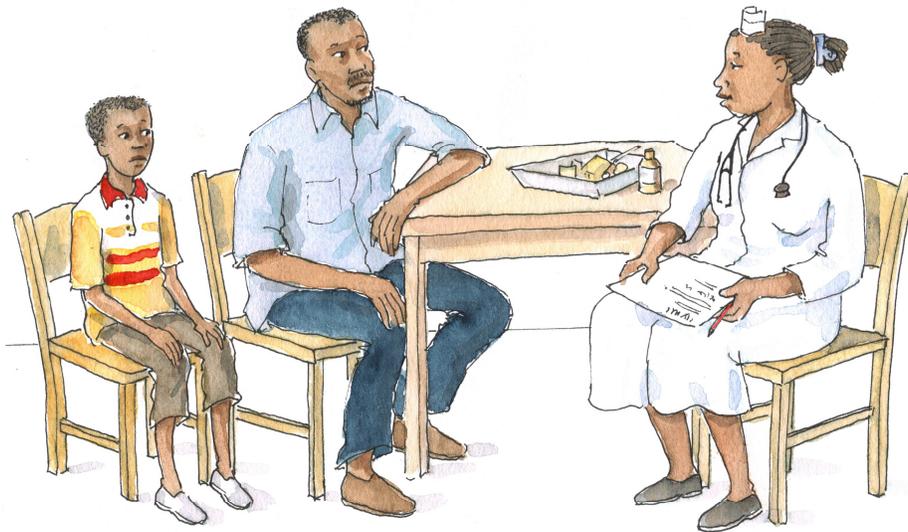
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<b>Session 7.1:</b>	<b>The Disclosure Process: A Developmental Approach</b>
<b>Session 7.2:</b>	<b>Disclosure Preparation, Counseling, and Support for Children, Young Adolescents, and Caregivers</b>
<b>Session 7.3:</b>	<b>Disclosure Counseling and Support for Adolescents Who Know Their Status</b>

### Learning Objectives

**After completing this module, participants will be able to:**

- Apply a developmental approach to the process of disclosure preparation
- Understand the reasons to disclose to children and young adolescents
- Discuss common barriers that health workers and caregivers have to disclosure and possible solutions for each
- Work with caregivers to understand the importance of disclosure and to prepare for and move through the disclosure process with children and adolescents
- Work through the disclosure process with children and young adolescents
- Provide counseling and support to adolescents on disclosing their HIV-status to others



## Session 7.1

# The Disclosure Process: A Developmental Approach

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### Session Objective

After completing this session, participants will be able to:

- Apply a developmental approach to the process of disclosure preparation

### Overview of Disclosure and ALHIV<sup>1,2</sup>

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#### What is disclosure?

- Disclosure should be seen as a process — not a one-time event — of telling a child/young adolescent that he or she has HIV and helping him or her understand what this means. It can also mean helping an ALHIV to disclose his or her HIV-status to others. It is a 2-way conversation that involves:
- Speaking truthfully with the child/adolescent (and sometimes the caregiver), over time, about his or her illness
- Disclosing the specific diagnosis at a time appropriate to the young person's needs, or helping the caregiver do so
- Helping the young person prepare to disclose to others and providing follow-up support during the process

#### Through the process, the child/young adolescent should come to know about:

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

#### Using a developmental approach to disclosure for children and adolescents:

- Decisions about when to start talking to children about their health should be based on the readiness of the caregiver and the developmental stage of the child.
- Each phase of childhood development has characteristic features. Understanding a child's/adolescent's developmental stage and needs is vital to disclosure. A young person's understanding of his or her HIV diagnosis will evolve as his or her brain becomes more equipped to absorb complex information and as his or her level of emotional maturity increases.
- Understanding childhood and adolescent development will help health workers and caregivers better guide the disclosure process, ensuring that appropriate information is presented at a time when the young person is able to cope with it.
- It is important to note that developmental stages are associated with approximate ages; however, just because a young person is a certain age does not necessarily mean that his or her development is the same as that of others in his or her age group. Therefore, it is essential that health workers ask questions to assess each young person's understanding.

See *Appendix 7A: Guidance for Developmentally Appropriate Disclosure* for additional information.

## Session 7.2

# Disclosure Preparation, Counseling, and Support for Children, Young Adolescents, and Caregivers

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### Session Objectives

After completing this session, participants will be able to:

- Understand the reasons to disclose to children and young adolescents
- Discuss common barriers that health workers and caregivers have to disclosure and possible solutions for each
- Work with caregivers to understand the importance of disclosure and to prepare for and move through the disclosure process with children and adolescents
- Work through the disclosure process with children and young adolescents

### Disclosure of HIV-Status to ALHIV

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To improve the chances that the disclosure process will proceed as smoothly as possible, health workers should start talking about disclosure with caregivers, and should start working with older children to prepare them for disclosure and assess their readiness for disclosure, WELL before a particular child becomes an adolescent. It is recommended that partial disclosure (see “Partial and Full Disclosure” on the next page) begin by the time the child is 6 years old. Ideally, the young person will already know about his or her HIV-status by the time he or she is a young adolescent. However, there are challenges associated with the disclosure process and health workers play an important role in helping families work through these barriers.

#### What are the reasons to disclose a child’s HIV-status?

- A literature review conducted by the WHO concluded that disclosing to HIV-infected children can result in health and psychological benefits. Also, there is little evidence of psychological or emotional harm caused by disclosing to a child. In most cases, initial emotional reactions to disclosure wear off over time and respond to adequate emotional support.<sup>3</sup>
- All children/adolescents have a right to know about their own health care.
- Adolescents often want and ask to know what is wrong. Adolescents are observant, smart, and curious.
- ALHIV who have not been disclosed to may:
  - Have frightening or incorrect ideas about their illness
  - Feel isolated and alone
  - Learn their HIV-status by mistake
  - Have poor adherence.
- Disclosure may help improve social functioning and school performance due to a decrease in stress.
- When children/young adolescents learn about their status directly from their caregivers, it can provide comfort and reassurance. Too often, they overhear health workers and caregivers talking about their health as if they were not in the room.
- Children and adolescents are exposed to unintended “clues” of their diagnosis; for example, HIV-related signs on the walls of the clinics they attend, etc.

- Disclosure is especially critical for orphaned or other vulnerable and most-at-risk children/young adolescents because they may wonder why they have lost a parent or been rejected by their family. Disclosure also helps them seek the services they need, especially in the case of those who do not have regular caregivers.
- Adolescents who know their HIV-status can access HIV care and treatment, take an active role in their care and treatment plan, and, when old enough, take steps to live positively, adhere to treatment, and prevent new infections.
- Disclosure affects the mental health of children, adolescents, and their caregivers. Non-disclosure does not protect children and adolescents. Levels of anxiety, depression, and low self-esteem have been shown to be higher in adolescents who have not been disclosed to. Parents who have disclosed the status to their children also experience better mental health outcomes (for example, less depression) than those who do not.

## Partial and Full Disclosure

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Disclosure to children and young adolescents should depend on their stage of development. Young children may only need to know that they are sick, that they have to go to the doctor, and that they need to take medicines to feel better (**partial disclosure**). Older children/young adolescents, on the other hand, should know that they have HIV, should understand the disease and their medications, and should actively participate in their own care and treatment (**full disclosure**). As a child/young adolescent develops, caregivers and health workers should eventually move from partial to full disclosure, gradually helping the child/young adolescent understand and cope with knowing his or her diagnosis.

### Partial disclosure:

Children develop the ability to think logically around 6 years of age. It is at this time that they are able to begin understanding the concept of illness and what causes it. Partial disclosure may therefore be considered around this age, particularly if the child has started asking questions related to his or her health. Partial disclosure:

- Refers to giving a child information about his or her illness without using the actual words “HIV” or “AIDS”
- Helps move the disclosure process forward and prepares the child/adolescent and caregivers for full disclosure later on
- Is an effective strategy to help caregivers who do not yet feel ready to use the terms “HIV” and “AIDS,” or for caregivers of young children who are not ready for full disclosure
- Is useful for creating a context in which full disclosure can be more meaningful for the child

**Full disclosure:**

“Full disclosure” is when a child/young adolescent is specifically told that he or she is HIV-infected and is given further HIV-related details, such as how HIV is transmitted and how he or she may have contracted it.

- Families and caregivers are ideally the ones who should decide at which point full disclosure is necessary. However, health workers should also assess the child’s readiness for disclosure, prepare him or her for disclosure, and provide follow-up information and support.
- It is generally recommended that children/young adolescents be fully disclosed to when they are developmentally ready to receive this information, which is typically by the time they are 10–12 years old.<sup>2</sup>
- A particularly important indication that full disclosure should be considered is when the child/young adolescent starts asking specific questions about his or her illness (for example, asking how he or she got the sickness) and no longer seems satisfied with the responses previously given.
- Full disclosure is easier for children/young adolescents if they have been partially disclosed to over time, understand some basics about their health and their care and medicines, and have been supported throughout the disclosure process by caregivers and health workers, including Adolescent Peer Educators if possible.

**There are occasional times when it may be more appropriate to delay the disclosure process with a child/young adolescent, such as:**

- When the child/young adolescent has severe cognitive and developmental delays
- When the child/young adolescent is grappling with serious health or mental health conditions
- When one or both parents/the caregiver has an acute health problem or mental health crisis

**Barriers to Disclosure**

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**Health worker barriers**

- Health workers experience some of the same barriers faced by caregivers, such as not knowing where to start or being concerned about harming the child/adolescent (see next section).
- Training is essential to equip health workers to support caregivers, children, and adolescents throughout the disclosure process. In addition, it is important that health workers ask the advice of peers who have been through this process with caregivers, children, and adolescents, and that they observe peers that have more experience.
- Knowing caregivers’ backgrounds, resources, and limitations will help improve health workers’ sense of understanding and comfort assisting and supporting the disclosure process.
- Table 7.1 includes a list of health worker barriers along with suggested solutions for each.

**Table 7.1: Solutions to health worker barriers to disclosure**

Health worker barrier	Suggested solutions
<b>Health worker is unsure about his or her role or thinks that the disclosure process is not his or her responsibility</b>	<ul style="list-style-type: none"> <li>• All members of the multidisciplinary team can support the disclosure process in various ways.</li> <li>• Discuss and define health workers’ roles in the disclosure process in order to promote effective coordination.</li> <li>• Make assessment of disclosure status a routine part of clinical review and multidisciplinary team case discussions about clients – the same way, for example, that CD4 count and growth/development are reviewed.</li> <li>• Use Adolescent Peer Educators and establish support groups for both caregivers and children/young adolescents.</li> </ul>
<b>Differences of opinion between health workers and caregivers</b>	<ul style="list-style-type: none"> <li>• Remember that disclosure is a process that takes time.</li> <li>• Try to prevent these situations by helping caregivers understand that as children become adolescents they have a greater need to know their HIV-status. This is to avoid accidental disclosure and unprotected sexual activity, and also so they can actively participate in their own care.</li> <li>• Carefully assess barriers to disclosure and work with the caregiver to reach an agreement on when and how to disclose to the adolescent.</li> <li>• Respect the caregiver’s decisions, but remember that health workers may have to directly assess and prepare the child/young adolescent for disclosure if they feel it is in the best interest of the client.</li> <li>• Discuss these situations with other members of the multidisciplinary team.</li> </ul>
<b>Differences of opinion among health workers — generally or related to a specific client</b>	<ul style="list-style-type: none"> <li>• If the differences of opinion were triggered by a specific client, convene a multidisciplinary case conference to bring together all the opinions about disclosure surrounding this client. If possible, invite an expert on disclosure to the meeting to add to the discussion. Use the eventual consensus as a precedent to inform future cases.</li> <li>• Discuss disclosure as an agenda item in the next multidisciplinary team meeting.</li> <li>• Invite adolescent clients, including Adolescent Peer Educators, to a discussion about the importance of disclosure during a regular team meeting or as a separately scheduled in-service training.</li> <li>• Identify which health workers on the team feel most confident in their abilities to work through the disclosure process with young clients and caregivers, and have these health workers train and mentor others.</li> <li>• Hold an in-service training on child/adolescent disclosure (using all or a portion of this module if desired) so that all members of the multidisciplinary team have the same information as well as a chance to discuss disclosure together.</li> </ul>

**Caregiver barriers**

Caregivers may not want to disclose their child’s HIV-status for a number of reasons, all of which should be explored and respected. Health workers should never judge a caregiver for their unwillingness to disclose, their fears about disclosure, or their “performance” during the disclosure process. Table 7.2 includes a partial list of caregiver barriers and suggested health worker responses for each. The health worker’s role in supporting caregivers and children/adolescents is discussed more in the next section.

**Table 7.2: Addressing caregiver barriers to disclosure**

Caregiver barrier	Suggested health worker responses/solutions
<p><b>Fear that disclosure will cause psychological harm to the child</b> (e.g. reduce will to live, make the child feel abnormal)</p>	<ul style="list-style-type: none"> <li>• Reassure caregivers of the positive psychological benefits of disclosure for children/adolescents and caregivers (e.g. higher self-esteem among young people who know their status, less depression among caregivers, etc.).</li> <li>• Connect caregivers to peers who have gone through the disclosure process and who are willing to share their experiences.</li> </ul>
<p><b>Concern that topic is too complicated for the child/adolescent to understand</b></p>	<ul style="list-style-type: none"> <li>• Reassure caregivers that health workers will work with them to ensure that all disclosure-related conversations are appropriate to the adolescent’s age and developmental status. Health workers can assess the client’s readiness and report impressions back to the caregiver.</li> <li>• The aim of the various conversations that should take place over many years is to help the child/adolescent become “appropriately aware of his or her illness” rather than to explain everything at once.</li> <li>• In some cases, health workers can play an active role in the actual disclosure process and in conversations with the child/young adolescent. This can reassure caregivers that they have support.</li> </ul>
<p><b>Uncertainty about where to start or how to respond to questions</b></p>	<ul style="list-style-type: none"> <li>• Begin talking to caregivers very early about the disclosure process — long before anything has been to the child/young adolescent.</li> <li>• Help caregivers plan where, when, and how to begin the process.</li> <li>• If requested by caregivers, health workers should be prepared to take a more active role in the disclosure process.</li> </ul>
<p><b>Lack of knowledge/comfort with topic</b></p>	<ul style="list-style-type: none"> <li>• Provide caregivers with the background information they need to discuss HIV with their children. Use job aides and offer take-away materials.</li> <li>• Ensure that caregivers’ questions are answered throughout the process.</li> <li>• Provide caregivers with possible answers to questions they anticipate the child/adolescent will ask.</li> <li>• Role play various disclosure scenarios to give caregivers practice.</li> <li>• Decide with caregivers what is appropriate/necessary to tell the child/young adolescent at each stage of development.</li> <li>• As above, sometimes health workers may need to take an active role in the disclosure process if caregivers feel uncomfortable.</li> </ul>
<p><b>Fear of stigma and discrimination against the child/adolescent and other family members</b></p>	<ul style="list-style-type: none"> <li>• Support caregivers to provide guidance to their children/adolescents about the people with whom they may safely speak about their illness.</li> <li>• Suggest that caregivers identify one or more trustworthy person to be a “safe” person — someone with whom the child can discuss his or her HIV-status, concerns, and treatment (this may be the health worker).</li> <li>• Involve caregivers and other family members early in the disclosure process to ensure that misinformation about HIV is corrected.</li> <li>• Refer the child/young adolescent and caregivers to support groups where others can provide advice on dealing with stigma.</li> <li>• Maintain a continuous open line of communication with the child/young adolescent to help him or her deal with his or her changing feelings about HIV and any negative reactions from society.</li> </ul>
<p><b>Parental guilt regarding transmission</b></p>	<ul style="list-style-type: none"> <li>• Remember that disclosure of HIV-status to children/young adolescents is often a family issue due to its relation to one/both parents’ HIV-status.</li> <li>• Help parents understand that they should not blame themselves.</li> <li>• Encourage parents to take care of themselves by going to the clinic regularly, taking their medication, etc.</li> <li>• Encourage parents to model positive living for their children. Healthy behaviors reflect a positive attitude toward life, thereby encouraging children to see their own lives with optimism.</li> </ul>

Table 7.2 adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; François-Xavier Bagnoud Center, University of Medicine and Dentistry of New Jersey. (2010). *HIV care & treatment training series, Module 6: Disclosure process for children ages 3 to 18 years of age living with HIV.*

## **The Health Worker's Role in the Disclosure Process: Overview**

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- The health worker plays a number of important roles in the disclosure process. Each of these roles is discussed in more detail in the sections that follow but, in summary, the health worker's role may include:
- Encouraging open dialogue and disclosure
- Offering practical and developmentally-appropriate strategies
- Assessing the child/young adolescent's readiness for partial or full disclosure and communicating impressions with caregivers
- Working with the caregiver/family to develop and follow a disclosure plan
- Preparing the child/young adolescent for disclosure
- Facilitating disclosure discussions — ideally with the caregiver but, in some cases, the health worker may have to take a more active role and lead these discussions
- Supporting the client and caregiver throughout the disclosure process
- Advocating for the needs of the child/young adolescent (which may, in some cases, put them in conflict with the caregiver)

It can be helpful for health workers to work as a team and to consult with each other to get suggestions on how to best support children, adolescents, caregivers, and families through the disclosure process.

## The Health Worker's Role in Supporting Caregivers with Disclosure

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**Supporting the caregiver during the disclosure process begins with his or her initial visits to the clinic. The health worker should:**

- Build trust by getting to know the caregiver; find out what HIV means to him or her.
- Assess the caregiver's readiness for the disclosure process, his or her psychosocial situation, and his or her ability to cope. Health workers can answer the caregiver's questions and identify his or her sources of support.
- Discuss the implications of disclosure with the caregiver and family to help them consider in advance the reactions of the child, other family members, friends, and teachers.
- Assess the child's readiness for disclosure and share your impressions with the caregiver, especially if he or she seems hesitant to disclose. Help caregivers consider the adolescent's stage of development and the implications thereof:
  - Children may only need to know that they are sick and have to go to the doctor and take medicines to feel better.
  - Young adolescents should know that they have HIV, should understand the disease and the medications they take, and should actively participate in their own care and treatment.
- Help the caregiver develop a disclosure plan for the child/young adolescent. The plan should:
  - List any preparations they need to make before starting the disclosure process
  - Include who will be involved in different stages of the disclosure process (and define the role of the health worker), what they will say, and how and where they will have disclosure discussions
  - Include plans for ongoing support throughout the disclosure process (from health workers, family members, peers, etc.)
- Arrange to see the caregiver (and the child/young adolescent) again to review where he or she is in the process.
- If there is disagreement between family members about the timing and process of disclosure, try to assess all family members' concerns, discuss the benefits and risks of disclosure, and discuss the potential harm of long-term non-disclosure. Collaborate with caregivers to make a plan tailored to meet the needs of the entire family.
- Always respect and try to understand caregivers' reasons for fearing or resisting disclosure. Validation of caregivers' concerns can foster a sense of partnership and can prevent an adversarial relationship from developing between caregivers and members of the health team.

**Remember: If the caregiver is not ready to disclose, the process cannot be forced. However, the health worker should always advocate for what is in the best interest of the child/young adolescent.**

Caregivers will also need ongoing support — from health workers, family members, and peers — as the disclosure process proceeds over time. Health workers should remember to use a developmental approach to disclosure, incorporating the techniques in *Appendix 7A: Guidance for Developmentally Appropriate Disclosure*.

Once the disclosure process has begun and the client knows more about his or her HIV-status (ideally well before the child has reached adolescence), health workers should ask the **caregiver** at each visit about support needs from health workers, family members, and peers:

- *Have you noticed any changes in your child's behavior since he or she learned about his or her HIV-status?*
- *Who else at home knows about the child's status?*
- *What kind of help, support, or information do you still need?*
  - Refer him or her to a caregiver support group if possible.
- *What feelings or concerns do you have about the disclosure process with your child?*
- *Who does your child have to talk with if he or she has questions?*
  - Remind the caregiver to offer support to the child/adolescent to cope with his or her emotions and feelings after disclosure.
- *What questions do you have?*
- *When will we meet again?*
  - Plan for a follow-up counseling session at the clinic with the child/adolescent and caregiver.

## **The Health Worker's Role in Supporting Children and Young Adolescents with Disclosure**

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In addition to helping caregivers prepare for and move through the disclosure process, health workers also play an important role in supporting children and young adolescents through this process.

- Health workers can **prepare the child/young adolescent** for disclosure through youth-friendly counseling and information sessions (see Module 4 for tips on communicating with children/adolescents) and by linking clients with peer support groups and Adolescent Peer Educators.
- Health workers can actively **assess the child/young adolescent's readiness** for partial or full disclosure by asking questions about his or her understanding of why he or she takes medicines and comes to the clinic. They can share impressions of the client's readiness for disclosure with caregivers and other members of the care team and work with them to make and implement an appropriate disclosure plan.
- In some cases, health workers may actually **be part of the disclosure discussions** with children/young adolescents. Ideally, these would be joint conversations with the health worker, client, and caregiver, but in some cases, the health worker may need to lead these discussions. It is always helpful to have the support of other members of the multidisciplinary team.
- Health workers should provide **post-disclosure and ongoing support** to the child/young adolescent. This is discussed more in the next section.

Health workers should remember to use a developmental approach to disclosure, incorporating some of the techniques in *Appendix 7A: Guidance for Developmentally Appropriate Disclosure*.

**Remember: Health workers can and should be advocates for the needs of their child/adolescent clients, including their disclosure needs.**

**Disclosure does not begin or end with a single conversation. As children/adolescents grow and develop, they need to be able to continue to ask questions and discuss their feelings.** Multiple forms of support — from health workers; caregivers and family members; and peers — are helpful. Once the disclosure process has begun (ideally well before the child has reached adolescence), health workers should ask the *client* at each visit (adjust to the age and developmental status of the client):

- *Why do you think you take these medications? What do you know about HIV?*
- *How have you been feeling since you learned about your HIV-status?*
- *Who else do you talk to about HIV and who do you ask if you have questions?*
  - Offer support to the young client to cope with his or her emotions and feelings after disclosure. Refer him or her to a peer support group and/or Adolescent Peer Educator if possible.
  - Make sure the client is given a chance to express his or her feelings — for example, through talking, role play, or drawing.
- *Who else knows about your HIV-status? What do you think about disclosing your status to (other) people you are close to?* (see the next session for more on supporting adolescents during their disclosure process to others)
- *What are some of the ways you are taking care of yourself? How do you think you can live positively with HIV?*
- *How are you doing with your medications?*
- *What other questions do you have?*
- *When should we meet again to talk more?*

### **Working with children and adolescents who do not have caregivers**

Sometimes children and adolescents do not have caregivers or do not have caregivers who play an active or consistent role in their care. Adolescents may be heads of households, they may be living with a sexual partner, or they may be homeless. In such situations, particularly if the client is coming to the clinic alone, the health worker (and if possible, more than one member of the multidisciplinary team) may have to take a more active or “parental” role in the disclosure process. This includes deciding when and how to begin and move forward with the disclosure process according to the client’s unique situation and developmental stage.

### **Working with children and adolescents in institutional care**

Sometimes children and adolescents live in institutional care instead of with a primary caregiver at home. This includes those who live in orphanages, foster homes, or education- or employment-related housing programs. In these cases, health workers should identify the person who is legally responsible for the child or adolescent and, if possible, invite that person (with the consent of the adolescent client) to the clinic for an educational and counseling session related to disclosure. As with children and adolescents who do not have primary caregivers, the health worker may have to take a more active or “parental” role in the disclosure process.

**Exercise 1: Supporting Caregivers with the Disclosure Process: Start-stop role plays and large group discussion**

<b>Purpose</b>	To give participants an opportunity to develop the knowledge, skills, and confidence to support caregivers and clients during the disclosure process
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Refer to *Appendix 7A: Guidance for Developmentally Appropriate Disclosure*.

**Start-Stop Role Play - Case Study 1:**

A mother named E\_\_\_ has been caring for her HIV-infected 10-year-old son, T\_\_\_. T\_\_\_ keeps asking you why he has to take these pills and says he wants to know when he will be done with them. When you ask his mother what T\_\_\_ knows about his health, she becomes quiet. *How would you proceed?*

**Start-Stop Role Play - Case Study 2:**

A\_\_\_ is 11 years old. She has lived with her grandmother since her mother died three years ago. A\_\_\_ and her grandmother have been coming to the clinic since A\_\_\_ started to become symptomatic and the doctor wants her to start ART soon. The grandmother is having problems giving A\_\_\_ her CTX. You believe that A\_\_\_ would cooperate better if she understood more about the medication and why she needs it, especially since ART is now about to become part of their everyday lives. The grandmother thinks A\_\_\_ is too young to know her status and insists she does not need to know yet. *How would you proceed?*

**Start-Stop Role Play - Case Study 3:**

G\_\_\_ is a 12-year-old boy living with HIV and taking ART. He lives with his mother, uncle, and 5 older siblings and cousins. G\_\_\_ has come to the clinic with his mother today. She tells you that before she thought she was doing the right thing by moving from partial to full disclosure with her son over the last couple of months. Now, however, she thinks she might have done the wrong thing by fully disclosing because her son hasn't asked any questions about his status, seems sad all the time, doesn't want to take his medicines, and is acting out in school. Today, G\_\_\_ seems very withdrawn even though he tells you, "I am fine." *How would you proceed?*

## Session 7.3

# Disclosure Counseling and Support for Adolescents Who Know Their Status

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### Session Objective

After completing this session, participants will be able to:

- Provide counseling and support to adolescents on disclosing their HIV-status to others

### Providing Disclosure Support to ALHIV

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Health workers can work with ALHIV to help them to understand why disclosure is important and to decide to whom they should disclose. Health workers can also help ALHIV prepare for disclosure and can provide them with follow-up support.

#### Advantages of disclosure may include:

- Avoiding the burden of secrecy and the feeling of hiding
- Avoiding anxiety about accidental or unwanted disclosure
- Gaining access to emotional and practical support from peers or family members, including the freedom to talk about symptoms and concerns
- Gaining easier access to health care
- Enhanced adherence to care and medication
- Enhanced ability to discuss safer sex and family planning choices with one's partner(s)
- Enhanced ability to refer partners for HIV counseling and testing, and to care and treatment if needed
- Gaining the freedom to ask a friend or relative to be a treatment buddy
- Gaining access to peer support groups and community organizations
- Serving as a disclosure role model for other people

#### Disadvantages of disclosure may include:

- Receiving blame by partner or family for "bringing HIV into the household"
- Distancing, fear, rejection, or abandonment by partners, family, or friends/classmates
- Discrimination or rejection at school
- Discrimination or rejection in the community
- Discrimination or rejection at work, including possible loss of job
- Others making assumptions about one's sexuality, promiscuity, or lifestyle choices
- Reluctance on the part of partners to enter into intimate relationships or have children
- Physical violence
- Self-stigma
- Loss of economic/subsistence support from family members or partners

## Helping ALHIV with the Disclosure Process

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### Disclosure counseling:

- Should not include pressure to disclose
- Is a confidential conversation that helps clients work through the issues related to telling others about their HIV-status
- Is important to reduce stigma, enhance adherence to care and treatment, and reduce the spread of HIV
- Is intended to promote informed decisions about whether or not clients should disclose their HIV-status and, if so, to whom
- Assists and supports clients who have decided to disclose their status
- Enhances coping strategies following disclosure
- Uses a tailored and developmental counseling approach — since each adolescent is unique
- Is an ongoing process that requires preparation, practice, and follow-up support

### Adolescents should make their own decisions about disclosure, but health workers can assist ALHIV in the disclosure process by:

- Using good communication and counseling skills (for example, the 7 Listening and Learning Skills from Module 4)
- Talking about the client’s feelings and fears around disclosure
- Discussing the advantages and disadvantages of disclosure specific to the client’s life
- Supporting clients to make their own decisions about disclosure
- Helping clients decide whom to disclose to, when, and where
- Helping clients identify barriers to and fears about disclosure
- Exploring possible options to overcome barriers
- Providing accurate and detailed information in response to questions
- Assisting the adolescent to anticipate likely responses to disclosure
- Talking about current and past sexual partners who need to be notified of their HIV risk
- Offering reassurance and emotional support
- Identifying sources of support and referring clients to peer support groups
- Encouraging clients to take the time needed to think things through
- Practicing disclosure through role plays, including providing practical suggestions about how they can start the conversation. For example, health workers can suggest the following “conversation starters” to clients who are unsure about what to say to family or friends:
  - *“I wanted to talk to you about something because I know you can help and support me.”*
  - *“I went to the clinic today for a checkup. They told me how it is important for everyone to get an HIV test because you cannot tell if someone has it by looking at them.”*
  - *“I want to talk with you about something very important. I am talking to you about it because I love you and I trust you.”*
  - *“I need to talk to you about something that is very difficult for me to discuss.”*
- Providing ongoing follow-up and support throughout the disclosure process

#### Peer support and disclosure

- Peer support can be an excellent resource for adolescent clients who are making decisions about disclosure:
- **Peer Educators and peer support groups:** Adolescents may find it helpful to meet each other for mutual support.
- **Groups for caregivers of ALHIV:** Family members of ALHIV may benefit from talking with other families or with a health worker in a support group setting.

### Deciding about disclosure

- A good way to understand disclosure and to help adolescents decide who they will disclose to is by creating “disclosure circles” (see Figure 7.1).
- The center of the circle is the adolescent (self).
- The next circle out is a person or people the adolescent is very close to, such as his or her mother, siblings, or partner (give the adolescent a piece of paper so that he or she can write the names of the people at this and the next layers of his or her own disclosure circles).
- The next circle includes larger groups of people that the person is not as close to, such as people at work or others in the community.
- There can be many levels to the circles of disclosure.
- Each level of disclosure represents a process in itself — preparing for disclosure, the actual disclosure process, and ongoing conversations after disclosure. Remember that the conversation does not end after disclosure — there will likely be ongoing discussions over time between the client and the person to whom he or she disclosed.
- The goal is NOT that all people will eventually disclose to all of the people included in the circles. Instead, the circles provide a way of discussing the disclosure process, of considering the risks and benefits of disclosing to different people, and of helping to prioritize disclosure activities.

**Figure 7.1: Disclosure circles**



Source: Colton, T., Costa, C., Twyman, P., Westra, L., and Abrams, E. (2009). *Comprehensive peer educator training curriculum, Trainer manual, Version 1.0*. ICAP.

**Exercise 2: Supporting ALHIV with the Disclosure Process: Role plays and large group discussion**

<b>Purpose</b>	To provide participants with an opportunity to discuss strategies for assisting ALHIV with the disclosure process
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**Case Study 1:**

C\_\_\_ is 15 years old and found out that he is HIV-infected at a VCT clinic 2 months ago. Today, he has returned to the ART clinic for a second visit and says that he has not yet told anyone about his HIV-status because he is too ashamed and scared to tell his family. *How would you help C\_\_\_?*

**Case Study 2:**

L\_\_\_ is a 16-year-old girl who was perinatally infected with HIV. L\_\_\_ mentions that she really wants to disclose her status to one of her male friends at school. L\_\_\_ likes this boy very much and she knows that he likes her, but she is nervous about her friend's reaction. They have been arguing recently because L\_\_\_ has been avoiding him. She asks your opinion about what to do. *How do you proceed?*

**Case Study 3:**

J\_\_\_ is a 14-year-old female orphan with HIV who lives with her maternal aunt and uncle. J\_\_\_ just started a new school and is afraid that she will be thought of as different from the other kids if anyone finds out she is living with HIV. She has not disclosed her status to anyone at school. *How would you proceed with J\_\_\_?*

**Case Study 4:**

An 18-year-old named I\_\_\_ tested positive for HIV about 2 years ago. He got tested because his girlfriend at that time found out she was HIV-infected. He has since changed girlfriends, however, and has not yet told his new girlfriend about his HIV-status. He takes good care of himself and feels fine. He has come to the clinic today for his regular appointment and wants to talk with you about how to tell his girlfriend that he is living with HIV. *How would you help I\_\_\_ prepare for the process of disclosing to his girlfriend?*



## Module 7: Key Points

- Disclosure is an ongoing process, not a one-time event. Most children, adolescents, and caregivers need support planning for disclosure as well as with the actual disclosure conversation and with post-disclosure follow up.
- Disclosure can help young clients access prevention, care, treatment, and support. It can also help improve adherence; help reduce stigma and discrimination by bringing HIV out into the open, and help slow the spread of HIV by helping people protect themselves and their partners.
- There is little evidence that disclosing to HIV-infected children/young adolescents results in psychological or emotional harm. Rather, studies suggest that disclosure can result in health benefits for the child/adolescent and caregiver.
- Health workers and caregivers may face barriers to disclosure, such as not knowing where to start or feeling concerned about harming the child/adolescent. Training, working together as a multidisciplinary team, and understanding the backgrounds, limitations, and resources of caregivers can help health workers overcome these barriers.
- Health workers play several important roles in the disclosure process, including assessing the client's and caregiver's readiness, working with the caregiver to develop and follow a disclosure plan, preparing the client for different stages in the disclosure process, and supporting the client and caregiver throughout the process.
- Health workers should advocate for the best interests of the child/adolescent and, in some cases, — such as when the caregiver does not want to/will not disclose or when there is no active participation of a primary caregiver — they may have to take a more active or “parental” role in the disclosure process.
- Health workers can support adolescents decide to whom to disclose their HIV status, when, and where; they can help them weigh the advantages and disadvantages of disclosure; and they can help them anticipate likely responses.

## Appendix 7A: Guidance for Developmentally Appropriate Disclosure

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent may have	Possible responses to questions or ways of explaining things to the adolescent
<b>Younger adolescents (approximately 10–13 years old)</b>			
<ul style="list-style-type: none"> <li>• Beginning to understand cause and effect, but still struggle with abstract concepts</li> <li>• Have growing vocabulary, but struggle to express ideas and feelings in words</li> <li>• Enjoy activities that give them a chance to control, organize, and order things</li> <li>• May regress and want help from adults if feeling insecure or unsure</li> </ul>	<ul style="list-style-type: none"> <li>• Be truthful.</li> <li>• Ideally, the disclosure process will have already started by this age.</li> <li>• Give more detailed information using concrete examples.</li> <li>• If they ask for more information (for example, “<i>What’s the germ called?</i>” or “<i>How did the germ get in my body?</i>”), give short, clear answers.</li> <li>• Help them deal with possible stigma.</li> <li>• Reassure them that they can ask further questions or share any of their concerns with you now or later.</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Why do I have to go to the clinic (so much)?</i></li> <li>• <i>Why am I sick?</i></li> <li>• <i>Why do I have to take medicine?</i></li> <li>• <i>Am I going to die?</i></li> <li>• <i>How did I get HIV?</i></li> <li>• <i>Who knows that I have HIV?</i></li> <li>• <i>Do I have to tell people I have HIV?</i></li> <li>• <i>What will happen if people find out I have HIV?</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Going to the clinic will help you stay well.</i></li> <li>• <i>You have a virus in your blood called HIV. It attacks the germ fighters in your body. This is why you get sick sometimes.</i></li> <li>• <i>You and I (if mother or caregiver is also HIV-infected) both have HIV in our bodies.</i></li> <li>• <i>You have to take medicine so the germ fighters can work and so you won’t get sick as much.</i></li> <li>• <i>You (and I, if appropriate) take medicine to keep you/ us strong.</i></li> <li>• <i>The medicines that we have to treat this virus are very good. If you take your medicine the right way, every day, and never miss a dose, you can stay healthy for a very long time.</i></li> <li>• <i>HIV is nothing to be ashamed of, but it is something private. You don’t have to tell other people if you don’t want to.</i></li> <li>• <i>You can talk to me about it at any time.</i></li> <li>• <i>Maybe we should keep this within the family for now?</i></li> </ul>
<b>Older adolescents (approximately 14–19 years old)</b>			
<ul style="list-style-type: none"> <li>• Beginning to be able to think in more abstract terms</li> <li>• Want solid, well-thought-out explanations</li> <li>• Body changes may create feelings of insecurity</li> </ul>	<ul style="list-style-type: none"> <li>• Ideally, they will have been fully disclosed to by this age.</li> <li>• Accurate and more detailed information can be given in response to questions.</li> <li>• Realistic information about health status should be given and all questions should be answered.</li> </ul>	<ul style="list-style-type: none"> <li>• <i>What is HIV?</i></li> <li>• <i>Why do I have HIV?</i></li> <li>• <i>Can I give HIV to my (girl/ boy) friend? How?</i></li> <li>• <i>Why do I have to go to the clinic so often?</i></li> <li>• <i>What are the health workers looking at in my blood?</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>You have the HIV virus. A virus is something that gets into your blood and can make you sick. Having HIV does not mean that you will be sick all the time.</i></li> <li>• <i>Health workers look at your blood to see how many healthy cells (called CD4 cells) are in it. The higher your CD4 count, the better.</i></li> </ul>

Age group characteristics	Disclosure considerations and guidance	Possible questions the adolescent may have	Possible responses to questions or ways of explaining things to the adolescent
<ul style="list-style-type: none"> <li>Forming a sense of identity — peer approval and social acceptance very important</li> </ul>	<ul style="list-style-type: none"> <li>Be sure to ask about and discuss their feelings and fears about HIV.</li> <li>Ask questions about their understanding and address misperceptions, for example, “<i>What have you heard about HIV?</i>”</li> <li>Ways to live meaningfully with HIV are a common concern (including having relationships). Issues like risk reduction and living positively with HIV should be discussed.</li> <li>It is very important that they are assured that their status and what they say is confidential.</li> <li>Normal adolescent striving for independence may complicate the response to disclosure (for example, it might result in a decline in adherence).</li> <li>Issues of disclosure to others should be discussed but adolescents should make their own decisions about this matter.</li> <li>Assurance of support and willingness to help should be given without seeming intrusive.</li> </ul>	<ul style="list-style-type: none"> <li><i>What if I want to get married and have children? Is that possible for people living with HIV?</i></li> <li><i>Who should I tell that I have HIV?</i></li> <li><i>Why are people mean to people with HIV?</i></li> </ul>	<ul style="list-style-type: none"> <li><i>You can control the virus by taking your medication every day, at the same time, and never missing a dose. But there is no way you can get rid of HIV completely.</i></li> <li><i>If you stop taking your medicine, the virus will get stronger and damage all of your healthy CD4 cells. If that happens, you can get sick.</i></li> <li><i>Knowing that you have HIV gives you a special responsibility to take extra good care of yourself and to not pass HIV to other people.</i></li> <li><i>People with HIV can and do live long lives, have relationships, and get married.</i></li> <li><i>If you have sex, it is important that you and your partner use a condom. Taking your ARVs the right way, every day, also lowers the amount of virus in your body and makes it less likely that you will pass HIV to your partner during sex.</i></li> <li><i>You can have a baby in the future, but there are risks of passing HIV to your partner or to the baby. There are many things you could do to lower the chances that your baby will get HIV. Taking your ARVs the right way, every day, will help lower the chance of passing HIV to either your partner or your baby. We can talk more about this whenever you like.</i></li> </ul>

Adapted from: The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. (2010). *HIV care & treatment training series, Module 6: Disclosure process for children ages 3 to 18 years of age living with HIV.*

## References

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<sup>1</sup> Adherence Networking Group. (2006). *Kids count: Guide for trainers, Children's ART adherence resource pack*.

<sup>2</sup> The South to South Partnership for Comprehensive Family HIV Care and Treatment Program; ICAP; François Xavier Bagnoud, University of Medicine and Dentistry of New Jersey. (2010). *HIV care & treatment training series, Module 6: Disclosure process for children ages 3 to 18 years of age living with HIV*.

<sup>3</sup> WHO. (2011). *Guidance on HIV disclosure counselling for children 12 years of age and younger: A look at the evidence (Draft)*.