

## Adolescent HIV Care and Treatment

### Module 7:

### Providing Disclosure Counseling and Support



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## Module 7 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

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## Session 7.1

### The Disclosure Process: A Developmental Approach

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## Session 7.1 Objective

### After completing this session, participants will be able to:

- Apply a developmental approach to the process of disclosure preparation

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## Discussion Questions

- *What have been some of your personal experiences and challenges working with caregivers who need assistance disclosing to children/adolescents?*
- *What about with ALHIV who know their status and need assistance disclosing to others?*



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## Discussion Questions

- *What is meant by the term “disclosure?” How does this translate into the local language?*
- *What do you think is meant by the phrase, “Disclosure is an ongoing process?”*
- *What is meant by a “developmental approach” to disclosure? What are some examples of this with younger and older adolescents?*

See Appendix 7A: Guidance for Developmentally Appropriate Disclosure.

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## Overview of Disclosure and ALHIV

- Disclosure is an **ongoing process** of:
  - Telling a child/young adolescent that he or she has HIV
  - Helping him or her understand what this means
  - Helping him or her disclose his or her HIV-status to others
- Disclosure is a **2-way conversation** that involves:
  - Speaking truthfully with the child/adolescent, over time, about his or her illness
  - Disclosing the diagnosis at an appropriate time, or helping the caregiver to do so
  - Helping the ALHIV prepare to disclose to others and providing follow-up support

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## Overview of Disclosure and ALHIV

(Continued)

The disclosure process should begin early by addressing the child's health status and his or her need for care and treatment. In the early stages, very simple terms should be used.

**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 (e.g., adherence) and his or her responsibilities now and in the future
- How to cope with the possible negative (and positive) reactions of others

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## Remember:



Ideally, adolescent clients will already know their HIV-status and their caregivers will be well into the disclosure process. However, some adolescent clients, especially those on the younger end of the adolescent spectrum, may not be fully disclosed to.

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## Overview of Disclosure and ALHIV

(Continued)

**Using a developmental approach to disclosure:**

- Decisions 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 and will help ensure that information is presented when the young person is able to cope with it.

Developmental stages are associated with **approximate ages**. It is essential that health workers ask questions to assess each ALHIV's understanding (see *Appendix 7A*).

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Questions or comments on  
this session?

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## Session 7.2

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

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## Session 7.2: 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

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## Discussion Questions

- *Do you think it is important for children and adolescents to know their HIV-status? Why or why not?*
- *When do you think the disclosure process should start? Why?*
- *What challenges have you encountered with adolescents who do not know their status? How can health workers prevent these challenges?*
- *What is the difference between partial and full disclosure? How does this apply to children and young adolescents?*
- *Do you think there are times when disclosure to a child/young adolescent should be delayed?*

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## Disclosure of HIV-Status to ALHIV

### Remember:

- Disclosure of a child's HIV-status is often one of the most sensitive issues for caregivers.
- All young people have a right to participate in decision-making about their health care.
- Start talking about disclosure with caregivers and start working with older children to prepare them for disclosure WELL before the child is an adolescent.
- Partial disclosure should begin by the time the child is 6 years old (for perinatally infected children).
- Full disclosure is recommended by age 10-12, but this depends on each individual child and family.

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## Reasons to Disclose a Child's HIV-Status

- Can result in health and psychological benefits for the child
- Children/adolescents have a right to know
- Adolescents often want and ask to know what is wrong
- Non-disclosure may lead to incorrect ideas, feelings of being alone, learning one's status by mistake, or poor adherence
- May improve social functioning and school performance
- Caregivers can provide comfort and reassurance
- Children are exposed to unintended "clues" of their diagnosis
- Orphans and other vulnerable children may wonder why they've lost a parent or been rejected by family
- They can then take an active role in their care and live positively
- Levels of anxiety, depression, and low self-esteem are higher in adolescents who have not been disclosed to
- Parents who have disclosed also experience better mental health outcomes

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## Partial and Full Disclosure

### Partial disclosure:

- Appropriate for younger children
- Refers to giving information about a child's illness without using the words "HIV" or "AIDS"
- Helps move the disclosure process forward; prepares client and caregivers for full disclosure later on
- Is an effective strategy to help caregivers who do not feel ready for full disclosure
- Is useful for creating a context in which full disclosure can be more meaningful for the child

Consider partial disclosure by the time a child is **6 years old**, particularly if he or she has started asking questions related to his or her health.

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## Partial and Full Disclosure (Continued)

### Full disclosure:

- When a child/young adolescent is told that he or she is HIV-infected and is given further HIV-related details
- Caregivers are ideally the ones who should decide when it is time for full disclosure
- It is generally recommended that full disclosure happen by the time a client is **10-12 years old**
- Full disclosure should be considered when the child/young adolescent starts asking specific questions about his or her illness
- Easiest if child/young adolescent has been partially disclosed to over time and has been supported throughout the disclosure process

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## Delaying Disclosure

- There are occasional times when it may be more appropriate to delay the disclosure process, 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

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## Brainstorming: Barriers to Disclosure

First, please write on flip chart:

- *What are some barriers that health workers have to disclosure?*
- *What are some barriers that caregivers have to disclosure?*

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## Barriers to Disclosure and Solutions

Next, as a large group discuss:

- *What are possible solutions to each barrier?*

See Tables 7.1 and 7.2.

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## Debriefing

- Health workers should start talking about disclosure with caregivers (and in some cases young clients) WELL before a particular child has become an adolescent.
- Health workers play an important role in helping children, adolescents, and their families negotiate the challenges and barriers to moving through the disclosure process.
- Knowledge of their status may help promote clients' adherence to care and treatment, while not knowing or having a confused understanding may cause difficulties with adherence, psychosocial well being, and positive living.

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## Discuss in Pairs

- *How would you summarize the health worker's role in the disclosure process with children/young adolescents?*



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## Health Worker's Role in Disclosure

- Encourage open dialogue and disclosure
- Offer practical and developmentally appropriate strategies
- Assess the child/young adolescent's readiness for disclosure and communicate impressions with caregivers
- Help family develop and follow a disclosure plan
- Prepare the client for disclosure
- Facilitate disclosure discussions and, if needed, take a more active role in the disclosure process
- Support client and caregiver throughout the process
- Advocate for the needs of the client

**Remember:** Work with and consult the MDT to best support children, adolescents, and caregivers through the disclosure process.

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## Discussion Questions

- *How can health workers help parents and caregivers prepare for different stages of the disclosure process?*
- *What is the health worker's role in the process?*
- *How would you respond if a caregiver did not seem ready to start or move forward with the disclosure process?*
- *How can health workers provide ongoing support to caregivers throughout the disclosure process?*

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## Overview of the Health Workers' Role in the Disclosure Process

### The health worker's role may include:

- Encouraging open dialogue and disclosure
- Offering practical and developmentally-appropriate strategies
- Assessing the child's readiness for partial/full disclosure
- Working with caregivers to develop and follow a disclosure plan
- Preparing the child for disclosure
- Facilitating disclosure discussions
- Supporting the client and caregiver throughout the disclosure process
- Advocating for the needs of the child/young adolescent

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

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

**Remember:** 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.

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## Providing Ongoing Disclosure Support to Caregivers

**Caregivers will also need ongoing support** — from health workers, family members, and peers — as the disclosure process proceeds over time.

### At each visit, ask the caregiver follow-up questions, such as:

- *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?*
- *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?*
- *What questions do you have?*
- *When will we meet again?*

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## Discussion Questions

- *How can health workers assess a child/young adolescent's readiness for disclosure?*
- *How can health workers help prepare children/young adolescents for disclosure?*
- *How can health workers advocate for the needs of the child/young adolescent client, especially if there is disagreement between caregivers and health workers regarding disclosure?*
- *How can health workers provide ongoing support to young clients through the disclosure process?*

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

- Prepare the child/young adolescent for disclosure.
- Actively assess the client's readiness for partial or full disclosure.
- In some cases, be part of the disclosure discussions with the client.
- Provide post-disclosure and ongoing support.
- See *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.

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## Providing Ongoing Disclosure Support to Children/Adolescents

**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.

**At each visit, ask the client questions about disclosure, such as:**

- *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?*

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## Providing Ongoing Disclosure Support to Children/Adolescents (Continued)

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

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## Special Cases

**When working with children and adolescents who do not have caregivers or do not have caregivers who are actively involved:**

- 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.

**When working with children and adolescents in institutional care:**

- Health workers should identify the person who is legally responsible for the child or adolescent and, if possible, invite that person to the clinic for a session related to disclosure.

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## Exercise 1

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

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## Exercise 1: Start-Stop Role Play 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 the mother what T\_\_\_ knows about his health, she becomes quiet.

→ *How would you proceed?*

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## Exercise 1: Case Study Discussion Questions

- *What types of questions is T\_\_\_ likely to ask about his illness? What are some possible responses? (See Appendix 7A.)*
- *What can the health worker do to help the caregiver prepare for the disclosure process?*
- *How can the health worker assess the caregiver’s readiness for or knowledge about disclosure?*
- *What age-specific activities, if any, can the health worker introduce during the session?*

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## Exercise 1: Start-Stop Role Play 2

A\_\_ is 11 years old. She has lived with her grandmother since her mother died 3 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?*

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## Exercise 1: Case Study Discussion Questions

- *What types of questions is A\_\_ likely to ask about her illness? What are some possible responses? (See Appendix 7A.)*
- *What can the health worker do to help the caregiver prepare for the disclosure process?*
- *How can the health worker assess the caregiver's readiness for or knowledge about disclosure?*
- *What age-specific activities, if any, can the health worker introduce during the session?*

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## Exercise 1: Start-Stop Role Play 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?*

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## Exercise 1: Case Study Discussion Questions

- *What types of questions is G\_\_ likely to ask? What are some possible responses? (See Appendix 7A.)*
- *What can the health worker do to support the caregiver?*
- *What can the health worker do to support the client?*
- *What age-specific activities, if any, can the health worker introduce during the session?*

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## Exercise 1: Debriefing

- *What did we learn?*
- **Key points:**
  - The disclosure process can be affected by many complex personal and family issues. We need to take a multidisciplinary approach to best support clients and families.
  - As health workers, we may be asked to act as intermediaries, helping to guide and support caregivers through the disclosure process and/or we may need to take a more active or "parental" role in disclosure preparation, discussion, and follow-up with young clients.
  - In all cases, it is important that we balance what is in the best interest of the client with the needs, wishes, and views of the caregivers.

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**Questions or comments on this session?**

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## Session 7.3

### Disclosure Counseling and Support for Adolescents Who Know Their Status

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## Session 7.3 Objective

After completing this session, participants will be able to:

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

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## Brainstorming

- *What are some potential advantages of disclosure for ALHIV?*
- *What are potential disadvantages?*



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## Advantages of Disclosure May Include:

- Avoiding the burden of secrecy
- Avoiding anxiety about accidental disclosure
- Gaining access to emotional and practical support
- Easier access to health care
- Better adherence
- Easier to discuss safer sex and family planning with partners
- Easier to talk about testing with partners
- Gaining the freed to find a treatment buddy
- Gaining access to peer support groups and community organizations
- Serving as a disclosure role model for others

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## Disadvantages of Disclosure May Include:

- Blame from partner or family
- Distancing, fear, rejection, or abandonment from family, partners, or friends
- Discrimination or rejection at school, in the community, or at work
- Assumptions made by others about one's sexuality, promiscuity, or lifestyle choices
- Partner reluctance to enter into intimate relationships or have children
- Physical violence
- Self-stigma
- Loss of economic/subsistence support from family members or partners

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## Remember:

- ALHIV can feel very isolated. Health workers can help adolescents understand that one of the advantages of disclosure is that they will have friends who know their diagnosis and who can support them.
- Because of their special status (no longer children, not yet adults), adolescents need support with the disclosure process from the entire MDT.
- Adolescents should always make their own decisions about disclosure.
- Health workers can support ALHIV to decide whom to disclose to, to decide when and where to disclose, to weigh the advantages and disadvantages of disclosure, and to anticipate likely responses.

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## Discussion Questions

- What are some different ways health workers can help support adolescents when they are considering disclosing their HIV-status to others?
- What are some of the main considerations when providing disclosure counseling to ALHIV?



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## Disclosure Counseling:

- Should not include pressure to disclose
- Is a confidential conversation that helps clients work through issues
- Is important to reduce stigma, enhance adherence, and reduce the spread of HIV
- Should promote informed decision-making
- Assists and supports clients who have decided to disclose
- Enhances coping strategies post-disclosure
- Uses a tailored and developmental approach
- Is an ongoing process requiring preparation, practice, and follow-up support

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## Remember:

- Because disclosure is a process, it is important that health workers **continue to check in with clients about the progress they are making and the challenges they are encountering** disclosing their HIV-status to others.
- This should NOT include putting pressure on clients to disclose, but should rather focus on supporting clients to work through issues related to disclosure and helping them make a plan.

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## Ways to Assist ALHIV in the Disclosure Process:

- Use good communication and counseling skills
- Talk about their feelings and fears
- Discuss advantages and disadvantages
- Support them to make their own decisions
- Help them decide whom to disclose to, when, and where
- Help them identify barriers and possible solutions
- Provide accurate information in response to questions
- Help them anticipate likely responses to disclosure
- Talk about sexual partners
- Offer reassurance and emotional support
- Identify sources of support and refer clients to peer support
- Encourage them to take time to think things through
- Practice disclosure through role plays
- Provide ongoing follow-up and support

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## Peer Support and Disclosure

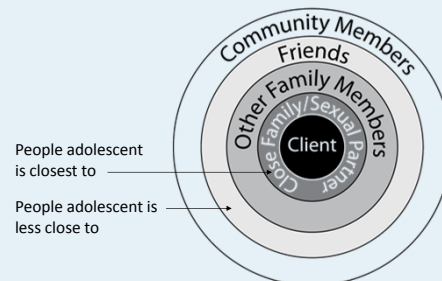


- Peer support can be an excellent resource for adolescents making decisions about disclosure.
- Peer Educators and peer support groups:** Adolescents may find it helpful to meet each other for mutual support.
- Groups for caregivers of ALHIV:** Family members of ALHIV may benefit from talking with other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

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## Deciding About Disclosure

- Creating disclosure circles can help adolescents decide who to disclose to; each level represents a process in itself (see Figure 7.1)



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## Exercise 2

### Supporting ALHIV with the Disclosure Process: Role plays and large group discussion

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## Exercise 2: 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\_\_\_?



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## Exercise 2: 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?

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## Exercise 2: 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\_\_\_?

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## Exercise 2: 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?

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## Exercise 2: Additional Case Study Discussion Questions

- How would you counsel and support the client during the disclosure process? How would you help them to prepare for disclosure?
- What are some of the client's potential questions/fears/concerns related to disclosure and how would you address them?
- What age-appropriate communication techniques/approaches would you use to build trust and rapport?

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## Exercise 2: Debriefing

- *What did we learn?*
- **Key points:**
  - Everyone needs a unique disclosure plan. Adolescents are a diverse group and we should take these differences into account when conducting disclosure counseling.
  - Creating disclosure circles can help clients think through their own disclosure process to others.
  - Our role as health workers is to support the disclosure process. Remember, it is the adolescent who will make the final decision about who to disclose to, when, and how.

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## Questions or comments on this session?

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## Module 7: Key Points

- Disclosure is an ongoing process, not a one-time event.
- Disclosure can help young clients access prevention, care, treatment, and support. It can also improve adherence, reduce stigma and discrimination, and slow the spread of HIV by helping people protect themselves and their partners.
- 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.

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## Module 7: Key Points (Continued)

- 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, they may have to take a more active or "parental" role in the disclosure process.
- Health workers can support adolescents to decide to whom to disclose, when, and where; to weigh the advantages and disadvantages of disclosure; and to anticipate likely responses.

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