

UNIT 12: ADOLESCENTS LIVING WITH HIV

INTRODUCTION:

According to the United Nations Joint Program on HIV (UNAIDS), 20% of new HIV infections globally occur among young women aged 15-24, and an additional 12% occur among young men of that age group. Over 2 million adolescents (aged 10-19) worldwide are living with HIV, and 26 new infections occur among adolescents every hour. In addition, with advances in HIV testing, treatment and care, more and more perinatally infected children are living into and through adolescence, leaving a generation of young people who have grown up with HIV reaching maturity. These young people need access to sexual and reproductive health services to prevent STI co-infection, HIV re-infection and unintended pregnancy, along with access to psychosocial support services and other care as they manage the transition from childhood to adulthood while also living with HIV.

UNIT TRAINING OBJECTIVE:

To orient service providers on the rights, responsibilities, and unique needs of adolescents living with HIV.




SPECIFIC LEARNING OBJECTIVES:

By the end of the unit, participants will be able to:

4. Understand the rights and responsibilities of adolescents living with HIV and their service providers, in particular related to disclosure.
5. Identify the care, transition, psychosocial support, and SRH service needs for adolescents living with HIV.
6. Understand the different modes of transmission of HIV for adolescents and their implications for clinical care.

TOTAL TIME: 3 HOURS 15 MINUTES

UNIT OVERVIEW:

| Session | Methods  | Materials  | Time  |
|--------------|---|---|--|
| 12.1 | Values clarification activity Trainer presentation | Agree/Disagree signs Character cards Slides 12.1-12.11 <i>Optional: Participant Handout 12a</i> | 1 hour |
| 12.2 | Lava pit game Group discussion | Support service cards Tape Case study cards or prepared flipcharts Flipcharts and markers Candies or small prizes | 30 minutes |
| 12.3 | Group discussion Trainer presentation Group work | Flipcharts and markers Slides 12.12-12.15 Participant Handout 12b | 1 hour 25 minutes |
| Unit Summary | Pair interview | | 20 minutes |



WORK FOR TRAINERS TO PREPARE IN ADVANCE:

- Review Slides 12.1-12.11
- SO 12.1: Prepare Agree/Disagree signs.
- SO 12.1: Research age of consent for HIV testing laws and policies, requirements for parental notification.
- SO 12.1: *OPTIONAL: Prepare Participant Handout 12a: Tips for Disclosure for Adolescents Living with*

HIV.

- SO 12.2: Prepare 3 sets of Support Service Cards, prepare case study cards, or prepare flip chart pages with case studies written on them.
- SO 12.3: Prepare flip charts with discussion questions in advance and set them up around the room.
- SO 12.3: Prepare Participant Handout 12b: Differences by Mode of Transmission.
- Review the content of the UNAIDS publication *Disability and HIV* included in the list of references to strengthen the understanding of the link between HIV and disability.



MAJOR REFERENCES AND TRAINING MATERIALS:

All in to #EndAdolescentAIDS Campaign: <http://allintoendadolescentaids.org/>

Colton, Tayla, Virginia Allread, Elaine Abrams, Anne Schoeneborn, Beatriz Thorne, and Ruby Fayorsey. 2012. *Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers*. New York: Columbia University Mailman School of Public Health.

De Beaudrap P. et al. 2017. Prevalence of HIV infection among people with disabilities: a population-based observational study in Yaoundé, Cameroon (HandiVIH). *Lancet HIV*. April 4(4): e161-e168.

De Beaudrap. 2019. VIH & Handicap en Afrique de l’Ouest : Une analyse combinée de 4 études conduites au Burkina Faso, Niger, Guinée Bissau et Cap Vert. Lyon: Humanity & Inclusion.

Duffy, M. H., H. Bergmann, and M. Sharer. 2014. *Toolkit for Transition of Care and Other Services for Adolescents Living with HIV*. Arlington, VA: AIDSTAR-One.

International Planned Parenthood Federation. 2010. *Healthy, Happy and Hot: A young person’s guide to their rights, sexuality and living with HIV*. London: IPPF.

Sharer, Melissa, and Andrew Fullem. 2012. *Transitioning of Care and Other Services for Adolescents Living with HIV in SubSaharan Africa*. Arlington, VA: USAID’s AIDS Support and Technical Assistance Resources, AIDSTAR-One, Task Order 1.

United Nations Joint Programme on HIV/AIDS (UNAIDS). 2016. *Global AIDS Update: 2016*. Geneva: UNAIDS.

United Nations Joint Programme on HIV/AIDS (UNAIDS). 2017. *Disability and HIV*. Geneva: UNAIDS. https://www.unaids.org/sites/default/files/media_asset/JC2905_disability-and-HIV_en.pdf

World Health Organization. 2014. *Adolescent HIV Testing, Counselling and Care: Implementation guidance for health providers and planners*. Geneva: WHO.

World Health Organization. 2013a. *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV*. Geneva: WHO.

World Health Organization. 2013b. *Guideline on HIV disclosure counselling for children up to 12 years of*

age. Geneva: WHO.

World Health Organization. 2010. *IMAI One-day Orientation on Adolescents Living with HIV*. Geneva: WHO.

SPECIFIC OBJECTIVE 12.1: UNDERSTAND THE RIGHTS AND RESPONSIBILITIES OF SERVICES PROVIDERS AND ADOLESCENTS LIVING WITH HIV, IN PARTICULAR RELATED TO DISCLOSURE



TIME

1 hour



METHODS

- Values clarification activity
- Trainer Presentation



MATERIALS NEEDED

- Agree/Disagree signs
- Character cards
- Slides 12.1-12.11



STEPS

1. Introduce the activity to the participants. Have participants stand together in the center of the room. Place a sign that says “Agree” and one that says “Disagree” on opposite sides of the room.

Time: 20 minutes

2. Tell participants that they should move closer to one sign or another based on how they feel about each of the following statements. The closer they are to the sign, the stronger they agree or disagree with the statement. Clarify that there are no “right” or “wrong” answers.
3. Read the first statement:
 - a. Young people living with HIV can have happy and satisfying sexual lives.
4. Ask participants to quietly look around the room at where they’re all standing.
5. Read the next statement and give participants time to shift their positions, then repeat the instruction to note where everyone is standing. Repeat for the full list of statements below:
 - a. Sexuality and sexual pleasure are important for all young people, regardless of their HIV status.
 - b. Sexuality and sexual pleasure are important for all young people, regardless of their HIV and disability status.
 - c. Adolescents living with HIV have the capacity to make decisions about their sexual health and reproductive intentions.
 - d. Adolescents with disabilities living with HIV have the capacity to make decisions about their sexual health and reproductive intentions
 - e. Adolescents living with HIV should be required to disclose their HIV status to their sexual partners.
 - f. Learning about sexual pleasure is an important part of growing up for all adolescents, including adolescents with disabilities, regardless of their HIV status.

- g. The provider has a responsibility to inform the parent or guardian of an adolescent in their care when that adolescent is diagnosed with HIV.
 - h. Young people living with HIV have the right to decide if, when, how many, and with whom to have children.
 - i. Young persons with disabilities living with HIV have the right to decide if, when, how many, and with whom to have children.
 - j. Adolescents with disabilities are less at risk to be infected by HIV virus compared to the general population.
6. Ask participants to return to the center of the room. Ask if anyone wants to volunteer how they felt looking around the room after each statement. Ask volunteers:
- a. *How did you feel about the activity?*
 - b. *Did any of your responses surprise you?*
 - c. *What did you learn about your own and the opinions of others on the rights of adolescents living with HIV?*
 - d. *Were there times where you felt tempted to move with the majority of the group? Did you end up moving? How did that feel?*
 - e. *What did you learn about stigma around the sexuality of adolescents living with HIV?*
 - f. *What did you learn about stigma around the sexuality of adolescents with disabilities living with HIV (also called double stigma)?*
 - g. *How might that stigma (or double stigma) impact our practice as health providers working with adolescents living with HIV?*
7. Debrief in particular the last 2 questions. If there were statements where the majority of participants stood on one side or the other, discuss this commonality. Discuss how differences in opinion affect our work with these clients.
8. Thank the group for their participation and invite them to sit back down.

Time: 40 minutes

9. Present **Content: Rights and Responsibilities of Adolescents Living with HIV and their Service Providers** (Slides 12.1-12.11), below.

Content: Rights and Responsibilities of Adolescents Living with HIV and their Service Providers (Slides 12.1-12.11)

Slide 12.1: Rights

Adolescents living with HIV have all the same sexual, reproductive, and human rights as any other adolescent. Adolescents with disabilities living with HIV are not an exception. They have the right to know their HIV status and make their own decisions about how, when, and to whom to disclose. Service providers working with adolescents living with HIV must understand both how to inform

the adolescent about their health status and how best to support them to know their rights and responsibilities when it comes to their own and their partners' sexual and reproductive health risks.

- **Trainers Note:** *Ask for a show of hands: How many participants have had to disclose to an adolescent client their HIV status? How many have had to do so multiple times? Can you recall any of these cases involving adolescents with disabilities?*

Slide 12.2-12.3: Disclosure to Adolescents

There are multiple scenarios where a service provider would find themselves in the position of informing an adolescent client of their HIV status.

Most commonly, service providers might disclose the HIV status to an adolescent who has come in for voluntary counseling and testing services, who has most likely been infected through sexual activity or injectable drug use. In other cases, service providers may encounter adolescents who have been perinatally infected who have either made it to adolescence without being diagnosed or have not been informed of their status by their caregivers or guardians. In either case, service providers should consider:

- Is the adolescent over the legal age of consent for HIV testing?
- Does the provider have a legal requirement to inform the parent or guardian?
- Has the screening of the adolescent raised concerns about the home environment and the adolescents' safety?

When service providers need to disclose the HIV status to adolescent clients with disabilities, it is important to remember that:

- In the future, they will face additional barriers in accessing information and services due to double stigma and discrimination and may need additional support. Just as their peers without disabilities, adolescent clients with disabilities have the right to decide about their sexual and reproductive life.
- They may be exposed to higher risks of violence and abuse at home and in the community.

Slide 12.4-12.6: Tips for Disclosing to an Adolescent Client

Once you have the results of an adolescent client's HIV test, consider the following:

- Adolescents have the same right to know their status as adult clients. Any and all clinical guidelines for disclosing a positive HIV test result to an adult client must be applied to an adolescent client.
- When clients are adolescents with disabilities, the provider needs to ensure that the

disclosure is accessible and understandable, taking into account the specific barriers that persons with different types of disabilities may face and managing them appropriately (for example, how to disclose HIV test results to an adolescent with visual impairment without breaking confidentiality rules). On communication with adolescents with different types of disabilities, please refer also to unit 7 and the “Adolescents with Disabilities” chapter.

While an adolescent client may choose to have a parent, caretaker, partner, or friend in the room to receive their results, ensure that this is their choice. If the adolescent seems uncomfortable or the parent, caretaker, or other support person seems to be making decisions for the adolescent, err on the side of asking to speak to the adolescent alone. Additional care must be taken for adolescents with intellectual and developmental disabilities, as quite often their rights to be informed and to confidentiality are not respected (i.e., their parents/guardians have the tendency to make decisions for them, etc.). Moreover, the concepts of legal protection and legal guardianship are typically not well defined nor respected.

- Clients of all ages may have strong emotional reactions to disclosure of a positive status. Remain calm and allow some time for their initial reaction to subside.
- Remind the client that HIV is a manageable disease. Reassure the client that with proper treatment and care, they can live a full life with no restrictions on their activities. Include the information that with advances in treatment and prevention, people living with HIV can have fulfilling sexual and romantic relationships with partners while protecting them against transmission, and that people living with HIV can still have biological children without passing on the virus.

10. Pause and ask participants if any of them know the legal age of consent for HIV testing. Ask if anyone knows the legal parental notification requirements. Clarify any inaccuracies before returning to the presentation with **Slide 12.7: Legal Disclosure Requirements**.

Slide 12.7-12.9: Legal Disclosure Requirements

If there is no legal requirement for disclosure to the parent or guardian and the adolescent is over the legal age of consent, the adolescent has the right to determine if, when or how to disclose to their parents or guardians. If the adolescent is under the legal age of consent, or if the parent or guardian is aware of their status and has not disclosed to the adolescent, the provider should work to engage the parent or guardian in the disclosure process.

WHO (2014) states: “Wherever possible, adolescents should be provided with an opportunity to ask questions, discuss the issues and the challenges they face, and be supported to tell others their HIV status in a safe way. Health care providers should provide adolescents essential post-diagnosis and/or post-disclosure support. This should include initiating and facilitating discussions to explore the benefits and challenges adolescents may experience knowing their status; and to discuss existing and potential support mechanisms, including peer support opportunities. Adolescents recently diagnosed should be asked who they may want to inform and be encouraged to seek out someone they trust to support them.”

Young people living with HIV have the right to decide if, when, and how to disclose their HIV status to others. There are many reasons why an adolescent may choose not to disclose their status, including fear of stigma and discrimination, concerns about disclosing their sexual activity or use of injectable drugs, worry about judgment or isolation from the community, or fear of violence. This may be particularly true for adolescents with disabilities who worry about experiencing double stigma and discrimination based on HIV and disability. The adolescent knows best if and when it is safe to disclose. Disclosure to others can also offer positive results: increased caretaking and community support, better treatment, retention, and adherence, and more ability to negotiate sexual protection with a partner.

As a provider, you can help the adolescent weigh the risks and benefits of disclosure and offer support to adolescents as they plan to disclose.

11. Pause and ask participants to brainstorm some ways that service providers can support adolescents considering disclosure. Return to the presentation with **Slide 12.10: Support for Adolescent Disclosure** below.

Slides 12.10-12.11: Support for Adolescent Disclosure

Some ways service providers can support adolescents considering telling people their HIV status include:

- Know the relevant laws and policies. Some countries require disclosure to any current or new sexual partners, while some have protections for people living with HIV who fear violence or discrimination.
- Equip them with the information they need. What are their risks of transmitting to a new partner? How can they protect themselves and their partners? What health consequences should they watch for? Help the adolescent think through the conversation and what information they might be asked for or need to manage their loved one's reaction.
- Talk with them about any concerns they may have related to intimate partner violence (IPV). If they reveal they are experiencing IPV, the provider should be able to provide first line support as well as referral to the IPV counselor (if this person is available) or other local GBV response services.

Service delivery sites must meet the following requirements before assessing young people's concerns of or experiences around IPV:

- A protocol or standard operating procedure for asking about violence.
- An established process for referrals or linkages to local GBV response services, including counseling, child protection services, police and legal support.
- Providers who have received specialized training in gender sensitive, adolescent-centered, and first line support in assessing and supporting adolescent experience of IPV. For example, providers must be able to:

- Listen respectfully and empathetically.
 - Inquire about adolescent worries, concerns and needs, and provide answers to questions.
 - Offer non-judgmental and validating responses that reassure the adolescent that they are not to blame for IPV, and that they have acted appropriately in disclosing it
 - Act to ensure the adolescent’s safety and minimize harm.
 - Provide the adolescent with emotional and practical support, such as a referral to GBV response services.
- A set of standardized questions that are used by providers to assess experience and/or fear of violence and to document responses.
 - Auditory and visual privacy that protects adolescent privacy, ensures their safety and minimizes harm.
- Help make a plan. Where should they have the conversation? How can they get out of the conversation if it goes badly? What’s the best time to have the conversation? Sometimes it helps for the service provider to be present or to have the conversation at the clinic.
 - Follow up with the adolescent. How did it go? How would they do it differently next time? Was there information they needed that they didn’t have?

It is important to remember, though, that over-emphasis on disclosure can discourage adolescents living with HIV from continuing treatment or care. At all times, emphasize all adolescent’s right to choose if, how, and when to disclose their status, and that disclosure is their choice.

12. Close the presentation by leaving time for any questions or concerns. If participants need more resources on these topics, direct them to the additional resources listed at the beginning of this unit.

➤ **Trainers Note:** You may also choose to distribute **Optional Participant Handout 12a: Tips for Disclosure for Adolescents Living with HIV** if participants are interested in more tools to support adolescents with disclosing to partners and family.



OPTIONAL PARTICIPANT HANDOUT 12A: TIPS ON HIV DISCLOSURE

1. FOR PROVIDERS WHO NEED TO ADVISE ADOLESCENTS OF THEIR HIV STATUS

SOURCE: WORLD HEALTH ORGANIZATION

Disclosure to an adolescent about their own HIV status should ideally occur between the ages of 6–12 years, before puberty and the onset of sexual exploration. Early disclosure helps young people to better adhere to treatment, to be more engaged in their own self-care, to have a better understanding of HIV and related conditions and to know where and how to obtain services that maintain their own health and enable them to avoid infecting others.

Disclosure of HIV status to adolescents, however, often occurs late, and is unplanned, creating confusion for adolescents who learn of their HIV status without appropriate information and support. This can lead to an increased sense of stigma, shame, and fear.

Ideally, a parent or caregiver should be involved when disclosing HIV status to an adolescent. Parents and caregivers also fear stigma for themselves and their child/ward, which may block their ability to disclose HIV status to the adolescent. Providers can support parents and caregivers to explore their concerns and fears and provide them with information. Providers must also consider how to address circumstances in which adolescents have frequently changing, disengaged, or absent caregivers.

Disclosure support for adolescents should go beyond just advising them of their HIV status. The common challenges surrounding HIV continue throughout adolescence, sometimes with different concerns for those infected as children – through mother-to-child transmission – and for those infected during adolescence. In addition, adolescents from key populations, including persons with disabilities, experience legal and social concerns.

Adolescents should be provided with an opportunity to ask questions, discuss the issues and the challenges they face, and be supported to tell others their HIV status in a safe way.

Health care providers should provide adolescents essential post-diagnosis and/or post-disclosure support. This should include discussions that explore the benefits and challenges to knowing their status; and to discuss existing and potential support mechanisms, including peer support opportunities. Adolescents recently diagnosed should be asked who they may want to inform and be encouraged to seek out someone they trust to support them.

Providers can practice disclosure skills by conducting role plays with colleagues. Role plays assist in preparing providers to deal with unfamiliar or difficult situations, exploring likely reactions and different approaches to responding to them. Role plays help to build provider skills and confidence to handle real life situations.

2. FOR HELPING ADOLESCENTS LIVING WITH HIV TO DISCLOSE THEIR STATUS TO OTHERS

SOURCE: IPPF 2010

- Practice disclosing to people you trust, this could include family members or friends. Remember though that people will not all react in the same way.
- Speak to other young people living with HIV, or members of your support group, to learn from their experiences on different ways to disclose.
- Consider things like the best time to tell the person. When dating, some people tell their partner when they first meet while others wait till later. Do whatever makes you the most comfortable. If you are in a long-term relationship, try to find a time when your partner is calm and has time for a long conversation.
- Test how your partner(s) may react to your HIV status by asking them questions like 'what do you think about HIV?' and 'have you met anyone with HIV?', or talking about a news story. This will help you get a sense of what they think about HIV and how they might react.
- Think of disclosing in a location that you feel comfortable and safe in — a private place like in your house, a friend's house, or in a public place where other people are around.
- If you think your partner(s) may get violent or angry, try to tell your partner in a safe environment and have a plan in place for your safety.
- Be ready for a conversation about HIV after you disclose. Your partner(s) may have questions about living with HIV, such as the risk of transmission, and safer sex. They may also have questions about your relationship. A counselor can also help with this.
- More often than not, disclosing is a process rather than a one-time event. Expect several conversations. Your partner(s) may need time to deal with their emotions. They may have new questions about HIV.
- Plan to go out with people you trust after you disclose. You can celebrate a positive outcome, discuss strategies for supporting a hesitant but willing partner, or get support for dealing with a negative reaction.

SPECIFIC OBJECTIVE 12.2: IDENTIFY THE CARE, PSYCHOSOCIAL SUPPORT, AND SRH SERVICE NEEDS FOR ADOLESCENTS LIVING WITH HIV



TIME

30 minutes



METHODS

- Lava pit game
- Group discussion



MATERIALS NEEDED

- 3 sets of colored cards or sheets of paper with various types of services written on them (see below), 3 of each
- Flipcharts (3) one per group
- Tape 3 rolls
- Case study cards – one per group (or case studies can be written on the flipcharts for each group)
- Candies or small prizes



STEPS

1. Set up three flip charts around the perimeter of the room. In the center of the room, scatter the colored cards with the various support services written on them.

Time: 30 minutes

2. Divide participants into three groups, ask each to stand by their flip chart.
3. Introduce activity to participants: explain that they will be retrieving the support services they think their adolescent needs from the center of the room and placing them on their flip chart with tape. The catch is that participants are not allowed to touch the ground in the center of the room: they can only step on the service cards. Additionally, only one person from each group can be in the center at a time. The first group to collect all the services they need will win a prize.
4. Give the groups **one minute** to discuss and make a plan for how to get the services they need.
5. Give the groups **5 minutes** to get as many services as they think they need out of the center of the room and onto their flip chart. Have the groups call out when they're finished.
6. Review each group's flip chart, in the order they finished. Have each group present their flip charts and answer the following questions:
 - Why did you select these services? Which ones did you think were most important, and why?
 - Which services did you think this adolescent didn't need? Why not?
 - Which supports can you provide, and which ones do you need to refer the adolescent to or bring in other support for yourself?

- What other resources might be available to this adolescent in their community?
 - Which additional support or resources might be important to provide in the case of adolescents with disabilities knowing that resources at the community level may not be accessible to them?
7. Check to see if any of the support services were left out by all three groups. If so, ask the group why they think none of them needed that support. Ask the group to reflect on which of the supports are available in their communities and how they can use them effectively.
 8. Restate that providers need to know how to respond to the needs of adolescent clients living with HIV and what services are available for them to refer to. Close the activity by rewarding all the participants with a candy or small prize.



TRAINERS TOOL: SUPPORT SERVICES CARDS

Color 1: Psychosocial Support (3 of each)

Mental Health Counseling

**Substance Abuse Counseling
or Support Groups**

**Death and Bereavement
Counseling**

**Positive Living Networks and
Groups**

Family Counseling

Legal Defense

Employment Support

**Tutoring or Educational
Support**

Faith-based Support Groups

Peer Support Networks

**Intimate Partner Violence
Screening and Counseling**

**Economic Strengthening
Support**

Color 2: Sexual and Reproductive Health Services (3 of each)

**Family Planning and
Contraceptive Services**

**STI Testing, Care and
Treatment**

**HPV Vaccination and Cervical
Cancer Screening**

**Prevention Information and
Education**

**Sexuality Education and
Information**

**Sexual and Gender Based
Violence and Post-Rape Care**

**Safe Abortion and Post-
Abortion Care**

PMTCT

**Disclosure Counseling (self
and others)**

Color 3: Care Needs (3 of each)

ARTs

Food Security

Nutritional Counseling

Housing

Compassion

**Health Information and
Services**

**Treatment for Opportunistic
Infections**

**Counseling on Treatment
Adherence**

**Transition from Pediatric to
Adult Care**

**Routine Tuberculosis (TB)
Screening and Preventive
Therapy (TBT)**

Viral Load Testing

Rehabilitation Services

Case Studies (1 of each)

Adolescent male, 15, with a hearing disability, sexually active, living at home with parents who are unaware of his HIV status, struggling with frequent illnesses.

Adolescent female, 17, perinatally infected, orphaned, living with an auntie, working in a market, not in school, goes on and off treatment based on earnings.

Adolescent female, 14, in school, engaged in transactional sex to pay school fees, newly infected.

SPECIFIC OBJECTIVE 12.3: UNDERSTAND THE DIFFERENT MODES OF TRANSMISSION OF HIV FOR ADOLESCENTS AND THEIR IMPLICATIONS FOR CARE



TIME

1 hour 25 minutes



METHODS

- Group discussion
- Trainer presentation
- Group work



MATERIALS NEEDED

- Flipcharts and markers
- Slides 12.12-12.15
- Participant Handout 12b: Difference by Mode of Transmission



STEPS

1. In advance of the session, set up the room by placing prepared flipcharts around the room with the following questions.
 - a. *Question 1: How do adolescents living with HIV make their first contact with health services?*
 - b. *Question 2: What makes it easier for an adolescent living with HIV to return to health services?*
 - c. *Question 3: What makes it harder for an adolescent living with HIV to return to health services?*

Time: 20 minutes

2. Explain to participants that you're going to start with a quick group discussion to set the scene for what we're learning today. Ask participants to raise their hands if they have had an adolescent living with HIV come to them for services in the past week, month or year.
3. Ask a volunteer to estimate how many young people living with HIV attend their clinic every month. Ask them to estimate how many of them were infected perinatally and how many acquired HIV as adolescents. Ask them to estimate how many of them had a disability. Ask one or two more volunteers for the same information.
4. Explain that we can expect to see more and more adolescents living with HIV coming into clinics. Ask participants why we expect this. Reasons can/should include:
 - As ART use increases and improves among perinatally infected children, young people born with HIV are reaching sexual maturity.
 - As HIV stigma decreases, more adolescents are getting tested and learning their status.
 - Adolescents still face higher rates of new infection than other age groups because they lack information, experience inequitable gender norms, and adolescent girls and young women are biologically susceptible to contracting HIV when having sex with an HIV +

partner. Stigma around expressing their sexuality creates barriers to information and condoms.

5. Turn participants' attention to Question 1: How do adolescents living with HIV make their first contact with health services? Have participants shout out ideas and record them on the flip chart. Are there differences based on mode of exposure to HIV and age at transmission?
6. Repeat with Questions 2 and 3 on separate flip charts.
7. Have participants call out which of their responses to Questions 2 and 3 are internal to the adolescent, which are related to the individual health worker, which are a part of the health service system, and which are related to other factors (peers, families, community, etc.). If none of the participants has mentioned disability in their responses, take the initiative to ask them if disability is in their opinion a factor that makes it easier or harder for an adolescent living with HIV to return to health services and why.
8. Conclude the activity by summarizing the main points of discussion, then introduce the presentation.

Time: 20 minutes

9. Introduce the presentation by saying: Sexual and reproductive health service providers are increasingly seeing a population of adolescents and young people living with HIV.
10. Ask participants to call out a few ideas why they are seeing more adolescents living with HIV. Present **Content: Adolescents Living with HIV** (Slides 12.12-12.15) below.

Content: Adolescents Living with HIV (Slides 12.12-12.15)

Slide 12.12: More Adolescents Living with HIV

For service providers, learning to care for adolescents living with HIV will be increasingly necessary in the coming years. Optimal HIV care and treatment for these adolescents will vary, depending on mode of transmission, age, sex, gender, disability, social factors and disease progression. This unit covers some basic considerations for providers working with adolescents living with HIV, but there are many more detailed guidance and training documents available, for those who wish to go more in depth.

- **Trainers note:** *Three key tools are listed in the additional resources section at the start of this unit:*
1. *Adolescent HIV Care and Treatment: A Training Curriculum for Health Workers.*
 2. *Transitioning of Care and Other Services for Adolescents Living with HIV in Sub-Saharan Africa.*
 3. *Adolescent HIV Testing, Counselling and Care: Implementation guidance for health providers and planners.*

If participants are interested in more information and support on these topics, consider adding more time and activities from the first tool to this training, or scheduling a more in-depth follow-up training.

11. Distribute **Participant Handout 12b: Differences by Mode of Transmission**. Return to the presentation with **Slide 12.13: Modes of Transmission** below.

Slide 12.13-12.15: Modes of Transmission

Source: Adapted from WHO 2013a

The specific needs and challenges of three groups should be considered:

1. *Adolescents infected perinatally, diagnosed early, and on treatment:* These adolescents may be on complex ART regimens and even last line treatment options, and need support to continue their treatment and care. For many health providers, this means helping the adolescent assume greater responsibility for their own care, addressing developmental delays, supporting safe and beneficial disclosure by the adolescent to family and peers, treating opportunistic infections, providing linkages to psycho-social support, family planning and reproductive health services, and ensuring access to PMTCT for pregnant adolescent girls living with HIV.
2. *Adolescents infected perinatally, not diagnosed early, and not on treatment:* A large number of perinatally infected adolescents may reach puberty undiagnosed or untreated, particularly in low-resource settings or generalized epidemics. Some adolescents may have been diagnosed but lost to follow-up or may be encountering HIV testing for the first time in their adolescence. These slow progressors may have chronic medical problems, opportunistic infections, or developmental delay issues that will need attention.
3. *Infected during adolescence:* For adolescents in generalized epidemic areas, the primary mode of transmission is through sexual intercourse. Adolescents may also acquire HIV through injecting drug use, unsafe medical practices or procedures, or harmful traditional practices. Approaches to care and treatment for these adolescents may differ from those infected perinatally and should consider the rights of adolescents to care and treatment which is free from stigma or discrimination on the basis of their sexuality, sexual orientation, or sexual activity.

12. Close the presentation by leaving time for questions and clarifications from the group.

Time: 45 minutes

13. Ask participants to take some time to review **Participant Handout 12b: Differences by Mode of Transmission**. Ask if there are any questions or additions to the two columns that have been filled out for them. Have the group reflect back on the warm-up activity, and the presentation, and ask them to fill out the third column with clinical or care strategies, working in pairs.

➤ **Trainer's Note:** *If participants are struggling with filling out the handout, provide a few clarifying examples from the Response Guide (below).*

14. Emphasize that in many cases, the care strategies for adolescents infected perinatally or during adolescence may be the same or similar.
15. Allow **15 minutes** for the pairs to complete the handout. Have participants combine their pair with another to form a group of four and spend an additional **10 minutes** comparing their responses.
16. In plenary, facilitate a discussion focusing on the following questions:
 - Are there places where care strategies differ for adolescents who are perinatally infected and those who are infected during adolescence? In what way?
 - Where are care strategies similar or the same?
 - How would care strategies differ for adolescents who are unaware of their HIV status?
 - Are there existing clinical guidelines or standards for these issues? How accessible are they for service providers?
17. Close the discussion by pointing out that those infected during adolescence may experience greater stigma related to their HIV status than those infected perinatally. Those infected during adolescence may be “blamed” for their own infection. Ask participants to reflect on how stigma and bias might affect their access to care and on the additional barriers adolescents with disabilities living with HIV may face as a result of disability and HIV-based discrimination.

PARTICIPANT HANDOUT 12B: DIFFERENCES BY MODE OF TRANSMISSION

Source: AIDSTAR One

| Mode of Transmission | | |
|---|---|---|
| Perinatally (P) | During adolescence (A) | 1-2 Care/Clinical Strategies relating to: |
| More likely to have opportunistic infections | Fewer opportunistic infections | P: |
| | | A: |
| More likely to not be on first line drugs and in need of complex ART regimens | ART resistance less likely | P: |
| | | A: |
| More obstacles to achieving self-management and autonomy, bereavement, and developmental delays | Less likely to experience obstacles to achieving self-management and autonomy, but may experience other obstacles such as stigma, grief, etc. | P: |
| | | A: |
| More physical and developmental delays | Less likely to have physical and developmental delays | P: |
| | | A: |
| Higher risks of complications during pregnancy | Lower number of complications during pregnancy | P: |
| | | A: |
| Higher mortality rates | Long-term chronic disease outlook | P: |
| | | A: |
| | | P: |

| Mode of Transmission | | |
|---|---|----|
| May not know HIV status although may have been in treatment and may experience Challenges to adherence if they do not know their status | May experience adherence challenges | A: |
| More likely to have experienced multiple losses related to HIV (parents, siblings, etc.) | More likely to have denial and fear of HIV | P: |
| | | A: |
| More secrecy regarding disclosure | More likely to be misinformed about HIV | P: |
| | | A: |
| May struggle with issues related to intimacy, sexuality, and sexual identity | May distrust clinical facilities | P: |
| | | A: |
| May have heightened concerns about pregnancy and starting families | Lack of belief in clinical treatment to prevent vertical HIV transmission | P: |
| | | A: |
| More likely to have support from family/caregiver and health provider | More likely to lack familial, clinical and social supports | P: |
| | | A: |

TRAINER TOOL 12A: RESPONSE GUIDE TO PARTICIPANT HANDOUT

Trainers Note: these responses are not comprehensive: participants may have additional responses to share with the group.

| Mode of Transmission | | |
|---|---|---|
| Perinatal (P) | During Adolescence (A) | Care Strategies relating to: |
| More like to have opportunistic infections | Fewer opportunistic infections | P: Clinical treatment for opportunistic infections |
| | | A: Education about symptoms and potential infections to be aware of |
| More like to not be on first line drugs and in need of complex ART regimens | ART resistance less likely | P: Treatment support and more complex regimens |
| | | A: Initial treatment |
| More obstacles to achieving self-management and autonomy | Less likely to experience obstacles to achieving self-management and autonomy, but may experience other obstacles such as stigma, grief, etc. | P: Psychosocial and educational support referrals, counseling on treatment and self-care |
| | | A: Counseling on treatment and self-care |
| More physical and developmental delays | Less likely to have physical and developmental delays | P: Clinical and medical treatment where appropriate, counseling on pubertal delays and effects of HIV |
| | | A: General SRH counseling and support services |
| | | P: Contraceptive services, antenatal care, PMTCT treatment |

| Mode of Transmission | | |
|---|--|---|
| Higher risks of complications during pregnancy | Lower number of complications during pregnancy | A: Contraceptive services, antenatal care, PMTCT treatment |
| Higher mortality rates | Long-term chronic disease outlook | P: Psychosocial support, service referrals |
| | | A: Counseling on treatment and self-care, psychosocial support service referrals |
| may not know HIV status although may have been in treatment and may experience challenges to adherence if they do not know their status | may experience more adherence challenges | P: Disclosure (self & others) |
| | | A: Treatment support |
| Perinatal (P) | During Adolescence (A) | Care Strategies relating to: |
| More likely to have experienced multiple losses related to HIV (parents, siblings, etc.) | More likely to have denial and fear of HIV | P: PSychosocial support service referrals, stigma and self-care counseling |
| | | A: Education and counseling on stigma and self-care |
| More secrecy regarding disclosure | More likely to be misinformed about HIV | P: Disclosure (self & others), education on rights and stigma |
| | | A: Education and counseling |
| May struggle with issues related to intimacy, sexuality, and sexual identity | May distrust clinical facilities | P: education and counseling on sexual rights of adolescents living with HIV |
| | | A: Education and counseling on sexual rights of adolescents living with HIV, stigma |

| Mode of Transmission | | |
|---|---|--|
| May have heightened concerns about pregnancy and starting families | Lack of belief in clinical treatment to prevent vertical HIV transmission | P: General sexual and reproductive health services, education and counseling |
| | | A: Counseling on PMTCT |
| More likely to have support from family/caregiver and health provider | More likely to lack familial, clinical and social supports | P: Psychosocial support referrals |
| | | A: Psychosocial support referrals |

UNIT 12 SUMMARY



TIME

20 minutes



METHODS

- Pair interview



MATERIALS NEEDED

- None



STEPS

1. Divide participants into pairs. Have them interview each other about the unit using the following questions:
 - Was there something new you learned today?
 - What experience do you have with adolescents living with HIV?
 - Do you feel confident about your ability to treat and work with adolescents living with HIV?
 - How do you feel about supporting adolescents with disabilities living with HIV?