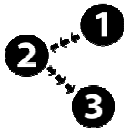
Module 13 Supporting the Transition to Adult Care

Total Module Time: 100 minutes (1 hour, 40 minutes)

Learning Objectives

After completing this module, participants will be able to:

- Understand the key considerations when transitioning a client from pediatric/adolescent care to adult care
- Prepare adolescents for and support them during the transition to adult care

Methodologies	
	• Interactive trainer presentation • Large group discussion • Brainstorming

Materials Needed	
	• Slide set for Module 13 • Flip chart and markers • Tape or Bostik (adhesive putty) • Participants should have their Participant Manuals. The Participant Manual contains background technical content and information for the exercises.

Resources	
	• AIDS institute, New York State Department of Health. (2011). *Transitioning HIV-infected adolescents into adult care, HIV clinical guidelines and best practices from New York State*. Available at: http://www.hivguidelines.org/clinical-guidelines/adolescents/transitioning-hiv-infected-adolescents-into-adult-care/ • Life Skills Subgroup of the AETC Adolescent HIV/AIDS Workgroup. (2006). *Adolescent transition workbook.* AIDS Education and Training Centers. Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-269 • WHO. (2010*). IMAI one-day orientation on adolescents living with HIV, Facilitator Guide,* Geneva: WHO Press. Available at: http://whqlibdoc.who.int/publications/2010/9789241598989_eng.pdf • Jacob, S. & Jearld, S. (2007). *Transitioning your HIV+ youth to healthy adulthood: A guide for health care providers*. New York: The Transition Consortium.

Advance Preparation	
	• Read through the entire module and ensure that all trainers are prepared and comfortable with the content and methodologies. • Review the appendices in this module ahead of time and prepare to incorporate them into the discussion.

Session 13.1: Key Considerations for Health Care Transition

Activity/Method	Time
Interactive trainer presentation and large group discussion	20 minutes
Questions and answers	5 minutes
Total Session Time	25 minutes

Session 13.2: Preparing and Empowering Adolescents to Transition into Adult Care

Activity/Method	Time
Interactive trainer presentation and large group discussion	30 minutes
Exercise 1: Supporting ALHIV in Their Transition to Adult Care: Case studies and large group discussion	30 minutes
Questions and answers	5 minutes
Review of key points	10 minutes
Total Session Time	75 minutes

Session 13.1 Key Considerations for Health Care Transition

Total Session Time: 25 minutes

Trainer Instructions
Slides 1–4

Step 1: Begin by reviewing the Module 13 learning objectives and the session objective, listed below.

Step 2: Ask participants if there are any questions before moving on.

Session Objective

After completing this session, participants will be able to:

- Understand the key considerations when transitioning a client from pediatric/adolescent care to adult care

Trainer Instructions
Slides 5–11

Step 3: Explain that, in some places, there are many ALHIV who attend pediatric clinics (for example, where there are no adolescent-specific clinics). These ALHIV may have been getting services at the pediatric clinic since birth, or for many years. After a certain age, however, these adolescents may have to transition from the pediatric clinic to the adult ART clinic.

Encouraging and helping older ALHIV transition to adult care supports their healthy development and increases their overall ability to advocate for themselves and to adequately manage their own care and treatment.

Step 4: Ask participants the following questions to facilitate discussion and record key points on flip chart. Fill in the discussion as needed using the content below and in the slides.

- *What are some fears, concerns, and challenges ALHIV might face when transitioning to adult care?*
- *What are some of the challenges that we, as health workers, face when transitioning our adolescent clients into adult care?* (Responses may include: breaking the emotional bonds that we have with our adolescent clients, losing patients, which may have funding implications, etc.).

- *How can health workers help manage these fears, concerns, and challenges, and support adolescents' transition to adult care?*

(optional) Ask the adolescent co-trainer to describe some of the fears, concerns, or expectations that he or she (or other adolescents) had when transitioning to the adult ART clinic.

Make These Points

- In some places, adolescents attend pediatric clinics, where they may have been getting services since birth, or for many years. After a certain age, however, they may have to transition to the adult ART clinic.
- This care transition can be difficult for many reasons. Adolescents may have concerns about leaving trusted providers and having new providers who do not know them well; they may worry about getting care in an unfamiliar, non-youth-friendly environment; they may fear stigma; or they may have concerns about quality of care, the size of the clinic, being seen there by other community members, etc.
- This health care transition affects health workers and clinic staff as well as adolescents and their caregivers because, leading up to and throughout the transition period, ALHIV have to start taking more responsibility for themselves and their care.
- The transition to adult care requires helping the adolescent client and his or her caregivers manage and adjust to changes in the way the client's care is organized. It is important to ensure good client–health worker and client–caregiver communication throughout the transition process.

Key Considerations for the Transition to Adult Care[1]

There are parallels between the maturation of adolescents into adults and the transition from pediatric to adult HIV programs. ALHIV may face challenges in their transition to adult care and in learning to independently manage their own care. These challenges affect both health workers in pediatric and adult clinics as well as adolescents and their caregivers.

The role of the health worker is to provide ALHIV and their caregivers with adequate support and to help ALHIV increase their capacity to manage their own care and to advocate for themselves in the clinical setting.

Some key challenges for ALHIV during the transition process may include:

- **Balancing complicated care:** Adolescents have to manage multiple medications and appointments and must deal with many different health workers and health services.
- **Leaving a familiar care network:** Adolescent clients may feel reluctant to leave a familiar care setting, which often means losing contact with support networks and friends there. They may also be fearful and uncertain about how to manage a new clinic setting with new providers.
- **Psychosocial and developmental challenges:** Adolescents are coping with the typical changes, feelings, and worries of adolescence (which may include relationships, employment, education, etc.) and they may be struggling with disclosing their HIV-status to peers and family. Given the number of life changes happening all at once, adherence to ART and visits to the clinic may become less of a priority. Health workers need to work closely with ALHIV who are about to transition to adult care to ensure that they continue to adhere to their ART regimen and to their care.
- **System challenges:** Adult clinics typically lack specific, youth-friendly services for adolescents as well as an understanding of and appreciation for adolescents' needs and issues.

Goal of transition

The goal of transition is to ensure the provision of uninterrupted, coordinated, developmentally- and age-appropriate, and comprehensive care before, during, and after the transition.

Transition is applicable to every ALHIV as they mature into adulthood — all adolescents require support both within and outside of the clinic setting to take greater ownership over their health care, behavior, lives, and adherence to care and treatment.

- The transition to adult care generally occurs in parallel with an adolescent's emotional and physical maturation into adulthood. Effective transition must allow for the fact that adolescents are undergoing changes that impact much more than just their clinical care. Adolescents' psychological maturation may be influenced by how and when they assume responsibility for their own care and vice versa.
- Health workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognizing their increasing maturation, capacity to make choices, and independence.
- Leading up to the transition, health workers should encourage ALHIV to develop as much independence as possible, both from their families and from health workers. This will help bridge the gap to adult services and help adolescents make informed decisions about their own care.
- Reaching the overall goal of helping adolescents achieve independent management of their own care is a gradual process and should, whenever possible, involve the caregivers and family.
- Some caregivers will need assistance understanding their changing role as the focus of care moves away from always having a caregiver present at appointments, and toward a confidential relationship between the adolescent and the health worker.

Note: Not every adolescent will be able to reach 100% independence from his or her caregivers. This is particularly true for adolescents who have moderate or severe developmental delays. In such cases, caregivers will likely need to stay involved in the adolescent's care after transition to the adult clinic. Pediatric/adolescent and adult clinics will need to consider special arrangements to accommodate developmentally or otherwise disabled clients.

	**Trainer Instructions** Slide 12
Step 5:	Allow 5 minutes for questions and answers on this session.

Session 13.2 Preparing and Empowering Adolescents to Transition into Adult Care

Total Session Time: 75 minutes (1 hour, 15 minutes)

Trainer Instructions
Slides 13–14

Step 1: Begin by reviewing the session objective listed below.

Step 2: Ask participants if there are any questions before moving on.

Session Objective

After completing this session, participants will be able to:

- Prepare adolescents for and support them during the transition to adult care

Trainer Instructions
Slides 15–23

Step 3: Start by explaining that, in many cases, programs and facilities do not adequately plan for client transition to adult care. This can result in: an abrupt transfer to adult services, maintaining adolescents in the pediatric clinic longer than may be appropriate, discontinuation of care, and adherence challenges. Regardless of how a program manages the transition process, helping all ALHIV achieve greater independence to manage their own care is essential.

Ask participants to reflect on how health workers and clinical programs can support ALHIV and their caregivers/families during the transition process. Ask the following questions to facilitate discussion, record key points on a flip chart, and fill in as needed using the content below and the slides:

- *What do you think is important for older adolescents to know when transitioning to the adult clinic?*
- *What youth-friendly activities and/or counseling methods/exercises do you think could help adolescents with the transition process?*
- *Who should be involved in the transition process?*

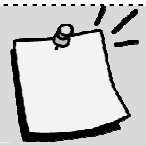
Step 4: Refer participants to Table 13.1: "A self-care and transition timeline for ALHIV" and to *Appendix 13A: Transition Checklist for Health Workers*. Review and discuss their content as a large group.

Explain that using these tools can help health workers plan for the transition process, can improve ALHIV's capacity for self-care and self-advocacy, and can ease the difficulties of transitioning to adult care.

Additional transition resources for health workers, adolescents, and families are listed in *Appendix 13B: Transition Resources for Health Workers and ALHIV.*

(optional) Ask the adolescent co-trainer (if willing and comfortable) to reflect on how much he or she has been involved in his or her own care and treatment decisions.

- *What do you have to know to independently manage your own care and treatment?*
- *What have been your experiences as a participant in your own care at the clinic? What are the challenges you have faced managing your own care as a young person?*
- *What were (or do you anticipate will be) your challenges transitioning to adult care?*



Make These Points

- It is possible for adolescents to have a smooth transition to adult care and to receive adolescent-friendly services in the adult clinic. The likelihood of a smooth transition depends on the organization of the adult clinic, the systems in place to support chronic care, the attitudes of health workers toward adolescents, and their understanding of the special needs of ALHIV.
- Adolescents need to be educated, motivated, and supported to take care of themselves and to communicate both what services they need as well as their concerns. This gives them a better sense of control (i.e. self-efficacy), makes them feel better about their situation, and helps them be more successful in caring for themselves in the long term.
- Not all ALHIV will be ready to make the transfer to adult care at the same age. Health workers must take into account each adolescent's cognitive and physical development, his or her emotional maturity, his or her support at home and in the community, and his or her health status.
- Health workers can help prepare and support older ALHIV before their transition to adult care, and they can keep ALHIV linked to youth-specific support groups, Adolescent Peer Educators, etc.
- The health worker should begin the transition process early, working as a team with the adolescent client, his or her caregivers, and other members of the multidisciplinary team.

Helping ALHIV Prepare for the Transition[1]

A successful transition involves a client-centered process and a developmental approach — it is not a one-time event. The following principles can help ensure a smooth transition from pediatric/adolescent to adult care programs:

- The health worker should begin the process early, working as a team with the adolescent client, his or her caregivers, and other members of the multidisciplinary team.
- The transition process should enhance the adolescent's autonomy, cultivate a sense of personal responsibility, facilitate self-reliance and self-efficacy, and boost the adolescent's capacity for self-care and self-advocacy.
- The transfer of care should be individualized and should consider each adolescent's developmental stage and readiness for transition.

There are many innovative strategies that health workers and programs can undertake to support transition. These may include:

- Orienting adult HIV providers on adolescent-friendly services and the needs of adolescent clients
- Bringing adult providers (nurses, counselors, etc.) to the pediatric/adolescent clinic for a joint weekly clinical session so that they can get to know more about adolescent clients and their unique needs (this is an especially helpful strategy when working with pregnant adolescents)
- Having a provider (doctor, nurse, counselor, etc.) from the pediatric/adolescent clinic attend the adult clinic on a regular basis for "transition sessions"

Health workers and Adolescent Peer Educators can support ALHIV and help them prepare for the transition process by:

- Reviewing the client's medical history together with the client, encouraging him or her to ask questions about his or her care and medicines, and discussing possible future changes
- Ensuring that the adolescent understands his or her diagnosis, his or her needed medications, the importance of adherence to care and medicines, and ways to prevent new HIV infections and to live positively (see Module 9 for more information about living positively with HIV)
- Promoting linkages to adolescent peer support groups and support groups at the adult clinic (for example, programs can consider having Adolescent Peer Educators make visits to both adolescent and adult clinics to organize support group meetings for transitioning adolescents)
- Transitioning adolescents to adult care in cohorts or groups if possible so that adolescents can support each other
- Organizing health talks for transitioning adolescent clients (consider having the talks led by an older adolescent who has already successfully transitioned to adult care)
- Encouraging older adolescents to take responsibility in making and keeping appointments and adhering to medicines (for example, by ensuring that they maintain a calendar of clinic appointments and a medication calendar)
- Identifying and orienting adult providers on the necessity of youth-friendly services, including providing specific information on the medical and psychosocial needs of ALHIV, through meetings, orientations, and trainings
- Accompanying the adolescent to the adult clinic for an orientation, to meet the clinic's health workers (including the adult Peer Educators or other lay counselors), and to discuss the client's specific concerns and questions
- Transferring the client's medical records to the new clinic and holding a case conference to discuss key issues in the adolescent's care

- Involving Peer Educators, social workers, and counselors when planning for a client's transition to adult care, especially for most-at-risk ALHIV or those with complex needs
- Using a variety of youth-friendly activities, such as journaling or creating a Transition Workbook (see *Appendix 13B: Transition Resources for Health Workers and ALHIV*), in which the adolescent records information about his or her health, future goals, and sources of support
- Connecting ALHIV to other community-based services, such as vocational training, social grants, food relief, etc.

Health workers can help older ALHIV be more involved in their own HIV care and treatment and can help prepare them for the transition to adult care. Ideally, adolescents should be able to do the following before transitioning:

- Make, cancel, and reschedule appointments
- Arrive to appointments on time
- Call ahead of time to schedule urgent visits
- Request prescription refills correctly and allow enough time for refills to be processed before medications run out
- Know when to seek medical care for symptoms or emergencies
- Identify symptoms and describe them
- Negotiate multiple providers and different types of clinic visits
- Establish a good working relationship with a case manager at the pediatric clinic, which will enable them to work effectively with the case manager at the adult ART clinic
- Ask questions and ask for help when needed
- Have a full understanding of their care and treatment plan, including the medicines they are taking
- Get the results of every test and understand the results
- Join an ALHIV association and support group
- Follow up on all referrals

Health workers can use *Appendix 13A: Transition Checklist for Health Workers* and Table 13.1 as tools to support ALHIV in the transition process. There are also a number of additional resources listed in *Appendix 13B: Transition Resources for Health Workers and ALHIV*. Please note that these resources can be adapted to many clinical or program settings.

Table 13.1: A self-care and transition timeline for ALHIV

10–12 years old	13–16 years old	17–19 years old
• Encourage caregivers to fully disclose to the child • Solicit direct conversation with the adolescent • Increase one-to-one meetings and counseling sessions with the adolescent • Begin to explain medications and adherence • Deal with early adherence issues and challenges • Link adolescent to support groups	• Assist adolescent with a calendar for appointments and medicines • Ensure adolescent understands diagnosis, needed medications, adherence, health precautions, positive living, and positive prevention	• Enforce responsibility in making and keeping appointments • Provide ALHIV with copies of medical records and any other forms or documents required by the adult clinic • Review medical history with the client • Encourage questions about adolescent's care plan, treatment regimen, and possible changes • Transfer medical records to new provider, highlight key issues • Visit the adult clinic with the adolescent client

Adapted from: AETC National Resource Center; New York/New Jersey AETC; Texas/Oklahoma AETC and Florida/Caribbean AETC. (2003). *The HIV perinatally-infected adolescent: A developmental approach, Practitioner transition checklist and timeline.* Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272

Trainer Instructions
Slides 24–28

Step 5: Lead participants through Exercise 1, which provides an opportunity to discuss how to help ALHIV plan for and carry out the transition to adult care.

Exercise 1: Supporting ALHIV in Their Transition to Adult Care: Case studies and large group discussion	
Purpose	To discuss particular issues related to ALHIV's transition to adult care and how health workers can help make the transition process smoother
Duration	30 minutes
Advance Preparation	None
Introduction	ALHIV need adequate preparation and ongoing support from health workers during their transition to the adult clinic. There are many differences between the pediatric, adolescent, and adult care models and adolescents may have many valid concerns about transitioning.
Activities 	**Large Group Discussion of Case Studies** 1. Ask participants to review the case studies and *Appendix 13A: Transition Checklist for Health Workers* in their Participant Manuals. 2. Read each case study out loud (or ask for a volunteer to do so). For each case study, ask the following questions to facilitate discussion: • *What fears or concerns do you think this client has about transitioning to adult care?* • *What could health workers do to prepare this client for his or her transition to adult care?* • *What follow up could health workers provide once the adolescent has enrolled in the adult clinic?* 3. (optional) Encourage participation by the adolescent co-trainer, who can draw on his or her own experience to discuss how the client might be feeling and what health workers could do to make the transition process easier.
Debriefing	• To prepare for the transition from the pediatric/adolescent to the adult clinic, older ALHIV need support from the entire multidisciplinary care team and from family members. • Ideally, health workers from the pediatric and adult clinics should collaborate and problem solve together during a client's transition. For example, they could use multidisciplinary team meetings to co-manage the client's transition from the beginning up until the ALHIV is fully discharged from the pediatric clinic. • As ALHIV transition to the adult clinic, health workers can help them advocate for themselves, be involved and understand their care and treatment, ask questions, and understand referrals and other aspects of their care. • Health workers can use *Appendix 13A: Transition Checklist for Health Workers* and can also adapt some of the other transition resources listed in *Appendix 13B: Transition Resources for Health Workers and ALHIV* to support ALHIV during the transition process.

Exercise 1: Supporting ALHIV in Their Transition to Adult Care: Case studies and large group discussion

Case Study 1:

P___ is a 16-year-old ALHIV. In a few months, he is moving to a new town with no pediatric clinic and he will have to start getting care and treatment at an adult clinic. He is nervous about this change because he does not know the staff there and because he will now have to deal with a large, crowded clinic.

Key points for trainers: P___

- **What fears or concerns do you think this client has about transitioning to adult care?** As noted in the case study, P___ is afraid of the unknown (new clinic staff, new setting with new philosophy of care, etc.) and he is afraid of going to a large, crowded clinic. Participants may suggest other fears, which will likely be correct as well.

- **What could health workers do to prepare this client for his or her transition to adult care?**
  - Starting as soon as possible, you (as the health worker at P___'s current clinic) should help P___ identify exactly what he is afraid of. (Is he scared of going someplace new? Is he worried that the new doctor will change his medications? Is he worried about getting lost in such a big building? Is he afraid he'll miss his support group?) Based on his specific fears, provide counseling to support him to recognize that he can make this change successfully. You should draw on the skills P___ has used in the past to adjust to change (maybe he changed schools last year?).
  - Review P___'s medical history with him, his current medications, and key points he should communicate to the new clinic.
  - Set up linkages with the new clinic. Do you or anyone else at your clinic know anyone working at P___'s new clinic? If so, use this personal relationship to identify someone at the new clinic. If not, then just call the new clinic and meet (by phone) a person who can assist him (a nurse, counselor, Peer Educator, or anyone else who can help him feel at home). Set up an appointment for P___'s first clinic visit and find out exactly what P___ needs to bring to that appointment. Also find out if the new clinic has Peer Educators, case managers, counselors, support groups, or other services that P___ needs.
  - Get P___ ready to take on greater responsibility for his own care. Right now, how does he remember to take his evening or morning ARVs? If his caregiver has to remind him, what can P___ do to wean himself from his caregiver's reminder and start remembering on his own?
  - During P___'s last visit to your clinic, make sure he has a copy of his medical record and enough medications to last him until his first appointment at the new clinic.
  - If P___'s new town isn't very far, maybe one of the Peer Educators can accompany him to his first visit (if possible).
  - If the new town is not far, maybe P___ could attend a support group meeting there before he moves, as a way of meeting some people who could ease his transition.

- Suggest that P___ keep a journal as a way of recording his feelings and goals and of charting his progress. He can also use the same journal as a planner to help him remember his clinic appointments and support group meetings.
- See *Appendix 13A: Transition Checklist for Health Workers* for additional activities to support P___'s transition.

- **What follow up could health workers provide once the adolescent has enrolled in the adult clinic?**
  - If P___ has access to a phone, call him the day before his appointment at the new clinic and find out if he is still scared. If he is, listen to his concerns and provide support. The phone call will also function as an appointment reminder.
  - The day after his appointment at the new clinic, call the new clinic to make sure he arrived, respond to any questions they may have about his social or medical history, and discuss if you can assist with any of the next steps that have been agreed on with him.

Case Study 2:
M___ is an ALHIV who is 19 years old. She has been receiving services from the adult clinic for the past year. Today, M___ has returned to the adolescent clinic to see you. When you ask her about her care and treatment, she tells you that she stopped taking her ARVs 3 weeks ago. When you try and discuss this situation with her in more detail, she cries and tells you that she doesn't like the people at the adult clinic.

Key points for trainers: M___

- **What fears or concerns do you think this client has about transitioning to adult care?**
  - Participants should discuss their ideas, but the change to the adult clinic was obviously quite difficult for M___. Assuming that she adhered to her ART regimen while attending your clinic, ask her what motivated her back then? Who reminded her? How are things different now? If she was taking her medications just to please the staff at the adolescent clinic, try to get her to recognize this. Let her know that, as an adult, she now needs to take care of herself for herself.

- **What could health workers do to prepare this client for his or her transition to adult care?**
  - Keep in mind that M___ already transitioned a year ago. Her case might suggest how the transition process in general should be changed. She was obviously unprepared for the transition; was that foreseeable? Did she need more counseling and support to take on the increased responsibility? Should the transition have been more gradual? Should it have happened later?
  - Help M___ figure out what she is afraid of and dislikes about the adult clinic. (Does she dislike how she is treated? Does she miss the comfort and familiarity of the pediatric clinic? Does she dislike the wait time or the number of other patients? Maybe she has to wait in a waiting area with very ill adult patients and this is difficult for her.) Try to figure out whether the key issues are M___'s reluctance to adjust or the adult clinic's unfriendly services.

- Try to address M___'s fears and/or the disadvantages of the adult clinic one by one. If she feels she is not been treated well there, find out which provider she saw and what happened. Is it possible to reach out to a specific health worker known to be youth-friendly and to make an appointment with him or her for M___'s next visit? Is it possible that staff at the adult clinic do not have an understanding of adolescents' needs? If so, can you meet with them and discuss how they could ease not only M___'s transition but also that of other adolescents?
- Ask M___ if she has remained connected to any support group — even if she has transitioned away from the adolescent clinic, she could likely still remain affiliated with the support group there. A support group for people who are transitioning to adult care that includes adolescents who have transitioned successfully would be particularly helpful in M___'s case.
- Encourage M___ to join a young person's support group affiliated with the adult clinic.
- Suggest she attend her next adult clinic appointment with a Peer Educator (if available). She could also take a friend with her for support.
- See *Appendix 13A: Transition Checklist for Health Workers* for additional activities to support M___'s transition.

- **What follow up could health workers provide once the adolescent has enrolled in the adult clinic?**
  - If there is a Peer Educator at your clinic, that person could meet M___ and accompany her to her next adult clinic appointment.
  - Link M___ with an older adolescent who has transitioned successfully to the adult clinic. Maybe this person could even function as M___'s treatment buddy.
  - Even if M___ is not being seen by your clinic medical staff, could you see her 1 or 2 more times for counseling and support? If so, make an appointment for a follow-up visit and plan to see M___ after her next appointment at the adult clinic (the same day or the following day) to find out how it went.

Case Study 3:

B___ is 20 years old and is a client at the pediatric clinic where you work. Her auntie supports her and usually brings her for clinic visits. B___ has been diagnosed with some learning problems and developmental delays and, although she should transition to the adult clinic soon because of her age, you have some concerns about her development and ability to independently manage her own care. You are afraid she will get "lost" at the adult clinic.

Key points for trainers: B___

- **What fears or concerns do you think this client has about transitioning to adult care?**
  - Although we know what the health worker's fears and concerns are, it is difficult to know what fears or concerns B___ has, since they are not articulated in the case study. Participants should discuss their ideas about B___'s and her auntie's possible concerns.

- **What could health workers do to prepare this client and her caregiver for his or her transition to adult care?**
  - Discuss the transition with B___ (and also with her auntie, who seems to be quite involved in her care) and find out what she thinks about it. Address her fears.
  - Encourage B___ to attend any presentations or meetings during which transitioning to adult care will be the main topic. Her auntie should also attend.
  - Take B___ and her auntie for a tour of the adult clinic and get her feedback.
  - Identify a health worker at the adult clinic who is particularly good with clients who have developmental delays; introduce B___ and her auntie to him or her and find out if this health worker can take a lead in managing B___'s care.
  - Keep in mind that B___ may not be able to completely transition to self-care. Because she has developmental delays, she may always require the help of her auntie or another adult caregiver.
  - Right now, how does B___ remember to take her evening or morning ARVs? If her auntie has to remind her, what can B___ do to start remembering on her own?
  - During B___'s last medical visit to your clinic, make sure she has a copy of her medical record as well as enough medications to last her until her first appointment at the new clinic. Again, ask her the names of her medications to help her remember and praise her when she successfully names the drugs she is taking. Make sure that she is taking more and more responsibility for remembering her appointments and taking her medicines, even if she still needs help from her auntie.
  - Once B___ starts feeling comfortable with the adult clinic, begin transferring her medical care. For her first visit (which will likely be with her auntie also), she should be accompanied by a Peer Educator with whom she feels comfortable (if available). Maybe this Peer Educator could accompany her to her second visit as well.
  - Stay in touch with B___ and provide her with counseling and support out of your clinic so that she remains connected with your clinic until she feels comfortable going to the adult clinic.
  - Ensure that B___ has a youth support group she can keep in touch with (or a specific group for adolescents with developmental delays, if available) as she makes the transition. This is so that something in her care remains constant during this period of adjustment.
  - Given B___'s special circumstances with developmental delays, carry out the transition very gradually, even if it takes a year. Again, her auntie will likely have to continue to help B___ with care even into adulthood.

- **What follow up could health workers provide once the adolescent has enrolled in the adult clinic?**
  - For this particular case, you would want to keep in touch with both B___ and her auntie as well as her adult clinic health workers for at least 6 months to monitor her progress and adjustment.
  - If possible, meet with B___ (and her auntie) at least a couple of times after the transition to see how she is doing. Plan to meet her the day of or the day after her first and second adult clinic appointments.

Trainer Instructions
Slide 29

Step 6: Allow 5 minutes for questions and answers on this session.

Trainer Instructions
Slides 30–31

Step 7: Ask participants what they think the key points of the module are. What information will they take away from this module?

Step 8: Summarize the key points of the module using participant feedback and the content below.

Step 9: Ask if there are any questions or clarifications.

Module 13: Key Points

- In some places, adolescents attend pediatric clinics where they may have been getting services since birth, or for many years. After a certain age, however, they usually have to transition to the adult ART clinic.
- This care transition can be difficult for adolescents, caregivers, and health workers because, during this period, adolescents have to adjust to a new, less nurturing environment and to new health workers. They also have to adjust to adult clinics, which usually expect their clients to take responsibility for their own care.
- Taking on a greater role in self-care and self-advocacy may be challenging for adolescents, depending on their level of development and maturation. Not all adolescents, especially those with developmental delays, will be able to achieve 100% transition and independence.
- Health workers should help ALHIV set and achieve goals for independence and self-management of care as a way of recognizing their increasing maturation, capacity to make choices, and independence.
- Not all ALHIV will be ready to make the transfer to adult care at the same age. Health workers must take into account their cognitive and physical development, their emotional maturity, their support at home and in the community, and their health status.
- It is possible for adolescents to have a smooth transition to adult care and to receive adolescent-friendly services at the adult clinic. This requires planning and preparation for transition with the adolescent and ensuring that adult clinic staff understand the special needs of ALHIV.

Appendix 13A: Transition Checklist for Health Workers

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

✓	Important steps and suggested activities to facilitate the transition process	Actions and comments
	1. Introduce the transition	
	Introduce and discuss transition during adolescent support group meetings and group sessions.	
	Discuss transition during clinical checkups and individual counseling sessions with adolescent clients.	
	Discuss transition with caregivers during group or individual sessions.	
	2. Encourage the adolescent to assume increasing responsibility for his or her own health care management	
	Make sure the adolescent understands his or her own health condition, care plan, and medications.	
	Talk about the transition and transfer to the adult clinic, discuss expectations, and answer any questions.	
	Talk about general coping, positive living, and building supportive relationships.	
	Give caregivers an opportunity to discuss their feelings about transition and any concerns.	
	3. Assess the client's ability to make independent health care decisions, assess his or her readiness for the transition, and determine additional support needs	
	Assess the client's understanding of his or her own care and the transition process.	
	Assess the caregiver's understanding of the client's care and the transition process.	
	Encourage the adolescent to make his or her own next clinic appointment and refill appointment.	
	Initiate any needed referrals, including to support groups.	
	4. Provide anticipatory guidance	
	Review plans for the client's continued adherence to care.	
	Review the client's adherence to medicines and ensure that he or she has a medicine calendar.	
	Ensure the client knows where to access help if he or she has questions about the new clinic.	

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

Appendix 13B: Transition Resources for Health Workers and ALHIV

Resources for Health Workers:

- **New York State Department of Health AIDS Institute. (2011).** ***Transitioning HIV-infected adolescents into adult care: HIV clinical guidelines and best practices from New York State.*** Available at: http://www.hivguidelines.org/clinical-guidelines/adolescents/transitioning-hiv-infected-adolescents-into-adult-care/

- **AIDS Education & Training Centers (AETC). (2004).** ***HIV perinatally-infected adolescents: A developmental approach.*** This curriculum slide set is designed to provide an introduction to issues faced by adolescents who have acquired HIV infection perinatally. It uses a developmental approach to explore issues from the perspective of the adolescent, the family, and the health provider. Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-272

- **Jacob, S. & Jearld, S. (2007).** ***Transitioning your HIV+ youth to healthy adulthood: A guide for health care providers.*** This is a comprehensive guide for health providers. It includes many tools and resources and although it is designed for perinatally infected youth, it is broadly applicable. Available at: http://hivcareforyouth.org/pdf/TransitioningYouth.pdf

- **AIDS Training and Education Centers National Resource Center.** ***Practitioner transition checklist and timeline.*** Available at: http://www.aids-ed.org/aidsetc?page=et-adol-checklist

- **Birnbaum JM.** ***Transitional care for HIV and AIDS from adolescence to adulthood. Slide presentation.*** Available at: http://www.hivguidelines.org/Admin/Files/ce/slide-presentations/trans-care.ppt

- **HRSA Care ACTION. (2007).** ***Transitioning from adolescent to adult care.*** Available at: ftp://ftp.hrsa.gov/hab/june2007.pdf

Resources for ALHIV and Families:

- **Life Skills Subgroup of the AETC Adolescent HIV/AIDS Workgroup. (2006).** ***Adolescent transition workbook.*** Available at: http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-269

- ***Adolescent Health Transition Project: A Resource for teens and young adults with special health care needs, chronic illness, physical or developmental disabilities.*** [website] Available at: http://depts.washington.edu/healthtr

- **USAID, AED, and collaborating organizations.** ***Adolescents living with HIV (ALHIV) toolkit.*** Available at: http://www.k4health.org/toolkits/alhiv

- **AIDS Alliance for Children, Teens, and Families. *Transitions in health care: A guide for teens with HIV/AIDS and their families.*** Available at: http://www.aids-alliance.org/resources/publications/transitionshealthcare.pdf

Journal Articles:

Blum, R. (1995). *Transition to adult health care: Setting the stage.* J Adolesc Health, 17, 3-5.

Cervia, J.S. (2007). *Transitioning HIV-infected children to adult care.* J Pediatr, *150:E1.*

Gilliam, P.P., Ellen, J.M., Leonar,d L., et al. (2011). *Transition of adolescents with HIV to adult care: Characteristics and current practices of the Adolescent Trials Network for HIV/AIDS Interventions.* J Assoc Nurses AIDS Care, *22(4)*, 283-293.

Kelly, A. (1995). *The primary care provider's role in caring for young people with chronic illness.* J Adolesc Health, *17*, 32-36.

Maturo, D., Powell, A., Major-Wilson H., et al. (2011). *Development of a protocol for transitioning adolescents with HIV infection to adult care.* J Pediatr Health Care, *25*, 16-23.

Miles, K., Edwards, S., & Clapson, M. (2004). *Transition from pediatric to adult services: Experiences of HIV-positive adolescents.* AIDS Care, *16*, 305-314.

Reiss, J.G., Gibson, R.W., & Walker, L.R. (2005). *Health care transition: Youth, family, and provider perspectives.* Pediatrics, *115*, 112-120.

Rosen, D.S., Blum, R.W., Britto, M., et al. (2003). *Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine.* J Adolesc Health, *33*, 309-311.

Scal, P., Evans, T., Blozis, S., Okinow, N. & Blum, R. (1999). *Trends in transition from pediatric to adult health care services for young adults with chronic conditions.* J Adolesc Health, *24*, 259-264.

Soanes, C., & Timmons, S. (2004). *Improving transition: A qualitative study examining the attitudes of young people with chronic illness transferring to adult care.* J Child Health Care, *8*, 102-112.

Valenzuela, J.M., Buchanan, C.L., Radcliffe, J., et al. (2011). *Transition to adult services among behaviorally infected adolescents with HIV: A qualitative study.* J Pediatr Psychol, *36*, 134-140.

Vijayan T., Benin, A.L., Wagner, K., et al. (2009). *We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine.* AIDS Care, *21*, 1222-1229.

Wiener, L.S., Kohrt, B.A., Battles, H.B., et al. (2011). *The HIV experience: Youth identified barriers for transitioning from pediatric to adult care.* J Pediatr Psychol, *36*, 141-154.

References

[1] New York State Department of Health AIDS Institute (2011). *Transitioning HIV-infected adolescents into adult care, HIV clinical guidelines and best practices from New York State.*