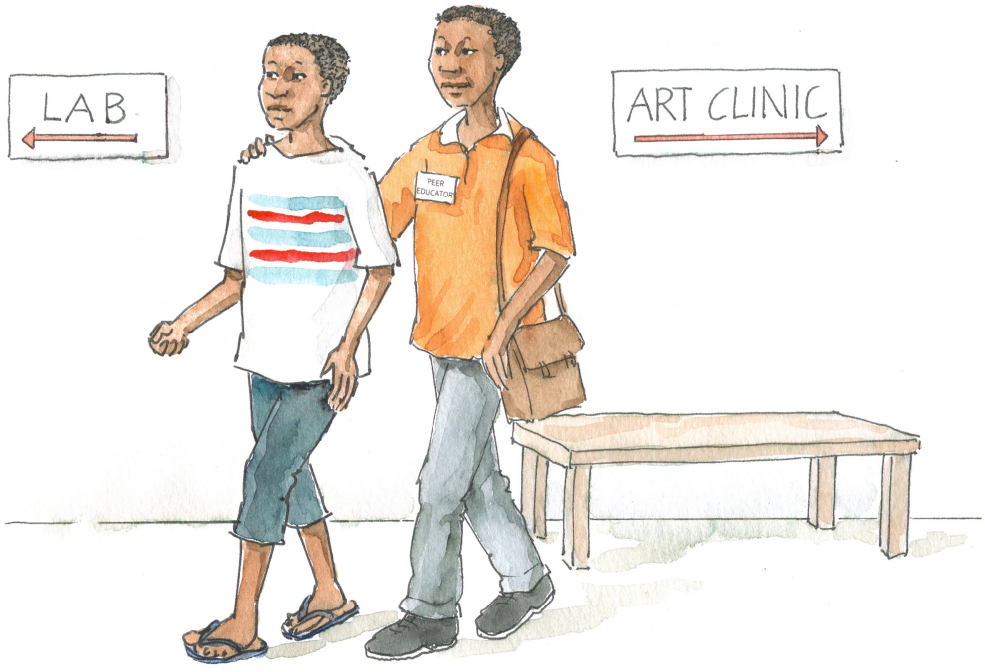
Module 13 Supporting the Transition to Adult Care

Session 13.1:	**Key Considerations for Health Care Transition**
Session 13.2:	**Preparing and Empowering Adolescents to Transition into Adult Care**

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



Session 13.1 Key Considerations for Health Care Transition

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

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.

Session 13.2 Preparing and Empowering Adolescents to Transition into Adult Care

Session Objective

After completing this session, participants will be able to:

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

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

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
Refer to *Appendix 13A: Transition Checklist for Health Workers.*	
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. **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. **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.	

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

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