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Adolescent and Youth Transition of Care Toolkit

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Acknowledgments

Acronyms

AGYWLHIV	adolescent girls and young women living with HIV
AYLHIV	adolescents and youth living with HIV
ARV	antiretroviral
ARVS	antiretroviral drugs
ART	antiretroviral therapy
CAYLHIV	children, adolescents, and youth living with HIV
CAYA	Committee of African Youth Advisors, EGPAF
DSD	differentiated service delivery
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HIV	human immunodeficiency virus
MDT	multidisciplinary team
PMTCT	prevention of mother-to-child transmission
PSS	psychosocial support
TB	tuberculosis
WHO	World Health Organization

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Transition of Care
Toolkit Overview

About This Toolkit

This toolkit was developed to address a gap that is well recognized among health care professionals, regarding practical guidance in supporting children, adolescents, and youth living with HIV (CAYLHIV), and their caregivers and treatment supporters, in successfully navigating various transitions in care and life settings. This Transition of Care Toolkit provides guidance and supporting tools for the transition of CAYLHIV from pediatric to adult clinical management in clinical and social settings, and throughout pregnancy and childbirth for young women living with HIV. The toolkit also includes a summary of available global transition resources.

The goal of this toolkit is to provide an understanding of how to implement and monitor the transition processes for CAYLHIV and their caregivers, educators, and partners. The toolkit serves as a practical reference for health care professionals and is designed to complement the existing national and global transition-of-care guidelines. It contains context, step-by-step guidance, assessments, monitoring and evaluation tools, and additional resources to assist with planning, supporting, and implementing successful transitions.

Target Audience

This toolkit is designed primarily for health care providers and multidisciplinary teams (MDTs) working with CAYLHIV and can be used by the diverse stakeholders involved throughout the transition processes.

Toolkit Structure

Each section in the toolkit covers a different form of transition and follows the same structure in outlining the **steps for transition**, aside from the Monitoring and Evaluation section:

- Planning and Preparation
- Client (and Caregiver/Treatment Supporter) Case Review and Assessment
- Transition Tasks
- Follow-Up
- Tracking and Reporting

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Introduction

Description and Goals of Transition of Care

Ongoing processes of change characterize childhood, adolescence, and young adulthood. The changes occur in surrounding social, educational, and health care settings, while children, adolescents, and youth themselves experience unprecedented social, emotional, and developmental transformations. Living with a health condition such as HIV adds significant complexity in navigating the processes of these transitions. CAYLHIV represent a highly heterogeneous group of people. This includes those living with perinatally and horizontally acquired HIV; adolescent pregnant women and mothers; those who are living at home or in boarding schools or with a relative; young key populations; and many others.

Globally, for CAYLHIV, transitions in care have traditionally posed significant challenges to health outcomes, including irregular access to care and antiretroviral drugs (ARVs), decreased adherence to antiretroviral therapy (ART), suboptimal retention, and lack of viral suppression.[1,2,3]

The process of transition involves the engagement of multiple supporters, including the children, adolescents, and youth themselves and their treatment supporters, such as caregivers, various providers, partners, peers, and others. **There is no one-size-fits-all approach to implementing the process of transition for children, adolescents, and youth.** Each person has their own specific needs and scenarios, and thus, while general approaches can be shared, individual transition plans need to be tailored to each person.

In recognizing that the process of transition needs to be individualized, it is important to ensure the inclusion of important components in planning and supporting transition. Among clients, several key factors may vary, such as their mode of HIV infection, their system of treatment support at home and within the community, their relationship with care providers, and their experience with the health sector leading up to the beginning of the transition, including care models, time on treatment, and treatment regimen. These factors have implications for planning the transition of care and treatment and for identifying barriers to and facilitators of transition to make it a success.[4,5]

> " *Transition is a complex necessary part of getting older and learning to manage your health and well-being."*
> — Male, 26 years, southern Africa

Regardless of the setting or model, successful transition assures **consistent access to uninterrupted quality care and treatment to support and sustain successful client and clinical outcomes**.

Challenges to and Facilitators of Transition

Transition is a complex and necessary part of growing up and living with a chronic health condition. It is important to invest the time and resources to avoid inadequate support, which is frequently associated with negative outcomes such as decreased retention in HIV care and treatment and increased morbidity and mortality.[6,7,8] The carefully planned transition can assure the delivery of uninterrupted quality care.[9]

Photo: Eric Bond, 2019/EGPAF

For example, in clinical settings, the uptake of triaging guidelines and basic transition planning has been shown to enable the provision of efficient support to adolescents and youth in successful transitions. The HIV care package should grow with the client's life experience and enhance understanding and skills for treatment, as well as future self-care.

> **It is important to note** that transition of care is not the same as referrals (sending a client to another service), transfers (required the movement of a client from one service department to another), or simple appointment blocking by age (age cohorts wait together for their care and treatment).

CHALLENGES TO SUCCESSFUL TRANSITION

The transition process needs to be tailored in an age-appropriate and developmentally appropriate way, considering the individual client's needs. CAYLHIV will face unique barriers during the transition that will affect the timeline. Cognitive impairments and education delays, for example, experienced frequently by perinatally-infected CAYLHIV, can impact preparation and decisions about the transition.[10]

During the transition of care, challenges can occur across multiple levels.[20,11] **Table 1** illustrates selected barriers across different levels.

❝ *Transition is not always easy, especially since we've been used to the environment and the method in the former group. Just make the new one your home and always go back to the health care workers who helped you transition in case of any problem."*

— Male, 20 years, East Africa

Table 1. Barriers to Transition of Care

Level of Effect	Barriers to Transition
Structural level	• Lack of national/regional policies or guidelines on transition[1] • Costs associated with HIV care influenced by subsidies, user fees, and household economy[12, 13] • Stigma and discrimination among providers, within schools, and in the community[14] • Lack of a system to monitor and track the transition of care[15] • Poverty and a lack of resources and food[16] • Lack of training of providers on adolescent- and youth-friendly care[13] • Failure to take into account adolescent and youth perspectives[17]
Facility level	• A limited number of practical tools and protocols supporting the transition[18] • Inadequate communication with CAYLHIV, with caregivers/ treatment supporters, and among providers[1,19] • Lack of provider capacity and skill[20] • Lack of adequate support for disclosure of HIV status: inadequate capacity, lack of tools and training, and abrupt transfers in care[5] • Changes in site service availability and structure, including the availability of psychosocial support groups and meeting the needs of young adults[21] • Lack of interdisciplinary involvement in the planning and management of the transition process[22]
Family level	• Lack of a home, or orphanhood[23] • Abusive environment[24] • Nondisclosure of HIV status by caregivers and parents[25, 26] • Lack of support from family/caregivers/treatment supporters[27, 28] • Bullying and social exclusion[29]
Peer level	• Negative peer influences or negative consequences for personal or romantic relationships[30] • Stigma from peers that affects adherence or academic performance[31]
Individual level	• Lack of self-esteem[32] • Self-stigma[5] • Fear of losing an established relationship with the pediatric/adolescent provider[15, 33] • Negative perceptions of adult providers and care[34] • Fear of change in health care settings, medication schedule, and providers[18, 35] • Anxiety over increased autonomy[36] • Hesitancy in disclosing HIV and treatment to other providers[37] • Suboptimal developmental readiness[15] • Lack of health and HIV knowledge and skills for self-management of care[21, 38]

FACILITATORS OF SUCCESSFUL TRANSITION

When done well, the transition of care can lead to multiple benefits.[20, 39]

Table 2 illustrates selected elements that can facilitate successful transition across different levels.

> " *It [transition] was not easy, because I felt like my life was that broad that I couldn't handle myself. But I came to realize it was my life, my ARV adherence, and my health—and also my future—were all dependent on the decisions and the steps I could take from this moment."*
>
> —Female, 23 years, West Africa

Photo: Eric Bond, 2019/EGPAF

Table 2. Facilitators of Transition of Care

Level of Effect	Facilitators of Transition
Structural level	• National/regional policies or guidelines on transition[39] • Affordable, accessible HIV care[40] • Competent adolescent- and youth-friendly providers[41] • Sound systems in place to monitor and track the transition of care[42] • Sufficient resources and food[1] • Acknowledgment of adolescent/youth perspectives[17]
Facility level	• Availability of practical tools and protocols supporting the transition[43] • Sufficient and appropriate communication with CAYLHIV, with caregivers, and among providers[44] • Competency of providers with the skills to support CAYLHIV transition[42] • Support for disclosure of HIV status: adequate capacity and available tools and training[23] • Consistency of services provided, including the availability of psychosocial support groups and meeting the needs of young adults[43] • Interdisciplinary involvement in the planning and management of the transition process[42]
Family level	• Stigma-free home environments[1] • Safe, inclusive households[45] • Disclosure of HIV status by caregivers and parents[17] • Support from family/caregivers[13]
Peer level	• Positive peer influences and relationships, both platonic and romantic[46] • Supportive peers[2]
Individual level	• Self-esteem[13] • Self-confidence[13] • Positive perceptions of adult providers and care[41] • Self-autonomy[47] • Ability to disclose HIV and treatment to other providers[17] • Developmental readiness[19] • Good level of health, HIV knowledge, and skills for self-management of care[19] • Preparedness for changes in health care settings, medication schedule, and providers[1] • Confidence in maintaining relationships and developing new bonds with providers[17]

TIMING OF TRANSITION OF CLINICAL CARE

The timing of the transition is defined in some African policies and guidelines, as summarized in **Table 3**. The range in age for the transition of care is broad, extending from 13 to 25 years of age, though the start of transition can occur earlier.[6, 48] Since transition is typically preceded by disclosure of HIV diagnosis, this chart also identifies the ages for full disclosure, as indicated in the majority of the national guidelines.

Table 3. Transition Guidance on Ages for Disclosure of HIV Status and Transition of Care by Individual African Countries

Country	Guidance on Age for Full Disclosure[49]	Guidance on Age of Transition	Guidelines on Disclosure	Guidelines on Transition
Cameroon	12 years	15–20 years	Cameroon HIV Guidelines, 2019.	Cameroon HIV Guidelines, 2019. Training of health care providers in global HIV care according to the new national guidelines, 2019.
Eswatini	≥8 years	17–19 years	Swaziland Paediatric HIV/AIDS Treatment Guidelines, 2006.	Swaziland Integrated HIV Management Guidelines, 2018.
Ethiopia	≥14 years	19 years[1]	National Guidelines for Comprehensive HIV Prevention, Care, and Treatment, 2014.	National Consolidated Guidelines for Comprehensive HIV Prevention, Care and Treatment, 2018. Presentation by Mirtie Getachew, HIV prevention, care, and treatment team lead, Federal Ministry of Health.
Kenya	9–12 years	13–16 years: start of counseling on transition ≥19 years: transition	Adolescent Package of Care, 2014, Annex 5.	Adolescent Package of Care, 2014.
Lesotho	10 years	10–24 years	Test and Treat Guidelines, 2016.	Adolescent and Youth Friendly Health Services Modular Training, Facilitator Manual, 2017.

Country	Guidance on Age for Full Disclosure[49]	Guidance on Age of Transition	Guidelines on Disclosure	Guidelines on Transition
Malawi	11–13 years	No age specified; begin transition process early	National Guidelines for Clinical Management of HIV in Children and Adults, 2016.	The Republic of Malawi, Youth Friendly Health Services Training Manual, Participants Handbook, 2016.
Nigeria	5–7 years	≥15 years[1]	National Guidelines for Paediatric HIV and AIDS Treatment and Care, 2007.	Presentation by Lynda Arthur (on behalf of Nigeria Ministry of Health), at New Horizon's Technical Workshop, 2018.
Rwanda	11–14 years	19 years	National Guidelines for Prevention and Management of HIV and Sexually Transmitted Infections, 2016.	Republic of Rwanda Ministry of Health, National Guidelines for Prevention and Management of HIV and Sexually Transmitted Infections, 2016.
Tanzania	8–10 years	17–19/20 years	HIV Services for Adolescents, 2018.	The National Package on Adolescents Living with HIV and AIDS Participant Manual, 2017.
Uganda	12 years	20–24 years[1]	Uganda HIV Testing Services Policy and Implementation Guidelines, 2016.	Consolidated Guidelines for Prevention and Treatment of HIV in Uganda, 2016.
Zambia	≥5–7 years	19–24 years[1]	Zambia National Guidelines for HIV Counseling and Testing of Children, 2011.	Presentation by Paul Zulu at New Horizon's Technical Workshop, 2018.
Zimbabwe	≥6 years	24 years[*]	Guidelines for Antiretroviral Therapy for the Prevention and Treatment of HIV in Zimbabwe, 2016.	No formal guidelines.

*   Personal correspondence with EGPAF technical directors or extracted from presentations by Ministry of Health representatives.

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Mapping Transition for Children, Adolescents, and Youth

Transition approaches vary by *type of facility, service delivery model*, and *client served*. Below we review the following transitions:

A. Transition between pediatric, adolescent, and adult HIV care and treatment, including differentiated service delivery (DSD)

B. Transition between caregivers and homes

C. Transition between schools and school levels

D. Transition of care for adolescent girls and young women living with HIV (AGYWLHIV) during and after pregnancy

This section provides a summary and visual overview of elements to consider in implementing these transitions. Sections 5–8 provide more in-depth guidance and steps.

> " *I learnt to be independent, I learnt to weigh the value of my life, I learnt to describe myself with all the positive names I could give myself, like a hero, a conqueror, and I also learnt to bring the best from me.*"
>
> **Female, 23 years, West Africa**

Photo: Eric Bond, 2017/EGPAF

A. Transition Between Pediatric, Adolescent, and Adult HIV Care and Treatment

This is the main transition process documented in the medical literature and programmatically in the field. This path of transition requires appropriate packages of care for purposeful planning and partnerships between clients, their caregivers/treatment supporters, providers, and clinics. Each transition process must be age-appropriate and developmentally appropriate and should recognize the needs of the caregivers/treatment supporters. The client's readiness level and their support system influence transition decisions. ***The goal of the transition is to sustain and improve clinical status over time***, and to avoid interruptions in care, missed appointments, non-adherence, or increase in viral load. **Figure 1** presents the major components of different stages of clinical transition by age.

PEDIATRIC (2-14 years)

- Mostly parent/caregiver care and antiretroviral adherence responsibility
- Start and completion of disclosure to the child
- Psychosocial support via art and games therapy
- Self-care with a focus on hygiene, basic nutrition, and puberty

ADOLESCENT/YOUTH (10-24 years)

- Shift in responsibility, with client more accountable for adherence
- Disclosure of HIV status
- Participation in support/peer groups and clubs
- Knowldege about HIV in relation to life and relationships
- Establishment of own treatment goals and plans
- Preparation for adult care and transition

ADULT (15+ years)

- Completion of transition to independent clinical and self-care
- Service options: young adult clubs, male adherence clubs, prevention of perinatal HIV transmission, mother-baby care, family clinics, and community antiretroviral therapy groups
- Client-led psychosocial support: maintaining supportive networks via online groups and discussions sharing personal successes, job opportunities, HIV events, and more
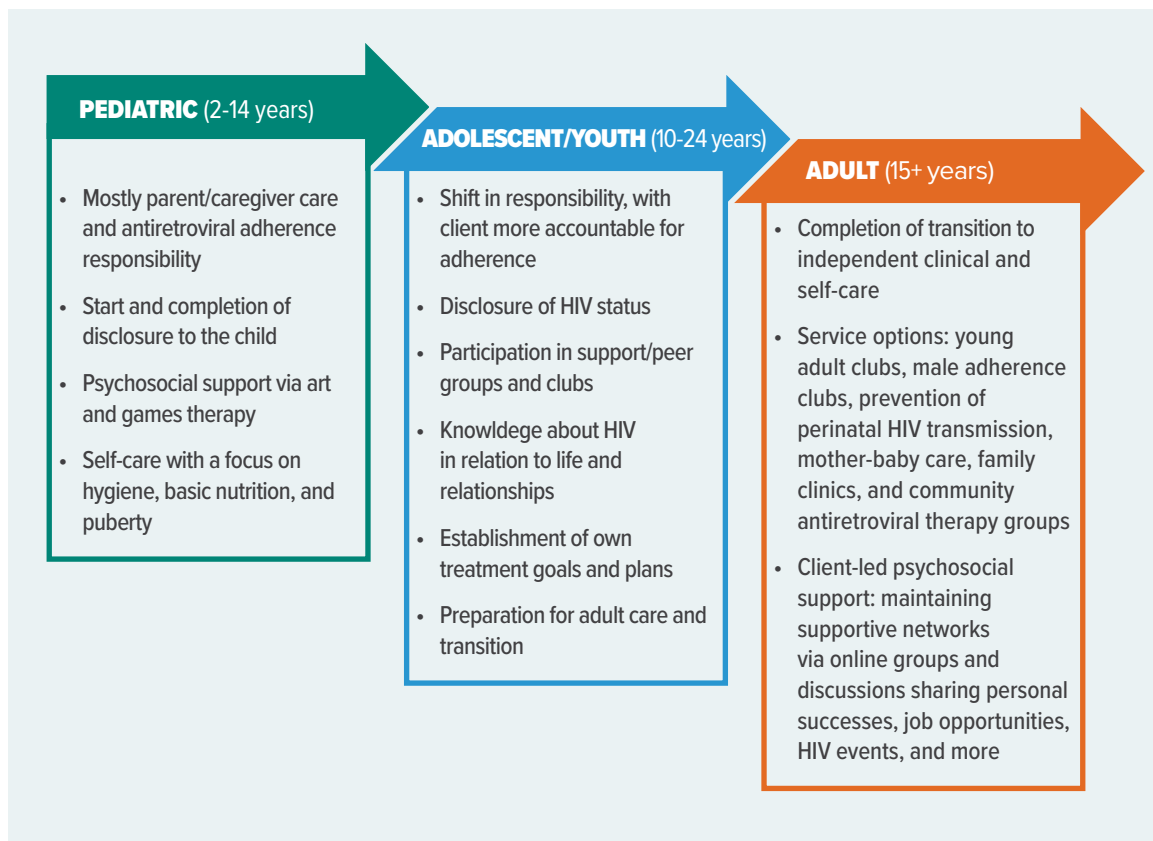
Figure 1. Major elements of the clinical transition process throughout the continuum of pediatric, adolescent, and adult HIV care

TRANSITION BETWEEN HIV SERVICE DELIVERY MODELS

With the scale-up of HIV treatment for all, CAYLHIV are experiencing different service delivery models that can change their package of services, frequency of visits, and provider focus.

DSD has proven successful with adults and is also recommended for younger clients.[50] DSD is a client-centered method of providing services to simplify the delivery and receipt of services for health systems and clients. DSD is dynamic, as clients move between models of care depending on their circumstances, usually based on their HIV viral load, co-infection status, or client-dependent issues.

There are multiple types of transitions between HIV care delivery models. The list below outlines common transition points within DSD:

- Stable client in general care ↔ multi-month ARV dispensation at the facility
- Stable client in general care ↔ community-based ART distribution models
- Unstable client in general care ↔ extra care / high viral load clinics, or specialized services for TB/HIV co-infection or advanced HIV disease

B. Transition between Caregivers and Homes

CAYLHIV often move places of residence for various reasons, including orphanhood, parent employment away from home, and more. The transition can involve moving to live with relatives, peers, or a partner; moving into an orphanage, or becoming a child-headed household. These changes may also include moving to a new community, city, or country and may be further complicated by the need to deal with grief or other emotional issues, or adjustment to a new school, a new community, and a new provider. This transition, which can occur once or repeatedly, can take a significant toll on any child, adolescent, or youth and is generally even more impactful for CAYLHIV. Complexities relating to disclosure, stigma, and management of treatment adherence and refills, and other HIV-care-related issues, emerge during a transition in caregivers. The environments the CAYLHIV move to, and the people they transition to live with will vary, as will their caregivers' ability to support their care and treatment. If the CAYLHIV are living with elderly or sick relatives or relatives with multiple children under their care, the CAYLHIV will need to take on more responsibility for their care early on. This change can also involve moving away and separating from siblings or family into different households.

Preparing for such transition involves adjusting to a new environment in which the CAYLHIV must learn new responsibilities and adapt their HIV care with the support of their clinical providers and caregivers. This is particularly challenging for CAYLHIV whose status has not yet been disclosed to them. In those cases, the current and future caregivers will play a central role during the preparation, in assessing the level of social support available in the new home environment and ways in which the child or adolescent can be best supported.

C. Transition between Schools and School Levels

Most CAYLHIV attend school and move between different school levels (primary, secondary, and tertiary) and/or schools (day to boarding and away from parents or caregivers) and eventually graduate or drop out. This change frequently affects their access and adherence to ARVs and clinical care.[51] *Planning for the transition between educational settings in coordination with HIV care is essential to sustain the uninterrupted continuum of care and treatment.*

Caregivers/treatment supporters and providers play an essential support role in adequately preparing CAYLHIV to transition between diverse school settings. At the primary and secondary school levels, there are many types of schools, including public and private; boarding and day; and all-female, all-male, and mixed schools. Across the various countries and regions of the world, school leadership

and staff have quite different levels of understanding of HIV care and support needs among learners living with HIV at schools. Tertiary school settings are usually associated with a complete transition to independent care and client-led decision-making. **Figure 2** depicts the elements present during the transition between varying education levels.

PRIMARY	SECONDARY	TERTIARY
• Support of parents/caregivers and family remains critical. • Disclosure status usually evolves from partial to full. • ART adherence is dependent on caregiver schedule and frequently requires support from school staff. • Fear of accidental disclosure and stigma.	• AYLHIV newly diagnosed and enrolled on ART need additional psychosocial support and counseling to cope with their HIV status. • AYLHIV aware of their HIV status consider disclosure to others, including school staff, and receive appropriate support. • AYLHIV seek independence and have more responsibilities. • AYLHIV start experiencing higher levels of peer pressure.	• AYLHIV attending tertiary-level programs often choose to keep their HIV status private. • Tertiary schools are less likely to ask about HIV status in enrollment or provide HIV treatment. • Schools in urban centers may have more active clubs and clinics, with integrated reproductive health services. • Students need to investigate their options, along with the pros and cons of transferring care nearby. • At this level, students may benefit from online psychosocial support and peer interactions on media platforms like WhatsApp. Peer interactions can facilitate discussion about relationships and stress associated with school that may be amplified with HIV.

Figure 2. Transitions between contexts of care in primary, secondary, and tertiary educational settings

D. Transition of Care for AGYWLHIV during and after Pregnancy

When empowered and supported, AGYWLHIV can have safe, planned, and desired pregnancies. Transition should focus on understanding the complex timelines and clinic changes, which coincide with significant physical and social transformations, including having a baby.

Unmarried AGYWLHIV with unplanned pregnancies may face challenges in staying in school, whether living with caregivers or parents or with partners. AGYWLHIV need extensive support to cope with pregnancy and prevent any potential issues, including emotional and physical violence, abuse, or self-injury. A range of professionals equipped to address their needs must include counselors, psychologists, social workers, and peer supporters/mother mentors. Home visits to evaluate and address the household challenges and concerns may assist families in accepting the pregnancy, welcoming the newborn baby home after delivery, and supporting the young mother to transition to independent young adulthood and return to school.

Photo: Eric Bond, 2018/EGPAF

The period during and after pregnancy features various transitions as the AGYWLHIV receive care as well as learn to support their children once born. **Figure 3** outlines an overview of the transitional process for AGWYLHIV during and after pregnancy.

START POINT

AGYW (HIV+ or HIV-)
- Pediatric care
- Adolescent care

Pregnancy planning

Pregnant

ANC / PMTCT

Newly diagnosed during pregnancy linked to care & treatment, PMTCT

Childbirth

Postnatal care & breastfeeding

Childcare & mother transition to general care

END POINT
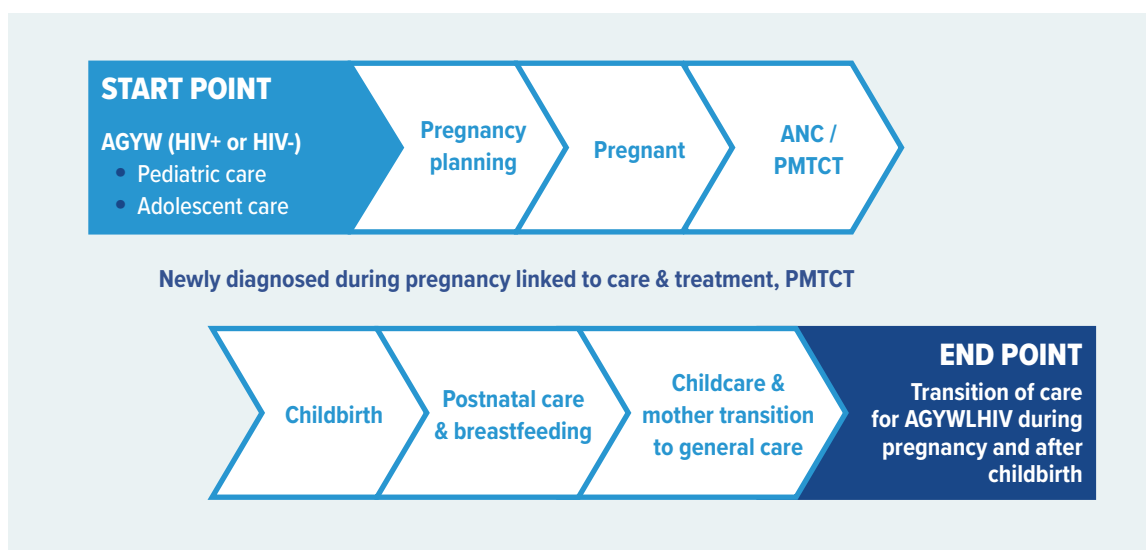**Transition of care for AGYWLHIV during pregnancy and after childbirth**

Figure 3. Overview of transition of care for AGYWLHIV during and after pregnancy

4
Stakeholders in Transition of Care

Transition processes require active participation by a range of stakeholders, including the following:

- The child, adolescent, or youth client
- Caregivers (parents, guardians) and/or treatment supporters (partners, peers, etc.)
- Health care providers (clinicians, nurses, etc.)
- Other providers (counselors, case managers, psychologists, pharmacists, etc.)
- School nurse or other school staff/advocateS

No single stakeholder can ensure a successful transition alone. ***A best practice is to form a multidisciplinary team (MDT) preferably led by a case manager.*** This is a clinical support team model involving professionals from different disciplines to evaluate client readiness from all aspects, planning and coordinating transition steps, and monitoring and evaluating the transition process to successful completion. This approach does not create additional work for health care providers but to integrate existing clinical team models where CAYLHIV health and progress are discussed.

Resources, Roles, and Responsibilities

Each stakeholder plays a role in the various transition processes, as outlined below.

THE CLIENT[52]

The role of the child, adolescent, or youth as the client continuously changes as their capacity for understanding and self-management grows throughout childhood and adolescence and into young adulthood. The role shifts from being a recipient of care, wherein their caregivers/treatment supporters play an active role in managing their treatment, to becoming responsible for their care. **Figure 4** depicts the shift in responsibility experienced by young clients as they move from childhood through adolescence to young adulthood.
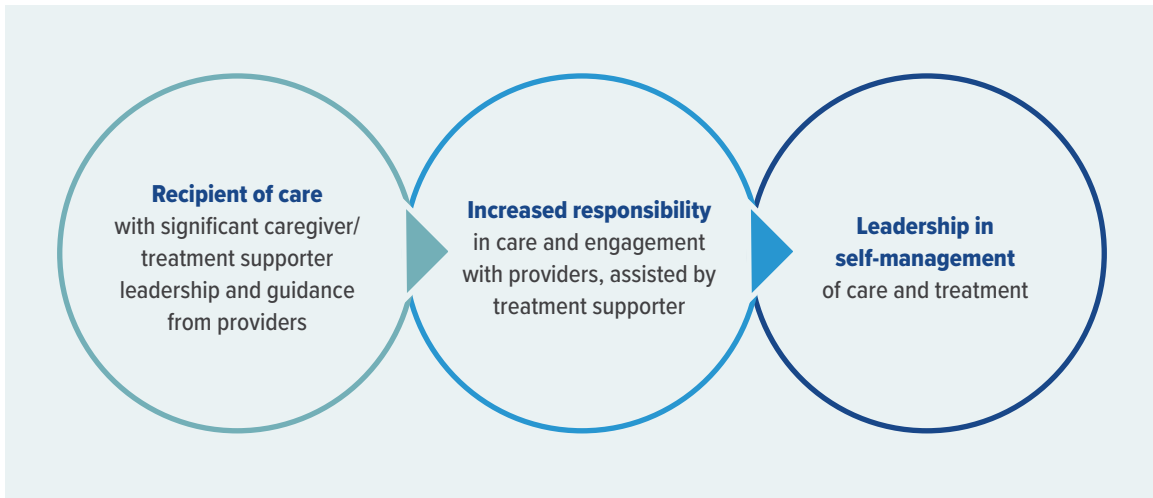

Photo: Eric Bond, 2017/EGPAF

Figure 4. Changes in client responsibility over time

TREATMENT SUPPORTERS

Treatment supporters help clients adhere to their care and treatment. The persons who fill this role change over time. For example, in childhood, the treatment supporter is usually the caregiver (parent, guardian, or family member), but this usually shifts to a peer or partner during late adolescence and young adulthood.

MULTIDISCIPLINARY TEAM

Setting up clinical MDTs is crucial to facilitate a successful transition.[12, 53] These teams are meant to be composed of different cadres of providers who plan, assist, and support the young clients and their caregivers/treatment supporters during the transition process and help manage challenges. These teams, which can be as small as two staff members from different cadres (e.g., a nurse or physician and a social worker or case manager), play a significant role in ensuring continuity of quality care for the client. Ideally, each client needs to be assigned a case manager to facilitate the engagement of other MDT members and respond to the individual needs of the client before, throughout, and after the transition process.

Jointly, the MDT is responsible for tracking the state of the client along the transition of services. The composition and size of the MDT can vary based on the facility and the availability of health providers. MDTs are built up over time, with initial teams frequently consisting of two individuals from different disciplines.

STAKEHOLDER RESPONSIBILITIES

There are a few responsibilities that are important for all stakeholders to take on:

- Support adherence, retention, and linkage of clients to care and other services as needed
- Support continuity of care throughout transitions
- Empower, encourage, and enable self-management skills for clients

Table 4 outlines the roles and responsibilities of different stakeholders that play various parts in ensuring successful transitions for CAYLHIV.

Table 4. Roles and Responsibilities of Key Stakeholders

Stakeholder	Roles and Responsibilities
Case manager*	• Review the full file of the transitioning young client. • Provide insight and suggestions on a case-by-case basis. • Discuss the challenges and solutions that may arise for clients and providers. • Encourage diverse participation of stakeholders. • Ensure that clients know their ARVs' name(s), doses, and dosing schedule. • Make a schedule to engage the MDT. • Assess client competency for transition. • Discuss transition plans within the MDT ahead of time for every type of transition. AGYW Specific • Understand the antenatal care and postnatal care needs of AGYWLHIV.
Caregiver/treatment supporter	• Fully disclose the HIV status to the child or adolescent, with the support of the provider. • Be a source of support for any challenges or issues. • Ensure that the child or adolescent understands their treatment regimen(s): • How often and when to take medications • With or without food • When and where to pick up refills • What to do when unable to take medicines • What to do when experiencing side effects • Support daily consistent adherence. • Support attendance at regular appointments at the clinic or health facility. • Help identify treatment supporters at school when possible. • Provide a safe confidential space for storage and taking of medications if needed. • Foster a stimulating and stigma-free home environment. • Provide appropriate nutrition to the child, adolescent, or youth. AGYW specific • Support AGYW during pregnancy and the post-pregnancy period to maintain the well-being of the young mother and her child.
Client (CAYLHIV)	• Take the medication as prescribed. • Attend appointments with their caregiver/treatment supporter and eventually independently. • Communicate with their provider or counselor (regarding challenges, concerns, questions, etc.). • Work to build self-esteem and capacity for self-management.

Stakeholder	Roles and Responsibilities
Client (CAYLHIV) *(continued)*	• Attend psychosocial support sessions. • Increase health literacy, including sexual and reproductive health literacy. • Know their medications (names of drugs and schedule for taking them). • Identify a "treatment buddy" or school-based supporter. • Discuss any changes in their caregiver, social support, or relationships with partner (for older clients). AGYW specific • Learn about and understand fertility and safe conception, along with responsibilities during pregnancy and postpartum for herself and her baby. • Ask questions to clarify unknown matters. • Disclose to partner, treatment supporter, and/or child.
Clinician **(doctor, nurse, clinical officer)**	• Support the disclosure process. • Evaluate health literacy and ensure that the client/treatment supporter(s) understand HIV, the ART regimen, sexual and reproductive health, and family planning. • Help identify treatment supporters in the client's new home and school environments. • Assess the caregiver's capacity to care for the client. • Discuss transition plans within the MDT beforehand for any type of transition. • Develop a transition plan jointly with the client and treatment supporter(s). • Engage with clinicians in the new facility to convey client information and support the transition. • Follow up with the young client after each transition and check on adherence, retention, and viral load with the case manager or other MDT members. • Link the client to other health facilities and share health records with the facility and the client if they move to another location, ensuring confidentiality. • Make referrals when necessary to the social worker, psychologist, etc. • Link to additional services such as psychosocial support, counseling, etc. AGYW specific • Understand the antenatal care and postnatal care needs of AGYW.
Counselor **(psychosocial support, adherence, expert client)**	• Assess and support the emotional and mental state of the client before and during the transition. • Bolster the client's understanding of positive living, self-care, dealing with stigma, challenges with adherence, and achieving and/or sustaining viral suppression. .

Stakeholder	Roles and Responsibilities
Counselor **(psychosocial support, adherence, expert client)** *(continued)*	• Assist with assessing the readiness of the client to transition care. • Follow up with the young person after the transition. • Empower the caregiver to disclose HIV status to the child or adolescent
Peer leader **(educator, champion, ambassador, navigator, mentor mother)**	• Provide insight and advice for adolescents/youth during and following transition. • Be a point of contact for adolescents/youth in need of support. • Ensure that clients know their ARV name(s), doses, and dosing schedule. • Attend the first appointment in the adult setting with the young person transitioning. • Follow up with the young person post-transition. • Share personal stories and advice, having gone through similar experiences. AGYW specific • Be a source of support for pregnant and breastfeeding AGYW.
Psychologist, nutritionist, reproductive health nurse	• Assist with and respond to referrals. • Provide specialized care for each client to improve health outcomes. • Help the client connect with new providers in the new location.
Pharmacist	• Ensure that the client knows their ARV name(s), doses, and dosing schedule. • Encourage adherence to ART and provide practical tips on taking ARVs. • Educate the client on other pharmacy commodities they may need, such as condoms, contraceptives, and pre-exposure prophylaxis for partners. • Discuss drug interactions with clients, for example, involving drugs for other chronic diseases.
Teacher/school personnel	• Support a non-stigmatizing school environment. • Provide up-to-date, age-appropriate information on HIV care and sex education. • Provide a safe, confidential space for storage and taking of medications, if needed. • Act as a focal person in the event of issues or emergencies (along with other stakeholders). • Support bidirectional health facility–school linkages. • Support clinical appointment attendance (along with other stakeholders).
Community/peer volunteer	• Support retention through the transition process. • Provide home-based care, as appropriate.

*Case managers can be providers with other roles, as well; for instance, they can be nurses or social workers. At different levels of health systems, the titles and responsibilities will differ based on availability and feasibility. The table simply outlines the responsibilities someone performing such a role would take on, even if this is not explicitly the person's cadre.

5
Clinical Care Transition

According to the World Health Organization definition, clinical transition refers to the planned, intentional process of providing age and developmentally appropriate uninterrupted care between pediatric, adolescent/youth, and adult/general health settings. The goals of clinical care transition include supporting a successful transition to maintain good health outcomes such as adherence, viral suppression, mental health, and maintaining psychosocial well-being.

> **DSD:** "A client-centered approach that simplifies and adapts HIV services in ways that both serve the needs of people living with HIV better and reduce unnecessary burdens on the health system." —WHO

Under the broader umbrella of clinical transition, AYLHIV will experience evolving HIV service delivery models, which can change the kinds of services they receive, how they receive care, and how they engage with providers. This includes transitioning between different DSD models for stable and unstable clients, including multi-month refills, community-based services, family services, or accessing special clubs or group care.

A variety of factors have been associated with successful clinical care transition:[12, 54, 55, 56]

- *Early engagement* with the CAYLHIV and family.
- *Engagement of the MDTs at the adolescent and adult clinics* from the planning stage.
- *Meaningful inclusion* of CAYLHIV in the transition process.
- *Individualized assessment* of client readiness to transition.
- Development of an *individualized transition plan*.
- *Involvement of pediatric, adolescent, and adult providers.*
- Assistance with the preliminary encounter with the adult provider.
- *Bidirectional communication between providers* regarding client flow.
- *Involvement of peer mentors and other types of peer support*.
- Coordination of family and social support during the transition.
- Maintenance of the comprehensive package of services, including clinical care, case management, nutritional support, and sexual and reproductive health counseling.
- *Tracking the outcome of the transition* on the individual and facility levels and beyond.

> ***Inter-facility transition** is the transition between facilities, which is a common occurrence and should be treated the same as clinical transition, involving all the same steps and processes outlined in this section.

Figure 5 outlines different models of clinical transition that children, adolescents, and youth can experience.
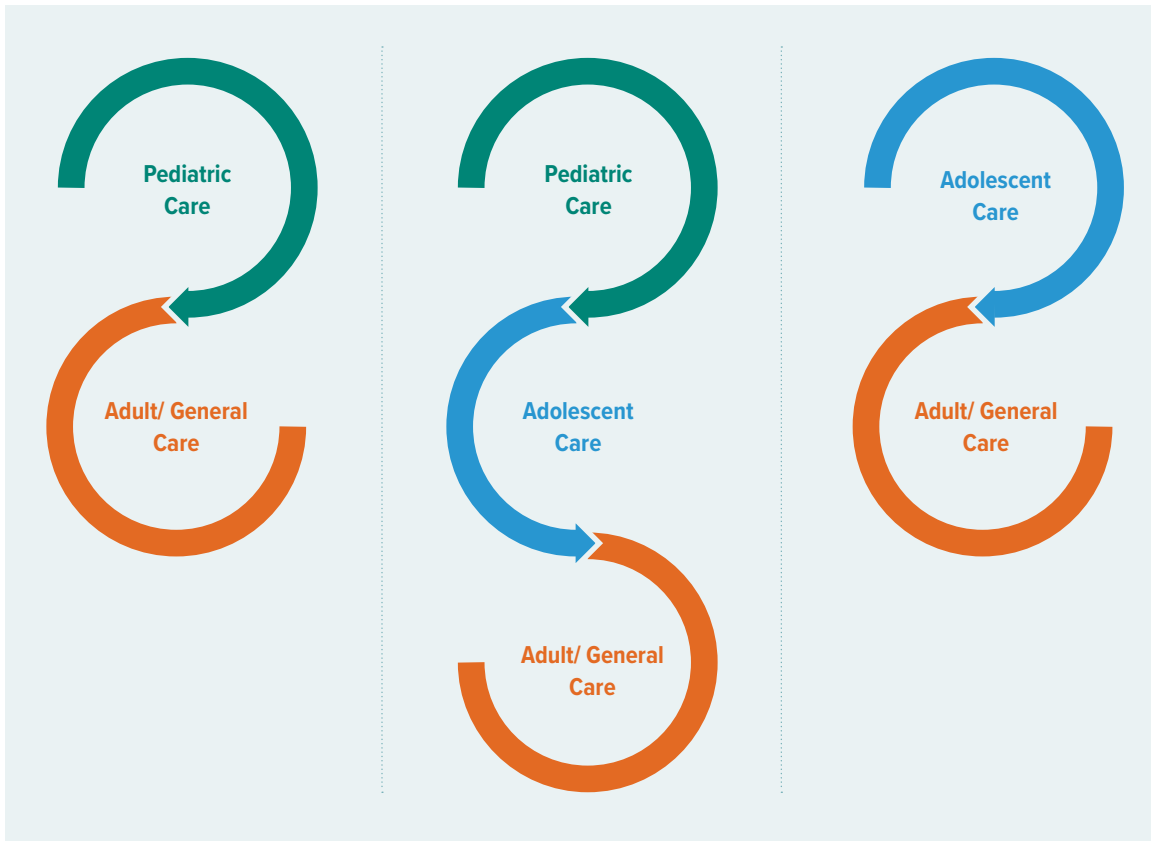
Figure 5. Types of clinical transition

Steps for Clinical Transition

1. PLANNING AND PREPARATION

KEY CONSIDERATIONS

- Health care providers need to know about the transition process to adequately prepare and support clients.
- Transition planning and preparation should start early with the client and their caregiver, preferably two years before the national guidance age of transition, and/or once disclosure to the child or adolescent has been fully completed.
- The timing of disclosure and transition depend on the national guidelines and the readiness of the child or adolescent.
- Understanding transition documentation for clients is important. Documentation could include a transition checklist in the client file, stand-alone cards, or as part of their existing file.

For DSD →

- Different facilities provide different HIV service, delivery models. High-volume sites are usually best positioned to offer different service models for different categories of similar clients.

- In supporting clients transitioning between HIV service delivery models, providers should understand their clients' needs, processes, and responsibilities as they support their continuity of care within and inter-between facilities.

ACTION ITEMS

✔ Review current national guidance on disclosure and transition.

✔ Become familiar with the transition process or refresh knowledge.

✔ Review and identify transition information and support at the national and facility level that will inform the client transition processes. Complete the National and Facility Transition Assessment (see below).

✔ Introduce the concept of transition to the client and caregiver or parents early (preferably two years before actual transition).

✔ If the client's status is still undisclosed, support completion of disclosure to the child or adolescent by the caregiver or provider.

Photo: Eric Bond, 2017/EGPAF

NATIONAL AND FACILITY TRANSITION ASSESSMENT

Identify the following information

NATIONAL LEVEL:

☐ Are there national/local guidelines to follow on how or when to support transition of care for children, adolescents, and youth living with HIV (CAYLHIV)?

FACILITY LEVEL:

☐ Do CAYLHIV receive care on a separate day or in a separate unit/clinic or receive specifically adolescent-focused care?

☐ What clinical transition model/pathways do CAYLHIV in the facility follow?

☐ For clinical transitions out of pediatric/adolescent care, are CAYLHIV transferred to adult/generalized care within the facility, to an outside/separate facility, or both?

  ◦ Does the facility transition CAYLHIV to tertiary care facilities, generalized primary care clinics, or both?

☐ If the facility transfers out CAYLHIV, does the facility have a standard practice for transferring adolescents/youth to another facility?

  ◦ If yes, is there a written protocol for transitioning CAYLHIV?

  ◦ If yes, which models of transition does it include?

☐ What is the official age of transition to non-pediatric services in the facility? If different ages are considered for each transition model, what are the ages for transition in each model in the facility?

☐ Who are the stakeholders who support CAYLHIV care transitions in the facility?

☐ Do clinical records include information on the schooling and education experiences of CAYLHIV?

☐ Does the facility offer prevention of mother-to-child transmission (PMTCT) and adult/general care in the same space, or does pregnancy-related care transition occur across separately located units?

☐ Does the facility have different HIV service delivery models for CAYLHIV?

☐ Does the facility use a transition readiness assessment?

  ◦ If yes, how is readiness assessed?

☐ Is there communication between pediatric/adolescent and adult care providers when a client undergoes transition?

  ◦ If yes, is it verbal, written, or both?

☐ Does the facility have a register / record sheet for recording and tracking CAYLHIV transition pathways?

☐ Are there places or people in the community who could be supportive of CAYLHIV as they transition in care?

  ◦ If yes, does the facility link CAYLHIV to these resources or discuss them with clients?

☐ For each model of transition, is there post-transition follow-up for adolescent/youth clients?

  ◦ If yes, how does it happen?

    • Contact adolescent/youth or caregiver   • Both

    • Contact receiving clinic/facility   • Other _____

☐ Does the facility apply transition criteria to determine when/which CAYLHIV experience different transitions?
Tick all that apply for each transition model:

Criteria	Clinical (→ adult care)	DSD models (stable ↔ unstable)	Pregnancy-related	School-related
Age	☐	☐	☐	☐
Full disclosure of HIV status/diagnosis	☐	☐	☐	☐
CD4 count	☐	☐	☐	☐
Viral load results	☐	☐	☐	☐
Readiness assessment	☐	☐	☐	☐
Marriage status	☐	☐	☐	☐
Pregnancy intentions	☐	☐	☐	☐
Pregnancy history	☐	☐	☐	☐
Demonstrated knowledge and understanding about HIV, adherence, ARVs	☐	☐	☐	☐
School attendance/graduation	☐	☐	☐	☐
Other (please note details)	☐	☐	☐	☐

- *Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations*[49]
  - Module B: Guide for Preparing and Supporting Caregiver in Disclosing Diagnosis of Vertically Acquired HIV

EGPAF Committee of African Youth Advisors (CAYA) Thoughts on Expectations for Adolescents and Receiving Providers

WHAT SHOULD ADOLESCENTS EXPECT WHEN MOVING TO ADULT CARE?	WHAT SHOULD PROVIDERS EXPECT FROM ADOLESCENTS MOVING TO ADULT CARE?
• You will self-manage more of your care. • There will be no escort to the facility. • You will see changes in services and the way services are provided. • You will need to know more about HIV, your health, and your treatment. • You can expect acceptance of your HIV status. • You will need to be concise, there is less time with your provider.	• This is a new environment for the youth. • They don't know everything. • They are afraid, anxious, and confused and may be in denial. • They have multiple questions to ask, and it would be beneficial for the provider to take time to answer them. • They appreciate respect. • Their psychosocial support needs are different from those of children and adults.

2. CLIENT CASE REVIEW AND ASSESSMENT

KEY CONSIDERATIONS

- Transition varies depending on the client and their unique situation.
  - The differences include variations in the setting of care, the location in which they will be receiving future services (different facilities, same facility but different day or providers), and their current service delivery model.
  - Clients may be experiencing simultaneous transitions, which can impact transition planning and the kind of support they receive.
- The Client Case Review Assessment checklist provides guidance on the elements that need to be assessed for each client and their transition situation (see below).
  - It has two sections: the first to be completed by the health care worker (part A) and the second to be completed by the client (part B); this allows clients to assess their competencies individually and thereafter further discuss the process with providers and caregivers/treatment supporters.
- Clinical transition forms need to be fully completed with the information specified in the box below and stored in client files.
- Transition plans need to be planned and carried on with a team of stakeholders, including the client, caregiver/treatment supporter, and MDT.

- A transition plan should not be a one-time static plan. Rather, it should provide a framework with checkmarks and a timeline for achieving the desired milestones and transition goals, based on the client's context, to fully prepare them for transition.
- The transition plan should not be completed in one sitting but can be built over time and should be documented in writing and be part of the medical record and transition files.
- It is important to understand client (and caregiver/treatment supporter) competencies and comfort level around HIV to identify lacking areas.

FOR DSD →

- The introduction of transition concerning the service delivery model, based on the type, can occur individually (during a consult or counseling session) or in a group format, such as in a support group, and should include an explanation of the DSD models on-site for clients with their status.
- Be aware of existing perceptions (positive or negative) toward service schedule changes from clients and be sure to emphasize continuous treatment support. Some clients may view the transition through DSD models as graduating or growing up, whereas others may feel that they are being pushed out or being treated unfairly with more time at the clinic.

INFORMATION TO DOCUMENT IN TRANSITION PLAN AND FORMS:

- Unique patient identifier or demographics: name, sex, date of birth
- Patient contact information: address, phone, and second and emergency contact
- Date/age of HIV diagnosis, method of acquisition
- Current medical regimen: ARVs and other meds, length of latest ART regimen, any challenges or side effects, history of previous ARVs (reasons for switching / side effects)
- Medical history: health conditions, sexual and reproductive health (including pregnancies for females), mental health issues, nutritional status
- Social history: living conditions, school and/or employment history, family support, previous counseling, substance use, etc.
- Clinical information:
    - Date and result of first CD4 count
    - Date and result of first viral load test
    - Date and result of most recent viral load test
    - Date and result of most recent CD4 count
    - Other significant labs or other test results (such as HIV resistance testing, X-ray findings, significant lab findings)
- Status of transition plan and next steps

ACTION ITEMS

✔ Review the client's case and adjust their transition approach accordingly.

✔ Review the client's treatment history and clinical records (adherence, viral load, attendance at psychosocial support (PSS) groups, disclosure status, etc.) with the MDT. Note any areas of concern anticipated during the transition period.

✔ Consider the types of HIV service delivery models available at the current facility and the facility where the client is moving.

✔ Complete a client case review assessment.

✔ Review the completed assessment and address any lacking areas.

✔ Complete a clinical transition form (can be done by any provider).

✔ Assess client and caregiver/treatment supporter competencies and knowledge of HIV and HIV care and treatment.

✔ Work with the client and their support systems (caregiver/treatment supporters) to reach the desired level of competency for transition.

✔ Introduce the type of transition/DSD to the client (and caregiver/treatment supporter) early, if applicable. (See sample scripts below.)

✔ Discuss transition expectations with the client (and caregiver/treatment supporter) either individually or in a group format.

FOR DSD →

○ Clarify the fluid nature of these transitions based on the individual management of the client's treatment.

○ All adolescents and youth transitioning can be brought together for a group discussion— what is available, pros and cons of this model, what to expect, what will be expected if they join this model, etc.

✔ Discuss individual-specific challenges with the client and caregiver/treatment supporter to ensure participation in the care and service delivery model in light of potential barriers such as competing priorities and opportunity costs.

✔ Update the client's transition documentation in their file accordingly.

Photo: Eric Bond, 2019/EGPAF

CLIENT CASE REVIEW ASSESSMENT

PART A:

Client transition checklist (to be completed by the health care worker)

Item	Completed (✔)
Identify primary caregiver/treatment supporter	☐
Assess the client's home environment	☐
Document the client's school status/information	☐
Identify the disclosure status of the client	☐
Assess the psychosocial support status of the client	☐
Review the clinical information of the client, including:	
HIV treatment / viral load history	☐
Mental health	☐
Intimate partner violence / gender-based violence	☐
Co-conditions	☐
Confirm that appropriate referrals have been completed	☐
Determine the type of transition(s): ☐ Clinical transition to adult care ☐ Transition of care in school settings ☐ Clinical transition between service delivery models ☐ Caregiver transition ☐ Transition of care for AGYWLHIV through pregnancy and after childbirth	☐
Assess the client's level of HIV understanding	☐
Assess the caregiver's level of HIV understanding, if appropriate	☐
Confirm that the client has completed the client self-management assessment	☐
Review the client self-management assessment with the client	☐

PART B:

Self-evaluation of self-management skills (*to be completed by the adolescent/youth*)

Client Self-Management Competencies	Achieved (✔)
I can name/describe my medications and the doses	☐
I take my medicines on schedule (when I am supposed to)	☐
I can pick up my medication (know where, when, and what to collect)	☐
I can say why and how long I have taken my medication	☐
I can talk with my health provider and ask questions when I have them	☐
I know when to seek additional care and where to go	☐
I can schedule my own appointments (know where, when, and my provider/clinic)	☐
I know when my last viral load test was done	☐
I know the results of my last viral load test	☐
I understand what my viral load test results mean for my treatment	☐

SAMPLE SCRIPT FOR TRANSITION WITHIN DSD MODEL FOR CLIENTS WITHOUT VIRAL SUPPRESSION

Provider: Hello, *(name of client)*. How are things going with you?

Young client: Fine, thanks. Things have been going pretty well.

Provider: I wanted to talk about making a few changes in the way you get care here at the clinic, if that's OK.

Young client: OK.

Provider: Great. If you have any questions as I'm talking, or if anything is unclear, just let me know and I can explain it using different words. I have reviewed your file and saw that your viral load is up and needs attention. That tells me that you may have been having some challenges with staying on your treatment in the last few months or that the medicine is not working the way it should. Do you want to talk about some of the things that might be making things hard (to adhere)?

Young client: Well, I guess I forget sometimes, and it's hard when I feel fine and don't want my friends to know that I'm taking tablets every day.

Provider: Thank you for sharing that. We can talk about ways to work on that with the counselor. Also, we want to suggest that you come a bit earlier on clinic days to hear from other young people who have had similar experiences who might have some helpful advice. We call this a Specialized Care Clinic. What do you think?

Young client: I guess it's OK. I'll try.

Provider: Let's try to work together on your adherence. We will continue to monitor the virus, how you are feeling, and whether your medicines need to be changed. We will support you to stay adherent and in any other way you need....

- Taking Charge of Your Health
  - A shortlist of self-management tasks for adolescents and youth living with HIV (AYLHIV) to help them take charge of their health and become their advocates

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YOUTH ADVICE: TIPS FOR HIV SELF-MANAGEMENT

- Use alarms/watches to remind you to take your medications.
- Use pillboxes to carry meds in your bag.
- Take your medication as prescribed by your doctors.
- Attend your appointments and viral load testing as scheduled.
- Attend support group meetings to meet with your peers.
- Find a routine that works for you and your schedule.
- Be proud of who you are and accept the things you can't change.
- Know that self-management is not easy, and you will forget or skip taking your medication. That's OK, but make sure you keep going.

– EGPAF Committee of African Youth Advisors (CAYA)

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3. TRANSITION TASKS

KEY CONSIDERATIONS

- The receiving provider or facility need to be notified of the transitioning client in order to plan a dedicated initial consult to review records and discuss care and mutual expectations.
- Monthly or quarterly MDT meetings are usually recommended, depending on the volume and complexity of the cases to address.
  - If there are separate MDTs for the adolescent and adult clinics, both should participate in the meetings.
- MDT meetings aim to review cases, update everyone on clients' status and progress, and discuss solutions to any challenges.
- When feasible, a peer cadre should accompany the client to the new provider or facility for the first appointment there.
- The transition to a new HIV service delivery model (or different facility) could occur at the facility or community level.
- A plan of action for individual self-management by clients (and caregivers/treatment supporters) can help clients to self-identify roles and responsibilities in managing their treatment.
  - The individual self-management plan needs to be completed by the client with a caregiver/treatment supporter or in a support group session.

ACTION ITEMS

- ✔ Liaise with the future care provider in planning the transition.
- ✔ Follow the transition plan, address challenges, and continuously assess transition progress.
- ✔ Complete and use a clinical transition form to document clinical and demographic information.
- ✔ Share the transitioning client's clinical summary and records preemptively with the new provider/facility.
  - ° This information can be shared with the receiving provider along with a transition-of-care summary or letter. Clients can also carry a sealed hard copy with them to their new facility.
- ✔ Complete and discuss care plans and address the expectations for and responsibilities of the client and caregiver/treatment supporter (visits, labs, treatment).
- ✔ Ensure that all the details of the model of care have been communicated to the client (and caregiver/treatment supporter), making sure to address the following questions:
  - ° When will they come to the clinic?
  - ° How long will they stay at the clinic?
  - ° What kinds of services will they receive?
  - ° When should they come back for refills?
- ✔ Support facilitation of the transition to:
  - ° Adult/general care
  - ° Multi-month refills (three months, six months)
  - ° Community-based ART groups or PSS groups
  - ° Community-based ART distribution points
  - ° Extra care models and/or intensified adherence counseling for high viral load results
  - ° TB clinic if co-infected
  - ° Antenatal care / PMTCT if pregnant
  - ° Another facility
- ✔ Complete the transition and document it in the client's medical and social record before closing the file at the original facility or clinic.
- ✔ Identify the person responsible for holding the follow-up discussion before the actual transfer.
- ✔ Ensure that current contact information (phone, address) is available for the client and caregiver/treatment supporter as applicable.

MDT-SPECIFIC ACTION ITEMS →

- ✔ Define MDT membership and responsibilities.
- ✔ Make a schedule to meet regularly.
  - ° Hold quarterly meetings to coordinate the management of CAYLHIV during their transition.

- Review the facility-based transition systems available and make plans accordingly. (See box below.)
- Evaluate which clients will be transitioning within the next 6–12 months. Adult providers could be notified at this point about the upcoming transition.
- Review the available documents for each young person planned for transition.
  - Clinical records
  - Social records, with a focus on disclosure status
- Plan transition for each case.
- Assess the best next steps in the transition.
- Discuss further action points when needed.
- Reassess clients regularly.
- Complete the individual transition flow sheet or other available documentation in the client folder to document transition progress.
- Discuss the post-transition progress of clients who have transitioned.

MDT — FACILITY-BASED TRANSITION SYSTEMS ASSESSMENT

ASSESS WHETHER THE FOLLOWING ELEMENTS ARE PRESENT AND AVAILABLE:

☐ A transition plan/policy to identify and prepare CAYLHIV for different types of transition, including mapping of providers, client needs, and skills

☐ A method of recording and flagging transition needs among CAYLHIV in a timely manner

☐ A regular review of collected information and updates to transition plans (semiannually/annually)

Photo: Eric Bond, 2018/EGPAF

- Transition Checklist for AYLHIV Throughout the Transition Process

- *Sample Introduction Letter to a New Provider*[57]
- *Sample Clinical Transition Form: Confidential Patient Medical Transition Summary*[58]

GROUP ACTIVITIES THAT CAN SUPPORT TRANSITION

- Introduce and discuss the topic of transition in support groups or clubs at the facility or in the community.
  - Invite a provider from the adult clinic to the adolescent PSS group or teen club on a regular basis.
    - Consider implementing joint events with adult health care providers.
  - Invite expert clients who have transitioned to discuss their experience, tips, and advice on staying adherent.
  - Hold a separate session for young women with reproductive potential, pregnant adolescents, and young mothers and invite young mentor mothers to have a discussion when feasible.
  - Hold a health education talks to introduce transition on adolescent clinic days or family clinic days
- Have a group of AYLHIV transition together to maintain a support network and hold a group initial clinic visit with adult providers to have a joint discussion on expectations.
- Engage youth mentors at adult clinics for transitioning AYLHIV.
- Sensitize adult providers to adolescent care by having them attend adolescent days or clinics along with pediatric health care providers.

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4. FOLLOW-UP

KEY CONSIDERATIONS

- A follow-up discussion is an opportunity to talk through the young client's experience and address any concerns or questions they may have.
- This should occur a month after transition and quarterly thereafter, based on need.
- Discussions can be conducted with a counselor, peer mentor, or PSS facilitator face-to-face at the new facility, over the phone, or via home visits and should be recorded in the client's folder.
- Client satisfaction throughout the transition process needs to be evaluated and discussed by the MDT. Changing the way clients receive services can have unintended effects that may result in worse health outcomes, even if the objective of a DSD model is to improve or sustain good health outcomes and well-being.

ACTION ITEMS

✔ Maintain up-to-date contact information for clients.
✔ Schedule a follow-up discussion with the client one month after their transition and quarterly thereafter, based on the client's needs.

- Hold a follow-up discussion with the young client post-transition, to address the following:
  - Adjustment to the client's change in receiving care
  - Challenges concerning adherence, attending appointments, getting refills, viral load, social support, mental health (depression, anxiety), etc.
  - Next steps in maintaining adherence, clinical appointments, and next viral load test, as well as participation in PSS clubs
  - Client feedback or suggestions concerning their transition experience
  - Scheduling another follow-up session to meet following the next viral load test six months post-transition
- Document viral load results at six months in new care settings when possible.
- Provide updates on transition completions and feedback at MDT meetings.

5. TRACKING AND REPORTING

KEY CONSIDERATIONS

- It is important to track clients' clinical outcomes and attendance at care and treatment appointments following the transition to identify any needs.
- It is important to monitor the viral loads of all those changing between tracks, as a proxy for adherence.

Ensuring that AYLHIV receive the intended services is crucial, so attendance at clinic visits or services needs to be monitored, and clients who have missed an appointment should be followed up with.

Update client information
(clinical, service delivery) in files

Follow up with clients/caregivers
who don't attend appointments

Ensure that new providers have updated records

Quality tracking and monitoring of clinical outcomes and attendance of transitioned clients

Figure 6. Tracking and monitoring clinical outcomes

ACTION ITEMS

- Document attendance, clinical information, and updates in the client record or folder, including viral load, treatment changes, referrals, and other follow-up items.

Photo: Eric Bond, 2019/EGPAF

✔ Follow up with any clients (and caregivers/treatment supporters if appropriate) who do not attend their appointments.

✔ Ensure that records have been received by the appropriate providers in the transitioned setting.

TOOLS: AVAILABLE IN MONITORING AND EVALUATION ❯

- Transition Planning for AYLHIV Clients: Facility and Client Information
- Sample Individual Transition Flow Sheet
- Sample Transition Data Summary
- Sample Health Care Transition Feedback Survey for AYLHIV and/or Caregiver(s)

6
Caregiver Transition

CAYLHIV who have lost their biological parents or have parents working far from home often reside with other relatives or caregivers. This may be a permanent situation until they reach adulthood or a temporary place of residence until they move to another home or boarding school. Changing homes and places of residence, or revolving caregivers can have a significant impact on the young person's ability to maintain ART adherence and retention in care. This can occur for several reasons, including moving away from the clinic the child, adolescent, or youth had attended and/or moving in with relatives or peers who are unaware of their status and unprepared to meet their needs.[59, 60]

In some cases, a caregiver may be a member of a child-headed household. It is important for each facility to maintain a list of all such cases and proactively link the clients to services for orphans and vulnerable children and children's departments for social services. Children should not be responsible as caregivers for children but need to be supported by a peer educator / expert client or community health worker or village health team.

Steps for Caregiver Transition

1. PLANNING AND PREPARATION

KEY CONSIDERATIONS

- Transition planning should begin as soon as the provider becomes aware of a pending transition in caregiver, home, or place of residence.
- Engaging both the current and prospective caregiver(s) and other relevant parties (e.g., new household members or peers) together with a client, when possible, in the planning process is critical.

ACTION ITEMS

- ✔ Identify CAYLHIV who are facing this transition.
- ✔ Discuss the details of the anticipated transition with the client, caregiver(s), and other relevant parties.
- ✔ Describe the expectations for the caregiver(s), relevant parties, the client, and the provider throughout the transition process.

2. CLIENT AND CAREGIVER CASE REVIEW AND ASSESSMENT

KEY CONSIDERATIONS

- Understanding the specific caregiver transition situation the young client is experiencing is important, along with any other factors such as disclosure status and level of social support.

- CAYLHIV may experience feelings of abandonment, separation, grief, or bereavement from losing a parent, guardian, or other family member or social support network.
- Understating the capacity of caregivers to support CAYLHIV is critical to assure continuity of care.
- Areas, where support is particularly needed, can be identified through reviewing client files and discussions with clients and their caregivers/treatment supporters.

> CAYLHIV experiencing caregiver transition may be simultaneously experiencing other forms of transition, including clinical, school, pregnancy, or DSD model transition, which can also significantly impact the ability of the CAYLHIV to adjust to the changing caregiver context as well. Adjust transition planning and support as necessary.

ACTION ITEMS

✔ Review or identify the type(s) of transition the young client is experiencing or will experience.
  ○ Consider different situations:
    - Moving in with relatives or peers, or into an orphanage
    - Moving to a new facility, region, or city/village
  ○ Assess whether the client is experiencing simultaneous transitions.
  ○ Assess whether the client is experiencing grief or other emotional distress.

✔ Make referrals to the social worker, the psychologist, peer support, or any other relevant services.

✔ Begin the process of identifying new facilities to link the client to if they are moving to a new location.
  ○ Share the most up-to-date health records, including comments, with the facility and the client and caregivers.

✔ Check with the client to make sure they are aware of and comfortable with the new caregiver.

✔ Assess the future caregiver's capacity and comfort/interest in caring for the client and make plans accordingly.
  ○ Evaluate whether the future caregiver is comfortable dealing with HIV or knowledgeable about it and link them with an expert caregiver or with a PSS group for caregivers.

✔ Determine the disclosure status of the client with the current and new caregiver.

✔ Help identify treatment supporters in the client's new home and/or school environments.

✔ Review the client's clinical records (treatment history, adherence, viral load) within the MDT, when possible.

✔ Discuss any key anticipated challenges with the client and caregiver.

✔ Recommend including a caregiver change document in the client's file. (See sample.)

Date _____

Previous caregiver name _____

 Contact details (phone) _____

New caregiver name _____

 Contact details_____

Client name_____

This change consists of *(insert details on life event, reason for change, location, future caregiver, etc.)*. This change will occur over *(insert time frame)*.

This *has / has not* been discussed with the client and they *are / are not* aware of the changes.

This note has been seen by the current and/or new caregiver. Any updates need be noted in the client's chart.

MDT staff member who confirmed this change _____

Signature _____

3. TRANSITION TASKS

KEY CONSIDERATIONS

- Transition support should be tailored to the needs of the client and caregiver(s), based on an assessment of:
  - Caregiver capacity
  - Social support
  - Disclosure status
  - Treatment schedule (ART regimen, frequency of follow-up)
  - Other significant factors
- Ensuring that the caregiver(s) and the client know their responsibilities regarding staying adherent and coming to scheduled clinic appointments is important (depending on the age or developmental stage of the client).
  - Use peer or caregiver groups or meetings to discuss this change regularly. If caregivers are not living with HIV, be sure to link them to treatment supporters.
- Maintaining an open dialogue with the client concerning their feelings and hesitations is critical to understanding any changes in their situation.

✔ Support and educate prospective caregivers on HIV and the needs of the client.

✔ Facilitate transition to another facility when indicated.

　○ Follow all action items for a clinical transition.

✔ Ensure understanding of treatment targets, disclosure status, knowledge of ART, and viral load testing by the prospective caregiver(s) and the client.

✔ If the client's status is undisclosed, complete disclosure to them and/or support the current caregiver in the disclosure process.

✔ Discuss disclosure plans with the prospective caregiver if transitioning an undisclosed client.

✔ Identify a treatment supporter if the primary caregiver is unable to provide adequate, appropriate care for the client.

✔ Discuss care plans and the expectations for and responsibilities of the client and caregiver(s) for clinic visits, lab visits, medicine pickup, peer support, and other visits.

　○ Share the handover document with the prospective caregiver.

✔ Provide contact information (names and phone numbers) for MDT members supporting the client for the caregiver's direct use.

✔ Identify a person responsible for setting up and conducting a follow-up discussion with the caregiver(s) and client.

✔ Update any contact information based on the client's transition to make sure current and future contact numbers are available.

WHAT TO INCLUDE IN A CAREGIVER HANDOVER DOCUMENT:

- Name of clinic/facility
- Child's/adolescent's typical appointment schedule
- Medication regimen and doses
- Timing of taking medication and any food/ nutrition needs
- Results from last viral load test and next test scheduled

- Any allergies
- Tips on child's/adolescent's special needs, with description of common challenges and tips on how to address them
- Anticipated psychosocial support (individual or group)
- Clinical/referral team (names and phone numbers)

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4. FOLLOW-UP

KEY CONSIDERATIONS

• Conducting follow-up at the new facility and with the client and prospective caregiver where the client has transitioned is highly beneficial to both past and current health care provider teams.

• Feedback sessions can be incorporated into counseling sessions with a counselor, nurse, and peers.

- It is important to regularly (monthly or quarterly) assess the client's adjustment to their new environment and the capacity of the caregiver(s) to continue caring for the client.

ACTION ITEMS

- ✔ Conduct follow-up discussions with the caregiver(s) and/or client a month after transition and as needed thereafter.
  - ° For younger clients, the caregiver(s) will participate in discussions.
- ✔ Pose simple questions to assess client adjustment:
  - ° Are you able to take your medication every day?
  - ° Are you being treated differently at home? How does it make you feel?
  - ° Have you been able to come to the clinic regularly?
- ✔ Pose simple questions to assess caregiver adjustment:
  - ° Are you able to support the child/adolescent/youth in taking their medication every day?
  - ° Are you able to support the child/adolescent/youth in attending the clinic?
  - ° How is the child/adolescent/youth adjusting to living with you in your home?
  - ° Do you feel confident in your understanding of HIV and how you can best support the child/adolescent/youth?
- ✔ Make appropriate referrals to other services and additional support, based on identified needs.

5. TRACKING AND REPORTING

ACTION ITEMS

- ✔ Document changes and update client files.
- ✔ Update individual and facility-level indicators.

Update client information
(clinical, service delivery) in files

Follow up with clients/caregivers
who don't attend appointments

Ensure that new providers have updated records

Quality tracking and monitoring of clinical outcomes and attendance of transitioned clients
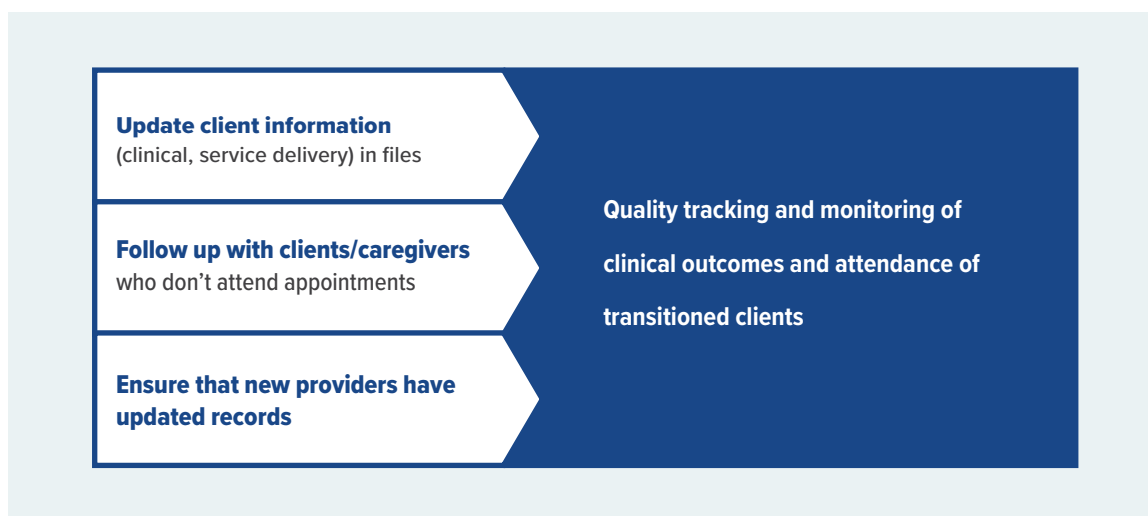
Figure 7. Tracking and monitoring clinical outcomes

7
Transition of Care in School Settings

Schools are a place for learning, engaging, and growing for children, adolescents, and young people. The school-age years are complex times for young learners as they navigate social and environmental changes while developing into autonomous and competent individuals. This section addresses transitions in educational environments and the support needs for CAYLHIV before, during, and after these transitions.

Types of school transition include the following:

- Primary school → secondary school
- Day school → boarding school
- Boarding school → day school
- Secondary school → tertiary education/college or university
- Out of school → return to/continuation of school
- School → out of school
- Tertiary education → employment

> ❝ *Being in a different world [new school] does not make you different; it just means you're moving to other heights. Treatment doesn't change with educational level, but shows your maturity."*
>
> Male, 20 years, East Africa

Children, adolescents, and young people spend the majority of the five-day week in school. In some countries, where boarding schools are a predominant educational structure, children and youth can live and spend up to eight months per year at school away from their caregivers or families.[61] During this time, CAYLHIV encounter enabling and disabling circumstances that can enhance or hinder their treatment success. For example, they might face stigma from peers and teachers, or social exclusion, and might experience educational delays.[18, 19, 27] At day schools and boarding schools, supportive environments can assist CAYLHIV in accessing care and treatment and being linked to ancillary services.[51]

Steps for Transition in School Settings

1. PLANNING AND PREPARATION

KEY CONSIDERATIONS

- Health care providers and treatment supporters play a critical role in optimizing treatment outcomes and contribute to the academic success of CAYLHIV, especially during times of transition of care.
- A change in school includes potential changes in a physical location (a different building or city), environment and lifestyle, community (new peers and teachers), schedule and structure, and responsibilities. Managing these changes is important to ensure continuity of care and treatment.
- Transition planning should begin as soon as an upcoming transition in the school setting has been identified.

- It is important to engage the caregiver(s) and the client, when possible, in the planning process.

ACTION ITEMS

- ✔ Identify CAYLHIV who may be experiencing this transition.
- ✔ Discuss the details of the school transition with caregivers and clients.
- ✔ Describe expectations for the caregiver(s), the client, and the provider throughout the transition process.

2. CLIENT CASE REVIEW AND ASSESSMENT[†]

KEY CONSIDERATIONS

- The support required by CAYLHIV varies based on individual needs and the type of school transition.
  - The transition to a boarding school environment, for example, brings different challenges than those faced by clients transitioning between day schools. **Table 5** highlights potential challenges arising during different transitions in educational settings.
- It is important to understand the specific school-transition situation the client will experience, along with any other factors that need to be considered, including disclosure status and level of social support available.
  - This includes understanding school policies and support available that would benefit or challenge the client.

ACTION ITEMS

- ✔ Review the type of school transition the client will experience.
- ✔ Consider:
  - The type of school transition
  - Whether the client is experiencing simultaneous transitions
  - The disclosure status of the client
- ✔ Make referrals when necessary to the social worker, psychologist, etc.
- ✔ Begin the process of identifying new facilities to link the client to if they are moving to a new location.
  - Share the most up-to-date health records with the facility and the client.
- ✔ Review the client's treatment history and clinical records with the MDT when feasible.
- ✔ Discuss key anticipated challenges with the client and caregiver(s) concerning maintaining academic performance and treatment success (limiting missed school days, for example).
- ✔ Determine the disclosure status of the client with the current caregiver(s) and/or the client; if undisclosed, initiate the disclosure process.
- ✔ Determine the status of the client's disclosure to school personnel and plans for school disclosure (desire to keep a secret or find confidential support).
- ✔ Determine the client's level of skills and understanding concerning HIV, adherence, and viral load.

[†] CAYLHIV may be simultaneously experiencing other forms of transition, including clinical, pregnancy, or DSD model transition, and these other transitions can also significantly impact the ability of the CAYLHIV to adjust to changing school contexts as well. Adjust transition planning and support as necessary.

✔ Check whether the client's clinical appointments are aligned with their school schedule and address any barriers that may exist.

Table 5. Potential Challenges in Transitions in School Environments

Type of School Transition	Potential Challenges
Primary school → secondary school	• Risk of accidental disclosure • Adjusting to a new medication schedule around the school timetable • Handling of disclosure with new peers, partners, teachers, and school nurse • Keeping or finding a new treatment supporter • Declining caregiver involvement in treatment management and clinic attendance
Day school ⟷ boarding school	• Risk of accidental disclosure • Adjusting to a new medication schedule • Handling disclosure with new peers, partners, teachers, and school nurse • Selecting a new facility and provider for HIV care • Adjusting the refill pickup schedule and PSS attendance—whether during holidays or finding another facility • Identifying a place to securely and confidentially store and take medications • Finding a confidential treatment "buddy" • Navigating more individual responsibility and less caregiver involvement daily • Interrupting the existing network of treatment support at home
Secondary school → tertiary education/college or university	• Adjusting to a new medication schedule • Handling disclosure with new peers and sexual partners • Increasing responsibility for treatment management and prevention of HIV transmission • Selecting a new facility for HIV care • Identifying a new, confidential treatment supporter • Increased self-management of HIV care and overall health, including sexual and reproductive health • Transitioning away from the network of treatment support at home and/or the previous school
Out of school → any school	• Adjusting life and HIV care schedules • Finding a confidential treatment buddy if there isn't one at school or home already

TOOLS: AVAILABLE IN RESOURCES ❯

- Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations[49]
  - **Module B:** Guide for Preparing and Supporting Caregiver in Disclosing Diagnosis of Vertically Acquired HIV
  - **Module D:** Guide for Supporting Adolescents in Disclosing His/Her Status to Friends, Social Network, School, or Work

3. TRANSITION TASKS

KEY CONSIDERATIONS

- Transition support needs to be tailored to the identified needs and competencies of the client and caregiver. **Table 6** presents different support steps for day and boarding school transitions.
- It is important to support the client to help them understand their responsibilities and plans for staying adherent and coming to scheduled clinic appointments, as well as what to do and whom to contact if they have problems.
- A plan of action for maintaining care and treatment efforts needs to be completed collaboratively with the client, caregiver(s), and provider, taking into account adjustment for the client's new schedule and school environment.
- The school schedule needs to be consulted to adjust the clinic appointment times or request school excuses.

ACTION ITEMS

✔ Support facilitation of the transition to another health care facility if applicable.
  - Follow all action items for a clinical transition.

✔ Ensure that the client and caregiver understand the client's treatment targets, including knowledge of ART, viral load results, etc.

✔ Depending on the type of school transition and client and caregiver preferences, decide together whether a disclosure to the school is beneficial for the client's well-being.

✔ If the decision to disclose is made, discuss potential support options at school with staff (adherence support, refill permissions, ART medication storage, and access).

✔ Determine the treatment plan based on the client's school schedule and needs. Discuss and provide support for:
  - Confidential storage of medication
  - Scheduling of taking medications
  - How/when/where to get refills and appointments
  - Whom to go to when having problems
  - Identifying treatment support in school environments, if needed

✔ Discuss care plans and the expectations for and responsibilities of the client and caregiver(s) (clinic visits, labs, medicines, peer support).

✔ Discuss potential challenges and solutions for the client in adjusting to their new environment and/or schedule and identify support if necessary.
  - See Youth Advice: Tips for HIV Self-Management.

- Identify a person responsible for setting up and conducting a follow-up discussion with the client and caregiver, if applicable.
- Update contact information based on the client's transition.

Table 6. Steps to Support HIV Care for CAYLHIV in School Settings

School Setting	Before Entering	While in School	During School Holidays
Day Schools	• Discuss decisions concerning disclosure in school settings with caregivers and CAYLHIV. • Review school timetables, policies, and possible support options. • Identify a suitable time to take ARVs as prescribed (once or more per day). • Adjust the dose timing to the school schedule. • Consider transferring CALHIV to a local facility if more convenient for them or their families for things like refills (especially if monthly visits are required); this will reduce missed class time.	• If CAYLHIV take their ARVs at school, a school official needs to become involved / arrange for storing ARVs and scheduling time to take them as prescribed. • Continue discussions concerning disclosure in school settings. • Identify a "treatment buddy" to confidentially support adherence at school when feasible.	• CAYLHIV might prefer to be engaged with clinic care and peer support during breaks. • CAYLHIV should maintain their ARV schedules during holidays.
Boarding Schools	Boarding schools have different policies than day schools on chronic illnesses, storage of medicines, and pill disbursement on school property. Caregivers/parents need to understand in advance how the school will keep HIV information confidential. Providers need to work with families, or CAYLHIV who have not disclosed their HIV status to their families, to support the planning of their medical care while attending school. Confidentiality of the student's health information is critical in any school setting. Storage of ARVs and daily confidential access to them are of crucial importance, as are managing refills and care appointments. Careful planning is necessary before transitioning CAYLHIV to boarding schools and might need to involve contacting school staff to advocate for the needs of CAYLHIV when feasible. Health care workers and support cadres can play an indispensable role in assisting CAYLHIV and their families with the transition to boarding schools and throughout the boarding school experience.		

4. FOLLOW-UP

KEY CONSIDERATIONS

- Following up with the new health care facility and/or school the client is attending after their school transition is complete can be highly beneficial.
- It is important to assess the client's ability to adjust to their new school and environment

and identify any areas of potential support needed.

- Feedback sessions can be incorporated into counseling sessions with a counselor, nurse, peer cadre, etc.
- If the client is new to the health care facility, ensure that they have access to the PSS groups with peers and support PSS at schools where available.

ACTION ITEMS

✔ Follow up after the transition (a month after or when feasible). A phone follow-up interview can be considered.

  ○ For example, during a holiday break for those in boarding school

✔ Pose simple questions to assess client adjustment:

  ○ Are you able to take your medication every day? If not, why not?

  ○ How are you adjusting to your new school?

✔ Make appropriate referrals to other services and additional support, based on identified needs.

5. TRACKING AND REPORTING

ACTION ITEMS

✔ Document changes and update client files.

✔ Update individual- and facility-level indicators.

Update client information
(clinical, service delivery) in files

Follow up with clients/caregivers
who don't attend appointments

Ensure that new providers have updated records

Quality tracking and monitoring of clinical outcomes and attendance of transitioned clients

Figure 8. Tracking and monitoring clinical outcomes

8
Transition of Care for AGYWLHIV during Pregnancy and After Childbirth

Compared to older women, adolescent girls and young women living with HIV (AGYWLHIV) are less likely to engage and be retained in maternal and child health services, including PMTCT services.[62] In South Africa, for example, pregnancy among AGYWLHIV has been associated with two to four times the risk of vertical HIV transmission to a child compared to adult mothers.[63, 64]

Fertility desires among adolescent girls and young women are high, meaning they have a desire to eventually have children.[65] AGYWLHIV are frequently identified as pregnant and HIV infected at the same time. They require a seamless cascade of services supporting their HIV, pregnancy, and sexual and reproductive health needs as they transition between PMTCT and HIV services and vice versa. Transition support for this population is especially critical in light of the frequency of adolescent pregnancy in countries heavily affected by the HIV epidemic. **Figure 9** outlines considerations for AGYWLHIV transition around and after pregnancy.

BARRIERS AND CHALLENGES IN TRANSITION BETWEEN HIV AND PMTCT SERVICES

Table 7 outlines various challenges at different levels and across different stakeholders that arise pertaining to AGYWLHIV and pregnancy and impact their transitions between HIV and PMTCT services.

Table 7. Challenges Impacting Transition of Care for AGYWLHIV Between HIV and PMTCT Services

Level of Effect	Challenges

Societal level	• Social and cultural norms around sexual activity influence providers, leading to bias in counseling adolescents to abstain from sex and targeting AGYWLHIV with messages of HIV transmission to their potential partners.
	• Health education for adolescents stresses how to avoid pregnancy and the negative effects of being pregnant too early for girls, their family, and their future.
	• Sexual and reproductive health education focuses on abstaining from sex, not on using condoms or engaging with family planning clinics.
	• AGYWLHIV are frequently stigmatized by older women for becoming pregnant and being infected young with HIV.
	• Emerging evidence suggests that pregnant AGYWLHIV frequently experience gender-based and sexual violence.
	  ◦ Estimates show that the prevalence of violence against pregnant women is the highest among women aged 15–35 years, ranging between 3.8% and 13.5% in African countries.[66]
	  ◦ HIV is a well-recognized additional risk factor for violence against young women.[67]

Level of Effect	Challenges
Facility/ provider level	• Providers, especially in pediatric centers, often focus on HIV treatment and have limited capacity to provide sexual and reproductive health education and care to AGYWLHIV. • Discussions about reaching an undetectable viral load, planned pregnancy with pre-exposure prophylaxis use for uninfected partners, and PMTCT information are limited for adolescents.
Individual level	• Adolescent girls and young women frequently delay pregnancy disclosure or confirmation of pregnancy in health care settings, due to negative norms around teen sex and early pregnancy.

BEFORE PREGNANCY

Planning:
Sexual and reproductive health education, including family planning, HIV prevention messaging, partner support, confidential gender-based violence screening, social support linkages

HIV+ & HIV

DURING PREGNANCY

PMTCT:
AGYW-friendly with appointment blocking for adolescent and young mothers

Specialized PSS:
mentor mothers and peer support

Household support:
staying in school

AFTER DELIVERY AND THROUGH 18–24 MONTHS

Baby HIV-uninfected

Baby HIV-infected

Mother-baby PSS:
includes safe breastfeeding education, early childhood development, and mother care to continue adherence and plan future pregnancies

Partner support:
Returning to / staying in school or work

HIV care option:
mother can return to adolescent clinic or transition to adult care models

HIV care option:
family clinic or separate

AGYW family planning option following birth

AGYW = adolescent girls and young women; PMTCT = prevention of mother-to-child transmission; PSS = psychosocial support
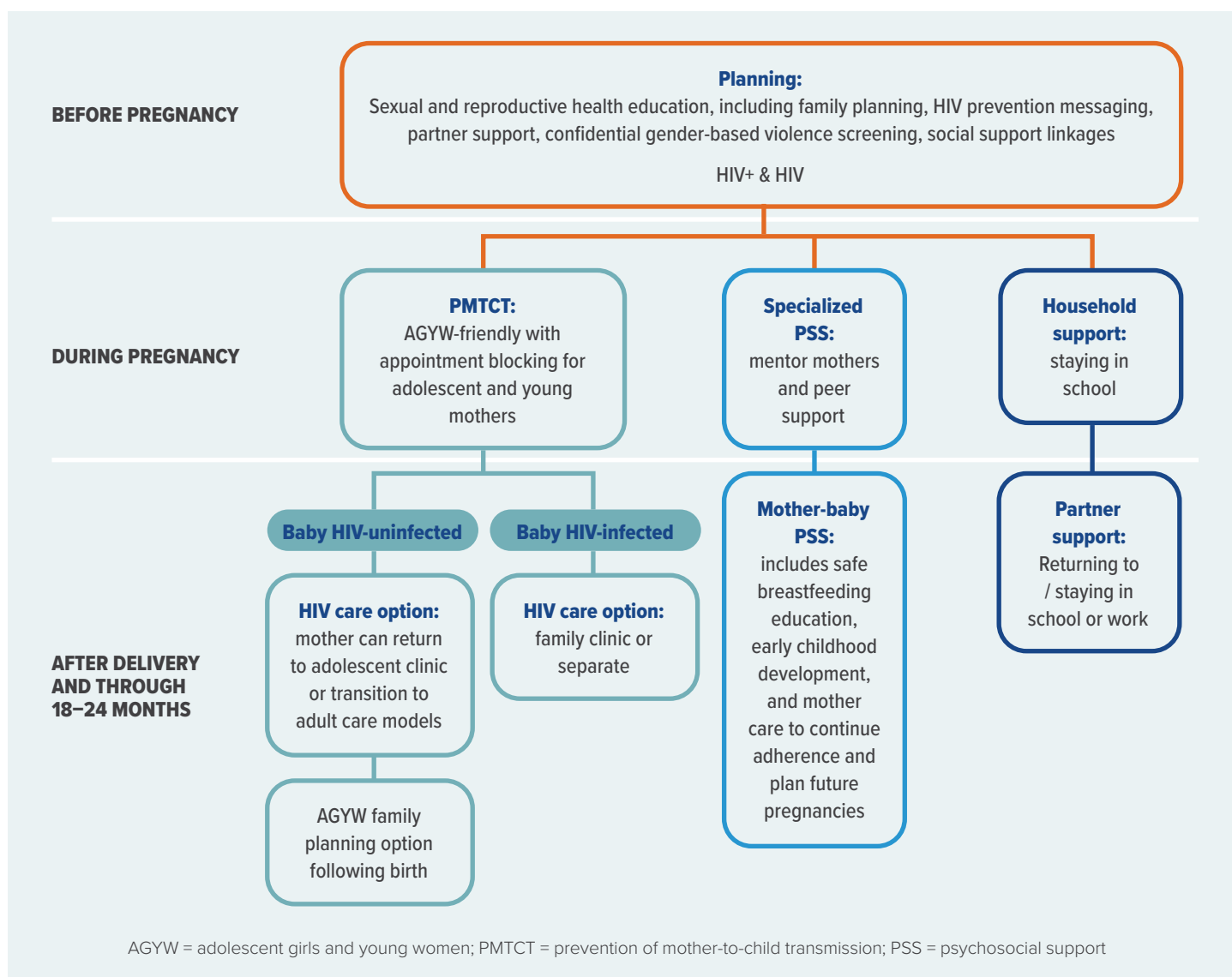
Figure 9. Considerations for AGYWLHIV transitions around and after pregnancy

Steps for Transition of Care Related to Pregnancy and Childbirth

1. PLANNING AND PREPARATION

KEY CONSIDERATIONS

- The provider should understand fertility awareness, safe conception, and the antenatal care and postnatal care needs of AGYWLHIV.

- It is important to provide and share appropriate materials for pregnant and young mothers on treatment literacy throughout the reproductive stages.

- Connecting AGYW to peer or mentor mothers can be beneficial in building social support and empowering clients from a shared experience.

- It is important to take more time with AGYWLHIV during their first and early pregnancies to share simple information and empower them through the process of pregnancy and HIV care.[68]

- Once pregnant, AGYWLHIV faces a transition in care from services with peers, frequently available during holidays and weekends, to more frequent clinic visits and a new cohort of "peers" such as older women in PMTCT clinics.

- For those AYGWLHIV who have experienced HIV care in pediatric settings, the new PMTCT-based HIV care settings can be less convenient and cause further stress in addition to that already caused by changes at home and in personal relationships.

ACTION ITEMS

- ✔ Review PMTCT registers to identify the proportion of clients aged 15–19 years and 20–24 years.

- ✔ Assess the client flow process with the MDT to facilitate a clear understanding of AGYW transition points.

- ✔ Consider how special AGYW support groups or clubs will benefit the transition process.
  - ○ Identify and share additional treatment literacy materials that are appropriate for pregnant and young mothers.
  - ○ Ensure that the MDT can adapt to meet the needs of unmarried women and survivors of violence.

- ✔ Schedule clinic visits with adequate time to discuss expectations for AGYWLHIV and providers throughout the transition process.

2. CLIENT CASE REVIEW AND ASSESSMENT[‡]

KEY CONSIDERATIONS

- Pregnant AGYWLHIV experience care via different models that impact the support they receive throughout the transition process. **Table 8** provides an overview of these different models.

- AGYWLHIV may experience bereavement if they lose social support networks because of their pregnancy and/or HIV status.

- Early adolescent pregnancy is frequently associated with the potential for coercion, early marriage, sexual abuse, or rape. These risks need to be evaluated and addressed, allowing for proper referrals to be made.

[‡] It is important to note that AGYWLHIV may be simultaneously experiencing other forms of transition, including clinical, school, or DSD model transition, and these other transitions can also significantly impact the ability of the AGYWLHIV to adjust to pregnancy contexts as well. Adjust transition planning and support as necessary.

- PSS is usually more complex, important, and intense, as additional education and care coordination are required for the first pregnancy in AGYWLHIV.

- Most importantly, the course and outcome of the pregnancy may significantly affect the short- and long-term health outcomes of the young mothers and their infants.

ACTION ITEMS

✔ Review the client's model of care, history of attendance, and, if documented, her pregnancy situation. Assess:

- Whether the pregnant client is experiencing other simultaneous transitions, such as post-violence care, a new marriage, school drop-out or other transitions and complex circumstances

- Involvement and support by the partner and/or family

✔ Check for documented referrals and additional MDT support from a counselor, social worker, and/or psychologist.

✔ Review the client's treatment history and clinical records (adherence, viral load). Note any areas of concern.

✔ Assess the client's situation:

- First or repeat pregnancy

- Newly diagnosed or established HIV

- Survivor of violence (recent or in the past)

- Social support network

- Disclosure status to the partner

- Attendance at support groups

✔ Explain the proposed referrals, agree on actions, and explain the steps to complete these successfully.

✔ Determine the client's level of skill and understanding concerning HIV, adherence, viral load, pregnancy, etc.

Table 8. Models of Care for AGYWLHIV

Model of Care	Description
Mixed antenatal care / PMTCT	The number of pregnant adolescent girls and young women is usually large, with lower numbers of them living with HIV. This model supports the unique needs of young clients. The benefit of mixing HIV-positive and HIV-negative PMTCT clients allows the inclusion of mentor mother talks and discussing the importance of knowing your sexual partner's HIV status and addressing seroconversion throughout the cascade of PMTCT services. Clinical care is provided as usual, but support is different, with the PSS groups led by a peer. A peer (nominated by the group and supported by the clinician) moderates informal health education sessions on nutrition, birth preparedness, partner engagement, and early child development. • The clinician observes and ensures that correct information is shared. All adolescent girls and young women (both HIV-positive and HIV-negative) are treated the same for the clinical and general discussion portions; then those who are in PMTCT care are offered the opportunity to stay longer for their ART refills via discreet invitations such as: "If you have any special needs, please stay behind."
AGYWLHIV PMTCT	If the proportion of AGYWLHIV in PMTCT is significant (>25 pregnant AGYWLHIV seen each month at the facility), high-volume clinics can schedule PMTCT services exclusively for those AGYWLHIV 15–24 years in joint appointment blocks. This is known to improve acceptability and provide space to discuss peer support and other topics relevant to this age cohort and life stage, including: • Challenges of pregnancy at home / with caregivers and partners (if unmarried or not public) • Financial planning: understanding the costs of delivery and preparations for a baby • Planning for after delivery: breastfeeding to reduce the risk of HIV transmission, staying on ART, child care, returning to school or work, and postpartum contraception/family planning • Healthy relationships and consent to sex
Community-based antenatal care / PMTCT	In places with high rates of teen pregnancy and high endemic HIV, community-based programming is effective. Innovative models are being developed to increase PMTCT access, delivery at a facility, and access to PSS. Elements of this model include: • Mentor mothers programming, including home visits, with counseling and education provided at the household and facility • DREAMS-lite: adapting the PEPFAR DREAMS[§] package for pregnant and breastfeeding mothers aged 15–24 years old, which includes health services (biomedical), behavioral programming (life skills, parenting lessons, and early childhood development), and structural support (financial planning, entrepreneurship, and support to return to school) • Comprehensive home-visiting programs, such as AIDSFree JUA Kenya,[¶] using a case management approach for highly vulnerable AGYWLHIV

[§] The PEPFAR DREAMS (Determined – Resilient – Empowered – AIDS-Free – Mentored – Safe) package is a partnership aimed at reducing HIV infections among adolescent girls and young women in 10 sub-Saharan African countries.

[¶] The AIDSFree Jielimishe Uzazi Na Afya (JUA) program, implemented by EGPAF, John Snow Inc., and civil society organizations in Kenya, employed a home visiting team model aimed at supporting pregnant adolescent and young mothers and their infants through the provision of antenatal, postnatal, and HIV prevention services. Tools can be found in the Resources section.

3. TRANSITION TASKS

KEY CONSIDERATIONS

✔ The transition between PMTCT and HIV services varies based on the provisions of the facility.

✔ In general, once a client is identified as pregnant she is transitioned into PMTCT through birth and follows her HIV-exposed infant until the age of two years.

　◦ If she was newly identified as HIV positive, she will directly enter PMTCT.

✔ Following postnatal care, the breastfeeding client will transition into either adolescent HIV care or adult/general HIV care, depending on her preference and national guidelines.

✔ A plan of action for maintaining care and treatment efforts need to be completed collaboratively with the client to provide a framework for understanding the process and the responsibilities of the provider and client.

ACTION ITEMS

✔ Support the client's ability to handle clinical changes throughout her pregnancy and the postpartum period.

✔ Build the client's competencies to successfully transition to life with a new baby:

　◦ Health: exclusively breastfeeding to reduce the risk of HIV transmission, staying on ART, child care, postpartum contraception/family planning

　◦ Behavioral: life skills, parenting, early childhood development

　◦ Social: consent to sex, healthy relationships, financial planning, entrepreneurship, return to school

✔ If the decision to disclose to a partner was made, support the disclosure process and monitor the effects on the client.

✔ Discuss care plans that include the expectations for and responsibilities of the client.

✔ Involve the client's partner and their families meaningfully, depending on the client's situation and desires.

　◦ Engage in conversations on pre-exposure prophylaxis for uninfected partners, if applicable.

✔ Support facilitation of the transition back into general care. Transition settings include:

　◦ Previous HIV care settings (adolescent clinic, for example)

　◦ New HIV care setting (adult/general clinic, for example)

　◦ New HIV care setting for clients newly diagnosed during pregnancy

✔ For clients transitioning into new settings, follow the action items for a clinical transition.

✔ For clients transitioning into previous HIV settings, ensure that all updated records and information have been shared and received.

✔ Identify a person responsible for setting up and conducting a follow-up discussion with the client after the full transition back into general care.

✔ Ensure that current contact information (phone, address) is available for the client and her partner and/or family as applicable.

TOOLS: AVAILABLE IN RESOURCES ❯

- *Disclosure of HIV Status Toolkit for Pediatric and Adolescent Populations*[49]
  - ◦ Module E: Guide for Supporting Adolescent to Disclose Their Status to Their Partner

4. FOLLOW-UP

KEY CONSIDERATIONS

- Follow-up sessions need to be held after the client has transitioned into general care.
- Feedback sessions need to be incorporated into counseling sessions with a counselor, nurse, and/or peer cadre.

ACTION ITEMS

- ✔ Follow up soon after the transition (within a couple of weeks) and a couple of months after.
- ✔ During follow-up, discuss:
  - ◦ Adjustment to motherhood
  - ◦ Challenges concerning adherence, attending clinical appointments, breastfeeding, child care, mental health, etc.
- ✔ Make appropriate referrals to other services and additional support (PSS groups, postpartum contraception, and nutritional support), based on client choices and needs.

5. TRACKING AND REPORTING

ACTION ITEMS

- ✔ Document changes and updates the client's and her child's files.
- ✔ Update individual- and facility-level indicators.

Update client information
(clinical, service delivery) in files

Follow-up with clients/caregivers
who don't attend appointments

Ensure that new providers have updated records

Quality tracking and monitoring of clinical outcomes and attendance of transitioned clients
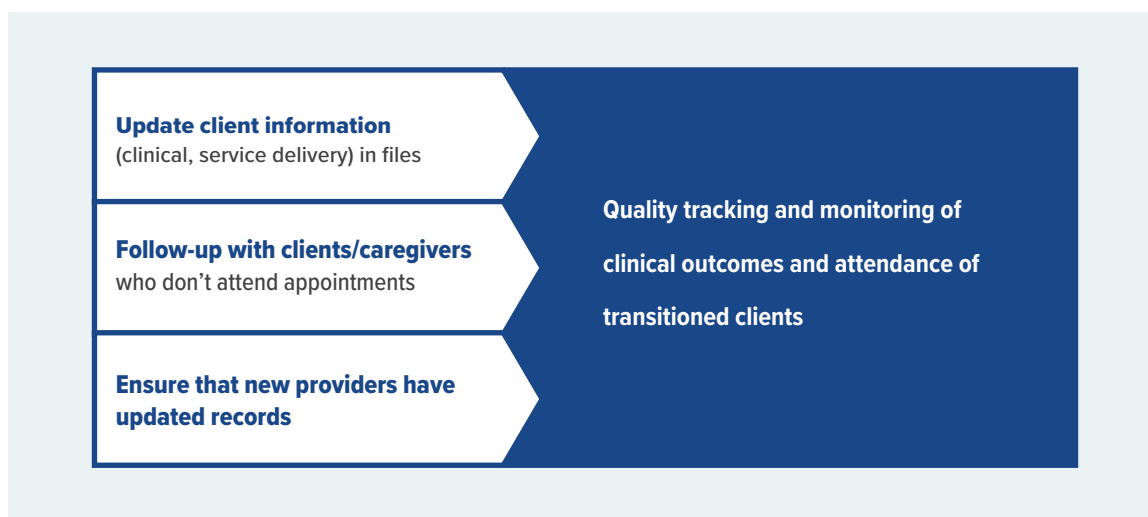
Figure 10. Tracking and monitoring clinical outcomes

9
Monitoring and Evaluation of Transition of Care

Monitoring and evaluating the transition of care is necessary to ensure successful transitioning and positive outcomes for CAYLHIV. Monitoring and evaluation can provide information for better planning and allocation of a facility's resources as well as up-to-date information on individual clients. It is crucial indicators are not just collected for the sake of routine reporting but critically reviewed quarterly or semiannually by the MDT to address bottlenecks and solutions. Effective monitoring and evaluation of transition, therefore, needs to happen at two levels at each facility: **the individual client level** and **the health care facility level**.

Identifying and Planning Implementation of Transition Models for CAYLHIV in Health Facilities

The first step in planning the implementation of transition models for CAYLHIV is to identify which models of transition are relevant and should be introduced or improved in the facility. For this, is it important to understand the client population of CAYLHIV who receives care at the facility. To help with this planning, complete **Table 9** below with available information and make a plan to collect any remaining missing information.

Photo: Eric Bond, 2019/EGPAF

Table 9. Transition Planning for AYLHIV Clients: Facility and Client Information[**]

Indicator	10–14 years old		15–19years old		20–24 years old	
	Male	Female	Male	Female	Male	Female
GENERAL INFORMATION						
Number of AYLHIV receiving care in this facility						
Number of parent/caregiver sessions held at the facility covering the topic of transition (age bands correspond to children of caregivers)						
CLINICAL TRANSITION						
Proportion/number of AYLHIV whose status has been fully disclosed to them [Proportion = #AYLHIV fully disclosed / #AYLHIV]						
Proportion/number of AYLHIV who are in adolescent-specific care (separate day, clinic, etc.) [Proportion = #AYLHIV in specific care / #AYLHIV]						
Proportion/number of AYLHIV who are eligible for transition by age [Proportion = #AYLHIV eligible / #AYLHIV]						
SCHOOL-RELATED TRANSITION						
Proportion/number of AYLHIV who are in primary school [Proportion = #AYLHIV in primary school / #AYLHIV]						
(If possible) Proportion/number who are in last year of primary school						
Proportion/number of AYLHIV who are in secondary school [Proportion = #AYLHIV in secondary school / #AYLHIV]						
(If possible) Proportion/number who are in last year of secondary school						

[**]   These data should be reassessed at a frequency that would be feasible for sites, be that on a quarterly or annual basis. Data should be reviewed whenever reporting is done for existing timelines and requirements but should not create additional reporting requirements.

Indicator	10–14 years old		15–19 years old		20–24 years old	
	Male	Female	Male	Female	Male	Female
Proportion/number of AYLHIV who are in tertiary education [Proportion = #AYLHIV in tertiary education / #AYLHIV]						
PREGNANCY-/MOTHERHOOD-RELATED TRANSITION						
Proportion/number of AGYWLHIV with intention of pregnancy [Proportion = #AGYWLHIV with pregnancy intention / # AGYWLHIV]						
Proportion/number of AGYWLHIV on contraception [Proportion = #AGYWLHIV on contraception / # AGYWLHIV]						
Types of contraception used						
Proportion/number of AGYWLHIV who were pregnant in the last year[a] [Proportion = #AGYWLHIV pregnant last year / # AGYWLHIV]						
DIFFERENTIATED SERVICE DELIVERY						
Number of CAYLHIV eligible for DSD models for unsuppressed clients[b]						
Number of CAYLHIV eligible for DSD models for suppressed clients[c]						

a Data on AGYWLHIV are critical, but it is also important to involve young male clients in discussions of safe contraception and prevention, including pre-exposure prophylaxis usage.

b Within the first 12 months of ART initiation (new to care), unsuppressed viral load (≥ 1000 copies/mL), sick/unwell (opportunistic infection), or as defined by your facility.

c On ART for >12 months and suppressed viral load (<1000 copies/mL but may be as low as <50 copies/mL, depending on the country), or as defined by your facility.

Individual-Level Monitoring and Evaluation of Transitions

When clients reach late childhood, several processes should begin that will eventually support the transition, including disclosure, increased health and treatment literacy, and provision of psychosocial support. It is important to start recording and tracking these elements early in the client's medical records. An individual's transition sheet could also be used to track progress in supporting transition throughout the client's care. Potential items to include in the individual transition flow sheet are indicated in **Table 10** below.

To ensure thorough assessment and preparation of a client's pre-transition care, as well as the post-transition follow-up, **individual transition progress summaries** should be completed for each client. These summaries should include the information summarized in Table 10.[††]

Table 10. Sample Individual Transition Flow Sheet

Client Name (LAST NAME, FIRST NAME) _____

Date of Birth _____ **Diagnosis (DATE)** _____

Disclosure completed (DATE) _____ Additional disclosure support (DATE) _____

Notes _____

_____

Transition models shared with client/caregiver (DATE) _____

Notes _____

_____

Type of transitions the client is experiencing (SELECT ALL THAT APPLY):

☐ Clinical   ☐ School   ☐ Sexual and reproductive health   ☐ HIV service delivery model

Notes on transition model(s) _____

_____

_____

DETAILS ON TRANSITION	Date	Notes
Transition assessment completed		
Transition plan started		
Transition plan finalized and shared with client/caregiver		
Medical summary updated and shared with client (and caregiver, if applicable)		

[††] Adapted from the Children's National Hospital and Got Transition's Six Core Elements of Health Care Transition 2.0: https://www.gottransition.org/providers/index.cfm.

	Date	Notes
Transition checklist completed		
Transition completed		
Transition follow-up with client		
Feedback survey collected from the client (and caregiver, if applicable)		

CLINICAL INFORMATION	Date	Notes
Primary diagnosis details		
Positive HIV test date		
ART start date		
Secondary diagnoses		
Treatment history		
Current regimen		

ORIGINAL/SENDING FACILITY INFORMATION	Date	Notes
Provider		
Last appointment		
Last viral load result		

RECEIVING FACILITY INFORMATION	Date	Notes
Receiving facility name		
Provider		
Provider's contact details		
First appointment date		
First viral load result		
Date of 6-month follow-up appointment		
6-month follow-up viral load result		
Date of 12-month follow-up appointment		
12-month follow-up viral load result		

Facility-Level Monitoring and Evaluation of Transitions

Depending on the volume of clients in each transition model—and the existing record-keeping for the child, adolescent, and youth clients—facility-level monitoring needs to be integrated into existing paper or electronic registers. Facilities and providers are already collecting high volumes of data, so any additional information recording needs to be simplified. Two types of information need to be monitored at the facility level:

1. Facility-wide information and policies
   - Part of the planning/preparation phase of clinical transition
2. Summaries of individual client data

CLIENT DATA SUMMARIES

Client data summaries capture data on important indicators to consider at each facility. Suggested summary items are presented in **the supplementary Excel sheet** linked below for consideration, with reporting stratified by the model of transition. Data summaries need to be collected regularly, **at least annually** and be integrated into existing reporting and data review processes.

⬇ **SAMPLE TRANSITION DATA SUMMARY: AVAILABLE HERE** (.ZIP)

POST-TRANSITION FEEDBACK

If possible, CAYLHIV and/or their caregiver(s) who have transitioned (successfully and not) should be contacted to collect feedback on what worked and what could be improved. The sample questionnaire below could be adapted and applied to a random or purposefully selected group of CAYLHIV and caregivers regularly. The questionnaire can be adopted or tailored based on the health facility and the clients and/or caregivers intended to complete it. This information will be useful for future planning and improvements of existing transition models. The section below outlines a sample transition feedback survey that could be used. The survey should be anonymous, and confidentiality needs to be emphasized and prioritized.

Photo: Eric Bond, 2018/EGPAF

SAMPLE HEALTH CARE TRANSITION FEEDBACK SURVEY FOR CAYLHIV AND/OR CAREGIVER(S)

You recently changed your health care provider and/or facility. We wanted to ask you some questions about your experiences so that we can improve our transition support to other young people like you. You do not have to answer all these questions. Your answers will be kept confidential. This is anonymous—do not put your name on it.

1. How often did your previous health care provider explain things in a way that was easy to understand?
   ☐ always   ☐ usually   ☐ sometimes   ☐ never

2. How often did your previous health care provider listen carefully to you?

   ☐ always   ☐ usually   ☐ sometimes   ☐ never

3. Did you feel prepared to change to your current health care provider?

   ☐ very prepared   ☐ somewhat prepared   ☐ not prepared

4. How often does your current health care provider explain things in a way that is easy to understand?

   ☐ always   ☐ usually   ☐ sometimes   ☐ never

5. How often does your current health care provider listen carefully to you?

   ☐ always   ☐ usually   ☐ sometimes   ☐ never

6. Does your current health care provider discuss with you changes concerning your health care?
   ☐ yes   ☐ no

7. Do you talk with your health care provider without your caregiver/treatment supporter in the room?
   ☐ yes   ☐ no

8. Does your current health care provider work with you to help you build skills to manage your own health and health care (e.g., know your medications and their side effects, know what to do in an emergency)?
   ☐ a lot   ☐ some   ☐ a little   ☐ not at all

9. Does your current health care provider work with you to help you think about and plan for the future (e.g., discuss future plans about education, work, relationships, independent living skills, health goals)?
   ☐ a lot   ☐ some   ☐ a little   ☐ not at all

10. Who helped you through the process of transitioning to your current health care provider?

    _____

11. Did you feel they helped you through the process and addressed concerns you may have had?
    ☐ a lot   ☐ some   ☐ a little   ☐ not at all   ☐ not applicable

12. How could your previous health care provider have made changing to an adult health setting better?

    _____

13. How could your current health care provider make changing to an adult health setting better?

    _____

10
Global Resources for Children, Adolescent, and Youth Transition of Care

In preparing this tool, a landscape review was completed to summarize available relevant resources that could be used or adapted.

Author	Date	Location	Tool	Transition Content	Source Link
Clinical Transition					
African Network for the Care of Children Affected by HIV/AIDS (ANECCA)	2018	Africa	Handbook on Counselling and Psychosocial Care for Children and Adolescents Living with and Affected by HIV in Africa	• Chapter 11: Transition from Pediatric to Adolescent to Adult HIV Care • Barriers to transition—chart • Key considerations for transition—checklist • Transition models • Role of providers to develop a transition plan, implement the plan, and follow up with the plan	https://aidsfree.usaid.gov/sites/default/files/2018.10.19_af_anecca_pss_handbook_tag.pdf
AmfAR/ViiV	2018	Asia-Pacific Region	Flip chart for transferring care (available in multiple languages)	• Reasons for transition • Difference between pediatric and adult HIV clinics • When to transition • What information about adult clinics you should know before transferring • HIV/CD4/VL/prevention	https://www.amfar.org/resources-support-transition-of-adolescents/
CDC	2018	USA	Adolescent Individualized Transition Plan	• Pre-21-year-old transition assessment • 24-year-old transition assessment	https://cdn.hivguidelines.org/wp-content/uploads/20180726095226/NYSDOH-AI-Adolescent-Transition-to-Adult-Care-2-Adolescent-Individualized-Transition-Plan_6-6-2018_HG.pdf
Children's National Hospital HIV Program	2019	USA	Children's Hospital Transition Tools	• Tips for appointments • Taking charge of your health one-pager • Farewell letter from the health facility • Transition packet checklist • Medical transmission summary • Case management transition summary • Introduction letter to new provider • Tracking sheet example • Example of informational sheets for adult facilities	https://childrensnational.org/departments/hiv-aids-services

Author	Date	Location	Tool	Transition Content	Source Link
Children's HIV Association (CHIVA)	2010; reviewed 2017	United Kingdom	Guidance on Transition for Adolescents Living with HIV	• Comprehensive list of additional complexities for ALHIV • Different models of transition a. Family clinics—integration b. Specialist services—hand over c. Specialist services—separate youth clinics • Process of multidisciplinary services a. When to start—phases chart b. What should be documented in the transition plan c. Meeting the adult team d. What should be done before transfer	https://www.chiva.org.uk/files/2814/8587/2242/CHIVA_Transition_Guidelines2017.pdf
CHIVA	2015	United Kingdom	Guidance for Clinics on Transition—from Young People	• Youth input: • Positive aspects of attending pediatric clinics • Key differences of adult clinics they transferred to • Ideas on how clinics can support the transition of a young person from pediatric to adult clinics	https://www.chiva.org.uk/files/1014/5079/3341/Guidance_for_Clinics_on_Transition.pdf
Cicatelli and Associates	2010	Global	Transition HIV+ Youth from Adolescent to Adult Services: Adolescent Provider Toolkit	Section 1: Transitioning Youth • What to expect • Steps to developing a relationship with the adult provider • Prepare youth to meet adult provider • Section 2: Creating the Young Adult Leader Program • Section 3: Program Supervision • Creating a supervision plan and checklist • Section 4: Policies and Procedures • Section 5: Supporting Young Adults Leaders • Self-management checklist • Life skills checklist	https://targethiv.org/library/transition-hiv-youth-adolescent-adult-services-adolescent-provider-toolkit
Got Transition— Program of the National Alliance to Advance Adolescent Health	2014	USA	Six Core Elements of Health Care Transition 2.0	Tools, samples, and evaluation measures for: • Transitioning youth to adult health care providers • Transitioning to an adult approach to health care without changing providers • Integrating young adults into adult care	https://www.gottransition.org/providers/index.cfm

Author	Date	Location	Tool	Transition Content	Source Link
International Center for AIDS Care and Treatment Programs (ICAP)	2012	Global	Adolescent HIV Care and Treatment Participant Manual	Module 13: Supporting the Transition to Adult Care • A self-care and transition timeline for ALHIV • Appendix 13A: Transition checklist for health workers and case studies • Appendix 13b: Transition resources for health workers and ALHIV	http://files.icap.columbia.edu/files/uploads/Module_13_-_PM_Adolescent.pdf
Kingdom of Swaziland Ministry of Health, WHO, PEPFAR	2018	Eswatini	Swaziland Integrated HIV Management Guidelines	• Key components of support for adolescents living with HIV during the transition process • The role of the health care worker • General principles for effective transitioning • Checklist for successful transitions to adult care with two sections: • a. Skills an adolescent should have before transitioning to adult care • b. Checklist for successful transition	https://pedaidsorg-my.sharepoint.com/:b:/g/personal/od_tlpo_pedaids_org/Eb9CuvCe49IKhCAitmvm0BsBtWtAZewUDDa_dnea0YNYmA?e=hqR964
PEPFAR, USAID Bophelo, EGPAF Lesotho	2017	Lesotho	Adolescent and Youth-Friendly Health Services Modular Training Facilitator Manual Adolescent and Youth-Friendly Health Services Modular Training—Module 5: Aging with HIV: Transitioning Care from Childhood to Adulthood (Slides)	• Module 5: Aging with HIV: Transitioning Care from Childhood to Adulthood • Key challenges for ALHIV during the transition process • Key considerations • Management of transition	http://www.pedaids.org/wp-content/uploads/2018/04/Final-Draft-AYFS-Modular-training-manual.pdf http://www.pedaids.org/wp-content/uploads/2018/04/AYFHS-Module-5-Aging-with-HIV-Transition-17.7.17-TV-tw.pdf
Republic of Kenya Ministry of Health, PEPFAR, UNICEF	2014	Kenya	Adolescents Package of Care in Kenya: A Health Care Provider Guide to Adolescent Care	• Section 10: Transition of ALHIV from Pediatric to Adult Services • Process of transitioning adolescents to adult care • Guide for age-specific transition plans • Transition algorithm • Transition template • PHQ-9 patient depression questionnaire	https://faces.ucsf.edu/sites/g/files/tkssra2096/f/AdolescentPackage.pdf
Republic of Uganda Ministry of Health	2016	Uganda	Consolidated Guidelines for Prevention and Treatment of HIV in Uganda	• Transition steps • Challenges related to transition	https://aidsfree.usaid.gov/sites/default/files/uganda_hiv_gl_2016.pdf

Author	Date	Location	Tool	Transition Content	Source Link
Tanzania Ministry of Health, Community Development, Gender, Elderly, and Children, EGPAF	2018	Tanzania	Adolescent HIV Services: A Guide for Health Care Workers	• Chapter 13: Supporting the Transition of ALHIV to Adult Care • Goals of transition • Barriers influencing transition • Roles of health care workers during transition • Transition approaches • ALHIV transition checklist for health care workers	http://www.pedaids.org/wp-content/uploads/2019/02/Tanz.-HCW-Guide-for-ALHIV-Services_6.22.18_PSC5bKC5d.pdf
USAID	2013	Global, sub-Saharan Africa (SSA)	AIDSTAR-One Adolescent Living with HIV Toolkit: Transitioning of Care and Other Services for ALHIV Toolkit	• 10 modules • Comprehensive transition checklist • Transition readiness checklist for health care provider, family/caregiver/adolescent • List of needs of transitioning adolescents living with HIV (ALHIV)	https://aidsfree.usaid.gov/resources/transitioning-care-services-alhiv
USAID	2014	Global, SSA	AIDSTAR-One Adolescent Living with HIV Training Manual	• Session 7: The Transition Process	https://aidsfree.usaid.gov/sites/default/files/final_alhivtrainingmanual_web.pdf
WHO	2014	Global	Adolescent HIV Testing, Counselling, and Care Implementation Guidance for Health Providers and Planners: Transition	• Practical approaches for transition • Role-play scenarios • Outpatient follow-up sheet (includes transition planning) • Comprehensive transition checklist • Developmentally appropriate transition • Adolescent checklist	http://apps.who.int/adolescent/hiv-testing-treatment/page/Transition
Wits Reproductive Health and HIV Institute and Southern African HIV Clinicians Society	2016	South Africa	Working with Adolescents Living with HIV: A Toolkit for Healthcare Providers	• Chapter 3: Development and Maturation of Adolescents Living with HIV • Chapter 22: Transition in Care	http://www.wrhi.ac.za/uploads/files/Working_with_Adolescents_Living_with_HIV_-_Toolkit.pdf
School Transition					
EGPAF	2018	Kenya	Adolescent Treatment Literacy Guide for Use in Support Group Settings	• Transition in the context of changing education environments and preparing for transition • How school can be a support network	http://www.pedaids.org/wp-content/uploads/2018/11/KenyaAdoTreatmentLiteracyGuide.pdf
UNESCO	2012	Global	Positive Learning: Meeting the Needs of Young People Living with HIV (YPLHIV) in the Education Sector	• Health and psychosocial needs of YPLHIV in school settings • Gaps in evidence in education needs of YPLHIV • General recommendations	https://unesdoc.unesco.org/ark:/48223/pf0000216485

Author	Date	Location	Tool	Transition Content	Source Link
Pregnant AGYW					
AIDSFree	2018	Kenya	AIDSFree Jielimishe Uzazi Na Afya (JUA) Program Curriculum for Pregnant Adolescents and Adolescents' Mothers Facilitator's Training Guide	• Facilitator training guide • Modules 1–8 • Module 2: Communicating with adolescents and adults in household • Module 3: Empowering adolescent to achieve zero new infections • Module 4: Antenatal care and PMTCT services—supporting retention and adherence of pregnant adolescents / adolescent mothers and their infants • Module 5: Postpartum care (mother and baby) and caring for infants/toddlers • Module 6: Supporting adolescent mothers with child development knowledge and skills	https://pedaidsorg-my.sharepoint.com/:w:/g/personal/od_tlpo_pedaids_org/EXyY4BUEp0NKg3t5hvEj5lEBvbSrsoYM0rRMC4GcHldv_g?e=GghJJo
AIDSFree	2018	Kenya	Standard Operating Procedure #1: Ethical Procedures & Code of Conduct	• Guiding principles for working with adolescents	https://pedaidsorg-my.sharepoint.com/:w:/g/personal/od_tlpo_pedaids_org/EW_-KRY_B9hJoFs0JTkAukcBwxUhLV9M_kzxGq_cUK9B5A?e=ZKBv2E
AIDSFree	2018	Kenya	Standard Operating Procedure #2: Case Management	• Case management model • Steps to identify adolescents and households • Home visiting teams • Tools: consent forms, register, screening tool, contact form, mapping template	https://pedaidsorg-my.sharepoint.com/:w:/g/personal/od_tlpo_pedaids_org/EViH_LWQUZhEoPHFu8lYdjMBgTLmiFn7RvoAva_s3M9Tzw?e=YSeFWe
AIDSFree	2018	Kenya	Standard Operating Procedure #3: Supportive Supervision	• Supportive supervision process • Before, during, after-visit process	https://pedaidsorg-my.sharepoint.com/:w:/g/personal/od_tlpo_pedaids_org/EckWQghGe51Ji4hV-apmSwEBW-mcu9JSo3cxLDuZeQPskg?e=kqtRkK
AIDSFree	2018	Kenya	Standard Operating Procedure #4: Program Monitoring	• Program monitoring • Forms, procedures • Data flow	https://pedaidsorg-my.sharepoint.com/:w:/g/personal/od_tlpo_pedaids_org/Efuo-lz94VVNrg_wfwl32dQBB8dKmmyFf97WNVb1PAtOoQ?e=BqayW8
Global Network of People Living with HIV (GNP+)	2016	SSA	Positive Health, Dignity and Prevention for Women and Their Babies: A Treatment Literacy Guide (available in French and English)	• 12 modules covering issues from human rights to treatment adherence to nutrition • Facilitator manual • Illustrated flip chart • Accessible poster	https://www.gnpplus.net/resources/positive-health-dignity-and-prevention-for-women-and-their-babies/
Republic of Kenya Ministry of Health	2016	Kenya	Mother and Child Health Handbook AFYA Ya Mama Na Mtoto	• Maternal health monitoring • Child health monitoring • Father's support for mother and child health • Practical charts and tools	https://pedaidsorg-my.sharepoint.com/:b:/g/personal/od_tlpo_pedaids_org/ET0AuvrOlZ5Fh2lHQa2l3UgBpzoXQsp2r-H6vEEfjU2vuA?e=Ayc1lJ

Author	Date	Location	Tool	Transition Content	Source Link
Barriers to Transition					
ANECCA	2018	Global	ANECCA Pocket Guide: Children and Social Support Scale	• The social support scale assesses the level of social support to identify gaps and address them appropriately through making referrals and linkages to available services	https://aidsfree.usaid.gov/sites/default/files/resources/2018.10.30_af-anecca-pocket-guide_0.pdf Pages 2–3
Contemporary Pediatrics	N/A	Global	The HEEADSSS (Home/Environment, Education/Employment, Eating/Exercise, Activities, Drugs/Substances, Sexuality, Suicide/Depression, Safety) tool	• To assess different aspects of an adolescent's life to assist a provider in obtaining a comprehensive understanding of an adolescent's psychosocial circumstances in order to be able to appropriately tailor care plans	HEEADSSS psychosocial interview for adolescents and guide
Republic of Uganda Ministry of Health	2016	Uganda	Uganda Consolidated Guidelines—Annex 9	• Home Education/Eating/Exercise Activities Drugs/Depression Sexuality Suicidality/Safety (HEADS) assessment tool for adolescents	https://aidsfree.usaid.gov/sites/default/files/uganda_hiv_gl_2016.pdf Annex 9 (149–150)
Additional Resources					
Avert	2018	Global	Boost	Modules on • HIV • Prevention • Testing • Treatment • Having children • Staying healthy • Living with HIV	https://boost.avert.org/
WHO	2019	Global	WHO Consolidated Guideline on Self-Care Interventions for Health	• Strategies for maintaining and enabling environments for self-care • Recommendations on providing high-quality sexual and reproductive health services	https://apps.who.int/iris/bitstream/handle/10665/325480/9789241550550-eng.pdf?ua=1

11
Annex: Transition Tools

Tools for Clinical Transition

TRANSITION CHECKLIST

The following transition checklist summarizes transition tasks.[17, 69, 70, 71, 72, 73] It is meant to serve as a guide for stakeholders at different time periods throughout the process of transition.

Tasks for completion during the transition process include the following:

- Make appropriate referrals/linkages (PSS, peer support, social support).
- Empower and build competencies for self-management by the young client.

TRANSITION CHECKLIST FOR CAYLHIV THROUGHOUT THE TRANSITION PROCESS

When	Who Is Involved	Transitioning Tasks	Discussed (✔)	Complete (✔)	Date / Attendees
Until full disclosure	• MDT • Client (CAYLHIV) • Caregiver/ treatment supporter	Support reaching full disclosure to child/ adolescent or to treatment supporter	☐	☐	
		Assess knowledge and discuss gaps in knowledge of HIV	☐	☐	
		Support client and caregiver in understanding when and how often to come to appointments	☐	☐	
		Maintain adherence support	☐	☐	
Post full disclosure	• MDT • Client • Caregiver/ treatment supporter	Ensure understanding of ART, viral load, prevention of transmission	☐	☐	
		Introduce concept of transition to client and caregiver	☐	☐	
		Evaluate and document self-management skills	☐	☐	
		Build competencies on HIV for client and caregiver—self-management and treatment	☐	☐	
		Identify and discuss adult providers/spaces with client and caregiver	☐	☐	
		Discuss positive living, healthy relationships, sexual and reproductive health, family planning	☐	☐	

When	Who Is Involved	Transitioning Tasks	Discussed (✔)	Complete (✔)	Date / Attendees
Preparing for transition	• MDT • Client • Caregiver/treatment supporter • Adult provider • Peer cadre	Discuss transition with client and caregiver, focusing on roles, responsibilities, and expectations	☐	☐	
		Engage MDT	☐	☐	
		Conduct readiness assessment	☐	☐	
		Create transition plan jointly with MDT, client, and caregiver	☐	☐	
		Engage adult provider	☐	☐	
		Provide copy of medical record and clinical transition form with up-to-date information (patient contact info) to adult health care provider, ensuring confidentiality	☐	☐	
		Continue to encourage self-management by client to take more responsibility in their care—adhere properly, make appointments, and attend independently	☐	☐	
		Prepare adolescent to enter adult care—schedule first appointment together	☐	☐	
		Ensure that peer/mentor relationship is available for additional support	☐	☐	
Implementing transition to adult clinic	• MDT • Client • Adult provider • Peer cadre	Accompany youth client to first adult care appointment (peer cadre)	☐	☐	
Post transition	• Client • Counselor • Adult provider • Peer cadre	Follow up post transition to address any concerns (after first appointment and 3–6 months after), in person or over phone	☐	☐	
		Track young client's post-transition outcome—retention, adherence, viral load, etc. (first VL 6 months post transition)	☐	☐	

TAKING CHARGE OF YOUR HEALTH‡

The following lists provide tips and advice for young clients in becoming their own advocates and building their competencies for self-management.

BE YOUR OWN ADVOCATE

- ✓ Learn about your status (the medications you take, your health history).
- ✓ Know when and where to seek help.
- ✓ Have an emergency contact—this can be a peer, partner, or caregiver.
- ✓ Learn to make your own appointments.
- ✓ Write down questions you have for your provider(s).
- ✓ Speak up and ask any questions if you have them, especially if you don't understand something.
- ✓ Talk to your provider about difficulties or concerns you may have (relationships, family planning, medicine side effects, negative/bad feelings).
- ✓ If not explained to you, ask your provider(s) to explain tests and their results.

TAKE CHARGE OF YOUR HEALTH INFORMATION

- ✓ Know the names of your medications and when / how often to take them.
- ✓ Know when to come for your refills.
- ✓ Know how to make appointments and when to come.
- ✓ Know who to come to with a problem.
- ✓ Understand the meaning of the viral load.

A JOB AND TREATMENT CAN GO TOGETHER

- ✓ Have your own file copies available of your last viral load test and your medication regimen and dose.
- ✓ Know your employer's leave policy to assess clinic appointment/refill schedules and prepare for leave in case of illness.
- ✓ Know your work schedule and consider how to adjust your ARV timing and meals to support treatment at work.
- ✓ Consider storage for ARVs while at work. Can you bring your dose daily and leave an emergency supply? You'll need a storage place at home and a pill carrier/box for work.

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‡ Adapted from the Taking Charge of Your Health resource from Children's National Hospital, Washington, DC, USA.

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