

NEW HORIZONS

ADVANCING PEDIATRIC HIV CARE



Elizabeth Glaser
Pediatric AIDS Foundation
Fighting for an AIDS-free generation

E2A New Horizons: Tools for Adolescent HIV Treatment Success in Africa

Agenda

- **Overview New Horizons Tools: Focus on ALHIV Treatment Access and Capacity:** Dr. Natella Rakhmanina and Cosima Lenz, EGPAF
- **Country Insight and Stakeholder Engagement: Transition Tool Development and Feedback:** Dr. Eleanor Magongo, Pediatric & Adolescent HIV Care and Treatment, Ministry of Health Uganda
- **Supporting Young People Living with HIV: About the Adolescent Treatment Coalition:** Julian Kerbogossian, Adolescent Treatment Coalition Coordinator
- **Youth Leadership: CAYA Contribution and Support:** Ismail Harelimana, CAYA Uganda
- **Closing:** Stacy Meyer, Vice President Global Public Health, Johnson & Johnson
- **Q&A/Discussion:** moderated by Maryanne Ombija, EGPAF

All lines are automatically muted. You can ask a questions via the Q&A button on the bottom of your Zoom window at any point during this webinar. We will answer all questions during our Discussion. For more information and questions around connectivity, email publications@pedaids.org.

Tools for Adolescent HIV Treatment Success in Africa

June 2020



Our Vision

A world in which young people living with HIV lead full and healthy lives, achieve their aspirations, and reach their potential

Our Mission

Through our collective effort, we will advance a holistic, integrated approach to high quality and sustainable pediatric HIV care and treatment with a specific focus on those in need of 2nd- and 3rd-line medicines

The Collaborative Goals 2014 — Present



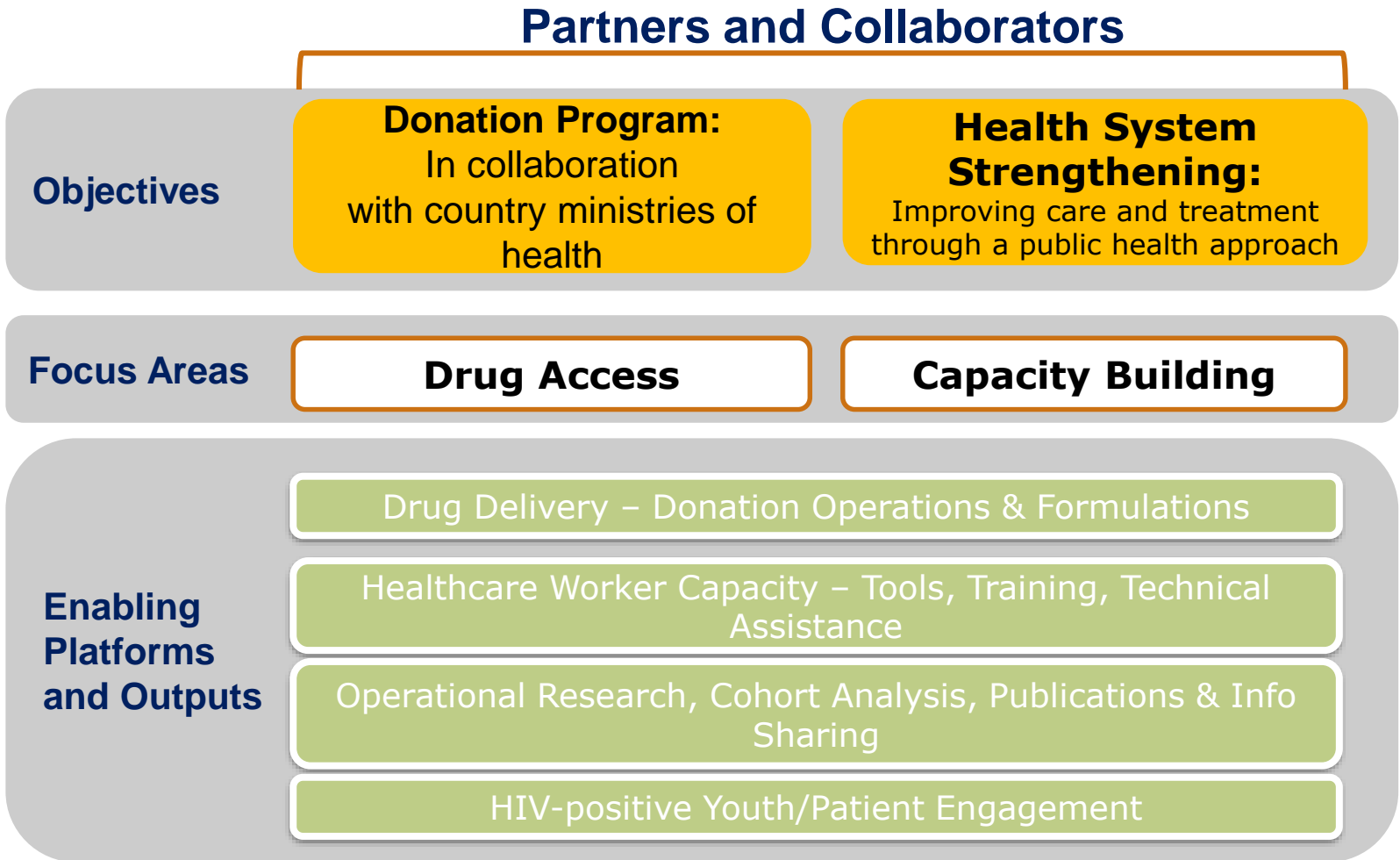
Contribute to UNAIDS
90-90-90 target

Ensure that
global HIV
response
addresses the
critical unmet
needs of
children &
adolescents

Promote
treatment
equity between
adults &
children

Link **5,000** pediatric patients to 2nd-
and 3rd-line **care & access to J&J
treatment** by the end of 2020

Meeting the Needs of Adolescents and Youth



New Horizon Collaborative Resources

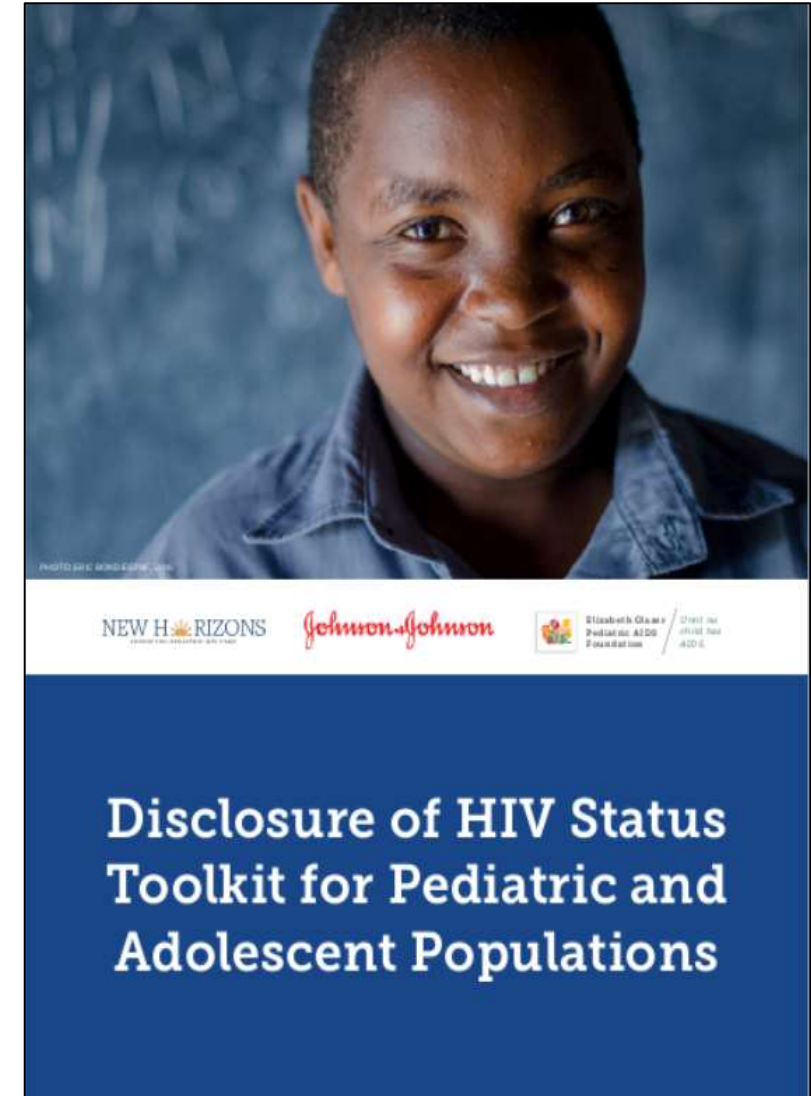
- ✓ Pediatric HIV online training module (PaedsHIVLearning.com)
- ✓ Training workshops
- ✓ Technical workshops
- ✓ Second- and third-line dosing cards
- ✓ Management of treatment failure algorithm
- ✓ Disclosure toolkit
- ✓ Transition toolkit



Disclosure Toolkit

- **Evidence-based with references to global sources**
- **Guidance and checklists for disclosure by:**
 - Healthcare workers
 - Caregivers
 - Adolescents/youth
- **Job aids:**
 - Algorithms
 - Readiness assessment checklists
 - Role playing scenarios (3) for each module
 - Testimonies by adolescents, caregivers, and healthcare workers

Available in English, French, and Portuguese



Designed for Multiple Users



Diverse Modules

A: Guide for HCW on Disclosing Diagnosis of Vertically-Acquired HIV

B: Guide for Preparing and Supporting Caregiver in Disclosing Diagnosis of Vertically-Acquired HIV

C: Guide for Supporting Adolescent in Disclosure his/her Status to Caregiver/Family

D: Guide for Supporting Adolescent in Disclosing his/her Status to Friends, Social Networks, School, Work

E: Guide for Supporting Adolescent to Disclose his/her Status to a Partner



Advice About Accepting One's Status from ALHIV on EGPAP's Committee of African Youth Advisors (CAYA)



Management of Treatment Failure Toolkit

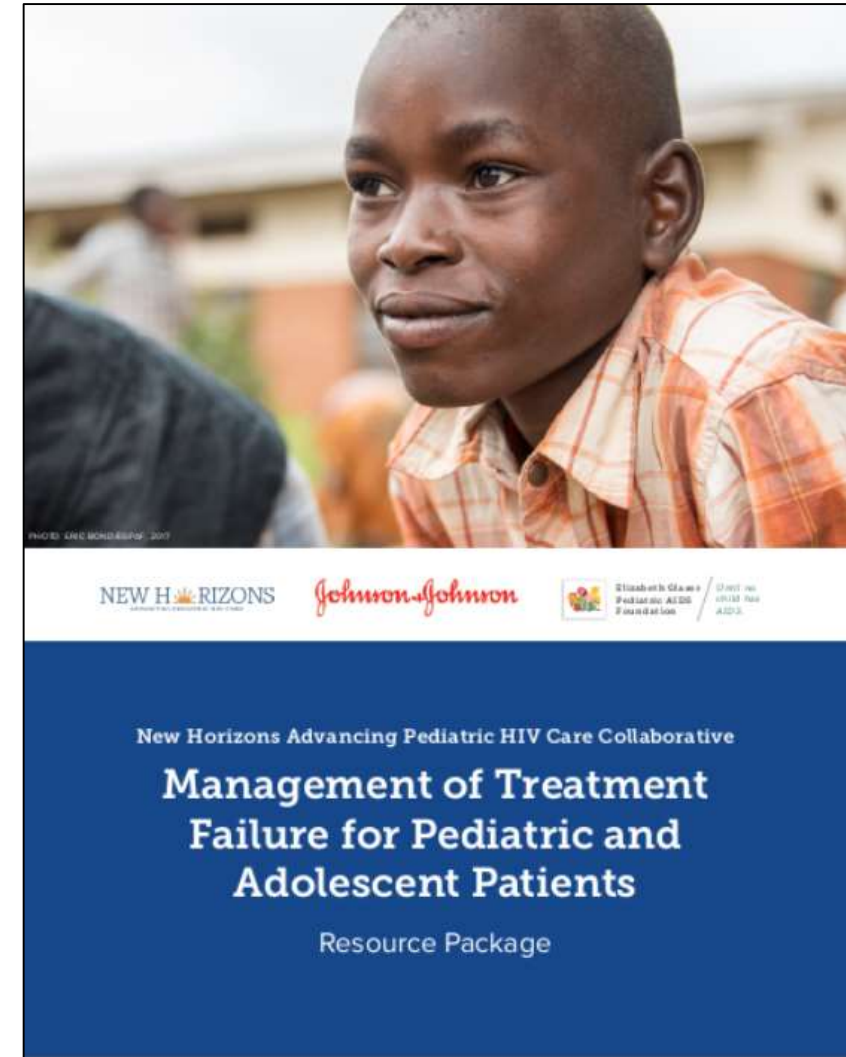
- **Aims:**

- Identify children and adolescents failing treatment
- Offer evaluation and action steps in managing children and youth failing their ART
- Enhance timely management of patients failing treatment

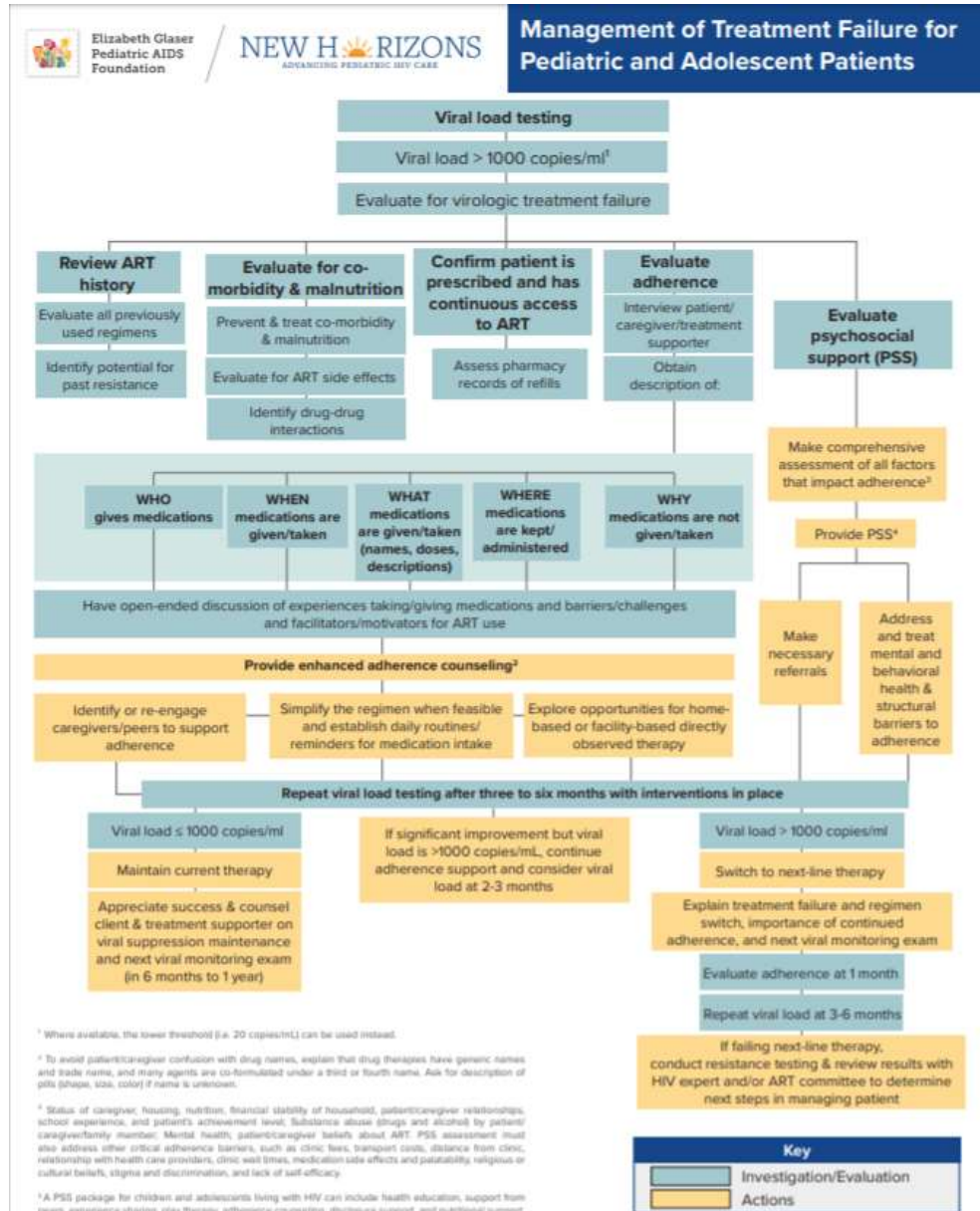
- **Audience:**

- Healthcare providers
- Lay counselors
- Multidisciplinary teams (MDTs)

Available in English, French, and Portuguese



Management of Treatment Failure Algorithm



Elizabeth Glaser Pediatric AIDS Foundation



Definitions

The WHO recommends that routine viral load monitoring be carried out at six months, at 12 months, and then every 12 months thereafter if the patient is stable on ART. Viral load testing is the preferred method for determining treatment failure.

Virologic Treatment Failure

Definition	Comments
Viral load above 1000 copies/mL based on two consecutive viral load measurements in three months, with enhanced adherence counseling following the first viral load test	An individual must be taking ART for at least six months before it can be determined that a regimen has failed.

Current WHO clinical and immunological criteria have low sensitivity and positive predictive value for identifying individuals with virological failure. There is currently no proposed alternative definition of treatment failure and no validated alternative definition of immunological failure.

Immunologic Treatment Failure

Definition	
Children Younger than five years Persistent CD4 levels below 200 cells/mm ³	Adolescents and Adults CD4 count at or below 250 cells/mm ³ following clinical failure or Persistent CD4 levels below 100 cells/mm ³
Comments	
Without concomitant or recent infection to cause a transient decline in the CD4 cell count.	

Clinical Treatment Failure

Definition	
Children New or recurrent clinical event indicating advanced or severe immunodeficiency (WHO clinical stage three and four clinical condition with exception of TB) after six months of effective treatment	Adolescents and Adults New or recurrent clinical event indicating severe immunodeficiency (WHO clinical stage four condition) after six months of effective treatment
Comments	
The condition must be differentiated from immune reconstitution inflammatory syndrome (IRIS) occurring after initiating ART. For adults, certain WHO clinical stage three conditions (pulmonary TB and severe bacterial infections) may also indicate treatment failure. IRIS is a worsening of pre-existing infectious conditions after ART initiation in HIV-positive patients due to inflammatory disorders.	

PSS for children living with HIV addresses their ongoing emotional, spiritual, cognitive, social, and physical needs. It aims to improve the social well-being of patients. PSS can be provided at clinic or community level. At the clinic, PSS can be provided one-on-one by a trained counselor, social worker, psychologist, or nurse. A PSS package for children and adolescents living with HIV can include health education, support from peers, experience sharing, play therapy, adherence counseling, disclosure support, and nutritional support.

Transition of Care Toolkit

- **Evidence-based with references to national and global sources**
- Supports different transitions to assure continuity of care
- **Guidance and checklists for disclosure by:**
 - Healthcare workers
 - Caregivers
 - Adolescents/youth
- **Job Aids, MDTs, School/Community Involvement**
- Monitoring at the facility level and through national health systems



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Adolescent and Youth Transition of Care Toolkit

SUPPORTED BY THE NEW HORIZONS COLLABORATIVE

Transition of Care Toolkit Components

- Mapping transition
- Major stakeholders
- Clinical care transition
- Caregiver transition
- Transition of care in school settings
- Transition of care for young women living with HIV during pregnancy and after childbirth
- Monitoring & evaluation
 - Facility and cohort-specific tools
- Global resources on transition of care

Changing client responsibility over time *Stakeholder Section*



Annex:

- Transition Checklist
- “Taking Charge of your Health” for clients

Transition of Care Toolkit Structure

Different forms of transition are discussed in the following steps:

1. Planning and preparation
2. Client (and caregiver/treatment supporter) case review and assessment
3. Transition tasks
4. Follow-up procedures
5. Tracking and reporting



“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



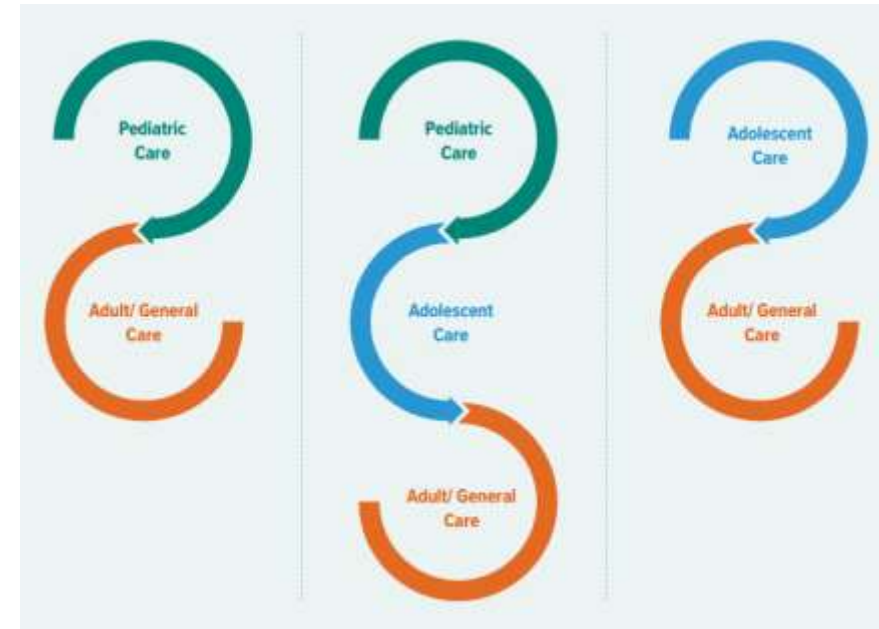
Transition Between Pediatric, Adolescent, and Adult Care

- **Guidance on clinical transition of care**
- **Guidance on transition between HIV service delivery models**

Tools/Resources:

- National and facility transition assessment tools
- Information to include in transition plan/forms for clients
- Client case review assessment forms including provider and client checklists
- MDT as facility-based transition systems
- Group activities to support transition
- Sample scripts for transition within differentiated service delivery (DSD) models for providers
- Youth advice–tips for self-management

Types of clinical transition



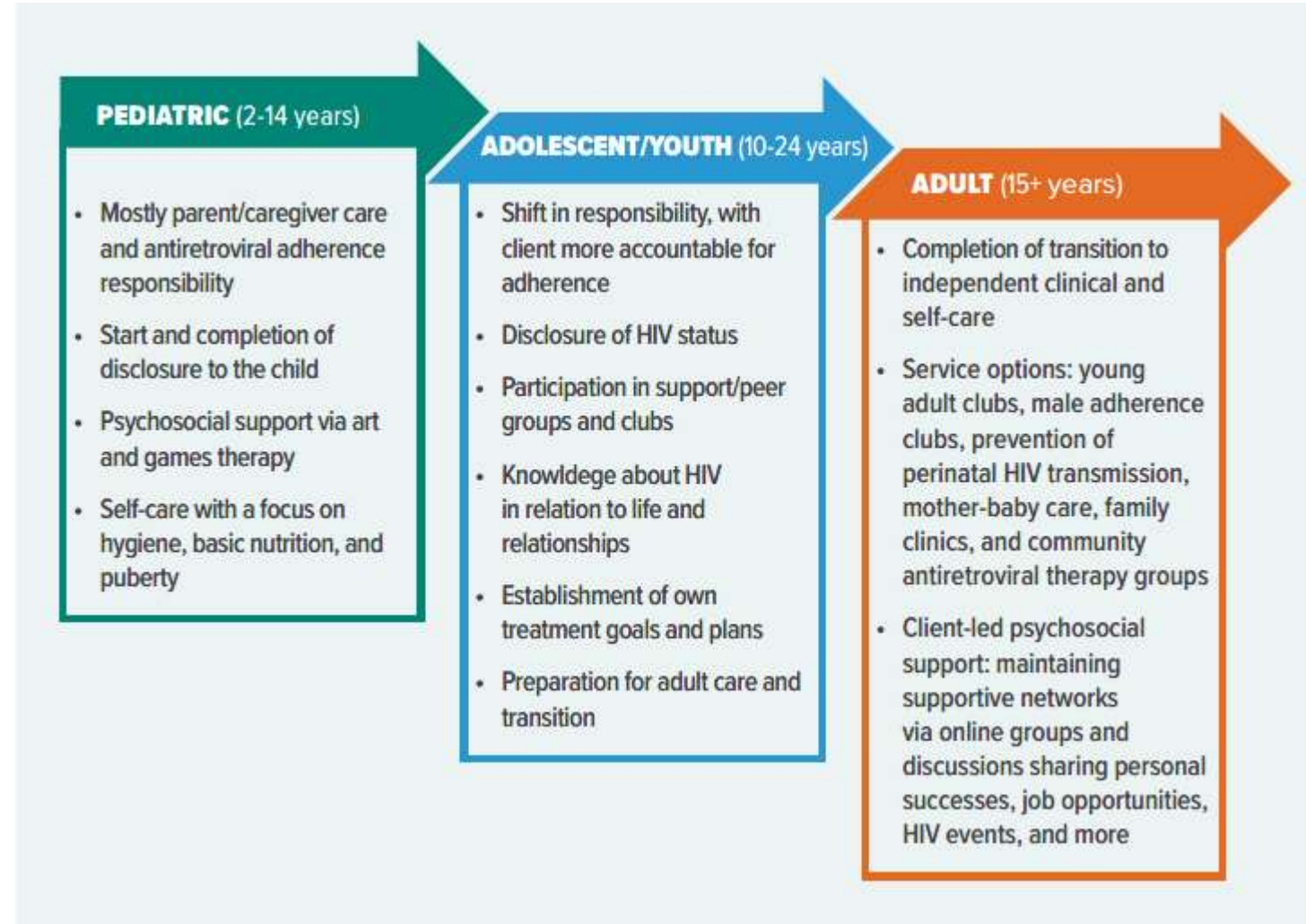
Audience:

healthcare providers
multi-disciplinary teams (MDTs)

Transition Between Pediatric, Adolescent, and Adult Care



Major elements of the clinical transition process throughout the continuum of pediatric, adolescent, adult HIV care



Caregiver Transition

Guidance for supporting CAYLHIV transitioning between caregivers and homes

Tools/Resources

Type of information to include in caregiver handover documents:

- Sample caregiver change documentation
- Sample follow-up questions to assess client and caregiver adjustment

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)

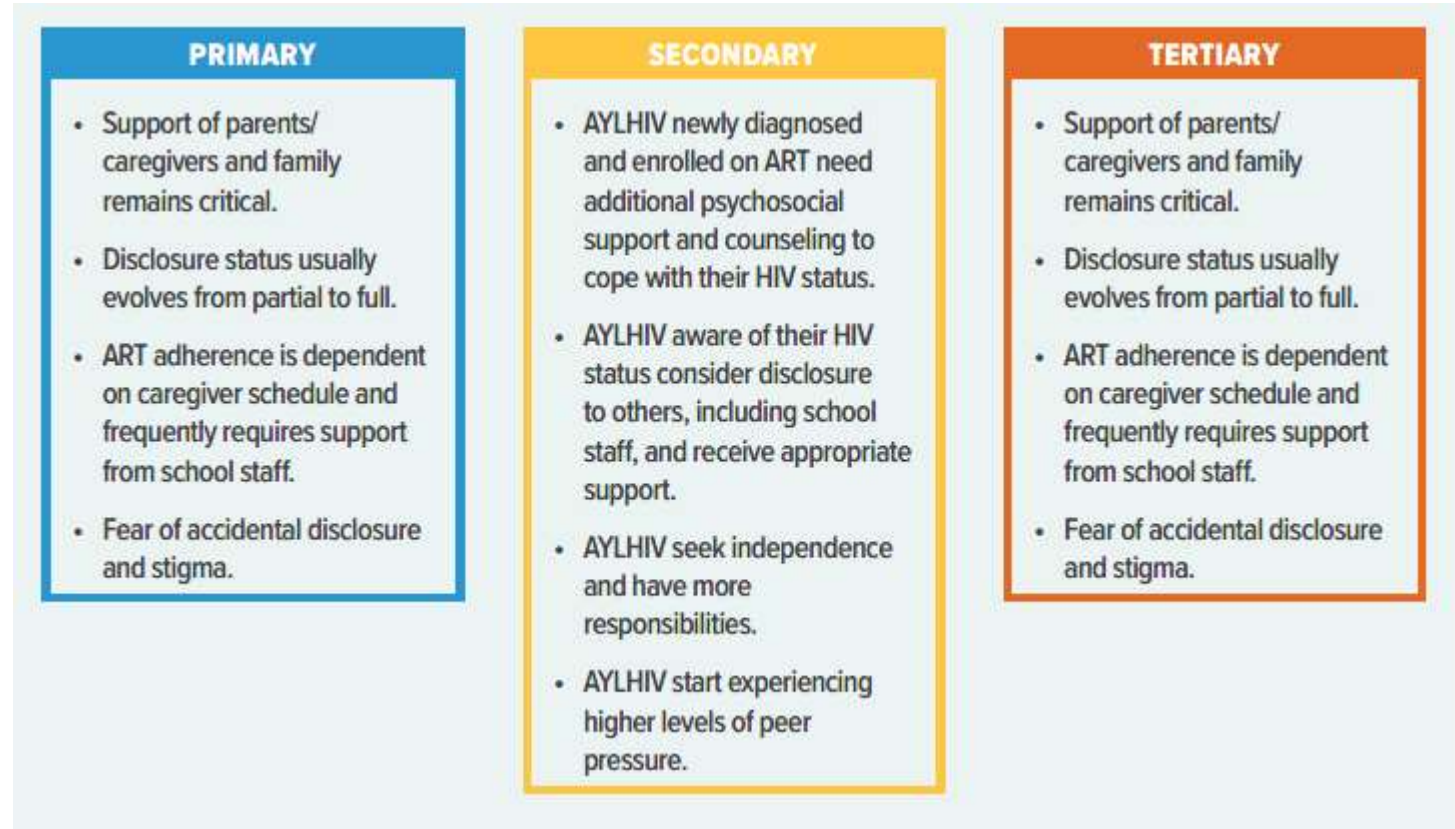


Transition of Care in School Settings

Guidance on supporting children and adolescents living with HIV during transitions between schools and school levels

Tools/Resources

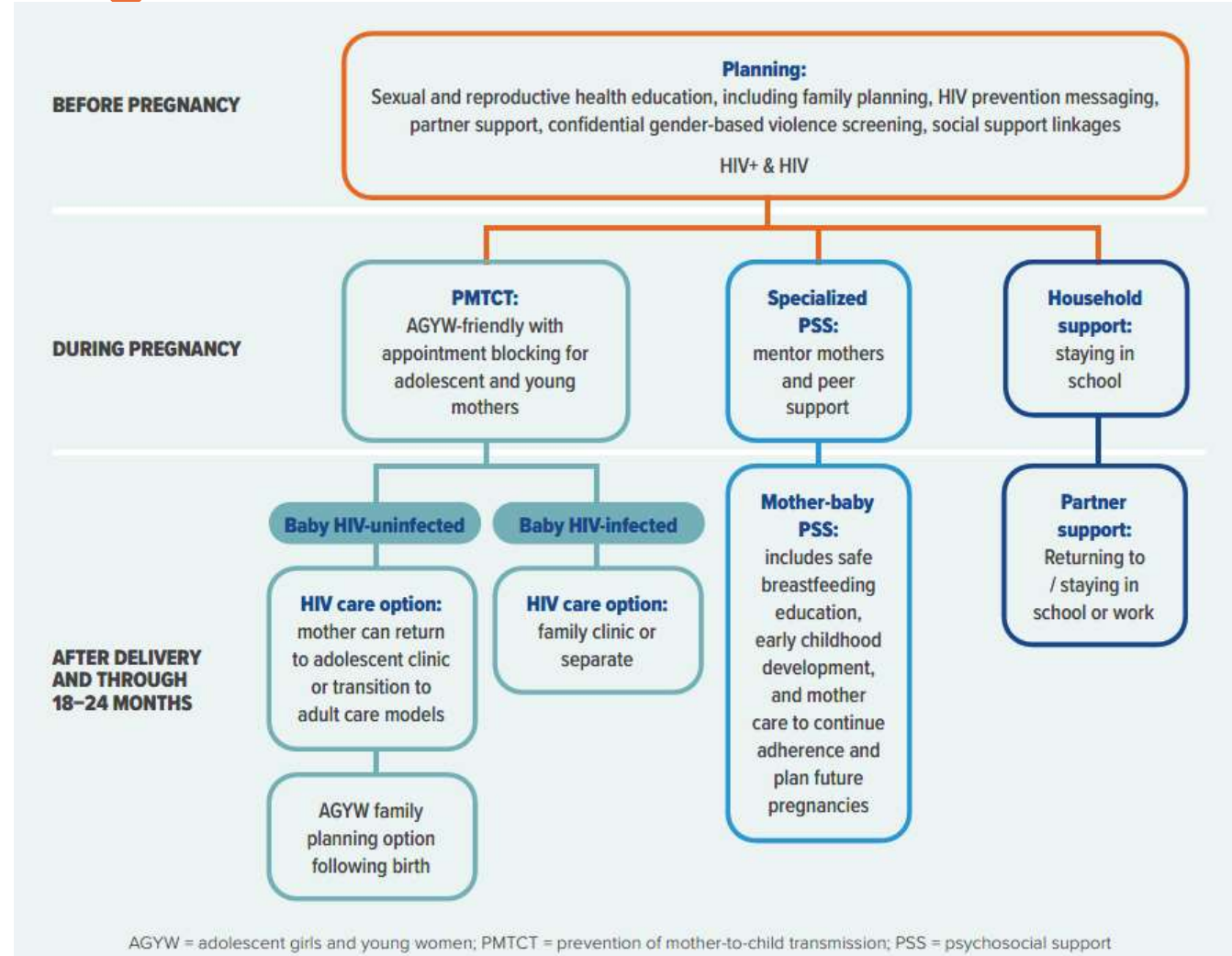
- Potential challenges in transitions in school environments
- Steps to support HIV care in school settings (day and boarding schools)



Transition in Care for Adolescent Girls and Young Women Living with HIV during and after Childbirth

Tools/Resources

- Challenges impacting transition of care for AGYW with HIV between HIV and prevention of mother-to-child transmission of HIV (PMTCT) services
- Considerations for AGYW with HIV transitions around and after pregnancy
- Models of care for AGYW with HIV



Monitoring and Evaluation of Transition of Care

Guidance on identifying, planning, and implementing monitoring and evaluation activities of transition of care

Tools/Resources

- Transition Planning Sheet for AYLHIV Clients: facility and client information
- Sample Individual Transition Flow Sheet
- Sample Transition Data Summary
 - Individual and aggregate
- Sample Health Care Transition Feedback Survey for CAYLHIV and/or Caregivers

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):			
<input type="checkbox"/> Clinical	<input type="checkbox"/> School	<input type="checkbox"/> Sexual and reproductive health	<input type="checkbox"/> 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)			

Appreciation and Recognition

Technical Working Group:

- **EGPAF HQ:** Natella Rakhmanina, Katie Wallner, Maryanne Ombija and Cosima Lenz
- **Uganda**
 - Lawrence Mugumya, EGPAF Uganda
 - CAYA Uganda: Bena Asiimwe
- **Zimbabwe**
 - Tichaona Nyamundaya, EGPAF Zimbabwe
 - CAYA Zimbabwe: Rosa Mahlasera
- **Eswatini**
 - Lydia Mpango, EGPAF Eswatini
 - CAYA Eswatini: Mthobisi Simelane
- **M&E Consultants** (Oxford University/Hey Baby Study, and J&J Transition Cohort)
 - Lucie Cluver
 - Elona Toska
 - Roxanna Haghighat

Significant contributors:

- **Participants of the stakeholder consultation in Uganda**
 - Uganda Ministry of Health
 - Makerere University Joint AIDS Program
 - Mubende Regional Hospital
 - Infection Disease institute
 - USAID
 - EGPAF Uganda
 - CAYA Uganda, Kenya, Zimbabwe
- **Three Uganda facilities providing initial site-level feedback**
 - Makerere University Joint AIDS Program
 - Mubende Regional Hospital
 - Infection Disease institute

Committee of African Youth Advisors (CAYA), EGPAF



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Country Insight: Transition Tool Development and Feedback



Dr. Eleanor Magongo

*Pediatric & Adolescent HIV Care
And Treatment Team Lead*

*Ministry Of Health-AIDS Control
Program-Uganda*



Some of the stakeholders reviewing the transition tool kit during the meeting at the Ministry of Health



How we learnt about the transition toolkit

- Uganda is part of the New Horizons Collaborative
- Annual meetings are held for country teams that are part of the collaborative
- Transition toolkit was presented at one of the annual meetings
- Uganda expressed interest in contributing to the development of the toolkit



The Preparatory Process!

- Date was agreed upon between the Uganda MOH and EGPAF
- Key stakeholders in Uganda were informed and invited for the meeting
 - Ministry of Health officers
 - Implementing Partners
 - Health Care Providers
 - Adolescents and Young People
- Draft tools were shared in advance for stakeholders to read through prior to the meeting



The Stakeholders Meeting!

- Presentation on the overview of the transition toolkit was made
- Toolkit was reviewed in segments, in groups and in plenary
- 3 health facilities supported by 3 different implementing partners were identified to implement the toolkit at HIV clinics
- The experiences were to further enrich the toolkit



Overview presentation of the toolkit by Maryanne, EGPAF USA



Site Visits



- Site visits were conducted to introduce the toolkit to the teams
- The 3 facilities selected to implement the transition toolkit were:
 - HIV specialized clinic-MJAP
 - Regional Referral Hospital-Mubende
 - Public HC III-Komamboga
- Participated in virtual discussions with EGPAF to provide insight on use of the toolkit at sites and feedback on the content



Introduction of toolkit at Mubende RRH: Presentation by a CAYA member



Key Highlights from Health Facilities

- The toolkit should address the simultaneous transitions that the adolescents face
- Merge existing tools /tables
- Need for more specified guidance on the timeline for transition
- Need for an adolescent transition register for longitudinal tracking & monitoring
- Use of a peer to identify adolescents undergoing simultaneous transitions
- The toolkit should capture information on physical address and phone contacts



Models of Transition at Komamboga HC III

- Transition of children 8-9 years to adolescent clinic or of adolescents to the adult clinic: This was done during family and adolescent clinic days.
- Transition from one caregiver to another: this was done on a case by case basis at caregiver meetings & peer support group meetings.
- Transitioning for school going children, through school levels (i.e. primary to secondary, secondary to tertiary, or through sections like day to boarding and vice versa).
- Transitioning of adolescent girls and young women living with HIV during and after pregnancy
- **Transitioning between DSDMs**
- Transitioning between health facilities (horizontal transitioning).



Recommendations

- All health care providers at the facilities should be oriented to the toolkit
- Information on transition clinics should be integrated into health education talks
- Adolescents should be categorized to appropriately tailor the transition package
- The transition process is comprehensive and should be handled by a well-trained counsellor



Acknowledgements

- Ministry of Health-Uganda
- Implementing Partners
- Health facility teams
- EGPAF
- New Horizons



A CAYA member presenting the group work after review of the document



ADOLESCENT
HIV TREATMENT
COALITION

Adolescent HIV Treatment Coalition

One World, One Coalition, One Voice

Coordinator: Julian Kerbogossian

Who are we?

Some of our members

- ▶ GNP+
- ▶ Y+ Network
- ▶ International AIDS society
- ▶ Frontline AIDS
- ▶ AIDS FONDS
- ▶ UNAIDS
- ▶ ITPC Global
- ▶ PATA
- ▶ Jovenes Positivos LAC
- ▶ EGPAF

About
us



History

Vision and Mission:

- ▶ Vision: Advocate for quality treatment and care for all adolescent and young people living with HIV through an amplified collective voice.
- ▶ Mission: To provide a global adolescent centered platform, to inform and advocate for better HIV treatment and care.



Four Key Advocacy Themes

1

- Meaningful engagement of adolescents living with HIV

2

- Differentiated service delivery for adolescent living with HIV

3

- Optimization of treatment options for adolescents

4

- Strategic information and data

Our Work!

- ▶ Global Paediatric and adolescent research agenda
- ▶ Intergenerational summit
- ▶ View point on ALHIV & YPLHIV engagement in the HIV response.
- ▶ Differentiated service delivery for adolescents living with HIV.
- ▶ Advocacy calendar





It's coming!

Coming SOON!

#ItsAboutTime

What is #ItsAboutTime?

- ▶ #ItsAboutTime is our new advocacy campaign which will be highlighting our key advocacy days for 2020-2021
- ▶ How? Through sharing blogs, Youth friendly material around treatment literacy, Adherence to treatment & Youth leadership.

Why #ItsAboutTime

- ▶ ItsAboutTime we become louder and bolder.
- ▶ ItsAboutTime we lead the HIV/AIDS response
- ▶ ItsAboutTime we make informed decisions about the treatment which effects our lives, our health & our bodies.

Thank you

Follow us:

► Facebook:

<https://www.facebook.com/adolescentHIVtx>

► Twitter:

<https://twitter.com/adolescentHIVtx>

► Visit our website:

<https://www.iasociety.org/HIV-Programmes/Programmes/Adolescent-HIV-Treatment-Coalition>



Youth Leadership: CAYA Contribution and Support

Ismail Harelimana, CAYA Uganda



The Committee of African Youth Advisors (CAYA)

20 young people (15-29 years) from 11 EGPAF countries



What is CAYA and How it Works

EGPAF recognizes that meaningful participation of youth is integral to future success of programs



A dynamic *partnership* with youth across EGPAF countries to better align global investments toward EGPAF's mission



Tema and Mthobisi – CAYA Members in Eswatini

CAYA Contribution to the Transition Toolkit

- CAYA leads (Uganda, Zimbabwe, Eswatini) a technical working group
- CAYA task: all members provided insight on transitions (August 2019)
- CAYA participated (Kenya, Eswatini) in a panel during the New Horizons Technical Workshop (October 2019)
- Uganda in-person stakeholder consultation and site visits included CAYA (February 2020)



2019

2020

CAYA Task: Experience, Needs, and Areas of Focus to Support AYLHIV in Transitions of Care

Survey completed by CAYA members from seven countries where they shared →

- Experiences with transition (clinical, PMTCT, school, service delivery models)
- Advice for providers in supporting adolescents and youth living with HIV (AYHLIV) experiencing transition
- Advice to other AYLHIV experiencing different transitions
- Advice to other AYLHIV on transitioning to self-management

“*Transition is a complex necessary part of getting older and learning to manage your health and well-being.*”

— Male, 26 years, southern Africa



Jane, CAYA Tanzania



CAYA Advice on Expectations During Transition for AYLHIV and Providers

WHAT SHOULD ADOLESCENTS EXPECT WHEN 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.

WHAT SHOULD PROVIDERS EXPECT FROM ADOLESCENTS MOVING TO ADULT CARE?

- 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.

Included in the
*Clinical Care
Transition*
chapter of the
Toolkit



CAYA Tips for HIV Self-Management

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.

“

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



CAYA: Challenges with Transitions in School Settings

“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

Type of School Transition	Potential Challenges
Primary school → secondary school	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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”
Secondary school → tertiary education/college or university	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• Adjusting life and HIV care schedules• Finding a confidential treatment buddy if there isn’t one at school or home already

CAYA Participation in New Horizons Technical Workshop

Mthobisi (CAYA Eswatini) and Joshua (CAYA Kenya) participated in a panel on Transition in HIV Care:

- Shared experiences
- Highlighted challenges
- Noted the occurrence and impact AYLHIV experience concerning transitions of caregivers and living situations →

Led to the inclusion of a chapter focusing on supporting AYLHIV experiencing various types of caregiver transition, including child headed households



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.

Stakeholder Consultation & Site Visits

Rosa (CAYA Zimbabwe), Ismail (CAYA Uganda), Joshua (CAYA Kenya) participated in:

- In-person stakeholder consultation
- Site visits to three facilities that read and used toolkit



Improvements:

- Emphasized the simultaneous different transitions AYLHIV experience
- Created a new checklist for caregivers during transition
- Integrated differentiated service delivery guidance into the clinical chapter
- Clarified role as a resource for sites to enhance transition for AYLHIV



Thank you!



Q&A

We encourage all to participate!

- We will answer messages coming in digitally, first (through the Q&A box of your screen)
- Click the Q&A box at the bottom of the screen, type in your question(s) and hit send – hosts will be notified and respond to your question.
- To ask your questions verbally, click "raise hand" in your toolbar, or if dialing in on the phone, click *9 to raise your hand. The host will then un-mute you when it is time to take your question. You will be notified when you are un-muted. Once un-muted please start with your name and affiliation, then your question
- We may not be able to get to all questions. If we are unable to get to your question, please email publications@pedaids.org with it. We will respond to all questions by the end of the day.