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# Going the Extra Mile: Optimizing HIV Care for Children and Adolescents in Southwest Uganda

## USAID-RHITES SW



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# Introduction

Globally, in 2015, 36.7 million people were living with HIV (PLHIV). Nineteen million were in Eastern and Southern Africa, and only 17 million (46%) worldwide were on antiretroviral therapy (ART)<sup>1</sup>. At end of 2017, of the estimated 26,000 CLHIV, only 7,706 (29%) were known HIV positive, 7,600 (99%) had received treatment, and 5,700 (76%) had attained viral load suppression of 1,000 copies/ml<sup>2</sup>. By December 2022, 39 million people are living with HIV, 86% of PLHIV knew their status and 29.8 million people (82%) were accessing ART, up from 7.7 million since 2010<sup>3</sup>. Uganda has an estimated 1.43 million PLHIV: 139,000 are children and adolescents (CALHIV), and 65% (91,000) have a known HIV positive status and are on ART. Of those on ART, 72,200 (79) have attained viral load suppression, (June 2023). Approximately 1.3 million (92%) know their HIV-positive status, 1.4 million (98%) are receiving ART, and 1.29 million (92%) on ART have attained viral load suppression. The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) used a program optimization approach to ensure quality improvement in program implementation and promoted collaboration, learning and adaptation, which have led to rapid achievements.

## POA Interventions to improve pediatric and adolescent outcomes

The Regional Health Integration to Enhance Services in the Southwest (RHITES-SW) project implemented differentiated client-centered services tailored to different age groups. These interventions included:

### Clinic-Level Service Optimization

#### Pediatric holiday activities

EGPAF conducted school holiday activities/camps for to provide clinical and psychosocial support services for over 8,800 CALHIV. Clinical services included nutrition assessment, dose adjustments, viral load testing sample collection, and treatment of opportunistic infections. EGPAF also offered psychosocial support services, such as support for HIV status disclosure, education on eating and exercise, screening for gender-based violence (GBV), orphans and vulnerable children screening, and a safety assessment tool for adolescents that addressed issues like drugs, depression, sexuality, and suicidality.

#### File coding

The facilities implemented a coded filing system to track the client through the various points of care. For example, those who needed viral load received yellow tags and those with non-suppressed viral load received red tags. These tags made it easier to review the files and the digital health system to determine which clients missed appointments or had improved.

#### Use of reminders for clinical appointments and adherence to treatment

- Reminder calls and text messages were sent to caregivers of CLHIV and ALHIV to ensure that patients kept appointments. Follow-up phone calls were made immediately after a clinic day to track caregivers and care recipients. Those who could not be reached were attached to a Village Health Team member (VHT) or peer mentor for physical follow-up as well as a review of weekly data on missed appointments.
- Appointment and adherence reminders using interactive voice response calls and SMS messages reduced the time health care workers spent ensuring that clients follow and

1 UNAIDS Global AIDS Update, 2016. Available on [https://www.unaids.org/sites/default/files/media\\_asset/global-AIDS-update-2016\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/global-AIDS-update-2016_en.pdf)

2 There were no estimates of adolescents living with HIV 10-19 years in 2017

3 The Path that Ends AIDS, 2023 Report - UNAIDS - Global Report 2023. Available on [thepath.unaids.org/wp-content/themes/unaids2023/assets/files/2023\\_report.pdf](https://thepath.unaids.org/wp-content/themes/unaids2023/assets/files/2023_report.pdf)

continue treatment. Reminder messages and routine calls were scheduled for all clients slated to attend an appointment. Two calls would go out based on a client's appointment date. The first would be sent seven days before and the last day before.

- To determine the effect of the appointment reminders on clients' attendance, we implemented an additional confirmation call. Three days after the appointment, clients received a self-reported yes-or-no survey on whether they attended. For no responses, a follow-up question asked the reason for missing an appointment so that staff could take appropriate action. Out of 806 clients to whom a phone call was placed, 76.47% received the call and listened to the entire message and 68% of these attended their appointment while 32% missed their appointment.

## Health education

At all points of care (inpatient and outpatient departments, maternal and child health, HIV clinics, young child clinics) clients received health talks to understand the benefits of different services like appointment keeping, viral load bleeding and suppression, adherence, and TB and nutrition screening.

## Community-Level Interventions

Children and adolescents require psychosocial support to help them address the stigma of living with or being affected by HIV. CALHIV living with the elderly or in boarding schools require tailored support to keep appointments and adhere to treatment. The following interventions were implemented:

### Ariel peer-led (adolescent youth peer) psychosocial support clubs

The Ariel psychosocial support clubs were implemented by EGPAF to increase access to psychosocial support for CALHIV and their caregivers, facilitate disclosure, and deliver treatment literacy. The Ariel peers worked with health care workers to provide health education sessions and in community groups to attach each targeted client with a peer group for psychosocial support. Through this approach, EGPAF strengthened psychosocial and adherence support, particularly for clients who have spent < 6 months in care.

### Customized materials for social behavioral change and communication

EGPAF participated with the Ministry of Health (MOH) and others, especially in the community, to develop SBCC messages and IEC materials (1,266 different copies on a range of topics) tailored to different categories of clients, such as caregivers of CALHIV.

### Scale-up of differentiated service delivery models

This included multi-month dispensing: community drug distribution integrated with follow-up efforts for clients who had missed appointments, home-based counseling for adherence to treatment, community viral load bleeding, bidirectional linkage to orphans and vulnerable children (OVC), and GBV management.

## Human Resource Investments for Pediatric and Adolescents HIV care

The project recruited and oriented 210 peer educators 113 linkage facilitators and 126 facility-based counselors) at high-client-load ART sites (sites with >300 CALHIV on ART) to better identify HIV-positive individuals and link them to care and treatment services, and much-needed psychosocial support. EGPAF conducted a training needs assessment for the peer educators, which informed the

development of training packages and materials on psychosocial support. Didactic trainings followed by in-person mentorships and continuous medical education were also provided, and these efforts continued throughout the project life.

## Data Utilization

RHITES-SW ensured quality routinely reported and non-routinely reported data collection and analysis to inform technical assistance efforts to the facility teams for timely course correction. The project designed tools to track performance and reporting, and ensure timely data collection, reporting, and data cleaning (such as data on ART optimization). Digitized tools were developed to improve data visualization and use, such as the e-psychosocial support reporting tool. We acknowledged deficiencies and took corrective actions, turning deficiencies into opportunities for innovation and creativity.

## Campaign approach for quick improvement of pediatric and adolescent outcomes

EGPAF supported implementing facilities to participate in regional and national pediatric and adolescent campaigns to quickly identify gaps along the care cascade and close them through short learning cycles (learning sessions that promoted cross-pollination of high-impact interventions). Some of these campaigns included optimization campaigns (from NNRTIs to LPV/r and from LPV/r to pediatric Dolutegravir). Campaign activities included chart reviews and listing CALHIV eligible for services (and ensuring that they received the mapped services and documentation). The percentage of children greater than 20 kilograms optimised to DTG improved from 1% in 2018 to 100% at the end of December 2021 at all 276 ART sites.

## Laboratory Services for Pediatric and Adolescent Care

While the program optimized HIV treatment services, we effectively transported laboratory commodities and viral load samples from one facility to another. The program also ensured that optimal regimens were available for children, supported health facilities to monitor stock of key pediatric and adolescent commodities (such as pediatric Dolutegravir, Abacavir, and Lamivudine). This led to quick improvements in pediatric regimen optimization efforts.

## Supply Chain for Pediatric and Adolescent Care

As the national HIV program continued to adapt optimal regimens for children, there was a requirement for a robust supply chain system to ensure optimization of pediatric regimens. From 2015, the project supported transition pediatric regimens from non-nucleoside reverse transcriptase inhibitors (Efavirenz and Nevirapine) to protease inhibitors (Lopinavir) and pediatric DTG. EGPAF supported the proper forecasting and quantification of pediatric formulations and built capacity of health workers to pull commodities from national warehouses and to manage stock and storage. EGPAF also played a key role in coordinating and monitoring pediatrics commodity security.

## Implementation Outputs

The number of clients receiving ART grew from 114,808 in 2015 to 178,984 by end of June 2023, according to data from southwest Uganda, where EGPAF has implemented programs for the past 13+ years. This translates to 94% of PLHIV with a known HIV status and 98% of PLHIV with a known HIV positive status on treatment and viral load suppression of 85%. At the end of June 2023, of the estimated 22,200 CALHIV in the southwest, 13,100 (60%) were known to be HIV positive, 10,600 (100%) with known HIV positive status were on ART, and 10,000 (89%) of CALHIV on ART with an up-to-date viral load test attained viral load suppression of 1,000 copies/ml. By the end of 2022, 70% of all CALHIV had been optimized to a DTG-containing regimen, up from 1% from 2018.

## Lessons Learned

- When implementing pre-appointment reminders, garner ownership from key stakeholders—specifically, health care workers and beneficiaries of the services.
- Automating pre-appointment reminders via electronic medical records system reduces the workload for health care workers.
- Client literacy is important in generating demand for services.

## Key Success Factors

- Building capacity for all cadres providing pediatric and adolescent HIV services ensuring stable stocks of laboratory and supply chain commodities.
- Conducting routine performance reviews, visualizations and data-driven interventions at the district and facility level.
- Institutionalizing pediatric and adolescent HIV services (this further consolidated client-centered approaches and led to improved treatment outcomes).
- Leveraging community structures to bring services closer to the recipients of care.



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