Transforming Paediatric HIV Care

Uganda's journey to sustainable, community-led models

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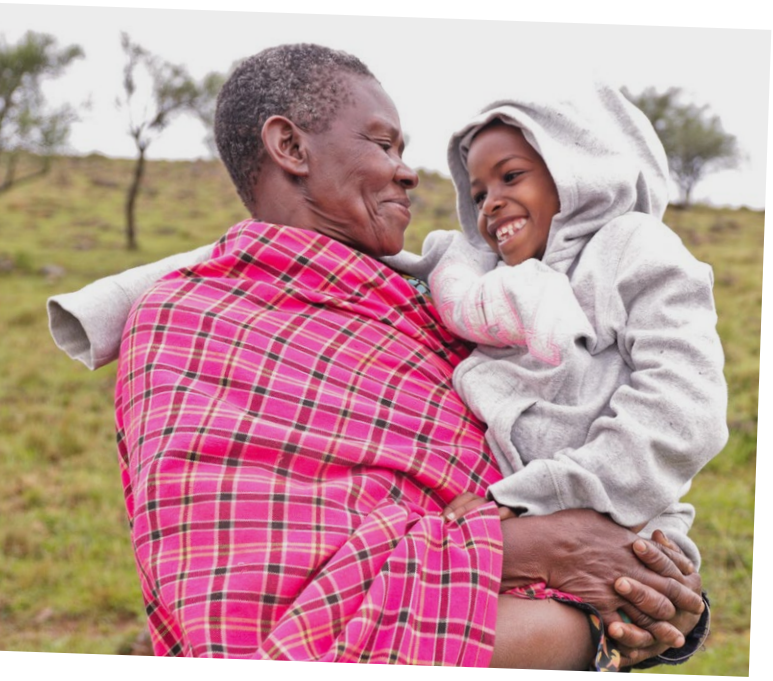
Summary

Uganda's transition to sustainable, community-led paediatric HIV care has transformed service delivery by strengthening government ownership, integrating community health structures, and fostering collaborative partnerships. Through the Paediatric HIV Care and Treatment Breakthrough Partnership (PBP) implemented between 2020 and 2025, Uganda has been using innovative models such as peer-led adherence support, community-based antiretroviral (ART) refills, and facility-community linkages to ensure long-term access to life-saving treatment for children and adolescents living with HIV. By embedding paediatric HIV services into national policies, prioritising resource allocation, and institutionalising accountability mechanisms, the country is providing a replicable model for sustainable, community-driven HIV care across Africa—ensuring service quality, long-term adherence, and improved health outcomes.



The PBP partners have played a crucial role, providing the necessary expertise and support to implement the change effectively. The Elizabeth Glaser Paediatric AIDS Foundation (EGPAF) provided technical support to strengthen healthcare workforce capacity and integrate paediatric HIV services into district health systems. PATA championed peer-led models like Young Adolescent Peer Supporters (YAPS), enhancing community-facility collaboration and adolescent-friendly services. Aidsfonds led the design of the sustainability framework, offering strategic leadership. The National Forum of People Living with HIV/AIDS Networks in Uganda (NAFOPHANU) spearheaded community advocacy and monitoring, while the Community Health Alliance Uganda (CHAU) and Health Need Uganda (HNU) focused on training community health workers and supporting grassroots interventions. Community partners and Paediatric-Adolescent Treatment Africa (PATA) played a critical role in empowering local structures. The partnerships created a cohesive transition plan that embedded paediatric HIV services into district health systems, fostering government ownership and long-term sustainability. This involved integrating paediatric HIV care into national and district health systems down to the lower administrative units: sub-county, Parish, and village levels.

This story of change is based on a series of interviews conducted by Aidsfonds consultants in December 2024.

The challenges with care of children living with hiv

Uganda has been a global success story in the fight against HIV and AIDS since the first case was discovered along the shores of Lake Victoria in 1982. According to the Uganda AIDS Commission (UAC), the HIV prevalence rate has declined from 30% in 1990 to 5.1% in 2022. This success was attributed to a well-coordinated multi-sectoral response. Despite the excellent progress, globally, Uganda ranks 5th among countries with the highest HIV burden. As of 2022, Uganda registered 52,000 new HIV infections and 17,000 deaths. Of the new HIV infections among young people, four out of five were adolescent girls. These figures, however, indicate a 40% decline in new infections and a 65% decline in deaths registered (UAC 2022).[1]

Despite progress in Uganda's HIV response, prior to 2020 paediatric HIV care faced critical gaps, particularly in ensuring continuity of care, adherence support, and sustainable service delivery. According to UNAIDS estimates, only 45% of children aged 0–14 living with HIV had access to ART, a stark contrast to the 95% of pregnant women receiving treatment.[2] (UNAIDS,2019). Children and adolescents living with HIV often struggled with inconsistent access to treatment, stigma, and weak facility-community linkages that hindered retention in care. Geographical barriers compounded the situation, limiting consistent ART supply and undermining the sustainability of services. These gaps were aggravated by limited early

1 https://uac.go.ug/images/2024/facttsheets/hiv-aids-factsheet-2022.pdf

2 https://pmc.ncbi.nlm.nih.gov/articles/PMC8792098/

Apio Mezia is pictured interacting with Asalo Christine, a midwife at Asuret HC III in Soroti. Apio is a caretaker and mentor mother who helps the facility combat stigma in the community and follow up on clients lost to care. December, 2024.

diagnosis, weak referral systems, lack of healthcare staff with paediatric expertise, and limited community engagement.[3]

Community structures like Village Health Teams (VHTs) were underutilised, and stigma deterred caregivers from seeking timely care for children. In addition, the fragmentation of paediatric HIV services—ranging from inconsistent integration of care between health facilities and communities to poor linkages between caregivers, health providers, and districts—made care both inaccessible and unsustainable. Barriers to sustainability were particularly evident in Uganda's reliance on external donor support, which had not been fully integrated into national and district health systems. This donor dependence, coupled with limited local leadership and inadequate resource allocation, posed a critical risk that paediatric HIV programmes could be discontinued once external funding ceased. **The healthcare system's failure to prioritise paediatric HIV at national and district levels made it clear that a new approach was needed—one that involved government-led, community-driven solutions to ensure continuity and sustainability of care for children and adolescents living with HIV.**

Community leaders like Florence Tusiime, who had been advocating for HIV care in Kyenjojo District since the early 2000s, witnessed firsthand how stigma, low treatment literacy, and fragmented services negatively impacted adherence and care for children. Florence recalls how caregivers were overwhelmed by logistical challenges in accessing HIV treatment, and the lack of psychosocial support left adolescents struggling to transition to adult care. Similarly, ART clinic leaders like Asiimwe Ronald in Kyenjojo district describe how limited paediatric expertise and poor community-clinic collaboration contributed to high rates of late diagnosis, poor health outcomes, and an inability to retain children in care. Below are their comments recorded during the interviews. Asiimwe Ronald, the ART clinic in-charge at Butunduzi Health Centre III in Kyenjojo district:

> **"Before the intervention of the Paediatric Breakthrough Partnership, we struggled with late diagnosis and initiation to treatment and management of children living with HIV. Clinically, our staff were not specifically equipped to handle these children's unique and specific needs. Limited access to treatment and adherence support led to poor health outcomes."**

Also, Florence Tusiime, a prominent HIV activist living with HIV in rural Kyenjojo, added:

> **"Before the Paediatric Breakthrough Partnership, our caregivers lacked both the knowledge and support needed to maintain treatment adherence for their children. Our caregivers were overwhelmed by the logistical and financial burden of accessing fragmented services at health centres. The disconnect at the individual, community, facility and district level made paediatric service delivery a distant dream."**

She explained:

> **"Our adolescents transitioning to adult care faced heightened challenges in retention and adherence due to insufficient psychosocial support at the facilities to help them navigate the change."**

3 https://www.unaids.org/sites/default/files/media_asset/2020_aids-data-book_en.pdf

What was the breakthrough approach?

The **partnership developed a transition plan** between 2023 and 2025 to improve the long-term sustainability of paediatric HIV care in Uganda, through a phased approach. The plan emphasises strengthening government ownership and leadership, community-led approaches, service delivery and facility-community linkages (C3), as well as advocacy and knowledge sharing.

A range of breakthrough approaches were taken to ensure sustainability:

Collaboration between healthcare facilities and community structures at different stages of the care continuum was crucial. The PBP formalised the roles of VHTs, YAPS, mentor mothers, and expert clients by equipping them with knowledge, skills, tools, and supervision to support case identification, treatment initiation, and adherence follow-up. Regular coordination meetings and integration into district health plans further strengthened the collaboration, creating a self-sufficient community support system capable of sustaining paediatric HIV services beyond the programme's lifespan.

Asiimwe Ronald, the ART clinic in charge at Butunduzi Health Centre III in Kyenjojo district, describes the importance of community structures in community-clinic collaboration and how this enables the facilities to support children living with HIV:

> "In identifying children and adolescents living with HIV, VHTs conduct household visits and community sensitisation to encourage HIV testing. Health workers provide HIV testing and counselling (HTS). Mentor mothers identify exposed infants and at-risk children during routine engagements with families. At the same time, Young Adolescent Peer Supporters (YAPS) mobilise adolescents for HIV testing and education in youth-friendly spaces. Pregnant women are tested at antenatal care clinics, ensuring early detection of HIV-exposed infants. Healthcare providers monitor missed appointments and loss to follow-up, triggering community-based follow-ups."

In linking children living with HIV to care and treatment, VHTs and YAPS escort newly diagnosed children and adolescents to health facilities, ensuring they start treatment immediately. Caregivers receive adherence counselling through mentor mothers and PLHIV networks before ART is initiated. Clinicians initiate ART straight after diagnosis and provide treatment literacy. Paediatricians conduct baseline assessments, including CD4 count and viral load tests, to determine the best treatment approach.According to Asalo Christine, a midwife at Asuret HC III in Soroti District, cooperation is essential:

> "In ensuing retention in care and adherence support of children and adolescents, YAPS and VHTs conduct home visits to monitor treatment adherence, address treatment challenges, and provide psychosocial support. We also have community-based ART refill models that reduce the burden on caregivers by making ART accessible at the village level. Caregiver savings groups help caregivers afford transport to health facilities and provide social support. Our facilities offer adolescent-friendly HIV clinics, providing age-appropriate counselling and peer support. Differentiated service delivery models allow stable patients to receive longer ART refills, reducing frequent visits. We also provide routine viral load monitoring to track treatment progress and adjust regimens when necessary."

By shifting caregiving responsibilities from health workers to community members and families, the model reduced the burden on health facilities and improved retention in care. A deliberate, structured shift was made, transferring treatment support from community health workers to caregivers,

mentor mothers, and VHTs, ensuring parents and guardians take a more active role in their children's HIV treatment and adherence. At Mitooma Health Centre IV, PLHIV networks and caregiver groups were trained to track compliance, retention, and service quality, reporting findings to district health offices. In Mityana, VHTs, YAPS, and mentor mothers receive additional training and are directly linked to district health systems for supervision and accountability. The district health office monitors and supports this now and in the future. According to Mono Denis, District Health Educator in Mityana:

> "Our role at the district is to mobilise and supervise the 1,330 VHTs, especially those trained in paediatric HIV. To ensure that our VHTs, peer mothers, and peer educators are incentivised, we incorporate them in community health programming like health surveillance, mosquito net distribution, and basic health care dissemination outreaches. VHTs and YAPS also work as linkage and referral assistants and cough monitors at health facilities where they draw allowances. Some VHTs like Siraje Walugembe in Mityana hold elective offices and have the power to influence communities, especially in combating stigma."

By employing community-differentiated service delivery models like community-led ART refills, community health structures counter paediatric HIV service delivery challenges. These models help combat facility congestion, reduce transport costs to facilities, and improve access for hard-to-reach communities. Expanding peer-led adherence support models (YAPS, mentor mothers, and expert clients) ensures that more children and adolescents receive the support they need. VHTs also play an ongoing role in HIV case identification, referral, and community-based follow-ups.

In Mityana, the empowered community structures, including health workers, community-based organisations, VHTs, and local leaders, served their communities better by **expanding facility-community referral systems** to ensure all children who test positive in community settings are linked to care. According to Mono Denis, District Health Educator in Mityana:

> "The Community collaboration model being implemented by community partners has revolutionised paediatric HIV care by empowering VHTs and YAPS with training on psychosocial support, Directly Observed Therapy, Intensive Adherence Counselling, treatment literacy, and nutrition. The VHTs and YAPS then transfer the knowledge to caregivers and peers, which empowers families affected by HIV to manage paediatric HIV." PBP community partners involved district leadership in their programming to sustain and consolidate the gains of the paediatric HIV intervention. According to Joselyn Mbawadde of NAFOPHANU: "We directly work with the sub-county and District AIDS Committees to identify service delivery gaps, review health budgets, and plan for PLHIV in our district. District officials under the District Health Office also monitor facilities in their districts to ensure that they have active ART clinics, sufficient resources like workforce, drug stock, testing kits, and active Adolescent-friendly corners to enable the YAPS to serve their peers."

At Gweri Heath Centre III, health providers prioritise client referrals from mentor mothers and YAPS. Establishing **formal referral pathways** ensures that children diagnosed at the community level are linked to treatment facilities and monitored. High-impact interventions such as home-based ART delivery, differentiated service delivery models (DSDMs), and youth-friendly HIV clinics are also being expanded at government facilities.

Joint advocacy efforts led by PBP partners targeted national and district governments to ensure paediatric HIV remains a priority in Uganda's health agenda. EGPAF worked with regional and subnational ministries, leveraging partnerships and promoting linkages between government structures, while UNICEF strengthened high-level advocacy for the national HIV response. As a result of these advocacy efforts, the Ministry of Health

(MOH) agreed to collaborate with NAFOPHANU and other PBP partners to increase domestic funding, jointly advocating for a higher (0.5%) district budget for HIV (currently 0.1%) at both the district and national levels. EGPAF leveraged the ViiV-PBP dashboard as a central tool to monitor progress toward key milestones and support advocacy efforts at both national and global levels. This dashboard provides real-time, data-driven insights, enabling stakeholders to track programme performance, identify trends, and address gaps in paediatric health interventions.

Another key change element linked to sustainability is technical mentorship and capacity building for healthcare providers. According to Musabe Vincent, ART in-charge at Kyembogo HC III, Kyenjojo:

> "Technical mentorship, health system strengthening (Quality Improvement Plan), and capacity building to healthcare providers facilitated by PBP clinical partners PATA and EGPAF have narrowed the paediatric HIV care knowledge gap among health service providers. Resource tools like the Psychosocial Support (PSS) Guide for Children and Adolescents Infected and Affected by HIV and AIDS, Case-Based Management, comprehensive HIV treatment, and integration equip community healthcare service providers with sustainable knowledge to aid the management of paediatric HIV care. Specialised training and conferences like the annual PATA Summit and quarterly PATA-REAL Linking and Learning Webinar allow healthcare providers to 'Review cases, engage peers, access experts, and Learn lessons' on paediatric HIV care."

The PBP's focus on strengthening families has **empowered primary and secondary caregivers** through treatment literacy and socio-economic support under Village Saving and Loan Associations (VSLAs). In Kyenjojo and Mityana, PBP community partner CHAU provided starting capital and financial literacy support to VHT and caregiver VSLAs, such as Kalindi Agahikaine Group of People Living with HIV/AIDS and

Caregivers. VSLAs offer affordable credit, social support, lay counselling services, and community services to caregivers, enabling them to afford transportation and nutritious food for their children in care. According to Kunihira Margret, Chairperson of Nyamabuga Tweyambe Savings and Credit Group:

> "This group helps us afford to transport our children for their monthly refills to ensure adherence and suppression. We also borrow money to purchase nutritious food for our children, especially when we have made money from selling our farm produce." In Banda Sub-County, Mityana district, the Community Development Officer (CDO), Ssentamu Benedict, works with caregiver VSLAs to equip them with management guidance and statutory compliance requirements. "We have invested in empowering our caregivers. We train them on how to manage the VSLAs. While health facilities, through the VHTs, also train them in treatment literacy. We also link caregivers to funding and training opportunities. Some members of these VSLAs have received money under the Parish Development Model, a government economic empowerment program that has helped eliminate some financial strain on caregivers. We believe an empowered caregiver has renewed zeal to retain children in care."

The transformation journey

The PBP intervention brought much-needed changes, strengthening the facility-community linkages and ensuring local leadership, government integration, and community empowerment. This shift was key to ensuring that paediatric HIV care was not only accessible but sustainable, providing long-term support to children and adolescents living with HIV across Uganda.

During 2021-2023 the Paediatric HIV Care and Treatment Breakthrough Programme (PBP) made significant strides in paediatric HIV case detection, treatment adherence, and the strengthening of collaborations between health facilities and community-based support systems. This laid a solid foundation for transforming paediatric HIV care but also revealed key challenges related to sustainability. The programme's heavy reliance on donor funding and minimal involvement of district health teams posed a risk to long-term success, as local governments were not yet fully invested in the programme. Despite effective community-led models, such as Young Adolescent Peer Supporters (YAPS) and mentor mothers, these structures were underused, and health workers remained at the centre of care, limiting the empowerment of families and caregivers.

Shift towards greater sustainability of care and integration

A transformative shift began to unfold as the programme transitioned 2024-2025, focusing on creating sustainable systems for paediatric HIV care. Central to this transition was strengthening government ownership and leadership at all levels, from national to community, ensuring that paediatric HIV care was integrated into the district health systems. In districts like Mityana, the success of community-led models like the Community Clinic Collaboration[4] (C3), which empowered community health workers, demonstrated a path forward. These models have become embedded into district health structures and are part and parcel of the district health office programming, ensuring continued care beyond the programme's timeline. The District Health Educator's Office works in partnership with local government leaders, community leaders, the Community Development Office, VHTs and the health facilities' leadership.

Instead of creating new infrastructure, the government used local support structures[5] from the PBP programme as outreach and adherence support hubs. At the facilities in four districts visited, the prioritisation of adolescent HIV support through initiating age-specific clinic days, engaging YAPs and providing adolescent-friendly services ensured that adolescents remained in care as they progressed into adulthood.

> **"My peers find it easier to engage with me because I am their age mate and can relate to their issues and challenges. We met outside the facility, where I offered psychosocial support and adherence guidance to my peers who were unable or uninterested in coming to the hospital. The facility also permitted me to deliver medications to my peers in their communities under the Differentiated Service Delivery initiative."**
>
> Akiisimiire Dorcus, YAPS, Mitooma HC IV

4 C3 - Clinic-CBO Collaboration Programme - PATA

5 Including Village Health Teams, community health workers, community groups (mentor mothers, caregivers of children with HIV, Young Adolescent Peer Supporters, people living with HIV) and local leaders.

The key impacts of transition

The programme has had significant and multiple benefits:

Critical role for carers
The transition has spotlighted the critical role of caregivers and families in paediatric HIV care. The approach shifted from reliance on health workers to empowering parents and other caregivers to take a more active role in their children's care. In Mitooma Health Centre IV, caregivers and networks of people living with HIV (PLHIV) were trained to monitor adherence and retention, linking them directly to district health systems for accountability. Similarly, in Mityana, VHTs, YAPS, and mentor mothers were provided additional training to reinforce their roles in HIV care, treatment literacy, and psychosocial support. As districts began allocating more resources to paediatric HIV services, Soroti became a shining example, with the district health team committing to dedicate part of its budget to support paediatric HIV care. Community structures supported this commitment, including caregiver groups and Village Saving and Loan Associations (VSLAs). The latter provided financial literacy and social support, helping caregivers cover treatment and transportation costs and improving adherence to treatment for their children living with HIV. The government community development officer currently mentors, oversees, and guides the VSLAs.

These community-driven initiatives demonstrated the power of local ownership and have shown lasting effects on the sustainability of HIV care. Furthermore, there is a reduction in facility congestion due to the expansion of community-based services and differentiated service delivery models[6] (DSDMs).

Collaborative and community-led approach improves HIV care
One of the most potent symbols of change was the collaborative effort between the Ministry of Health, district health teams, and HIV partners. This collaboration has led to the integration of paediatric HIV services into national policies, such as the Paediatric HIV Advocacy Strategy and the introduction of child-friendly, single-pill treatments that have significantly improved adherence. Districts have also been empowered to monitor health service delivery, ensuring that paediatric HIV care remains a priority and that the government continues to allocate necessary resources. The transition plan marks a significant shift from donor reliance to government ownership, with districts committing to paediatric HIV care.

Evidence of change
Through these efforts, the programme has not only transformed paediatric HIV care at the facility level but has also woven community health structures into the fabric of Uganda's health system. Statements from district health educators (e.g., Soroti, Mityana) confirm increased district-level budget allocations and active involvement in paediatric HIV care. The rollout of community-based services like home-based ART delivery and training for caregivers and VHTs indicates the long-term integration of these models into the health system. The introduction of new child-friendly ARVs (single-pill treatment) has resulted in improved adherence, evidenced by testimonies from caregivers and health staff. These changes are now visible in stronger district health systems, improved patient outcomes,[7] (5) and a community deeply invested in the care and support of children living with HIV.

6 differentiatedservicedelivery.org/about_dsd

7 https://pedaids.org/resource/the-power-of-peer-centric-high-impact-approaches-toward-achieving-gains-along-the-hiv-care-continuum-for-adolescents-living-with-hiv-in-uganda/

Evidence from PMTCT intervention

According to the PBP programme's Year Two report, 'from January to March 2022 in Kyenjojo District, because of community engagement in the prevention of mother-to-child transmission (PMTCT) programme:

- All mothers from Kyembogo Holy Cross had HIV-free babies
- In Kyarusozi only two babies out of 28 were HIV positive
- In Kigoyera only six babies were HIV positive
- Viral load suppression among children living with HIV improved, with 405 children out of 444 virally suppressed.

The PBP programme's Year 4 report (July-December 2024) found:

- 234 VHTs work independently to strengthen referrals and the linkage between communities and health centres
- The VHTs referred 1,853 children and adolescents to facilities for HIV testing.
- 1,429 children and adolescents were tested – 41 children and adolescents tested positive and were initiated on ART.
- Most referred clients who did not reach health centres for services were followed up, and challenges were addressed.
- By the end of December 2024, only six children living with HIV from three pilot districts were recorded for non-adherence to treatment.
- In Soroti, VHTs visited 3,727 households with children and adolescents exposed and living with HIV and lost to follow up, with missed appointments and viral non-suppression. Most children had missed appointments due to high transport costs to the health centres.

These results were highly significant; the pro-active VHTs immediately impact the elimination of mother to child transmission (EMCT) and substantially increase the chance of survival for children living with HIV in a sustainable health system.

The key role of Ministry of Health, the Uganda AIDS Commission and District Health Offices
The efforts of a wide range of partners were critical to the programme's success.

Uganda's Ministry of Health (MoH), is responsible for leading the integration of paediatric HIV services into national policies and programmes, providing technical guidance, training, and policy formulation, overseeing funding allocations for HIV programmes, ensuring sustainability beyond donor funding and strengthening supply chain systems for uninterrupted ART provision for children and adolescents. The Uganda AIDS Commission (UAC) ensures the alignment of paediatric HIV programmes with national and global HIV response goals.

District Health Offices (DHOs) led service delivery at the district level, allocated resources, and integrated community structures into health systems. Community Development Offices supported VHTs and YAPS and mentored mothers to tackle social barriers and promote community ownership. USAID partners (Baylor, IDI) provided technical support and resources to strengthen facility-based HIV care and build health workforce capacity. Between 2021 and 2024, advocacy efforts by PATA and EGPAF successfully integrated paediatric HIV into district development plans and annual budgets, ensuring financial and logistical support for key activities. Local governments also worked with other key partners that offered paediatric HIV care, like Baylor in Mityana, to ensure the continuity of gains from the PBP project and the absorption of community health personnel into their structures. Mityana District also launched a comprehensive HIV/AIDS Strategic Plan in 2023 with the backing of CHAU and NAFOPHANU.

District Health Offices assumed responsibility for managing paediatric HIV care at the district level through health service providers and facilities, overseeing health facility performance and service delivery. Local governments were committed to increasing health budget allocations and supervising community health programmes. To secure the sustainability of paediatric HIV care, the Uganda government and PBP partners implemented community-led monitoring and accountability. PLHIV networks and caregiver groups tracked service quality and patient retention, ensuring transparency and responsiveness at district and national levels. District health teams led quarterly review meetings, analysing performance data and identifying areas for improvement. Local leaders actively participated in community engagement initiatives.

What were the main factors driving success? According to Joselyn Mbawadde of NAFOPHANU:

> **Paediatric HIV services were embedded within district health structures through a combination of policy integration, financial commitment, workforce capacity building, and strengthened community-facility linkages to ensure sustainability beyond the PBP timeline.**

Memorandums of Understanding (MOUs) between district health offices and community health workers (VHTs, YAPS, mentor mothers) were adopted to outline the formal roles of community health workers in HIV service delivery. This formal recognition motivated these community health workers and allowed them to remain engaged. For instance, in Kyenjojo, all VHTs, PLHIV networks, and Caretaker VSLAs established under the PBP were registered with the district to ensure they benefited from government planning and development programmes.

District health teams committed to progressively increasing budget allocations for paediatric HIV services. In Soroti, William Oriokot, the District Health Educator, affirmed the district's commitment to dedicating part of its health budget to paediatric HIV care.

> **As a district, we are alive to the realities of paediatric HIV care gaps, and we knew that we had to take action to ensure our children stayed in care, even if it meant sacrificing extra funds for this effort.**

Similarly, in districts like Mityana, best practices from PBP, such as peer-led adherence support mentor mothers and VHT-led follow-ups, were institutionalised in the different facilities.

The MoH leveraged existing human resources within communities and the public health system to ensure efficient service delivery without increasing government expenditure. The community health structures under which VHTs, expert clients, and peer support operated were government-oriented and supplemented formal public health structures. While community health workers did not draw a government salary, health facilities formulated creative ways to incentivise VHTs and YAPS, incorporating them into health systems with clear reporting lines to district health officers. District health teams integrated paediatric HIV services into their annual health plans, showing commitment to sustaining these efforts.

At Asuret HC III, Soroti, Mitooma HC IV, and all 84 health facilities implementing the PBP programme, VHTs, expert clients, mentor mothers, CoRPS, and YAPs participated in community-facility activities like outreaches, where they earned modest stipends out of the public health care funds issued to these facilities by the government. These community health workers facilitated task-shifting from healthcare providers and eased their workload by working, for example, as lay counsellors.

Asiimwe Olivia, 17, poses for a photo at Mitooma HC IV in Mitooma. January 2025.

Health facilities also offered continuous medical education to their VHTs and invited VHT leaders to facility review meetings, ensuring community health workers remained invested in their work. District health teams invested in training healthcare workers in facilities on community engagement, ensuring seamless referral systems between facilities and local support networks. Formalising community-health facility collaboration through MOUs between local governments and community health networks, especially caregivers and expert clients, also ensured clear roles and accountability in service delivery related to paediatric HIV. William Oriokot, the Soroti District Health Educator, noted:

> "The district monitored and supervised the VHTs to ensure conformity with government policy. VHTs submitted quarterly reports to the facilities in their district to update the district and Ministry on their work through the Health Ministry Information System. The information submitted helped the Government collect data that informed decisions relating to staffing, stocking, and funding these health facilities."

The Ministry continued to leverage working relationships with other HIV programme-implementing partners through campaigns like the national Munoonye (Find the Child) Campaign, organised by MoH and PEPFAR between April and September 2024, which aimed to identify and start treatment for over 10,000 children and adolescents living with HIV who had not yet been diagnosed.

The government fostered collaboration between its agencies and HIV partners. For instance, PATA cooperated with MoH resource persons to build the capacity of peer supporters on treatment literacy, TB screening, Intensive Adherence Counselling, follow-up for adherence and retention, viral load monitoring, and community testing. Collaborations like this were a sustainable way of strengthening referral pathways without

significantly affecting the government health budget, leading to a higher retention rate among children and adolescents on ART.

According to Joselyn Mbawadde of NAFOPHANU, advocacy efforts by PBP partners moved the MoH to consider rolling out, scaling, or streamlining the adoption of key game-changer interventions, including strengthening entry point and index testing, leveraging audit tools and trackers to line-list children and siblings of index clients, and integrating HIV testing services (HTS) with existing community interventions. Other practical approaches included precision mapping for targeting high-burden hotspots, caregiver-assisted self-test kits, engaging youth peers for outreach, and fostering community partnerships with faith-based organisations and civil society groups. To ensure sustainability, the Ministry encouraged the designation of focal persons, the integration of HTS into existing interventions, securing leadership buy-in, and utilising data for targeted interventions and performance improvement. These best practices are being produced as a toolkit for nationwide scaling.

Similarly, advocacy and advisory efforts by PBP and other HIV implementing partners resulted in the adoption of policies, guidelines, and plans in support of paediatric HIV, such as the National Paediatric and Adolescent HIV Advocacy Strategy and Road Map 2022-2026, which aims to "complement and catalyse the ongoing national programs targeted at improving paediatric and adolescent HIV outcomes by addressing the policy and resource allocation gaps." This policy change further strengthened cooperation between the government and PBP partners. Documentation and feedback by PBP and other HIV implementing partners has resulted in the adoption of the approved single-pill child-friendly treatment (PLD), specifically designed for infants and young children with HIV. Arongat Miriam, a peer educator at Asuret Health Centre III, says:

> "The introduction of the single pill for children significantly reduced the pill burden among our children. Adherence and viral load suppression improved, which was easier since the new medicine was easier to administer. Some children would vomit after swallowing the pills. There were reduced cases of patients suffering nightmares with the new pDTG drugs."

Due to advocacy efforts, the MoH agreed to join in advocacy efforts with NAFOPHANU and partners to increase domestic funding. The MoH would share their priorities. NAFOPHANU would share project achievements and best practices to jointly advocate for a higher (0.5%) district budget for HIV (currently 0.1%) at both district and National Levels.

Another strong indication of the MOH's commitment to sustainability and ownership of paediatric HIV is linked to the efforts of the National Medical Stores and Joint Medical Stores to ensure that paediatric HIV medical resources, like testing kits, did not run out at facilities. Caregivers reported minimal instances of drug stockouts. The MoH incorporated cost-effective resource utilisation strategies by leveraging existing community caregiver networks and Decentralised Drug Distribution to make medication more accessible, reducing travel burdens for families. According to Outeke Billy, ART in charge, Gweri HC III, Soroti,

"ART refills were available at community-based points, reducing transport burdens on families. Similarly, expanding home-based care was a sustainable way of ensuring adherence through VHTs and trained caregivers who supported home-based ART delivery and monitoring. As a result, reliance on facility visits decreased. The Government also provided Ready to Eat food to counter nutrition concerns among paediatric HIV patients."

Limitations & lessons

What were the programme's limitations?
Despite efforts to integrate paediatric HIV services into national and district health systems, gaps in government ownership and policy adoption remain a challenge. While community health workers (VHTs, YAPS, mentor mothers) are now recognised as essential in paediatric HIV care, especially in retention and adherence, they are still not formally considered part of the formal health workforce; they do not draw a government salary and lack contractual assurances.

Uneven commitment across districts is a challenge. Some districts, such as Soroti and Mityana, have embraced paediatric HIV programme integration, while others struggle with limited political will and competing health priorities. For instance, in Mitooma, VHTs have not been embraced by the facilities.

Uganda's healthcare budget is stretched across multiple health needs, making it difficult to secure stable funding for paediatric HIV programmes at the district level.

Human resource constraints at facilities are ongoing threats to the sustainability of the programme's gains. At most facilities visited, low staffing levels mean that healthcare workers are often overburdened, especially in high-demand districts like Mityana and Soroti. Staff shortages limit their ability to provide consistent follow-up and support to mothers, children, and adolescents living with HIV. To compound the crisis, the loss of trained VHTs, YAPS, and healthcare workers to transfers leaves gaps and hampers the continuity of services in some areas. The government needs to find ways to ensure staff retention, avoiding disruption to service provision.

Key lessons learned
The partnership provides overwhelming evidence that government and community ownership are key to sustainability and that Clinic-Community-Collaboration plays a key role in this. The consistent engagement of VHTs, YAPS, caregivers, local leaders, and mentor mothers has ensured retention and adherence among children and adolescents, while consistent paediatric services are provided at the clinics. We hope these lessons will facilitate the take up of the model in other African contexts.

Building capacity: Linking community health workers with health facility workers improves coordination and cooperation, enhancing linkage and client retention. However, capacity building and monitoring must be continuous to improve outcomes. The high turnover rates among trained community health workers and healthcare providers highlight the need for ongoing training and mentorship.

Addressing local challenges: The programme's varying success across districts highlights the importance of understanding the local challenges (e.g., socio-political factors, healthcare infrastructure, community engagement levels) in order to refine strategies. This underscores the need for flexible and context-driven interventions rather than a one-size-fits-all approach.

Funding: The instability of USAID funding requires diversifying funding sources and creating partnerships beyond the donor-driven model. Projects relying heavily on one funding stream can become vulnerable to donor priorities or funding level shifts. The Uganda government issued a directive towards integration of any specialised HIV services into the regular health services. However, the PBP experience shows that integration should be approached gradually, allowing time for programme adjustments and adaptation to the local context.

Data collection: The importance of establishing clear metrics for tracking progress, even in unstable environments, cannot be overstated. This highlights the

need for adaptable monitoring and evaluation frameworks that can capture quantitative and qualitative data, particularly during transition periods.

Engaging government: Early government engagement accelerates transition. The involvement of health authorities at various levels contributes significantly to the sense of ownership and an enabling environment for government support. Their support and ownership are crucial for sustainability. Policy integration must, therefore, be prioritised. Continuous advocacy at the national level is required to ensure local governments allocate adequate funds to maintain paediatric HIV services without reliance on external donors.

Village Health Team attached to Mitooma HC IV pose for a photo after a planning meeting at the facility. Mitooma, January 2025.

Looking ahead

The programme highlights the importance of ensuring that gains made in paediatric HIV care are sustainable. Paediatric HIV interventions not only reduce infant infection (PMTCT) but also improve adherence to treatment, which significantly reduces mortality. Paediatric care also reduces the social and economic cost of treatment and death. Ensuring smooth government uptake reduces reliance on external funding and guarantees the gains made outlive the programme.

Long-term Implications:
Looking ahead, the long-term effects of this change are expected to be transformative. For children and adolescents, it can improve their access to vital services and opportunities for growth, contributing to their overall wellbeing. Children of women living with HIV who avoid HIV through eMTCT lead healthier lives, and equally, adherence reduces the financial burden of treating opportunistic illness and reduces the likelihood of HIV-related death. Caregivers are also set to benefit as the change strengthens support mechanisms, providing them with better tools to care for their families. The Social Return On Investment (SROI) analysis conducted under Towards an Aids-Free Generation in Uganda (TAFU), a precursor programme to the PBP, found that paediatric interventions improved caregivers' Quality adjustment life Years. The analysis also found that VHTs and Community own Resource Persons (CoRPs) organised under VSLAs improved their financial comfort levels from 0.38 to 0.82 after the intervention of TAFU. Community VSLA members also showed improvement in income, wellbeing and health. In addition, a cost-effectiveness study conducted at the end of TAFU phase 2 showed that the cost-effectiveness ratio for the community-based TAFU interventions is, on average, 10 times more cost-effective than the WHO recommended threshold. These findings suggest that in the long term, interventions under paediatric HIV care will continue to positively improve the lives of the beneficiaries.

The impact will also be felt within partner organisations as they integrate more efficient and sustainable practices. Over time, these improvements influence policy changes, shifting the focus of national and local governments toward more robust frameworks that support vulnerable populations. The broader societal impact will likely be substantial, affecting both social and economic systems in the long run. For instance, family-based care reduces the burden on health facilities and saves them money, which can be directed to other needs. In addition, community partners like CHAU will be more involved in the formulation of HIV care policies and in guiding the government on policy and programming. Through the MoH, the Ugandan government developed a National Paediatric and Adolescent Strategy and Roadmap (2022-2026) to address the challenges hindering progress towards the 2030 paediatric HIV elimination goals. This strategy identified ineffective policies and resource allocation gaps in the national response to paediatric and adolescent HIV as key bottlenecks. Through advocacy by community partners and PLHIV networks, the policy is being monitored to support the implementation of community engagement activities, particularly by allocating more resources to lower-level healthcare delivery structures such as VHTs.