Healthy, thriving children: How to find and support children living with HIV in communities

Results and best practices from the Towards an AIDS Free Generation in Uganda programme 2015-2022

Towards an AIDS Free Generation in Uganda

Around 98,000 children in Uganda under the age of 15 were living with HIV when the Towards an AIDS Free Generation in Uganda (TAFU) programme started in 2015[1]. 35% of children living with HIV nationally were not accessing HIV care[2] and in some communities this figure was as high as 88.5%[3].

The TAFU programme was Aidsfonds' first paediatric HIV community intervention programme.[4] The programme trained up community health workers to identify HIV positive children, and link individuals to care and ongoing support. The programme was co-created through community leadership and engagement with key stakeholders, building on community knowledge of the needs of children living with HIV. Towards an AIDS Free Generation in Uganda changed the way that community-based paediatric HIV services were delivered.
The TAFU programme aimed to achieve the following objectives:

- Improve uptake and retention of pregnant and lactating women living with HIV and exposed infants in vertical transmission prevention services
- Increase HIV testing of children 0-14 years of age
- Increase access to and retention in life-long care and treatment for children living with HIV

[1] Elizabeth Glaser Pediatric AIDS Foundation (2022), Uganda Program: Country Fact Sheet.
[2] ibid
[3] TAFU 1 baseline, conducted 2015.
[4] Aidsfonds (2018), Final TAFU Model Report.

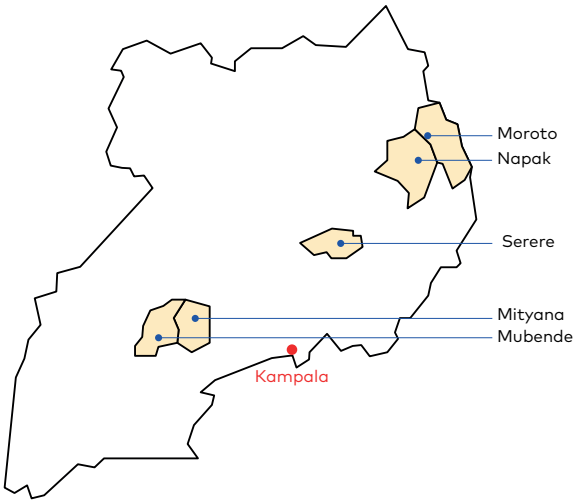
Kids to Care model

The learning and documentation from the TAFU programme, together with the integration of evidence-based frameworks such as the PATA Clinic-Community Collaboration approach and the UNICEF paediatric HIV service delivery framework, resulted in the Kids to Care model[7].

This is a four-stage model that has been utilised by community-based partners in Zimbabwe, South Africa, Mozambique and Nigeria since 2018. The Aidsfonds Kids to Care model empowers communities to strengthen the links between communities and health facilities to find, test, treat and retain children, and pregnant and lactating mothers, living with HIV. The Kids to Care model is built on the following foundational principles:

- Community-owned and community-led
- Builds on existing community structures
- Child and family centred
- Builds on government frameworks and policies
- Key stakeholders are meaningfully involved from the beginning
- Interventions are informed by data
- Committed to sustainability and long-term support

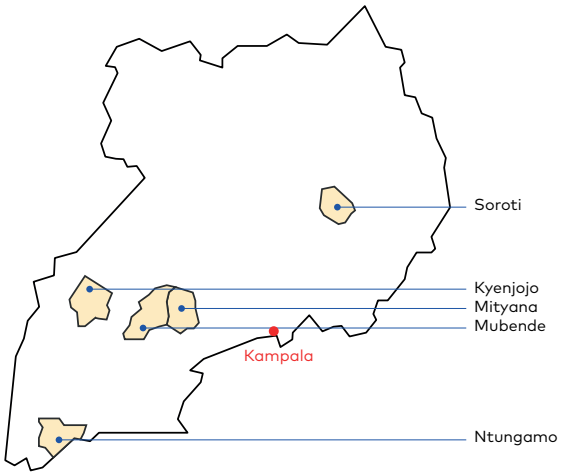
TAFU programme phase 1 (2015-2017)



Partners:

Community Health Alliance Uganda
Deliverance Church Uganda - The AIDS Intervention Program Health Need Uganda
ICCO Cooperation
National Forum of People Living with HIV Networks in Uganda (NAFOPHANU)
Pentecostal Assemblies of God – Karamoja Integrated Development Program

TAFU programme phase 2 (2017-2019) & phase 3 (2019-2022)



Partners:

ARISE Uganda
Community Health Alliance Uganda
Health Need Uganda
National Forum of People Living with HIV Networks in Uganda (NAFOPHANU)

TAFU programme interventions

The programme interventions placed community health workers at the centre of the response. Within TAFU, these are known as village health teams, who are the crucial link between children and their caregivers, community members and health facilities at all four stages of care. Village health teams are supported by community resource persons, who are influential people known and trusted within the community. They include primary and secondary school teachers, religious leaders, community leaders, and expert clients. Community resource persons provide support to strengthen peer-to-peer support groups, village savings and loans associations; lead community dialogues; share key messages through channels of influence and participate in advocacy efforts. Village savings and loans associations are groups in which members meet together regularly to save and to access rotating loans for health services, business and income-generating activities. Groups that involve people living with HIV or caregivers also become a supportive space for discussion about the challenges faced and to share experience of stigma and discrimination.

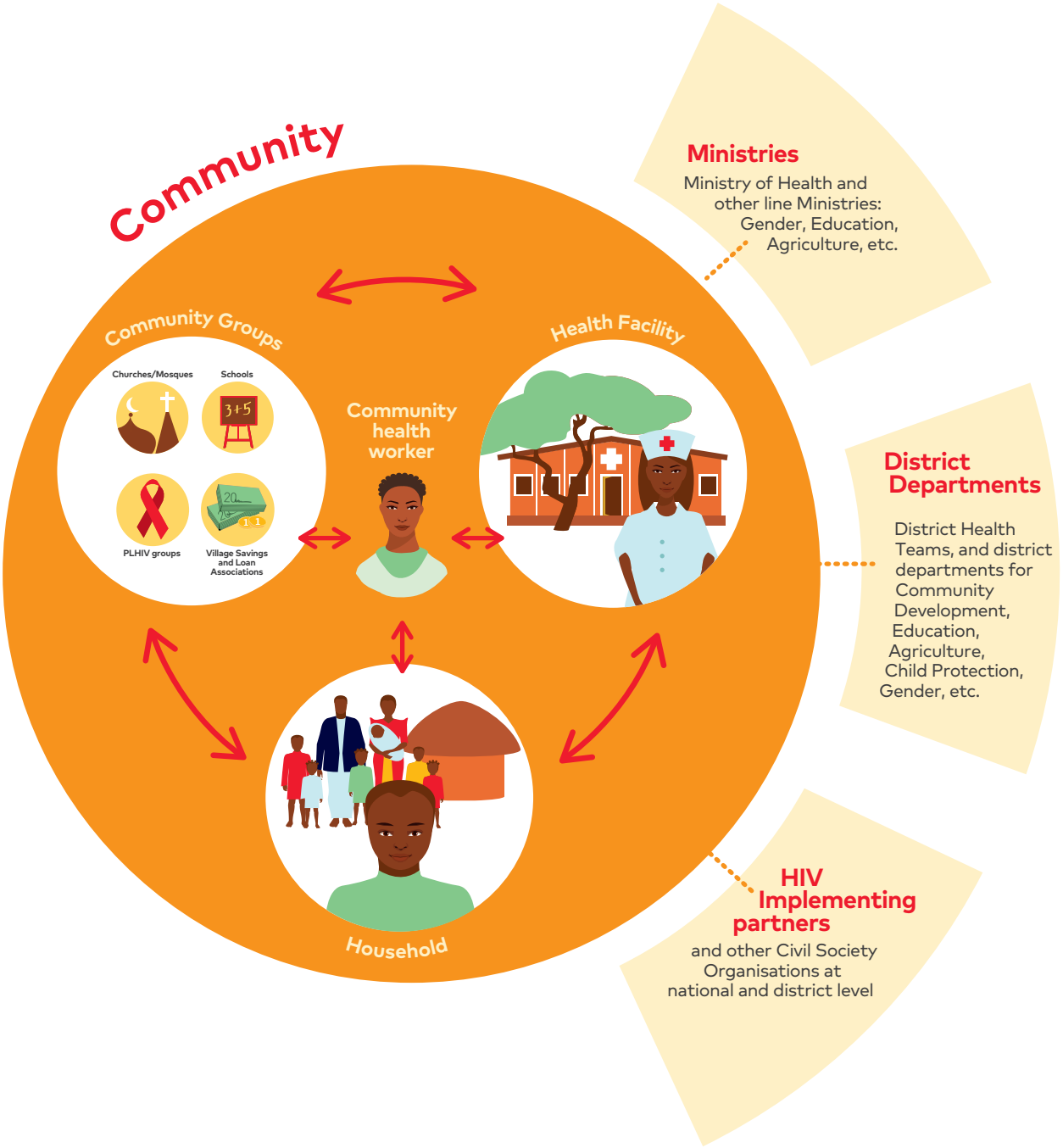
Village health teams were trained and equipped to integrate paediatric HIV support into their existing activities, which included:

Find - identifying children living with HIV through household visits, community outreach, community dialogues and working with community resource persons. In this stage, village health teams provide critical support to reduce stigma and fear, provide accurate information about HIV and to refer children, pregnant and lactating mothers for additional services.

Test - supporting children to be tested for HIV through home-based HIV testing services, mobile testing outreach and referral for confirmatory testing. Linking pregnant women to testing through antenatal care and supporting early infant diagnosis for children exposed to HIV. Community-clinic collaboration and joint coordination with government health systems is a critical component of the success of this stage. Community dialogues and community sensitisation contribute to reducing stigma and fear about HIV testing.

Treat - building the structures needed to support treatment literacy and adherence through peer-to-peer support groups, continued household visits, mentor mothers for pregnant women living with HIV and nutrition education and support.

Retain - creating the support system for long-term retention in care through household economic empowerment, establishment of village savings and loans associations, vegetable gardens for nutritious food, ongoing household visits, support through transitions in care and strengthening of peer-to-peer support groups. It is critical to engage village health teams in village savings and loans associations to enable them to sustain their work over the long-term.



Advocacy has been integrated into all of TAFU's interventions:

- Advocacy aimed to reduce HIV treatment and HIV test-kit stockouts; to improve the availability of human resources for health and the quality of care available at health facilities; and to ensure that paediatric HIV care was available at the lowest levels of health system delivery.

- Advocacy issues were identified by village health teams, expert clients, community resource persons and caregivers. They were then escalated to the health facility and supported with higher-level advocacy at district and national levels towards the Ministry of Health and Medical Stores Department with the engagement of NAFOPHANU.

- One of the major outcomes of TAFU's advocacy efforts was re-distribution of antiretrovirals and HIV test kits, reducing stockouts and interruptions in access to medications. The implementing partners re-distributed test kits from health facilities that were well stocked to those that experienced shortages as they waited for more supplies.

Impact of the TAFU programme

"All our HIV exposed babies are HIV negative. This is because the village health teams and health workers support mothers to attend antenatal care, adhere to antiretroviral therapy and give birth at the health facility."

- Healthcare worker, Soroti District

- Caregivers have better treatment literacy, less fear of HIV and feel more confident to support children living with HIV to live healthy, productive lives.
- Households have more capacity to provide for their needs including adequate nutrition and transport to clinics to refill HIV treatment regularly.
- Village health teams are better equipped to support households and families because of their training on paediatric HIV, as well as their participation in village savings and loans associations.
- Linkages between communities and health facilities have improved with two-way referral systems that support people living with HIV to access and use services effectively.
- Community resource persons are actively promoting increased understanding of paediatric HIV within their spaces of influence.

Innocent is a six-year-old boy identified by a village health team called Hawa during a household visit. Innocent's mother said, **"Hawa visits us regularly and gives us hope, helping me to join the caregiver group and a village savings and loans association and supporting us to keep our clinic appointments and continue with our treatment."**

- District health officials and key healthcare workers have committed to improving the quality of paediatric HIV services by working with village health teams to identify children living with HIV, reintegrate children who have dropped out of care and support retention over the long-term.

Impact in numbers

- 23,935 household visits conducted by 1,097 trained village health teams
- 8,373 children (0-14 years) tested for HIV
- 2,567 children tested positive (30.6%) and enrolled in care
- 3,285 pregnant women enrolled in antenatal care including HIV testing and access to treatment[8]
- 113 village savings and loans associations formed supporting 3,045 caregivers
- 25 village savings and loans associations formed to support village health teams

A cost-effectiveness study was conducted at the end of TAFU phase 2. This concluded that the cost-effectiveness ratio for the community-based TAFU interventions is on average 10 times more cost-effective than the WHO recommended threshold. The estimated cost **savings from infections averted due to the TAFU intervention was** US$310,000.

A social return on investment analysis was conducted at the end of TAFU phase 3. In total TAFU phase 3 has led to the creation of circa €9.5 millions of social value. Of this €1.6 million is directly attributable to TAFU 3. Around three-quarters of the value is created through the avoidance of HIV for children of women living with HIV who take part in the prevention of mother-to-child transmission programme. **For every €1 invested in TAFU, an estimated €3.40 is created**, which represents good value for money.

"Community empowerment is critical in achieving an AIDS-free generation. Community structures can easily identify children, and when equipped, they can provide the necessary support for children; finally, they can link with health services and healthcare workers to complete the continuum of care."

– Joselyne, programme coordinator NAFOPHANU

[8] Challenges with gaps in data at some health facilities for infants created difficulty in tracking the number of babies born free of HIV following prevention of vertical transmission interventions

Best practices to identify and support children living with HIV

- **Training village health teams of people who are living with HIV, so called 'expert clients'**, helps to reduce stigma and discrimination through household visits, peer-to-peer support groups and community awareness/dialogues.
- **Household visits** by trusted village health teams and community resource persons helps to encourage openness to HIV testing, treatment literacy and disclosure.
- **Caregiver support groups** provide access to information on treatment, an understanding of how HIV affects the body and reduces stigma, improving care for children.
- **Village savings and loans associations support caregivers and pregnant women to increase their income** so that they can afford to pay for transport to a health facility and buy nutritious food to support retention of their children.
    - ✓ Village savings and loans associations require support from implementing organisations in the formation stage to reach a level of self-governance to operate independently. They also need to be linked to government structures and initiatives for long-term support.
    - ✓ To support village health teams with their work, some TAFU implementing partners adopted a Volunteer Development Assistance model, in which village health teams join village savings and loans associations and develop income-generating activities.
- **Mobile testing** of children and pregnant women in remote areas enables access to HIV testing services for hard-to-reach communities.
- **Monthly coordination meetings** between village health teams and healthcare workers strengthens the referral pathway and enables two-way referrals (community to clinic and clinic to community). During these meetings issues affecting prevention of vertical transmission and paediatric HIV care can be discussed, and advocacy action can be planned.
- **Joint monitoring and coordination** with other implementing organisations, government officials, healthcare facilities and community structures create opportunities to identify advocacy issues and to communicate those to district officials and Ministry of Health representatives. Joint supervision and monitoring, and regular updates on data and progress helps prioritise paediatric HIV within district workplans and budgets.
- **Community monitoring of paediatric HIV and elimination of mother-to-child transmission supplies** helps reduce the likelihood of stockouts because of timely reporting of the issue and response.
- **Community dialogues** create opportunities to discuss challenging issues related to HIV stigma and discrimination, fear and barriers to HIV testing, treatment and retention, as well as disclosure.

What's next to reach an AIDS Free Generation in Uganda?

One of the main challenges of the TAFU programme was the two-year funding cycles that led to interruptions in the flow of services and support to communities. Long-term funding cycles and a long-term vision are essential for supporting community structures to build the capacity and effectiveness to provide life-long support to children living with HIV so that they can truly thrive.

Moving ahead, TAFU partners are confident that the gains achieved in the programme will be sustained as a result of the following factors:

- Embedded capacity within existing community structures
- Long-term engagement with the government health system, district officials and implementing partners to coordinate and jointly monitor programme efforts
- Established self-governing support structures for people living with HIV, including peer-to-peer support groups and village saving and loans associations.

The Ministry of Health in Uganda introduced paediatric dolutegravir for children, but this is not consistently available. To scale up the approach and achieve greater impact, this must be consistently available at the local level.

The cost-effectiveness study conducted on the TAFU programme concluded that the programme demonstrates value for money. Scaling-up is a justifiable strategy for improving HIV care and treatment outcomes among women and infants in rural settings.

Where TAFU has been implemented the structures and gains will be sustained. However, there are more children in need of support within Uganda and beyond. Scaling up the Kids to Care model is the way forward for realising a generation free of HIV.

About Aidsfonds

Aidsfonds is a non-governmental organisation based in the Netherlands that is working to end AIDS by 2030. Aidsfonds works with community partners in regions most affected by HIV and AIDS, to accelerate and strengthen efforts to meet this goal, ending deaths from AIDS and ending new HIV infections. A critical component of this is to improve paediatric HIV and prevention of vertical transmission services. Aidsfonds together with community partners, co-created the Kids to Care model as a key strategy toward their goal to see the end of AIDS by 2030.

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